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The Impact of Culture & Ethnicity on the Counseling Process:
Perspectives of Genetic Counselors from Minority Ethnic Groups

by

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Dedication

I dedicate this thesis to my amazing parents, my wonderful siblings, and my incredible circle of family and friends. Your prayers and support have carried me through; words can't express how blessed I am to have you. I also dedicate this thesis to Betty Lou and Ella Mae, my strong and loving grandmothers, who always encouraged me to "get my lesson".

Acknowledgements

My deepest gratitude goes out to Crystal, Barb, and Dr. Hardy for assisting me throughout this long process. Thank you for all of your time and input, and for helping me to develop my thoughts into something real and meaningful; it means the world to me. A huge thank you to Peggy as well, who has been a lifesaver time and time again.

Abstract

In the genetic counseling profession, discussions about cross-cultural counseling and cultural competence emphasize the importance of patient culture as well as counselor culture in a counseling session. A culturally competent counselor should be aware of the influence of his or her own cultural values on interactions with patients and peers (Uhlmann, Schuette, & Yashar, 2011; Weil, 2000). Focusing specifically on counselors from cultural/ethnic minorities, this mixed-methods study sought to empirically evaluate the influence of a counselor's cultural values and ethnic identity on the genetic counseling process. 162 genetic counselors, 58 of whom self-identified as being from an ethnic minority group, completed the Multigroup Ethnic Identity Measure (MEIM) scale (Phinney, 1992). The survey also included additional questions from the Benet-Martinez Acculturation scale (BMAS) (Benet-Martinez, 2006), demographic data, and questions regarding patient preference and cross-cultural counseling. 20 counselors participated in semi-structured telephone interviews to discuss cultural values, cultural competency, preference, and experiences surrounding cross-cultural counseling. Results showed that patient preference and cross-cultural changes in counseling were not significantly associated with ethnic identity or acculturation, but were significantly associated with the counselor's age and years of experience; younger counselors and counselors with less clinical experience are more likely to alter their counseling based on cultural similarity. The importance of family and education were cultural values that were considered to directly influence the respondents' approach to genetic counseling. While some changes

in counseling based on cultural differences were noted, counselors generally felt that the needs of the patient were more influential than the cultural similarity between them. A discussion of common genetic counselor traits and recommendations for improved cultural competency are provided.

Keywords: Genetic counselors, diversity, cross-cultural counseling, cultural competence, minority groups, ethnic identity

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List of Symbols

N   Total study sample number

n   Number of participants for in specific category

M   Mean value

Md   Mode value

Mdn   Median value

df   Degrees of freedom

SD   Standard deviation

p   Significance value

F   ANOVA value

r   rho, correlation value

X^2 Chi-square value

List of Abbreviations

Chapter 1: Background

1.1   What is culture?

As humans, we are linked by conserved sequences of billions of nucleotides that spell out a universal code. Infinitesimal changes to that code lead to certain physical differences, but it is the influence of environmental factors, such as culture, that truly makes us unique individuals. The following excerpt is a case example from the online Genetic Counseling Cultural Competency Toolkit (GCCCT):

> Michele is a [prenatal] genetic counselor… meeting with a couple… to discuss the prenatal diagnosis in their fetus of a full left upper limb amputation, which is likely due to Amniotic Band Syndrome… From the intake forms, Michele learns that [the couple is] in their mid-twenties and self-identify as Asian American… As Michelle explains to the couple that their son appears to be very healthy but his left arm did not form properly, [the wife] hangs her head... turns to [the husband] and says, "I'm so sorry - I didn't mean for this to happen." Michele tries to address the emotions of the couple by asking them, "How do you feel about your son's diagnosis?" The couple remain[s] quiet. Finally, [the husband] ask[s] Michelle to explain exactly how this could have happened. Michelle felt that she had no choice but to… accept that the couple would not share their feelings. Michele left the session feeling that she really didn't know how [they] felt… or how she could have been more helpful to them.

As the previous vignette indicates, we encounter patients and colleagues whose cultures differ from our own; it the responsibility of genetic counselors to question how culture influences these encounters. Thus, it is important to have an understanding of how to define culture. Although several variations of the definition exist, "culture" refers to the distinctive features and way of life shared by a group of people in a place or time; this includes shared "beliefs and values, habits, customs and norms, language, religion, history, geography, or kinship" (Uhlmann et al., 2011, Diversity is Cultural section). Culture influences the way we act and think, communicate, structure societies, "make or build things, express feelings and emotions, and respond to the world" (Uhlmann et al., 2011, Diversity is Cultural section). All cultures are learned behaviors heavily influenced by familial and societal socialization.

A group of individuals with a shared culture can be classified as an ethnic group. Ethnicity is a classification given when people identify themselves as being a part of an ethnic group, establishing their cultural and ethnic identity. Cultural identity is a construct that encompasses a person's "cultural practices, values, and identifications" (Schwartz, Unger, Zamboanga, & Szapocznik, 2010, p. 237). A component of cultural identity, ethnic identity can be defined as "an enduring, fundamental aspect of the self that includes a sense of membership in an ethnic group and the attitudes and feelings associated with that membership" (Phinney, 1996, p. 922), and is influenced by the experience of acculturation. This identity reflects the value individuals place on their native culture when "surrounded by receiving-culture peers, media influences, beliefs, and customs" (Schwartz, Zamboanga, Rodriguez, & Wang, 2007, p. 160). In the U.S., ethnic identity levels are higher in ethnic minority individuals than in White Americans,

likely because American culture is perceived to encompass White American values and practices; White Americans may not consider themselves as members of an ethnic group (Schwartz et al., 2007).

The term "acculturation" describes the process by which an individual adapts to a different culture, typically by adopting and identifying with some of the cultural practices and values of the dominant culture (Tsai, Chentsova-Dutton, & Wong, 2002). Several factors may motivate one to become acculturated into the dominant culture; the prime motivation being survival by gaining acceptance from the in-group. It is common to feel threatened by what is different or not well understood, and history has repeatedly shown how fear rapidly evolves into discrimination and violence (Frederickson, 2009; Stephan & Stephan, 2000). The belief is that by becoming more like the majority, one becomes less "different" and more acceptable, thereby becoming less of a threat. Acculturation was previously believed to have an antagonistic effect on ethnic identity; the more acculturated one becomes, the weaker his or her ethnic identity becomes (Hamm & Coleman, 2001); this is phenomenon is now more commonly referred to as assimilation (Schwartz et al., 2010). While assimilation may occur, it is also possible for a person to adopt practices of the mainstream culture while maintaining his or her own cultural beliefs and a fundamental sense of belonging to a certain ethnic group (Smith, 2006). This person incorporates portions of both cultures into his or her identity and exhibits biculturalism. This incorporation is an acculturation strategy that is becoming more prevalent in American society, primarily in younger, and second or third-generation individuals (Schwartz et al., 2010). Biculturalism may occur in different ways; while some view their cultural identities as interconnected, others may view their cultures as

separated. The degree of integration has an impact on cognition and behavior. More integrated individuals often perceive themselves as similar to both cultures and form more culturally diverse friendships. Less integrated individuals are more likely to reject the cultural norms of in-groups (Morris, Mok, & Mor, 2011).

The development of cultural and ethnic identity occurs in a stage-wise manner throughout a person's lifetime. According to the Racial/Cultural Identity Development Model (R/CID), this process occurs in five stages and reflects an individual's understanding of his or her relationship with the dominant culture. These stages include: conformity, dissonance, resistance and immersion, introspection, and integrative awareness. Ideally, once a person has reached the final stage, he or she is able to appreciate and respect his or her native culture and the dominant culture (Sue & Sue, 1990). Although establishment of cultural identity is important in any individual, ethnic identity of minority-group individuals may be more complex in some situations, as these people must face issues such as "their retention of their own cultural heritage, relationships with the dominant culture, and experience with prejudice and discrimination" (Phinney, 1992, p. 163). Identifying with individuals with similar background and values is an important part of "developing both a positive personal identity and feelings of self-esteem and self-efficacy rather than self-blame and powerlessness," particularly in ethnic groups who have suffered from systematic oppression (Phinney, 1992, p. 163).

Cultural and ethnic identities are important components of an individual's overall identity. As previously discussed, identity is developed in stages over the course of a lifetime; it requires periods of self-reflection when an individual must evaluate who she

is, her values, what roles she is suited for, and what makes her unique (Smith, 2006). Overall, establishing these identities is necessary for developing a healthy personal identity; individuals with a clear ethnic identity have better mental health, and are more confident in their behavior and interpersonal relationships (Smith, 2006).

1.2   How does diversity influence healthcare?

The face of America is changing. While the majority of Americans are of European descent, populations from ethnic minorities are steadily increasing; according to the 2010 census, the Asian and Hispanic populations have both increased by 43% within the last 10 years. There is also an increased number (2.8%) of individuals who designate themselves as biracial or identify with more than one ethnic group. In 2011 alone, more than one million individuals immigrated to the U.S. (Centers for Disease Control and Prevention, 2011). A nation of immigrants, the United States has often been lauded as a "melting pot" of ethnic groups, a blending of several cultures to create something distinctly "American." In recent years, the melting pot ideology has been replaced with a "mixed salad" theory, which highlights the diversity of the U.S. population; while acculturation has created unique American values, the ideology of multiculturalism and cultural pluralism allows for individuals to retain values unique to their native culture (Kumar & Van Hillegersberg, 2000).

In the United States, national studies have revealed that individuals from minority ethnic groups are more likely to have health issues (U.S. Department of Health and Human Services, 2012). They are also generally more severely affected by chronic health conditions and are least able to properly manage them. This situation is exacerbated by barriers to health care access; it is reported that these groups are more

likely to be offered fewer, lower quality health services, possibly due to discrimination based on ethnicity or socioeconomic status. Research suggests that these ethnic disparities in health care are also heightened by the lack of minority health professionals in the U.S. (Schoonveld, Veach, & LeRoy, 2007). African Americans, Hispanic Americans, and American Indians make up more than 25% of the U.S. population, but represent only 9% of nurses, 6% of physicians, and 5% of dentists (Mitchell & Lassiter, 2006). Asian Americans are slightly more represented in the medical field as 15% of physicians and 6% of nursing populations. These disparities extend to the genetic counseling workforce; compared to other mental health and health care providers, genetic counselors are "among the least likely to be African American, Native American or Hispanic" (Mittman & Downs, 2008). According the 2012 National Society of Genetic Counselors (NSGC) Professional Status Survey, approximately 1% of genetic counselors identify themselves as African-American/Black, 5% identify as Asian, 2% identify as Hispanic/Latino, and 1% identify as "other". The native populations of Hawaii/Pacific Islands, America, and Alaska collectively comprise 0.5% of the genetic counseling population. Several factors have been proposed to account for the relatively low increase of diversity in the field, including education, socioeconomic status, acculturation, and the impact of "external and internal perceptions regarding racial/ethnic minorities and their career behaviors and abilities" (Oh & Lewis, 2005, p. 72).

