

1-1-2013

A Qualitative Study on How Prenatal Genetic Counselors Prioritize Cultural Issues When Counseling Patients

Darcy Katherine Berry
University of South Carolina

Follow this and additional works at: <https://scholarcommons.sc.edu/etd>



Part of the [Genetics and Genomics Commons](#)

Recommended Citation

Berry, D. K.(2013). *A Qualitative Study on How Prenatal Genetic Counselors Prioritize Cultural Issues When Counseling Patients*. (Master's thesis). Retrieved from <https://scholarcommons.sc.edu/etd/1249>

This Open Access Thesis is brought to you by Scholar Commons. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of Scholar Commons. For more information, please contact digres@mailbox.sc.edu.

A Qualitative Study on How Prenatal Genetic Counselors Prioritize Cultural Issues When
Counseling Patients

by

Darcy Berry

Bachelor of Science
Miami University of Ohio, 2011

Submitted in Partial Fulfillment of the Requirements

For the Degree of Master of Science in

Genetic Counseling

School of Medicine

University of South Carolina

2013

Accepted by:

Victoria Vincent, Director of Thesis

Rachel Belk, Reader

Susan T. Vadaparampil, Reader

Nancy Steinberg Warren, Reader

Lacy Ford, Vice Provost and Dean of Graduate Studies

© Copyright by Darcy Berry, 2013
All Rights Reserved.

Dedication

I would like to dedicate this study to families everywhere who have been impacted by genetic disease. Thank you for opening your hearts to help us understand the world from your perspective. Know that we regard you not as patients, but as equals in the journey to care for those whose health has been compromised by genetic differences. Know that at the end of the day we do not forget your concerns, your stories, or your tears, but we carry them with us. They make us better people and better genetic counselors. God bless you and your loved ones.

Acknowledgements

I'd like to thank the faculty at the University of South Carolina for training me to be a genetic counselor, for their encouragement, and their wisdom. I'd especially like to thank my committee, Victoria Vincent, Rachel Belk, Dr. Susan Vadaparampil, and Nancy Warren, and our thesis coordinator, Peggy Walker. Their input was invaluable due to their varied expertise in cultural competency, the field of genetic counseling, and scientific writing. I'd also like to thank Janice Edwards for all of the time and effort she spent to help us develop into the best genetic counselors, and into the best people we can be.

I'd like to thank my husband, Niall, for all of the love and support he's shown me during graduate school. No wife could hope for a more loyal, self-sacrificing, and patient partner to share her life with. Thank you to my family for all of the times you told me how proud you were of my scholastic accomplishments and of the person I have become. I'd like to thank the graduating classes of 2012, 2013, and 2014. We all banded together when the stress became unbearable and held each other up.

Lastly, I'd like to acknowledge my Lord and Savior for bearing this weight for me and for giving me the strength to meet this challenge. He says, "Come to me, all you who are weary and burdened, and I will give you rest (Matthew 11:28)". "Those who hope in the Lord will renew their strength. They will soar on wings like eagles; they will run and not grow weary, they will walk and not be faint (Isaiah 40:22)".

Abstract

The genetic counseling community has long recognized that the successful outcome of a session with a patient whose cultural background differs from the genetic counselor's is best achieved through recognition of the cultural differences and implementation of specific skills to overcome cultural barriers. Although research has examined the need and effects of cultural competency in genetic counseling, no prior study has evaluated how genetic counselors perceive the importance of addressing cultural issues in a genetic counseling session. Prenatal genetic counselors were recruited by emailing all NSGC members. For this study, sixteen prenatal genetic counselors were interviewed and asked to prioritize issues based on three hypothetical case examples in which the patients belonged to different cultural groups: Deaf, Hispanic, and Asian Indian. Study participants mentioned educational elements of the session more frequently than how cultural issues might impact the perception of that education. Participants recognized how cultural beliefs could affect the session but instead of relying on personal biases they favored strategies that highlighted patient individualization such as empathizing, asking pertinent questions, and showing respect. Several potential barriers to discussing patient culture were identified including concern of personal biases, concern about offending the patient, and feeling uncomfortable when the patients' cultural views are different from their own, for example gender roles and perception of assigning fault to the mother of a child with a birth defect. Further research is needed to explore the skills used by genetic

counselors in cross cultural genetic counseling sessions, and their perceived comfort and limitations.