It appears that the slowly increasing diversity of health care providers does not reflect the rapidly increasing diversity of their patient population; this discrepancy may directly influence the state of current healthcare interactions. Research consistently shows that patients are more likely to seek treatment or counseling from a healthcare

provider of similar background, someone they feel they can trust. In some studies, patients perceive health care providers from a dissimilar background less helpful (Davis & Gelsomino, 1994). Similarly, minority health care providers are more likely to serve patients from similar ethnic groups due to preference, and commonly choose to practice in areas where these patients can access their services more readily. Schoonveld et al. (2007) corroborated these findings; the study revealed common perceptions, including acknowledgement that "underrepresented status builds trust and rapport" and that "interacting with others of a similar background is helpful." In one study, when interviewed about the potential benefits of being a genetic counselor, African American potential students ranked "giving back to their community" among one of the highest benefits, along with "personal satisfaction" (Schneider, Collins, Huether, & Warren, 2009).

This mutual preference may be associated with the differences between culturally matched and culturally mismatched practitioner/patient interactions. Berman identified that college counselors are more expressive and navigate a session easier when interacting with culture-matched patients (Berman, 1979). In many situations, patient-practitioner similarity fosters a positive working relationship; "individuals perceive that [the provider is] better able to understand and empathize with their situations because of the congruence in ethnicity" (Nezu, 2010, p. 174). While identifying with the patient may be beneficial to establishing a connection, over-identifying may result in countertransference. Countertransference refers to the way a counselor unconsciously relates and reacts to a patient; this phenomenon may also occur when interacting with someone who is in great opposition to one's own beliefs (Veach, LeRoy, & Bartels,

2003). Responses may involve projecting one's own feelings onto the patient, which could jeopardize the professional relationship; this emphasizes the importance of being aware one's sense of cultural identity, which can influence one's mental and emotional triggers.

As diversity increases, it will become more common for provider-patient dyads to be culturally mismatched. In one study, it was found that counselors perceived themselves as "less comfortable and less effective" when performing cross cultural counseling (Davis, 1994, p. 117). This reality has necessitated research into cross-cultural counseling with a particular focus on methods for improvement. An important tenant of cross-cultural counseling is recognition that different cultures will require different counseling approaches (Sue & Sue, 1990). One popular strategy suggests that a counselor should introduce themselves in the patient's native language and intersperse their counseling with (correctly interpreted) phrases; this indicates that a counselor has knowledge and respect of the patient's background. Recent cross-cultural studies have identified therapist-self-disclosure (TSD) as an effective tool in cross-cultural counseling. This method serves to reveal the counselor or therapist's "sensitivity to cultural and racial issues", which will ultimately lead to "an increase of trust, greater perception of therapist credibility, and an improved therapeutic relationship with culturally diverse clients" (Burkard, Knox, Groen, Perez, & Hess, 2006, p. 15). It may also be helpful for White therapists to openly discuss cultural similarities and differences and be willing to disclose their personal experiences.

Much of the research surrounding cross-cultural counseling examines the counselor-patient relationship between a White counselor and non-White patient. While

valuable, this information does not provide insight into the dynamics of other culturally dissimilar dyads and does not reflect the increasing (albeit slowly) diversity of counselors and other health care providers. As such, the majority of literature about counseling theories is created in a context that primarily "reflects the biases of the dominant culture" (Stampley, 2008, p. 41). In one account of cross cultural counseling between two ethnic minorities, the practitioner reflects that, as with culture-matched patients, some interactions are positive and some are negative; he also notes that he is often perceived as "someone who is more sensitive than other professionals because [he is] an ethnic minority" (Nezu, 2010, p. 174). Generally, the less aligned the patient feels to the practitioner, the less likely the patient is to establish a connection, even if there is a shared culture, affirming the fact that there is "diversity among the diverse" (Nezu, 2010, p. 174).

Cultural mores impact how patients speak, interact with healthcare providers, and perceive information about genetics and testing. As previously mentioned, counseling should be approached with awareness and respect for the patient's culture. For example, some members of the African American community have a longstanding distrust of the government and healthcare system, stemming from centuries of abuse and unethical medical treatment. Examples include the Tuskegee syphilis experiment, which followed 399 African American men infected with syphilis for 40 years without their consent and without treatment (Oh & Lewis, 2005), the sickle cell screening program of the 1970's (Long, Thomas, Grubs, Gettig, & Krishnamurti, 2011), and the popularity of scientific racism in the 1800s, during which tools such as physical anthropology were used to establish certain ethnic and racial groups as genetically inferior in order to validate

discrimination and perpetuate racial stereotypes (Dennis, 1995; & Sussner et al., 2011); the psychosocial impact of these incidents are still felt keenly by the African American community. Historically, this distrust has been associated with reduced interaction with healthcare providers and less awareness about etiology and management of medical conditions; this includes a lack of education about genetically associated conditions such as sickle cell disease and trait, which are most prevalent in individuals of African descent, and less genetic testing (Kessler, Collier, & Halbert, 2007). When counseling members of this group, it may be important to avoid the "color-blind" mentality that ignores race, argues that an African American patient is the same as any other patient, and may invalidate the patient's cultural experiences; and the paternalistic mindset, which discredits a patient's issues as a reaction to "racism or minority status" (Sue & Sue, 1990, p. 219). It may also be beneficial to actively foster trust through honest, straightforward dialogue rather than passively letting a connection form (Sue & Sue, 1990).

In traditional South Asian culture, privacy is highly valued by some individuals. Public display of emotional instability may reflect poorly, not only on the individual but on his or her family as well. To avoid shame, it can be common not to share problems or seek advice from someone outside of the family (Kumar & Nevid, 2010). In the East Asian culture, there is an emphasis on honor and status; illness signifies weakness which leads to shame, therefore discussion and acceptance of illness may not be commonly practiced. Asian individuals who highly value emotional self-control may feel less comfortable discussing personal issues; this value negatively influences the chance that counseling with true depth and empathy can be achieved (Wang & Kim, 2010). When counseling these groups, it may be helpful to take an active and directive stance, provide

concrete solutions, and educate patients about the purpose of counseling prior to the first session (Sue & Sue, 1990).

In the Hispanic/Latino community, there is a strong belief in the power of God; some Latinos may consider life events and medical conditions as manifestations of God's will, even when they understand the scientific causes behind the occurrences. Typically, these beliefs are more strongly held by those of lower class and education level, but regardless of class, many Latinos still express distrust for Western medicine. This distrust may stem from fear of social organizations in the United States, as well as having an undocumented status (Penchaszadeh, 2001). When working with this group, the importance of patient interaction is emphasized; it may be helpful to have patients explain what their problems are and prioritize them. The counselor should then paraphrase the information to show that he or she understands, and work with the patient to create solutions to the problems at hand (Sue & Sue, 1990).

A person's degree of acculturation and his or her sense of cultural identity greatly color the way he or she approaches healthcare and respond to counseling. It is also important to recognize that an individual's personality is multifaceted; while one's cultural background may influence his or her beliefs and actions, it does not completely define them. However, being mindful of cultural trends creates a framework to better understand patients from different backgrounds and will help to improve cultural competence.

1.3   What is cultural competency?

Just as our overall identity is shaped by culture, our communication patterns and perceptions are also influenced by cultural values. Therefore, when people from differing

cultures interact, they do so using their respective "cultural codes". These codes determine what an individual considers "right or wrong, good or bad, sacred or profane, important or unimportant" (Uhlmann et al., 2011, Diversity is Cultural section). This means that interacting individuals can have different interpretations of the interaction, which can lead to ineffective communication. In order to reduce these communication barriers, one must develop cultural competence.

Cultural competence can be defined as the "ability to effectively work across culture… not limited to age, race, class, gender, or sexual orientation… an evolving process in which an organization incorporates practices, policies, and training opportunities into the daily life of the organization" **(NSGC Membership Committee, 2013).** Ideally, the goal of cultural competency in genetic counseling is to allow providers and patients to "discuss health concerns without cultural differences hindering the conversation" (Warren & Wilson, 2013, p. 6). Generally, cultural competence involves enhancement of three key elements: knowledge, skills and attitudes. It is also driven by a fourth element: desire. Counselors must genuinely want to learn about diversity and expand beyond their own conceptions; otherwise true growth is less likely to occur (GCCCT).

With well-developed cultural competency, health care providers have a better understanding of what motivates patients, such as religious or familial values, and can utilize skills that will create more meaningful connections with patients, allowing us to be better patient advocates. Cultural competency is a necessary skill for providers in all subsets of patient care; from physicians and nurses to social workers and psychologists. With tools such as A Physician's Practical Guide to Culturally Competent Care, the

Think Cultural Health initiative of the Department of Health and Human Services' Office of Minority Health, and the Transcultural C.A.R.E. Associates, providers may now access a variety of sources to receive training in cultural competence.

Within the genetic counseling profession, there are also career-specific tools. The GCCCT, spearheaded by Nancy Steinberg Warren, serves as an online resource for genetic counselors interested in self-assessment and self-improvement; it offers case examples, quizzes, and relevant information about cultural interactions. There are also efforts being made to improve disparities in both patient and counselor populations by promoting diversity and developing methods to improve recruitment of underrepresented individuals. Increasing the ethnic minority presence in the field would provide more patients with an opportunity to seek counseling with a provider with a similar background, thus increasing the amount of culturally diverse patients as well. Diversity in the workplace can be a rewarding "educational experience… as it challenges stereotypes, enhances cultural competence and fosters lasting relationships" (Mittman & Downs, 2008, p. 302).

Effective cultural competency in a counseling environment requires a counselor to utilize four skills and attitudes. The first skill has been previously discussed; one must have knowledge about a patient's values and perceptions, particularly about illness, emotion, and family relationships. Second, a culturally competent counselor should be humble and appreciative of the diversity of cultures. One must be mindful that there is no "right" or "wrong" culture, and that there is always an opportunity to learn from someone who is different. Third, the counselor should be able to use the patient's cultural codes as tools for a more effective counseling process; the patient's "values and

beliefs should be considered valuable resources" rather than viewed as barriers to counseling (Uhlmann et al., 2011). As a fourth skill, a counselor should have awareness of one's own cultural values and their impact on how one thinks, acts, communicates, and perceives reality, including biases. This skill of provider self-awareness will be discussed further below.

1.4   How does culture influence the health care provider?

As mentioned previously, culturally competent counselors should be aware of the impact of their personal cultural values. Cultural mores may impact how patients interact with healthcare providers, but may also influence how providers respond to these patients. For some, culture may influence the technique of information delivery. A study performed in 1980 found that, in general, counseling styles vary between Black and White counselors. While White counselors were found to be more "attending", utilizing more open ended questions and reflection of feelings, Black counselors were more "expressive" and provided more directions and interpretations (Fry, Kropf, & Coe, 1980). Similarly, in a comparison of social workers, White providers were found to spend more time discussing patient's psychological and internal issues while Black providers devoted more time to discussing solutions to external issues (Davis & Gelsomino, 1994). Japanese psychologist Arthur Nezu identified the influence of Asian culture values on his technique;

> [W]hether it is because of my background (i.e., the Asian American
> community values education)… a substantial role characterizing what I do
> as a therapist should be as an 'educator'. In other words, it is important

for me to explain to clients why I believe they are experiencing the

problems that they are… (Nezu, 2010, p. 5).

For individuals from ethnic minorities, culture may impact one's awareness and sensitivity to diversity.

Being a member of the majority rarely requires someone to question the

world view of the majority and frequently reinforces the notion that their

worldview is the correct worldview. Being a member of the minority

group always reminds one that he or she is one of the 'others' (Nezu,

2010, p. 4).

This awareness may allow a counselor to better understand the importance of how the patient's culture has shaped his or her experience. Minority health care providers may also be more mindful of how their ethnicity influences their patients:

I… learned a valuable personal lesson. I am a stimulus—whether I have

Asian facial features, wear a tie, have pictures of my family on my desk,

or have a picture of a sunset of the beach as my screensaver—I am a

stimulus! (Nezu, 2010, p. 6)

The previous examples highlight the influence of culture in social work, college counseling, and psychotherapy; while culture is an important component of genetic counseling, available literature more commonly focuses on the impact of a patient's culture rather than that of the counselor. There have been studies on genetic counselors' religion and values, which may be influenced by one's culture. In an assessment of genetic counselors' values, Pirzadeh, Veach, Bartels, Kao, and LeRoy (2007) identified "benevolence, self-direction, achievement, and universalism" as values of high

importance to counselors, while less importance was given to the values of "stimulation, tradition, and power." This study recognized the importance of genetic counselor personal values in patient interactions. Traditionally, genetic counseling has been considered a "value neutral" profession, in which the provider's beliefs or values should not infringe on patient autonomy. But our values, which we may rely on even subconsciously, can impact "presentation of facts and options to patients , if and how they engage patients in consideration of the moral consequences of their decisions, and how they respond to ethically challenging situations" (Pirzadeh et al., 2007, pp. 763-764). Because of this reality, genetic counseling cannot truly be considered a value-neutral or culture-neutral profession.

The values that dictate a person's actions may be directly influenced by that person's spiritual or religious beliefs. Research has shown that genetic counselors as a group may be overall less religious and spiritual than the general population (Cragun, Woltanski, Myers, & Cragun, 2009). People with lower religiosity and spirituality may be more naturally attracted to the profession, because less religious individuals tend to be more empathic and tolerant, less prejudiced and authoritative, and more comfortable with controversial issues such as abortion. This study also acknowledged that it does not examine how religion impacts the genetic counseling process, which is a topic that warrants further investigation. Wyatt, Best, Vincent, and Edwards (1996) found that 95% of participating genetic counselors believed their personal beliefs did not affect their ability to remain "nondirective" in counseling sessions, and 64% of counselors recognized that there were situations that conflicted with their religious convictions.

Examining the influence of ethnicity and gender rather than religiosity, Schoonveld et al. (2007) evaluated the overall experience of genetic counselors and counseling students from minority groups. The study overviews a number of issues this group faces, such as loss of cultural identity, feelings of being different or alone, the need to work harder to belong, misperceptions from patients and peers who expect them to act a certain way because of their ethnicity, and the pressure to be model representations of their ethnic group and make a greater impact with patients from a similar group. The value of such a study is undeniable, and many participants appreciated that their ethnic backgrounds could raise awareness about cultural diversity by offering their peers a different perspective. Our current study takes a closer look at some of the findings of Schoonveld et al. (2007), specifically focusing on the role cultural and ethnic identity plays in creating the genetic counselor persona and relating counselors' perceptions of their cultures to their counseling styles and interactions with patients of various cultures.

Chapter 2: The Impact of Culture & Ethnicity on the Counseling Process: Perspectives of Genetic Counselors from Minority Ethnic Groups[1]

2.1 Abstract

In the genetic counseling profession, discussions about cross-cultural counseling and cultural competence emphasize the importance of patient culture as well as counselor culture in a counseling session. A culturally competent counselor should be aware of the influence of his or her own cultural values on interactions with patients and peers (Uhlmann, Schuette, & Yashar, 2011; Weil, 2000). Focusing specifically on counselors from cultural/ethnic minorities, this mixed-methods study sought to empirically evaluate the influence of a counselor's cultural values and ethnic identity on the genetic counseling process. 162 genetic counselors, 58 of whom self-identified as being from an ethnic minority group, completed the Multigroup Ethnic Identity Measure (MEIM) scale (Phinney, 1992) The survey also included additional questions from the Benet-Martinez Acculturation scale (BMAS) (Benet-Martinez, 2006), demographic data, and questions regarding patient preference and cross-cultural counseling. 20 counselors participated in semi-structured telephone interviews to discuss cultural values, cultural competency, preference, experiences surrounding cross-cultural counseling. Results showed that patient preference and cross-cultural changes in counseling were not significantly associated with ethnic identity or acculturation, but were significantly associated with the counselor's age and years of experience; younger counselors and counselors with less clinical experience are more likely to alter their counseling based on cultural similarity. The importance of family and education were cultural values that were considered to directly influence the respondents' approach to genetic counseling. While some changes in counseling based on cultural differences were noted, counselors generally felt that the needs of the patient were more influential than the cultural similarity between them. A

discussion of common genetic counselor traits and recommendations for improved cultural competency are provided.

2.2   Introduction

Culture can be defined as the distinctive features and way of life shared by a group of people in a place or time; this includes shared "beliefs and values, habits, customs and norms, language, religion, history, geography, or kinship" (Uhlmann et al., 2011, Diversity is Cultural section).   Culture impacts the way we communicate, structure societies, "make or build things, express feelings and emotions, and respond to the world" (Uhlmann et al., 2011, Diversity is Cultural section).   All cultures are learned behaviors heavily influenced by familial and societal socialization. As people learn from their environment and experiences, they develop a sense of ethnic and cultural identity, which is a construct that encompasses a person's cultural practices, values, and identifications (Schwartz et al., 2007).   A component of cultural identity, ethnic identity refers to "an enduring, fundamental aspect of the self that includes a sense of membership in an ethnic group and the attitudes and feelings associated with that membership" (Phinney, 1996, p. 922), and is influenced by the experience of acculturation.

A person's degree of acculturation and his or her sense of cultural and ethnic identity may greatly color the way he or she approaches healthcare, perceive information about genetics and testing, and respond to counseling. For example, some people in the African American community have had a longstanding distrust of the government and healthcare system, stemming from centuries of abuse and unethical medical treatment, and more often may negatively perceive genetic counseling (Long et al., 2011).   Broadly speaking, Asian Americans may be more likely to be unfamiliar with the idea of

counseling and have difficulty understanding the process; because of this, they typically negatively rate the credibility of counselors and the therapeutic alliance (Nezu, 2010). It is important to recognize that an individual's personality is multifaceted; one's cultural background may influence her beliefs and actions to varying degrees, but does not completely define her. However, being mindful of cultural trends creates a framework to better understand patients from different backgrounds and can help to improve cultural competence.

In genetic counseling, counselors are encouraged to expand their sense of cultural competency, defined as "the ability to effectively work across culture and is not limited to age, race, class, gender, or sexual orientation." (NSGC Membership Committee, 2013). Ideally, the goal of cultural competency in genetic counseling is to allow providers and patients to "discuss health concerns without cultural differences hindering the conversation" (Warren & Wilson, 2013). This is particularly pertinent as the nation's population becomes increasingly diverse; it will become more common to counsel individuals whose cultural backgrounds differ from the majority population and differ from the counselor him or herself. In order to most effectively communicate with patients, counselors must be mindful of the ways patients' cultural and ethnic identities may influence their perception of genetics, testing, and counseling in general. In the same manner, genetic counselors must also learn to be aware of how their own beliefs and sense of cultural identity impact the counseling session.

While cultural awareness and respect for diversity are important components of genetic counseling, limited research has been performed on the topic of counselors' cultural beliefs, particularly pertaining to genetic counselors from minority ethnic

backgrounds. There have been studies on genetic counselors' religion and values, which may be influenced by one's culture. Pirzadeh et al. (2007) identified "benevolence, self-direction, achievement, and universalism" as values of high importance to counselors; less importance was given to the values of "stimulation, tradition, and power." This study recognizes the importance of genetic counselor personal values, which can impact "presentation of facts and options to patients , if and how they engage patients in consideration of the moral consequences of their decisions, and how they respond to ethically challenging situations" (Pirzadeh et al., 2007, pp. 763-764). Because of this reality, the idea that genetic counseling can be value-neutral or culture-neutral is unfounded. Relating religious beliefs to counseling practice, Wyatt et al. (1996) found that 95% of participating genetic counselors believed their personal beliefs did not affect their ability to remain "nondirective" in counseling sessions, and 64% of counselors recognized that there were situations that conflicted with their religious convictions.

In a study most relevant to the current research, Schoonveld et al. (2007) evaluated the overall experience of genetic counselors and counseling students from minority ethnic groups. The study overviews a number of issues this group may face, such as loss of cultural identity, feelings of being different or alone, the need to work harder to belong, and misperceptions from patients and peers. The study provided valuable insight from the underrepresented population of genetic counselors; many participants appreciated that their ethnic backgrounds could raise awareness about cultural diversity by sharing their perspectives with colleagues and peers.

The goal of our current study is to contribute to the discussion of culture's role in genetic counseling, focusing on the influence of ethnic and cultural identity on creating

the genetic counselor persona by relating a counselor's views on culture to his or her counseling styles and interactions with patients. Specifically, this study addresses topics such as personal counseling techniques, career fulfillment, counselor's patient preference and experiences with countertransference, and cross-cultural counseling, relating these insights to a counselor's personal beliefs about his or her cultural identity. We predict that while there will be overlapping beliefs that may be inherent in the "genetic counselor" personality, there will also be differences in the counseling strategies of participants who perceive themselves as having a stronger connection to their traditional cultural and ethnic group compared to participants who are more acculturated. In examining this topic, we seek to add to the discussion of diversity and cultural competence in genetic counseling.

2.3 Materials and methods

2.3.1 Participants

The target participants of this study were clinical genetic counselors who self-reported themselves as being from a minority ethnic group (e.g. African-American/Black, Hispanic/Latino, East Asian, South Asian, etc). Counselors from all clinical specialties were invited. Both male and female counselors were invited to participate; because the study's target population is ethnic minorities, males were not classified as a minority group. Counselors from the ethnic majority (Caucasian) were invited to participate in the interview portion of the study. Genetic counselors were recruited via an email through the NSGC. This email included an invitation to participate in both the survey and the interview portions of the study, and provided participants with the option to opt out of

either portion. The survey was made available online via SurveyMonkey.com, and follow-up interviews were scheduled after consent from participants was obtained.