Keywords: Genetic counseling, cultural competency, prenatal genetics, minorities

Table of Contents

Dedication.....	iii
Acknowledgements.....	iv
Abstract.....	v
List of Tables.....	ix
List of Abbreviations.....	x
Chapter 1: Background.....	1
1.1 Healthcare Disparities Among Minorities.....	1
1.2 How Culture Impacts Genetic Counseling.....	8
1.3 Improving Cultural Competency in Genetic Counseling.....	22
1.4 Rationale.....	24
1.5 Purpose.....	25
1.6 Hypothesis.....	26
Chapter 2: Manuscript.....	27
2.1 Abstract.....	27
2.2 Introduction.....	28
2.3 Methods.....	33
2.4 Results.....	36
2.5 Discussion.....	56
2.6 Conclusions.....	61
Chapter 3: Conclusions.....	63

References.....	65
Appendices.....	71
Appendix A- Invitation Letter.....	72
Appendix B- Verbal Consent Form.....	74
Appendix C- Phone Survey.....	75
Appendix D- NSGC Geographic Regions.....	79

List of Tables

Table 2.1 Participant Characteristics.....	38
Table 2.2 Important Issues to Address in Case Examples	39
Table 2.3 Concerns When Counseling Patients from a Cultural Minority	40
Table D.1 NSGC Regions.....	79

List of Abbreviations

ABGC.....	American Board of Genetic Counseling
AMA.....	Advanced Maternal Age
ASL.....	American Sign Language
AFP.....	Alpha-fetoprotein
BRCA1/2.....	BRCA1 and BRCA2
BSL.....	British Sign Language
d/Deaf.....	An inclusive term for all people with deafness, those who see their deafness as a disability and those who consider themselves part of the Deaf community
IOM.....	Institute of Medicine
MSAFP.....	Maternal Serum Alpha-fetoprotein
NT.....	Nuchal Translucency
NSGC.....	National Society of Genetic Counselors
PGD.....	Preimplantation Genetic Diagnosis
RNID.....	Royal National Institute for Deaf People
STD.....	Sexually Transmitted Disease
UK.....	United Kingdom
U.S.	United States of America
WWII.....	World War II

Chapter 1: Background

1.1 Healthcare Disparities Among Minorities

The genetic counseling community has long recognized that the successful outcome of a session with a patient whose cultural background differs from the genetic counselor's is best achieved through recognition of the cultural differences and implementation of specific skills to overcome cultural barriers. The American Board of Genetic Counseling (ABGC) practice-based competencies include the expectations that genetic counselors are able to identify cultural differences and adjust their sessions accordingly (ABGC, 2010). In the most succinct description, genetic counselors are expected to "understand, listen, communicate, and manage a genetic counseling case in a culturally responsive manner" (ABGC, 2010, p. 17). The term culture can be defined as the values, goals, expectations, beliefs, perceptions and behaviors of a group of people who share similar origins, customs, and styles of living (Randall-David, 1989). Cultural competence is defined by Dr. Linwood Lewis as, "the ability to provide skilled treatment to members of diverging cultural backgrounds through the use and knowledge of differing cultures, and self-awareness of one's attitudes, beliefs, behaviors, and biases linked to culture and cultural differences" (Leroy, Veach & Bartels, 2010, p. 227) . Although research has been performed on cultural competence in the genetic counseling session (Baldwin, Boudreault, Fox, Sinsheimer, & Palmer, 2012; Barlow-Stewart et al., 2006; Browner, Preloran, Casado, Bass, & Walker, 2003; Eichmeyer et al., 2005; Middleton, Ahmed, & Levene, 2005; Weil, 2001), no study to date has investigated how genetic counselors

prioritize the importance of cultural competence against other aspects of the genetic counseling exchange. Therefore, it is appropriate to investigate how genetic counselors recognize and rank cultural issues, and how their recognition of these issues impacts the outcome of the session.