2.3.2 Research Methods

The study consisted of two components: a cultural identity survey and a follow up interview portion. Participants completed the Multigroup Ethnic Identity Measure (MEIM) scale (Phinney, 1992) online via SurveyMonkey.com [See Appendix A]. This identity scale is designed to assess ethnic identity when surveying a group of ethnically diverse individuals. This scale analyzes four aspects of ethnic identity, which includes self-identification as being a member of a specific ethnic group, the extent in which a person participates in cultural or traditional activities, one's feelings about being part of that ethnic group, and awareness that ethnic identity development is a fluid, ongoing process (Phinney, 1992). Items were rated on a four point Likert scale ranging from strongly agree (4) to strongly disagree (1).

The survey included additional questions that assessed acculturation, using components of the Benet-Martinez Acculturation scale (BMAS) (modified for a multi-group population). The BMAS questions were designed to analyze the degree to which an individual felt affiliated to his or her native, traditional culture and to the dominant, receiving culture. Some questions were presented on a Likert scale from strongly agree (4) to strongly disagree (1), while others used a binary, "either/or" scale; the questions measure elements of identity that are universal between ethnic groups. The survey also included fields for participants to list their ethnicity, and ended with three questions about interactions with patients; participants were given the option to elaborate on these final responses.

Interviews were conducted via telephone, with an average duration of approximately 25 minutes. During the interview, each participant was asked a series of open-ended qualitative questions concerning his or her clinical experiences and interactions with patients, comparing interactions with patients from similar and different cultural backgrounds [See Appendix B]. Ultimately, the questions focused on the role of cultural identity in these interactions with patients.

Once the interviews were completed, the responses from each question were transcribed and evaluated using grounded theory analysis. Interview responses from counselors in minority groups were also compared to responses from those in the majority group. To protect participants' privacy, responses from the internet surveys were access-restricted and password protected. The surveys were anonymous unless participants chose to provide contact information. In the event contact information was provided, it remained confidential. The participants' survey responses were collected and saved in an encrypted folder and stored on a single user, password-protected laptop. Interviews were recorded and saved to the laptop, also in a protected folder. Interviewees were de-identified and their responses were coded based on the order in which they were interviewed.

2.3.3 Statistical Analysis and Statistical Methods

Quantitative and qualitative analysis methods were used to establish correlations between the cultural identity survey responses and interview question responses. Quantitative analysis of the demographic data and survey responses was performed by using IBM SPSS Statistic version 22.0 software to run analysis of variance (ANOVA), t-

test, chi-square, Fisher's exact, and correlational analyses such as point biserial and Spearman's rho.

MEIM ethnic identity scores were obtained by reversing negatively worded items, summing total items, and calculating the mean (missing items were not calculated in the mean); scores range from 4 (which indicated high ethnic identity) to 1 (low). Cronbach's alpha calculations were performed to verify the reliability of the MEIM scale and partial BMAS scale.

T-test, Spearman's rho, and point biserial correlation were used to compare respondents' MEIM scores to their responses about acculturation, patient preference, and changes in counseling approach. ANOVA calculations evaluated for differences based on ethnic identity and ethnicity. Point biserial correlation examined relationships between the demographic data and acculturation responses compared to the responses about preference and counseling changes; Fisher's exact and Chi-square analyses also examined associations between these variables.

Qualitative analysis based in grounded theory was used to determine the major and supporting themes of participants' responses to semi-structured interviews with open-ended questions, and included descriptive statistics.

2.4   Results

2.4.1 Sample

A total of 2,921 genetic counselors were invited to the study via email; an invitation, including a link the online survey, was extended to all registered members of the NSGC using the NSGC mailing list. The target group was designated as members

who self-reported as being from an ethnic minority group; the exclusion group included counselors from the ethnic majority (i.e., Caucasian, Western/Northern European).

A total of 191 NSGC members participated by starting the online survey (6.5% response rate); 29 provided only demographic data and these results were discarded. Of the remaining 162 participants, the majority ($n = 104$) of respondents self-reported as Caucasian; 58 participants reported an ethnic minority group, which was the target population for this study. The following analyses include the responses of the target group; responses from the "majority" population were analyzed separately. All questions were optional, therefore target respondents were not eliminated based on completeness of the survey; missing responses were not calculated in data analysis. A total of 147 respondents (77%) completed the survey in its entirety. Of the 58 target respondents, 20 provided contact information for a follow-up interview; 16 were successfully contacted and interviewed (27.6% response rate). Five Caucasian respondents who provided contact information were randomly selected and participated in follow-up interviews.

2.4.2 Respondent demographics

Frequency analyses indicated that of the 58 participants in the target group, 56 self-identified themselves as female (96.6%), while two self-identified as male (3.4%). The following table displays additional demographic data (Table 2.1). Other reported specialty areas included: genomics, adult, bleeding disorders, and public health.

2.4.3 Ethnic identity score (MEIM)

The MEIM questionnaire was employed to measure the level of affiliation respondents feel to their native ethnic group. The survey consisted of 19 questions. The scale had a high level of reliability, as determined by a Cronbach's alpha score of .84, $n = 19$. Ethnic

identity scores ranged from 2.21 to 3.79, with a mean identity score of 3.06 (*SD* = .36).

The questions from the BMAS had lower reliability as a score, α = .66, *n* = 4, thus

acculturation responses were analyzed individually.

Table 2.1

Demographic data for ethnicity, age, experience, geographic region, and specialty

Demographic	Number of participants (%)
Ethnicity	
Asian, Asian American	12 (20.7%)
Black, African American	6 (10.3%)
Hispanic, Latino	7 (12.1%)
Jewish (Ashkenazi)	11 (19.0%)
Mixed ethnicity	12 (20.7%)
Native American, American Indian	0 (0%)
Other	10 (17.2%)
Age	
20-29	28 (48.3%)
30-39	17 (29.3%)
40-49	9 (15.5%)
50-59	2 (3.4%)
60-69	2 (3.4%)
>69	0 (0%)
Years of counseling experience	
1-4	32 (55.2%)
5-9	12 (20.7%)
10-14	6 (10.3%)
15-19	2 (3.4%)
20-25	3 (5.2%)
>25	3 (5.2%)
Geographic region	
Midwest	13 (23.6%)
Northeast	18 (32.7%)
South	8 (14.5%)
West	16 (29.1%)
Counseling specialty	
Prenatal	16 (30.2%)
Pediatric	2 (3.8%)
Cancer	18 (34.0%)
Laboratory	4 (7.5%)
Research	2 (3.8%)
Multiple	6 (11.3%)
Other	5 (9.4%)

Notes: data excludes respondents who did not answer this field. *n* =55 (geographic region); *n* =53 (specialty) In the Ethnicity section, "Other" includes participants who self-reported as Middle Eastern or South Asian/Indian (the majority of whom selected "Other" rather than "Asian")

ANOVA was performed to compare reported ethnicity to ethnic identity score. The mean ethnic identity score was significantly different between ethnic groups, $F(5, 52) = 3.75$, $p = .006$, $\eta^2 = .27$. As a group, Black/African American respondents had the highest mean ethnic identity score ($M = 3.26$, $SD = .43$) compared to respondents of other ethnicities, while individuals who reported mixed ethnicity had the lowest ($M = 2.73$, $SD = .30$) (Figure 2.1). Tukey post-hoc analysis revealed that the differences in identity scores between those who reported Black/African American versus Mixed ethnicity (.53, 95% CI [0.02, 1.04], $p = .04$), Ashkenazi Jewish versus Mixed ethnicity (.49, 95% CI [.10, .89], $p = .007$), and Other versus Mixed ethnicity (.42, 95% CI [.02, .83], $p = .04$) were statistically significant; no other group differences were statistically significant. ANOVA analyses did not discover significant differences in ethnic identity based on age, $F(4, 53) = .98$, $p = .44$, although youngest counselors (age 20-29) had the lowest mean identity score ($n = 28$, $M = 2.97$, $SD = .38$).
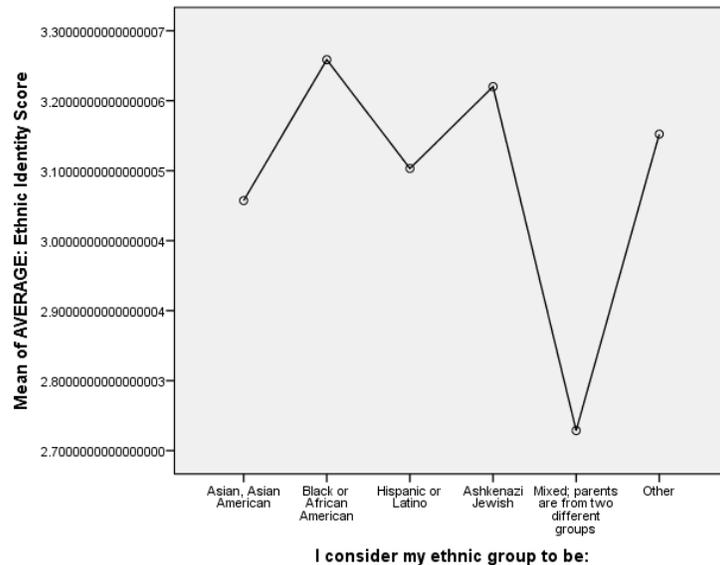

Figure 2.1: Line graph comparing reported ethnicity to mean Ethnic Identity Score

2.4.4 Ethnic identity and acculturation

Most respondents agreed or strongly agreed with the statement, "I feel like an American" ($n = 55$, $M = 3.34$, $Md = 4$); most also agreed with the statement "I feel like a member of my ethnic group" ($n = 55$, $M = 3.21$, $Md = 4$). There was a significant, moderately negative correlation between the ethnic identity score and identifying with the phrase "I feel like an American", $r(56) = -0.34$, $p = 0.012$, and a significant, moderately positive correlation between the ethnic identity score and identifying with the phrase "I feel like a member of my ethnic group", $r(56) = 0.44$, $p = 0.001$.

Independent samples t-tests were also used to further evaluate this relationship. These analyses showed no significant differences in mean ethnic identity score between acculturation responses (Table 2.2).

Table 2.2

T-test analyses comparing identity score to acculturation responses

Acculturation Questions (part A vs. part B)	n(A)	n(B)	t	df	Sig
I combine both cultures vs. I keep both cultures separate	41	15	.92	19.89	.45
I don't feel caught between the cultures vs. I feel caught/conflicted between two cultures	47	10	.25	55	.80
I feel "Ethnic-group" American vs. I feel like a ___ living in (North) America	44	9	-1.39	51	.17
I feel as part of a combined culture vs. I feel as someone moving between two cultures	39	17	-.85	54	.39

Notes: n(A) = respondents who chose "part A" responses in each question, n(B) = respondents who chose "part B" responses.

2.4.5 Patient preference and changes in counseling style

At the end of the survey, respondents were asked the following question: "Do you prefer to counsel patients from a similar background? Why or why not?"
Forty nine participants (84.5%) responded to the question; the majority (n = 38) answered "no" (77.6%), and 11 answered "yes" (22.4%). In explaining her choice of "no", one respondent wrote, "Every patient is different, even when from similar backgrounds, and I love that challenge of genetic counseling." As a respondent who answered "yes" explained, "It helps to build another layer of rapport with my patients."

Respondents were also asked: "Compared to when counseling a similar patient; do you think your counseling practices change when counseling patients from a different background? Why or why not?" Fifty three participants (91.4%) responded; 30 answered "no" (56.6%), and 23 answered "yes" (43.4%). One respondent who answered "no" elaborated on her choice; "[Her counseling approach] would only change if comprehension of the English language was different." A respondent who answered "yes" stated;

> With each session, each patient, each case, there is always a difference...
> whether it stems from educational background, [socioeconomic status],
> health literacy, language, knowledge of family history, etc. Each case is
> always treated differently to meet each individual's needs even outside of
> ethnicity.

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2.4.6 Ethnic identity/acculturation and preference/counseling style

There was no significant correlation between respondents' ethnic identity scores and patient preference, $r(47) = .22$, $p = .13$; correlation was also insignificant between identity scores and counseling style changes $r(51) = .16$, $p = .25$.

Chi-square analysis revealed no statistically significant associations between respondents' acculturation responses and patient preference or counseling changes (Table 2.3). Point biserial correlation also found no significant relationships between these variables (Table 2.4).

Table 2.3

Chi-square analyses comparing acculturation responses to preference and counseling responses.

Acculturation Questions (part A vs. part B)	n(A)	n(B)	Patient Preference		Change In Counseling Style	
			X^2	Sig	X^2	Sig
I combine both cultures vs. I keep both cultures separate	41	15	.51	.47	.46	.50
I don't feel caught between the cultures vs. I feel caught/conflicted between two cultures	47	10	.00	.99	3.55	.06
I feel "Ethnic-group" American vs. I feel like a ___ living in (North) America	44	9	.42	.52	.16	.69
I feel as part of a combined culture vs. I feel as someone moving between two cultures	39	17	.03	.88	1.35	.25

Notes: $df = 1$ for all X^2 values displayed in table. n(A) = respondents who chose "part A" responses in each question, n(B) = respondents who chose "part B" responses.

Table 2.4

Point biserial correlation analyses: acculturation compared to patient preference and counseling change

Acculturation Questions	Patient Preference		Change In Counseling Style	
	r	Sig	r	Sig
I feel like an American	-.08	.58	-.02	.90
I feel like a member of my native Ethnic group	.01	.97	1.5	.30

2.4.7 Demographic factors and preference/counseling style

Point biserial correlation was performed to determine relationships between age and years of counseling experience with participant's patient preference and culturally-influenced changes in counseling practice. There were no significant correlations with preference, but there were significant, moderately positive correlations between counseling style and both age and experience: age, $r(51) = .33$, $p = .02$; years of experience, $r(51) = .35$, $p = .01$. This significant association was also reflected in the results of Fisher's exact analysis (Table 2.5, Figures 2.2 & 2.3); there were no significant associations with patient preference.

Table 2.5

Fisher's exact analyses comparing patient preference and counseling changes to demographic data

Demographic variables	Patient Preference		Change in Counseling Style	
	Fisher's value	Sig	Fisher's value	Sig
Ethnicity	6.31	.24	2.91	.74
Age	3.74	.42	**9.23**	**.03**
Years of Counseling Experience	3.20	.72	**10.93**	**.02**
Geographic Region	6.51	.07	.76	.92

Notes: Significant values are bolded

There were also no significant associations between geographic region or ethnicity and patient preference or changes in counseling style (Table 2.5).
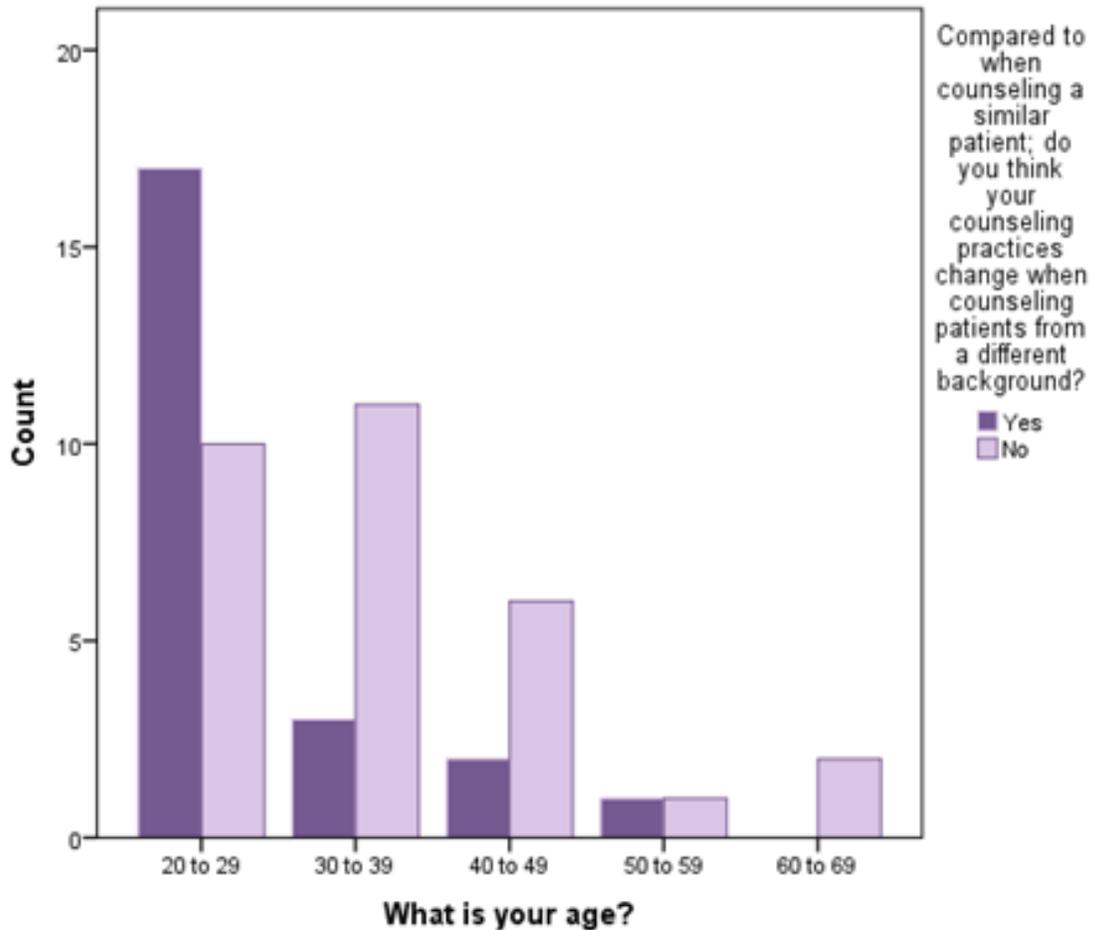

Figure 2.2: Counselor's age compared to changes in counseling style based on culture
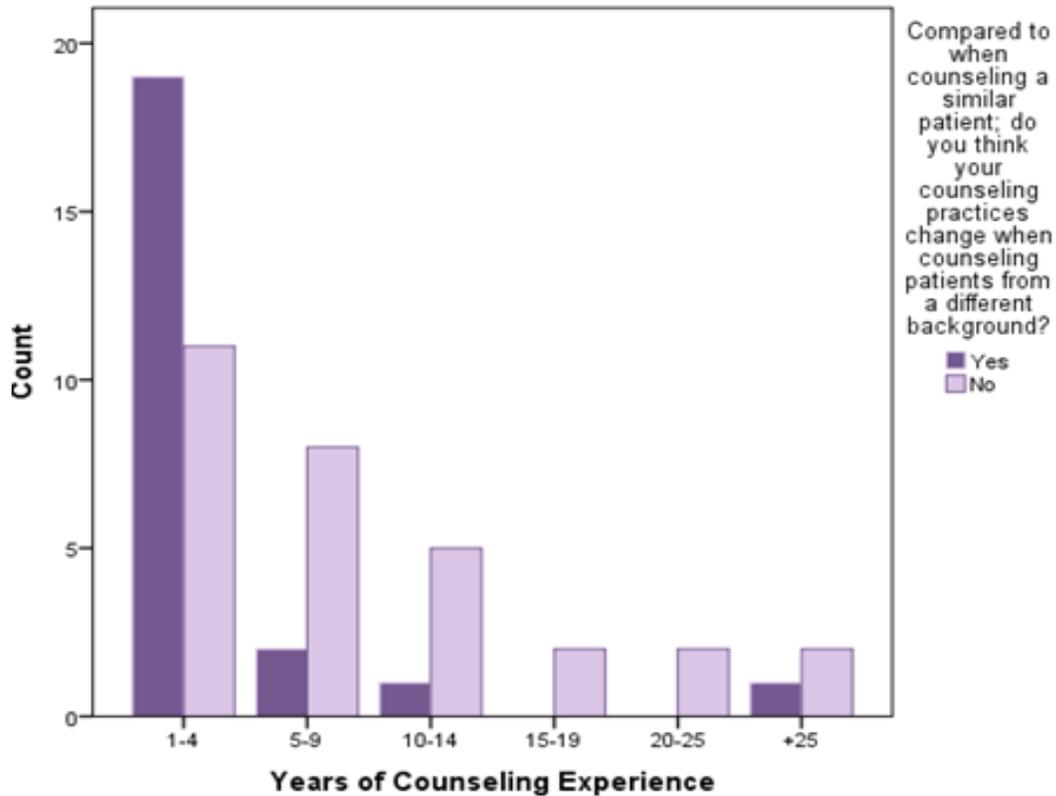
Figure 2.3: Years of counseling experience compared to changes in counseling style based on culture.

2.4.8 Qualitative responses

Twenty-one interviews were recorded; one sample was omitted from the qualitative analysis due to poor audio quality. The remaining 20 responses were coded thematically using grounded theory analysis, which yielded 11 major themes, which will be discussed below (Table 2.6 & Table 2.7).

In the interview population, the mean ethnic identity score was 3.06 (*SD* = .31); scores ranged from 2.47 to 3.68. The majority of participants were aged 20 to 29 (*n* = 8) or aged 30 to 39 (*n* = 7); five participants were over age 40. All but two responded "no" on the survey to having a preference for shared-cultural counseling (one said "yes; the other did not respond); 10 (52.6%) responded "no" to changing their counseling in cross-cultural situations.