This review will focus on barriers to healthcare among cultural minorities, how culture can impact patient-provider interactions, how culture can be especially pertinent to a genetic counseling session, and lastly, recommendations to genetic counselors regarding cultural competence. Some cultural minorities have been researched more thoroughly than others, such as the Hispanic population, and this review will serve to reflect the current research pertinent to the aforementioned topics. Therefore, although not all cultures are discussed, this review can still provide insight into how cultural beliefs as a whole can impact healthcare and genetic counseling. As the study focuses on genetic counselors' views specifically about how Deaf, Hispanic, and Indian cultures impact a session, these cultures will be discussed in greater depth.

Minority populations face many barriers to healthcare including socioeconomic, language, and cultural barriers (Weil, 2001). Derose & Baker (2000) found that Hispanics who did not speak fluent English reported 22% fewer physician visits than native English-speakers or Hispanics who spoke English, even after controlling for factors such as insurance coverage and literacy level. This study also found that the Hispanics who were not proficient English-speakers rated their health as lower than native English-speakers or Hispanics who were more proficient in English (Derose & Baker, 2000). In short, the population with the worst self-ratings of health had the fewest number of physician visits. Studies have also shown that the D/deaf population utilizes healthcare

differently than the general population (Barnett & Franks, 2002). In one study, adults who were prelingually deaf had fewer physician visits than the general population while adults who had postlingual hearing loss had more physician visits than in the general population (Barnett & Franks, 2002). The reason for the increased number of physician visits in adults with postlingual hearing loss may have been due to communication barriers between the patients and the physicians. A study by the Royal National Institute for Deaf People (RNID) in the United Kingdom (UK) showed that one in three individuals who used British Sign Language (BSL) were either unclear about the instructions on their medication, or they had taken the wrong dose of medication due to a communication problem (Adams-Spink, 2004).

In addition to language barriers, there are many reasons why immigrants are at risk of receiving poor healthcare in the United States (Derose, Escarce, & Lurie, 2007; Weil, 2001). They may not have legal residency which can restrict their access to proper medical care (Derose et al., 2007). Immigrants may not speak English and can be stigmatized for their accent, dress, and cultural differences. There may not be educational materials in patients' native language and immigrants may be unfamiliar with Western medicine practices. Logistics, such as transportation and lack of education and resources also play a role in not being able to receive adequate healthcare (Simmons et al., 2011). Since people belonging to a minority often have lower incomes, they may not be able to afford to take time off from work for healthcare visits (Weil, 2001). Although some barriers may apply to multiple cultural groups, each culture and ethnicity is likely to experience distinct barriers to healthcare.

Because many immigrants do not share a common language with their healthcare providers, it may be more difficult to build rapport and relay important information about the patient's health. In one study, Latina patients did not share as much information with their physicians if they did not feel that their physician was compassionate (Julliard et al., 2008). When an interpreter was present, many patients felt uncomfortable sharing personal information, such as sexual health, family planning, domestic abuse, and drug use. When an interpreter was not available, the patient was asked to use a relative which also made it more difficult to discuss sensitive topics. Patients felt that they would be judged by the healthcare provider if they disclosed that they had an STD or were the victim of domestic violence (Julliard et al., 2008). The Latinas felt that the doctors and nurses did not treat them in a caring way because they spoke a different language than the healthcare providers and often did not have insurance coverage. So, in addition to the communication barrier, the Latinas felt discriminated because of their insurance status.