Table 2.6

Themes gathered from interview responses: counseling values

Themes and sub-themes	Participant Quotes
Empathy as a primary counseling strength • Responding to nonverbal cues	"I feel like it's easy for me to empathize with patients, and I understand where they're coming from even if I would make a different decision…"
Importance of helping/being a patient advocate	"[Y]ou genuinely help people in an area where they probably wouldn't otherwise get that help. From talking about cancer risks to prenatal testing,… in research… I find that to be rewarding."
Language is a larger barrier than ethnicity/culture	"I think the biggest barrier for rapport might be language rather than culture, and once you have that shared language with your patient… you can use different things to build that rapport"
Most counselors do not prefer to counsel patients from shared culture • No preference overall • Prefer to counsel different culture	"No, I think I'd get bored if it was all the same!… part of what I love about this job is getting to know people of all different kinds."
Countertransference is situational rather than culturally based	"If I've had countertransference… things that came to the forefront were not so much culture things, but more the patient and that particular situation… Just kind of acknowledging it…just so long as I'm aware of it, not letting it get in the way of patient care and putting the patient first."
Rewards of genetic counseling profession • Being able to help people • Combines interests of science/genetics and patient interaction • Avoidance of medical school • Being a resource for underrepresented patient population	"The combination of science and the people skills; it's the best of both worlds, in my mind. I get to interact with patients without having to go through a med school degree to get there." "I wanted to work with patients with a shared cultural background because I know there's a lack of that in our profession. So being able to provide those services was an incentive that drew me into it as well."

Improving cultural competency
• The importance of education in cultural competency
   ○ During and after training
   ○ Workshops, seminars, refresher courses
   ○ Learning from peer experiences
• The importance of exposure to diversity
• Increased minority presence needed in the field
• Respect and appreciate cultural differences
• Recognize personal biases
	"…Having certain guest speakers from various cultural backgrounds to share about their experiences or perceptions would be helpful… periodic refreshers in the workplace, especially if there's certain cultural groups that tend to make up a portion of the patient population. Just to have a sense of struggles, concerns, you know."
	
	"I think it's all about your exposure to those cultures… understand who you are and mak[e] sure that you are tolerant person… recognize your own biases."

Table 2.7

Themes from interview responses: counseling practices

Themes	Participant Quotes
Shared cultural vs. cross-cultural counseling • Rapport building easier when from a similar background • Having to try harder with someone from a different background • More comfortable with counseling model with patients from a shared culture • Finding commonalities with patient • Pressure from patients from similar background • Distrust	"I feel like it's easier for me to build rapport if the patient is from the culture similar to mine. But for the patient from a different culture, I have to try my best." "Well certainly with a shared culture there's probably more opportunity to bring up something, but… [f]or the most part, there was always something; we're all the same, really. Our lives may be different, but we're the same…"

Counseling style changes are reflective of patient's culture more than provider's culture
• Preference for the teaching model over the counseling model
   o No change in model based on cross-cultural differences
   o Exception: Asian counselors more likely to use teaching model with Asian patients
• General discomfort with directive counseling (unless for medical management recommendations)
   o More directive with patients who are more comfortable with paternalistic medical care
	"I think for me and probably for a lot of other people, it's easy to get into the teaching mode… I think it applies in any area of genetics… there's a lot we're trying to disseminate to our patients in a short period of time"
	
	"I think there are certain cultures where I may go into more counseling or more teaching. But I don't think it's based on whether it's more different or shared from mine."
	
	"…[T]here are some cultures where they actually want you to be more directive than not. So I do feel comfortable in those types of situations being directive because I know that's what they're seeking out."

Cultural values that influence counseling practice • The importance of Family o Family values, dynamics, communication & sharing information • The importance of Education • Underrepresented status increases a counselor's sensitivity to diversity • Caucasian counselors less cognizant of cultural influence	"I think it helps me be more mindful of family communication and dynamics… So much of what we do with genetic counseling is educating our patients and giving them the tools to understand and… educate their family about genetics; it's not just about the person but about their family." "…just being raised by parents who lived… outside of the States… contributed to what I try to be at least more open minded and acknowledge different viewpoints, perhaps a little more?"
Personal/cultural challenges in clinical practice • Patriarchal family structure • Pregnancy termination • Sharing information with relatives	"[O]ne that challenges me the most and always kind of grates on me a bit is in some cultures where the husband is the one and only decision maker and he's telling his wife what to do. That is easily one of my least favorite things that is very different from my cultural background." "[W]hen patients specifically tell me that they're not going to share risk or disease information with their family. I think that is when I start to get very uncomfortable."

2.5   Discussion

2.5.1 Cultural and ethnic identity

In the current study, the target sample had a mean ethnic identity score of 3.06 ($SD = .36$), indicating that as a group, these individuals feel more affiliated with their native ethnic group than not; there is an overall moderately high sense of cultural identity. This is compared to the mean score of the Caucasian sample ($M = 2.66$, $SD = .39$), which could be interpreted as a moderate, but lesser, sense of cultural identity. This supports the observations of Schwartz et al. (2007) and parallels the results of the initial MEIM study of Phinney (1992), in which Caucasian participants had comparatively lower ethnic identity scores. The relatively higher mean ethnicity identity score of Black/African American participants ($M = 3.26$, $SD = .43$) and lower score of mixed ethnicity participants ($M = 2.73$, $SD = .30$) also correspond with the findings of the Phinney (1992) study. The responses of the acculturation segment of the survey also suggest that the majority of participants feel some degree of acculturation into the culture of the United States, with the majority responding affirmatively to the phrases "I feel like a '___'-American", "I don't feel caught between two cultures", and "I feel as part of a combined culture." This sense of affiliation with Western, American culture may allow individuals to more readily accept Western views on illness and medical treatment. This facilitates the ability to enter a career that requires regular discussion of genetic etiologies, testing, and management, which could be a source of conflict for people who more closely identify with traditional beliefs and lore of their native ethnic group.

2.5.2 Preference and counseling change

The majority of participants did not have a preference for counseling patients that have a similar background over patients that do not, and did not change their counseling style when counseling cross-culturally. Contrary to our predictions, based on the study's findings, counselors' ethnic identity scores and levels of acculturation did not significantly impact their views on preference or counseling practice. Appreciation of diversity, having the opportunity to improve cross-cultural skills, and pressures from patients with shared cultures were reasons offered for this preference choice. These reasons suggest that consideration of the patient's cultural views have greater influence on counseling practice than the views of the counselor; this was a recurring theme during interviews. When determining whether counseling components such as teaching versus psychosocial methods, rapport building techniques, and directiveness varied in shared-culture versus cross-culture scenarios, some counselors acknowledged differences based on shared culture (discussed in subsequent section) while other counselors stated that in most cases, these components changed based on patients' needs rather than if they had a similar background. While cultural similarity may impact a session, we agree that patient-centered counseling should be the goal in clinical interactions; this approach is considered valid throughout the profession, as evidenced by the fact that the majority of training programs endorse the use of the patient-centered model in counseling practice (Veach et al., 2003).

Although changes in counseling approach did not significantly vary based on a counselor's sense of affiliation to an ethnic group, this study revealed that younger counselors and counselors with less clinical experience are significantly more likely to

approach cross-cultural counseling differently than they would when counseling someone from a shared culture. Additionally, interview respondents who have counseled for a longer period more frequently expressed that did not notice a change because they make an effort to treat everyone the same. This change may reflect the shift in ideology that occurred throughout the 1980s and 1990s, when the focus on didactic counseling transitioned into placing more emphasis on addressing the social, cultural, and familial factors that influence a patient's understanding and decisions (Veach et al., 2003). The emphasis on cultural sensitivity instilled during training may allow emerging counselors to feel well-equipped to modify their counseling with respect to the cultural values of their patients.

While counselors currently entering the field may be comfortable with the concept of counseling with respect to culture, participants from all experience levels acknowledged that counseling must also be approached with respect to patients' goals and needs, which may not always be aligned with their cultural views. "I think the techniques I use are probably the same… just a lot of… trying to pick up on things they're bringing up… I guess that'll vary from person to person regardless of what their culture is." This reinforces the importance of contracting with patients at the onset of a session and building rapport throughout the conversation by active listening, and allowing patients to discuss their perspectives, ensuring mutual understanding during the decision-making process (Weil, 2000).

2.5.3 Cross-cultural counseling

Although counselors from the target sample and the Caucasian sample generally expressed no preference for shared-cultural counseling, both groups acknowledged that

counseling patients from similar backgrounds is easier than cross-cultural counseling. Some respondents mentioned that with patients from shared backgrounds, it was easier to relate to the patients; when patients recognize a shared culture, they quickly become more at ease, which also helped make the counselor comfortable. Respondents also reported that in many cases, patients can more easily share in jokes and stories when the culture is shared; this comfort and familiarity generally promotes trust and rapport throughout the session. These findings support Schoonveld et al. (2007) and their observations about cultural similarity and rapport: "…the patient/provider relationship is more open and honest when ethnic or culture backgrounds are concordant." As one participant noted, "I think that without even knowing a person, having something to relate to, a similar culture or language, I think there's that automatic connection that's almost there in some sense, just a level of understanding."

In relation to the comfort of counseling similar patients, some counselors felt they have to "work/try harder" when working cross-culturally; they are more mindful of the cultural difference, and consciously analyze information about patients' backgrounds and desires in order to respond in an appropriate and sensitive manner. Some counselors also devote attention to highlighting things they have in common with patients as a rapport-building strategy. One counselor explained, "[U]sually it's not too hard to find some kind of commonality or some shared experience because in some of these cultures, there are more similarities than differences." This is compared to shared-cultural counseling, when educating patients and facilitating decisions may require less conscious effort because the counselor understands the cultural norms and motivations of the patient. One

counselor also recognized that similarity assisted her in assessing patients' goals and allowed her to ask better probing questions during intake.

While shared-cultural counseling generally benefitted rapport, counselors from the target group also noted disadvantages to having greater cultural similarity with a patient. One drawback included the expectation of patients for preferential treatment, discounts, or additional services based on familiarity or community; as counselors cannot ethically provide these services, refusal to do so potentially diminishes rapport with patients. Additionally, some counselors (particularly from Asian backgrounds) noted that shared culture occasionally fostered distrust from patients who feared that counselors from their community would know their personal information and share it with other members of the community; we feel counselors should work to dispel this distrust, as it could result in inaccurate and absent family and medical history, which hinders the assessment and discussion of available testing and management options. We expected that countertransference would be an issue when counseling patients from similar backgrounds; while some did note a cultural link to the occurrence, most counselors who recognized instances of countertransference noted that cultural similarity was not a factor in the situation.

Another recurring theme was the issue of language barriers, which was perceived by some counselors to be more significant than cultural barriers. Several expressed their appreciation for interpreters and stressed their importance to the counseling session, while others emphasized the benefit of multilingual counselors; to maximize this benefit, improved recruitment of diverse counselors and continued language education for currently practicing counselors were suggested.