Since the Hispanic population is growing rapidly in the United States (U.S.), there has been a significant amount of research performed concerning how their culture can impact their medical care and how they interact with medical providers (DeNavas-Walt, Carmen, Proctor, & Smith, 2011). Since Hispanics in the U.S. are a diverse group of people originating from many countries, with various levels of acculturation and cultural backgrounds, like any cultural group the characteristics provided here are meant to serve as a guide but are not to be assumed simply based on Hispanic ethnicity. Three terms in Spanish that describe how Hispanics' reactions to provider interactions can be impacted are *familismo*, *machismo*, and *personalismo*. Hispanics are strongly connected to their extended family, called *familismo*, and believe that the good of the family bears greater

priority than the good of the individual (Perez-Stable, 1987). Also, while Hispanic men believe that showing weakness, illness, or emotion to physicians is shameful, called *machismo*, Hispanic women believe that acting calm after receiving bad news is shameful (Perez-Stable, 1987). Hispanic women, therefore, tend to react in a very open and emotional way. Hispanics expect their doctors to be friendly and to share a similar relationship with them as they do with their priests, called *personalismo*. A doctor who is impersonal may be regarded as a poor physician, despite his or her medical expertise. Therefore, Hispanic patients may react differently to unexpected news, may expect familiarity from their healthcare provider and may make medical decisions based on the greatest benefit to the family unit instead of the individual.

Since hearing people may overlook the cultural needs of people who are Deaf because they do not belong to an easily identifiable ethnic minority, individuals from the Deaf community also face barriers to receiving proper healthcare. For this paper the word “deaf” with a lower-case “d” will refer to the medical condition of audiologically-measurable deafness while “Deaf” with an upper-case “D” will refer to the culture of those who associate themselves with the Deaf community regardless of whether they are medically deaf (though some level of deafness is an important factor in being accepted as part of the Deaf community). Individuals who are Deaf share a similar language, belief system, values, historically attended deaf schools (though less so in recent years), and political structure (Swanson, 1997; Woodward, 1972). Individuals with deafness who do not identify as culturally Deaf may identify more with the hearing world, may use spoken language and lip-reading in preference to signed language and may be more likely to have lost their hearing due to age, illness, or injury rather than having been deaf from

birth. The term d/Deaf will be used to signify both groups of individuals with deafness. Signed languages have a distinct grammar, word-order, and syntax and, indeed, differ from country to country. For example, American Sign Language (ASL) has very different vocabulary from BSL, despite the majority language in both countries being English. Because of the grammatical differences, a Deaf person whose preferred language is a signed language may have a lower level of literacy in English compared to someone whose first language was spoken English (Harris & Bamford, 2001; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006).

One study showed that patients who are d/Deaf were extremely dissatisfied with communication between themselves and their physicians (Steinberg et al., 2006). The patients all emphasized that they needed an interpreter who was medically-trained in ASL, but rarely one was provided. Physicians expected deaf patients to lip-read, even when impossible, such as when wearing surgical masks, or to write back and forth. The patients noted that grammar is different in ASL than in written English and that they had a difficult time following the notes because of these differences, medical jargon, or just handwriting. Several patients were told by their physicians that it was too expensive to have ASL interpreters. d/Deaf patients reported fear that they were not being properly understood, which could result in inappropriate medical care, mistrust, and frustration that their cultural difference was an inconvenience to the physician. One patient explained, “I don’t like doctors’ attitudes when they say that I need an interpreter, (saying) “Do you need an interpreter?” You know, I don’t need an interpreter, but if they can’t sign, then WE (emphasis added) need an interpreter.” (Steinburg et al., 2006, p. 264).

Legislative discrimination against the Deaf community continues even to this day. The Human Fertilization and Embryology Act of 2008 in the United Kingdom, which updated the previous Human Fertilization Act of 1990, made it illegal for people to purposefully select a pregnancy that had a disability or illness (Emery, Burke, Middleton, Belk, & Turner, 2008). A clause was included with specific accompanying guidance to specify that deaf individuals could not select for embryos containing genetic mutations for deafness when undergoing preimplantation genetic testing if embryos without the mutations were available. This law could potentially limit the reproduction of deaf individuals by making it illegal for deaf adults to donate their gametes. This amendment insinuated that the life of someone who is deaf is less desirable than that of a hearing person. Since the d/Deaf population is a minority, their views and perspectives may not be appreciated or respected by legislative bodies.

Asian Indians are more likely to use alternative medicine techniques which Western providers may not recognize (Koenig, Dutta, Kandula, & Palaniappan, 2012; Misra, Balagopal, Klatt, & Geraghty, 2010). One study showed that 63% of Indians living in America practice some form of complementary or alternative medicine, the most common being vegetarian diet, dietary and herbal supplements, and Ayurveda (traditional holistic Indian medicine) (Misra et al., 2010). Another study that interviewed Indians living in America about their interactions with providers showed that participants believed since providers did not understand their culture, they would be less able to provide effective healthcare for them (Koenig et al., 2012). The participants mentioned how important their dietary preferences were for maintaining their culture, respecting their Hindu religion, and maintaining a connection with their ancestors (Koenig et al.,

2012). One woman expressed, “I think, fundamentally, they [providers] do not understand that we are not [like] Americans- that our bodies are different... they try to help but... because our metabolism is different, our diet is different, our stress levels are different, our family life is different... I think you would get much better healthcare if the doctors would really know where you’re coming from” (Koenig et al., 2012, p. 822). Another participant added, “Their advice is totally way off, like generally, we don’t eat pizzas or burgers, you know, all kinds of pastries and chocolate... So... it doesn’t really make any sense” (Koenig et al., 2012, p. 823). The participants felt as though providers needed to recognize the differences between American and Indian culture in order to provide care for them and displayed frustration and a lack of trust due to the providers’ naivety concerning their culture.

As a field, genetic counselors are less culturally diverse than the general population. Genetic counseling has traditionally had a lower percentage of minority professionals than other health-related fields (Mittman & Downs, 2008). While Blacks, Hispanics, and Native Americans make up nearly a third of the American population, in 2006 these populations were only represented by about 3% of genetic counselors. A field that expects cultural competency of its practitioners must be diligent in learning how to better serve minority populations.

1.2 How Culture Impacts Genetic Counseling

1.2.1 Counseling models. The priority a genetic counselor gives to a patient’s culture may depend on whether the counselor follows the teaching or counseling model in their practice. While the teaching model focuses on providing education and information, the counseling model focuses on individual factors in the patient’s life that

affect how they receive and act on the information. The counseling model of practice emphasizes the emotional impact created by the information discussed in the session (Kessler, 1997). A genetic counselor using the teaching model may feel, regardless of cultural background, the client will make an informed decision if properly educated by the counselor (Lewis, 2002). The teaching model espouses that cultural issues are secondary to the medical issues, unless the patient's culture directly impacts communication with the counselor or the client's genetic risk factors. A genetic counselor using the counseling model strives to understand the client's cultural perspective in order to help a patient arrive at an informed decision. Education is not the end goal, but rather a means to help the patient incorporate the information into their own belief system (Kessler, 1997).

Genetic counselors also utilize Rogers' Client-Centered Therapy model during their counseling. This method focuses on strengthening the relationship between the patient and the counselor through unconditional positive regard, empathy, and genuineness (Weil, 2000). Some counselors may feel that as long as they are open and genuine with their patients and they provide an emotionally non-threatening environment to discuss their feelings, that addressing the patient's cultural background may not be necessary.

Regardless of the counseling model used, genetic counselors strive to provide nondirective counseling in order to increase patient autonomy and promote self-directedness. Nondirective counseling will educate a patient concerning their options without influencing the patient about which course of action to take (Kessler, 2001). The medical system and the role of healthcare providers in other countries often differ from

that in America. For example, Hispanics and other ethnic groups may misinterpret a genetic counselor's nondirective style of counseling as a professional or personality flaw (Awwad, Veach, Bartels, & LeRoy, 2008; Penchaszadeh, 2001). Hispanics are accustomed to direct recommendations from their healthcare professionals, and nondirective counseling can be understood as a lack of knowledge, apathy, or even unfriendliness (Penchaszadeh, 2001).