Ultimately, the patient's cultural values were more influential than the counselor's. Some counselors stated that they would likely be more comfortable delving into psychosocial issues with someone from a similar background, and more likely to be directive with this person because rapport was more readily established. However, many other counselors noted that these changes occurred with respect to the patient's cultural cues, not based on similarity. Some counselors shared that they may more commonly use the teaching model and are more directive with Asian and Hispanic patients; not particularly because of similarity or affiliation, but because experiences have shown them that some individuals from these groups may prefer or benefit from these adjustments in their counseling. In general, shared versus cross-cultural counseling differ in delivery and mentality, not in content. In either setting, the goal is to provide patients with the information they will need in order to make thoughtful, autonomous decisions. Although counselors are trained to recognize and respond to cultural cues, several participants in both the survey and interview populations emphasized the importance of acknowledging the patient's needs as an individual rather than based on a set of cultural generalizations;

> I assess each patient individually; culture may be a part of that, but I assess patient's needs individually and it's not necessarily based solely on culture, and it certainly doesn't change because their culture is the same or different from mine.

As stated previously, in order to appropriately respond to these needs, counselors should continue to do the "extra" work towards building rapport and following the lead of the patient. As the study shows that some counselors work more during cross-culture situations, resources such as the self-assessment test available in the GCCCT may be

useful for evaluating interactions with patients and continuing to develop effective methods for connecting with patients from all backgrounds.

2.5.4 Influence of cultural and ethnic values on the counseling process

During the interview, participants were asked to discuss values from their culture that they feel have an influence on their counseling process. Many respondents from ethnic minorities described the value of their underrepresented status; in recognizing that they are different from the majority, counselors may have an increased sensitivity to diversity which allows them to be more open-minded and understanding. Although the Caucasian counselors interviewed were aware and respectful of diversity, as members of the cultural norm, they were relatively less cognizant of cultural influences in their lives, and the values they described were associated with being American rather than being White. As one Caucasian counselor stated, "It's hard for me to really define culture… it's not something I even have to think about very often…" Another stated, "It's really a hard thing to try to describe, I guess. I feel very average, you know? I feel very similar to a lot of people." Despite recognizing a lesser sense of ethnic identity, the counselors provided values that closely aligned with those of members of the target group, highlighting the fact that certain values may be universally important.

A majority of interview participants, from both the target and Caucasian groups, mentioned family as an integral component of their cultural values and commented that their views on family influenced their approach to genetic counseling. Sub-themes included acknowledging family dynamics such as privacy and respect for the family's elders, maintaining the family image, and the value of the family unit above the individual; while counselors from Asian and Middle Eastern backgrounds more strongly

emphasized the influence of the family, counselors from all backgrounds acknowledged that these factors impacted counselors' perceptions about communication within families regarding the sharing of genetic information. For some counselors, this influence leads them to manage sessions following the family systems model of counseling, discussing the implications of diagnoses and medical decisions as they affect the individual *and* the family (Veach et al., 2003). Other counselors are impacted by the stigma associated with illness and the taboo placed on sharing medical knowledge in their cultural groups, and thus feel more compelled to advise or recommend that patients share their information with relatives; although compelled, one counselor noted feeling a conflict between her westernized views of medicine and her understanding of the value her Persian culture places on privacy.

The importance of education was also discussed as an influential cultural value in several groups; education may be perceived as a source of honor and prestige in Eastern cultures, and an important tool for achieving one's dreams in Western cultures. The value of education not only encouraged interviewees to pursue advanced degrees, but in some cases also shaped the priorities of the counselor. Counselors who placed significant value on education also valued educating their patients and helping them feel informed and thus dedicate much of their sessions to education rather than psychosocial assessment. As family and education impact the development of a counselor's clinical practice, we believe that devoting substantial training time to discuss these influences and role-play relevant scenarios would enrich counselors and improve self-awareness during sessions.

When asked about clinical scenarios that were culturally difficult to approach, the majority of counselors mentioned discomfort in situations when a male partner speaks on the behalf of the patient; while some counselors comply with the patriarchal structure of the family and primarily address the partner, most counselors stated that they make attempts to redirect focus from the partner and speak directly with the patient. Some counselors also expressed having difficulty with situations where patients refuse to share genetic information with relatives; counselors described feeling irritated with these patients and learning to address the benefit of sharing with the family while maintaining their support of the patient's autonomy. We agree with the views of the counselors and those of Hogsdon & Gaff (2011); one's personal feelings about sharing information could lead to a counselor criticizing the patient or allowing the needs of the family to overshadow the patient's. This could significantly damage the counselor-patient relationship and lead the patient to make medical decisions that are not truly his or her own. Pregnancy termination was also considered to be an area of cultural conflict; for one counselor, growing up in a culture where terminations are standard for pregnancies with anomalies or disorders, she occasionally disagreed with patients who continue pregnancies with disorders, but emphasized the importance of not letting her biases influence her counseling or the information she shared with patients.

These responses are the primary goal of this study; they reflect the interview participants' steps toward achievement of one key element of being a culturally competent counselor: self-awareness of how one's own cultural values influence their counseling interactions. Many counselors made comments such as, "that's a really great question" or "I had never thought about that", suggesting that while we as counselors

may recognize that our cultures impact who we are, we may benefit from focused self-reflection on the role of culture in counseling. As our personal and cultural identities constantly evolve, we believe that ideally, this self-evaluation should be a regular process throughout a counselor's career. As stated previously, counselors from both interview groups identified similar values and influences on their counseling, which may suggest that, as a group, genetic counselors often practice under a set of common values; this idea is discussed below.

2.5.5 Genetic counseling cultural values

Analysis of recurrent themes revealed traits that may be considered common components of the genetic counseling persona. The counselors interviewed in this study valued being able to be empathic with patients, and a significant majority described being able to help people, being a patient advocate, or making a difference as the most rewarding aspects of their career. Counselors also valued their roles as educators and problem solvers. The population interviewed, which was solely female, was also decidedly critical of patriarchal family systems, but this may be related to the role as an advocate and ensuring that the patient is making autonomous decisions. As previously stated, counselors were also markedly uncomfortable with nondirective counseling, aside from the discussion of medical management guidelines; we recognized that this is possibly more reflective of counselors' training than of counselors' beliefs. While this sample is not necessarily representative of the entire genetic counseling profession, these traits were consistently mentioned regardless of ethnic background or age, which may suggest that these are all values associated with being a genetic counselor. Similar to the observations of Cragun et al. (2009), we believe the requirements of the genetic counseling profession attract

specific personalities with specific values, essentially creating a cultural group of choice rather than of birth or locale. These data may be useful in locating candidates for recruitment.

2.5.6 Improving cultural competency

For years, the relative homogeneity of the genetic counseling provider population has sparked conversation about increasing diversity and training culturally competent counselors. When the interviewees were asked for their suggestions on improving cultural competence, education, experience, and respect for diversity were the most common themes that emerged from their responses. Respondents suggested that education measures should be performed both during training and as a part of continuing education. Counselors mentioned strategies such as requiring comparative cultures courses and culture-based assignments during school, holding cultural issues seminars and workshops in classes, jobs, or annual conferences, or simply having open conversations about cultural differences with peers from various backgrounds. The latter suggestion is a potential source of tension for some students and professionals from minority groups who may feel these discussions increase "pressure from classmates, instructors, and colleagues to be *diversity experts* regarding all cultural/ethnic groups and to figure out how to increase diversity within the field" (Schoonveld et al., 2007). While some may feel pressured, others may enjoy the opportunity to share their stories, like one participant of our study who stated,

> Let me be a resource, and let me provide guidance when there is a question about Indian individuals or Asian individuals. Because we've got to learn in a way that is comfortable and asking counselors is probably

the most comfortable way to do it because there's no patient, there's no actual family history, there's no… you know, it's realistic but without being intrusive.

These findings support the widespread sentiment that an increasingly diverse counselor population not only benefits the patients but also enriches the education of the providers (Warren & Wilson, 2013).

In contrast to suggestions of class presentations and workshops, one respondent felt that the profession's general approach to cultural competence is well-intentioned but misguided, and framed around the majority population's perceptions of their interactions with the cultural "other"; meaning cross-cultural counseling is a technique we learn to use when the patient is not like us, which has historically meant "not a White female". As a member of the "other", this respondent felt that,

There's only so much that you can do besides being aware that people have different cultures and recognize that you might have to have some flexibility around that… to be culturally competent can't necessarily be taught but it's something to strive for; it's more of a sensitivity that should be inherent to genetic counseling overall, opposed to some subset of practice that you're doing.

Other respondents acknowledged that improved competence requires a counselor to respect cultural differences, examine and resolve personal biases, recognize that "every patient has their own culture… it's not unique to people that are necessarily "different" from you… everyone is different from you, so you have to learn each patient's culture… to provide… the care that they need."

We agree that cultural competence is a matter of sensitivity and respect; we also recognize that independent of whether someone identifies with the ethnic majority or a different group, it is often natural to judge or even fear what one does not understand, thus a lack of insight could breed a lack of sensitivity and jeopardize the counseling relationship. We feel that educational measures help counselors gain insights that decrease bias and increase sensitivity and thus cultural competence, which will allow them to more effectively engage with patients from different backgrounds.

Irrespective of whether respondents felt more formal training is needed or felt no need for additional training, simply more respect and sensitivity, the majority of interview participants acknowledged that the most effective way to foster this competence is through life experience and exposure to different cultures, both in and out of the clinic. The respondents echoed the sentiments of NSGC Diversity scholarship recipients Liu, Patek, and Wolfe-Schneider (2011), suggesting that students should have opportunities to rotate at locations with larger populations of underrepresented persons, that students and counselors alike should participate in outreach activities in these communities, and that funding through training programs or through NSGC should be established to allow for international training opportunities. Counselors from majority and minority populations alike acknowledged that counselors from underrepresented groups may have an innate sensitivity to diversity which benefits competency, and that there are more opportunities for this population to gain proficiency in cross-cultural counseling because in most scenarios, these counselors will be culturally dissimilar from their patients (Nezu, 2010). While this may be a valid observation, we feel that all counselors and students should take advantage of opportunities to learn about and learn

from individuals with unique worldviews in an effort to increase their understanding and respect for others.

2.5.7 Study limitations and research recommendations

Although 58 participants from ethnic minorities is an impressive representation for the study's target population, in population that is already limited, the views of this sample may not be generalizable to minority counselors as a whole. Additionally, the majority of participants were in their 20s with one to four years of experience; as the study revealed, the age of the counselors in this sample more significantly influenced responses than their ethnic affiliation, which may have influenced the data for patient preference and counseling changes. Although no significant association was seen, the overall young age of the sample may have also influenced the mean ethnic identity score, as our identities constantly evolve over time (Smith, 2006). Another limitation would be the limited number of male participants in the in the study, who may have provided insights being from two minority groups. Another possible limitation is the potential of false report; the online survey was confidential, and while we would certainly hope for open, honest discussion amongst peers, we cannot verify that the responses participants provided are an accurate reflection of their views and practices. These factors potentially limit the analytic capability of this study.

Further studies could expand our research to evaluate the minority population from perspectives other than ethnicity and include populations such as male counselors and counselors from the Deaf and Persons with Disability communities. This research could not only examine the influence of being in the minority as it relates to counseling patients, but could also further explore the interactions individuals in this population have

with their colleagues and peers. Studies such as this could be performed periodically to assess this population's views on cross cultural counseling and gauge the success of competency measures that are currently underway.

2.6   Conclusions

Culture and ethnicity are factors that undeniably impact how individuals process information and interact with one another. It becomes imperative to discuss the ways by which culture impacts genetic counseling interactions as both patient and provider populations continue to diversify. As genetic counselors, we are encouraged to examine the role of our own cultural values in our counseling process; this study sought to describe and analyze the impact of some of these values. Family dynamics/communication and education are values that commonly affect a counselor's frame of reference and counseling approach; this supports the practice of comprehensive training in these areas. Awareness of common counselor characteristics such as empathy or appreciation of education may allow for more effective recruitment of individuals who have a natural interest in the field. While interactions with patients from similar cultures offer the provider ease and comfort, counselors of all ethnic backgrounds are generally welcoming and encouraging of diversity, and newer counselors are increasingly prepared to offer culturally sensitive care. Overall, these findings are promising, as they suggest that competency efforts have had a positive effect on the profession and that increased efforts in clinical, didactic, and recruitment realms would not be in vain.

Chapter 3: Conclusions

Culture and ethnicity are factors that undeniably impact how individuals process information and interact with one another. It becomes imperative to discuss the ways by which culture impacts genetic counseling interactions as both patient and provider populations continue to diversify. As genetic counselors, we are encouraged to examine the role of our own cultural values in our counseling process; this study sought to describe and analyze the impact of some of these values. Family dynamics/communication and education are values that commonly affect a counselor's frame of reference and counseling approach; this supports the practice of comprehensive training in these areas. Awareness of common counselor characteristics such as empathy or appreciation of education may allow for more effective recruitment of individuals who have a natural interest in the field. While interactions with patients from similar cultures offer the provider ease and comfort, counselors of all ethnic backgrounds are generally welcoming and encouraging of diversity, and newer counselors are increasingly prepared to offer culturally sensitive care. Overall, these findings are promising, as they suggest that competency efforts have had a positive effect on the profession and that increased efforts in clinical, didactic, and recruitment realms would not be in vain.

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Appendix A – Online Survey (Modified MEIM scale)

The Impact of Culture on the Genetic Counseling Process
Survey Introduction

Dear Participant,

Thank you for participating in my graduate research study, which examines the impact of a counselor's culture on the genetic counseling process, focusing specifically on genetic counselors from minority ethnic groups.

The goal of this survey is to evaluate the participant's sense of affiliation with his or her ethnic group, relating their sense of ethnic identity and acculturation to their counseling practices. The 30-question survey requires approximately 10 to 15 minutes of your time.

All responses gathered will remain confidential. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey. At the end of the study, we only ask for your name and contact information if you are interested in participating in the interview segment of the study. It is not necessary that you provide this information.

Your participation in this research is voluntary. Completion of the survey or participation in the interview serves as consent that you have read and understand this information. You may withdraw from the study at any time.

Thank you again for your participation. Your input may help educate fellow genetic counselors about diversity within the field, leading to increased cultural competency.

Sincerely,

Brittanie Morris
University of South Carolina- School of Medicine.

Demographic Information

*1. Your Gender:

○ Male   ○ Female

*2. What is your age?

○ 20 to 29   ○ 30 to 39   ○ 40 to 49   ○ 50 to 59   ○ 60 to 69   ○ 69 or older

*3. Years of Counseling Experience

○ 1-4   ○ 5-9   ○ 10-14   ○ 15-19   ○ 20-25   ○ +25

4. Please indicate your genetic counseling specialty. (e.g. Prenatal, Pediatric, Cancer, etc.)

[   ]

Please indicate your genetic counseling specialty. (e.g. Prenatal, Pediatric, Cancer, etc.)

5. Geographic Region

○ West   ○ Midwest   ○ South   ○ Northeast

Cultural Identity

6. Please indicate how much you agree or disagree with the following statements.

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
I have spent time trying to find out more about my own ethnic group, such as its history, traditions, and customs.	○	○	○	○
I am active in organizations or social groups that include mostly members of my own ethnic group.	○	○	○	○
I have a clear sense of my ethnic background and what it means for me.	○	○	○	○
I like meeting and getting to know people from ethnic groups other than my own.	○	○	○	○
I think a lot about how my life will be affected by my ethnic group membership.	○	○	○	○
I am happy that I am a member of the group I belong to.	○	○	○	○
I sometimes feel it would be better if different ethnic groups didn't try to mix together.	○	○	○	○
I am not very clear about the role of my ethnicity in my life.	○	○	○	○
I often spend time with people from ethnic groups other than my own.	○	○	○	○
I have a strong sense of belonging to my own ethnic group.	○	○	○	○
I understand pretty well what my ethnic group membership means to me, in terms of how to relate to my own group and other groups.	○	○	○	○
In order to learn more about my ethnic background, I have often talked to other people about my ethnic group.	○	○	○	○
I have a lot of pride in my ethnic group and its accomplishments.	○	○	○	○
I don't try to become friends with people from other ethnic groups.	○	○	○	○
I participate in cultural practices of my own group, such as special food, music, or customs.	○	○	○	○
I am involved in activities with people from other ethnic groups.	○	○	○	○
I feel a strong attachment towards my own ethnic group.	○	○	○	○
I enjoy being around people from ethnic groups other than my own.	○	○	○	○
I feel good about my cultural or ethnic background.	○	○	○	○

7. I consider my ethnic group to be:

☐ I consider my ethnic group to be: Asian, Asian American

☐ Black or African American

☐ Hispanic or Latino

☐ White, Caucasian, European, not Hispanic

☐ American Indian

☐ Mixed; parents are from two different groups

☐ Other (please write in)

---

8. My father's ethnicity is:

My father's ethnicity is:

9. My mother's ethnicity is:

My mother's ethnicity is:

Acculturation

10. Please indicate how much you agree or disagree with the following statements.

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
I feel like an American.	○	○	○	○
I feel like a member of my native ethnic group.	○	○	○	○

Please think about how much the cultures of your native group and America (United States) feel as separate or combined cultures for you. Next, read the statements below and choose only one that best describes your particular experience. (If both are more or less true, choose the one that is most true to you).

11. Which statement best describes your particular experience?

○ I combine both cultures (e.g., I feel a mixture of American and my ethnic group most of the time)

○ I keep both cultures separate (e.g., Most of the time I feel American in some places and part of my ethnic group in others)

12. Which statement best describes your particular experience?

○ I don't feel caught between the two cultures

○ I feel caught (i.e., conflicted) between two cultures (e.g., I usually feel like I must choose between being American OR a member of my ethnic group)

13. Which statement best describes your particular experience?

○ I feel "Ethnic-group"-American (i.e., a mixture of these cultures; African-American, Asian-American)

○ I feel like a _____ in North America

14. Which statement best describes your particular experience?

○ I feel as part of a combined culture.

○ I feel as someone moving between the two cultures.

Counselor-Patient Interactions

15. What percentages of your patients are:

	<10%	10-20%	30-40%	50-60%	70-80%	>80%
From a cultural background similar to yours?	○	○	○	○	○	○
From a (non-Caucasian) cultural background different from yours?	○	○	○	○	○	○
From the majority ethnicity (Caucasian)?	○	○	○	○	○	○

16. Do you prefer to counsel patients from a similar background?

○   Yes   ○   No

Why or Why not? (optional)

17. Compared to when counseling a similar patient; do you think your counseling practices change when counseling patients from a different background?

○   Yes   ○   No

Why or Why not? (optional)

The Impact of Culture on the Genetic Counseling Process

If you would like to participate in the interview portion of this study, please provide your contact information below so that an interview can be scheduled. Thank you.

18. Please provide contact information below

Name:

Email Address:

Phone Number:

Appendix B: Interview Questions

1. What do you feel is your strongest trait as a counselor?
2. What attracted you to genetic counseling?
3. What do you find most rewarding about your career?
4. Tell me about your culture. (What values do you identify as being a part of your cultural group?)
5. What/How do your cultural values influence how you counsel?
6. Which teaching model do you use more often/more comfortable with; teaching or counseling?
   6a. When counseling someone with a shared culture/from a different culture
7. How do you build rapport?
   7a.When counseling someone with a shared culture/from a different culture
8. How comfortable are you with being directive with patients?
   8a. When counseling someone with a shared culture/from a different culture
9. What counseling scenarios do you find personally challenging or conflicting to your cultural beliefs?
   9a. How do you handle these sessions?
10. Do you prefer counseling patients with a similar cultural background? Why (or why not)?
11. Do patients with a similar cultural background respond differently to you than patients who do not?
    11a. How does it make you feel, and what do you do when you encounter this?
12. What has been your experience with countertransference?
    12a. Were these experiences with patients with a shared culture?
13. What suggestions do you have for improving cultural competency in genetic counseling?

Appendix C: Study Invitation

University of South Carolina School of Medicine
USC Genetic Counseling Program

Dear Potential Participant,

   I am a graduate student in the genetic counseling training program at the University Of South Carolina School Of Medicine. I would like to invite you to participate in my graduate research study, which examines the impact of a counselor's culture on the genetic counseling process, focusing specifically on genetic counselors from minority ethnic groups. The study involves participating in a phone or Skype interview and completing an online survey.

   The interview allows the participant to share their experiences in genetic counseling and their perspectives about culture. The goal of the survey is to evaluate the participant's sense of affiliation with his or her ethnic group, relating their sense of ethnic identity and acculturation to their counseling practices. Although the study's primary focus is genetic counselors from minority ethnic groups, individuals of Caucasian ancestry are encouraged to participate in the interview segment of the study. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey. All responses gathered will remain anonymous and confidential. At the end of the study, we only ask for your name and contact information if you are interested in participating in the interview segment of the study. It is not necessary that you provide this information. **If you would like to participate in the interview segment without completing the survey, please send your contact information to my email address, listed below**. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

   Your participation in this research is voluntary. Completion of the survey or participation in the interview serves as consent that you have read and understand this information. You may withdraw from the study at any time.

Thank you for your time and consideration to participate in this survey.   Your participation would be greatly appreciated; your responses may educate fellow genetic counselors about diversity within the field and increase cultural competency. If you have any questions or comments regarding this study, please contact either myself or my thesis advisor, Crystal-Hill Chapman, PhD, LP, NCSP using the contact information provided below. For questions concerning your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

Sincerely,

Brittanie Morris, B.S.	Crystal-Hill Chapman, PhD, LP, NCSP
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