1.2.2 Prenatal. Miscommunication between Hispanic patients and prenatal genetic counselors can impact the outcome of a genetic counseling session. One study showed that when determining whether Hispanic patients with a positive maternal serum alpha-fetoprotein (MSAFP) screen would like to have their AFP levels measured through amniocentesis, many patients did not understand the difference between alpha-fetoprotein (AFP) and the "protein" coming from their diet (Browner et al., 2003). Therefore, when they were asked if they would like to proceed with amniocentesis, many refused, responding that they would simply eat more protein to correct the imbalance. A genetic counselor in that study avoided correcting this misconception because she did not want to offend her culturally-different patients. Other sources of misinformation resulted from lack of trust, truncated translation by the interpreter, and the patient misunderstanding the counselor's nondirective counseling. One can imagine that if a genetic counselor anticipated that concepts could be misunderstood by a patient whose first language was not English, then he or she could explain the information in a way that avoided such common misinterpretations. This study gives one clear example of how important cultural competency can be.

In an attempt to be culturally sensitive, some providers deliver less complete information about patient options. A study of providers, including physicians, nurses, social workers, medical assistants, and genetic counselors, offering genetic prenatal care for Hispanics in Texas revealed that they did not provide as much information about amniocentesis to Hispanics as compared to their Caucasian population (Hunt & de Voogd, 2005). So it is not only patients' cultural beliefs, but also providers' beliefs about their culturally-different patients that can impact the information conveyed in a session. The providers rationalized that since Hispanic culture is fatalistic and superstitious, Hispanics are less likely to pursue amniocentesis and so it is culturally appropriate to provide less information. Despite provider beliefs, Hispanics in the study had a comparable uptake rate of amniocentesis as women in the general population. The Hispanic women who were interviewed by the authors did not mention superstitious beliefs. While providers believed that Hispanics often avoided amniocentesis because of their fear of needles, the authors found that the majority of Hispanic women who did have a fear of needles underwent amniocentesis regardless.

Another study examining genetic counseling for British Pakistanis also revealed provider beliefs that this population would not undergo prenatal testing (Modell et al., 2000). The authors showed that British Pakistanis, most of whom are Muslim, were provided with inadequate information concerning carrier screening for thalassemia because of the providers' belief that this patient population would refuse prenatal screening for cultural reasons (Modell et al., 2000). However, contrary to the provider beliefs, 70% of the British Pakistani population that was offered prenatal screening pursued screening and 90% of the affected fetuses were terminated (Modell et al., 2000).

In fact, a third of the patients with at-risk pregnancies for a recessive condition discovered their risk only after the birth of an affected child and only 50% of patients received appropriate healthcare for their risks during the prenatal period. These studies demonstrate how provider misconceptions about a patient's cultural beliefs can result in unequal and discriminatory healthcare. This type of cultural exclusion runs contrary to the National Society of Genetic Counselors (NSGC) Code of Ethics which espouses that genetic counselors "enable their clients to make informed decisions" (NSGC Code of Ethics, 1992). Clients who are not properly informed of their risks cannot make informed decisions concerning those risks.

Not only can a genetic counselor's perception of their patient affect a session, but a patient's perception of genetic counseling can also impact patient care. People who are culturally Deaf may have different perceptions of genetic counseling than the general population. In a study that evaluated attitudes of d/Deaf people towards genetics and interest in prenatal testing for deafness, many d/Deaf participants viewed genetic testing for deafness susceptibility negatively (Middleton, Hewison, & Mueller, 1998). Of the d/Deaf adults, 82% selected no positive words to describe genetics pertaining to deafness and 21% chose the word 'horrified' to describe their views of the advances in genetics. These feelings may stem from past experiences of discrimination against the d/Deaf community, including being the target of genocide in WWII and the perception that modern genetic counseling services still have eugenic roots (Emery et al., 2008; Lane, 2005).

The perception of genetics in regards to deafness differs when measured in the culturally hearing population (Palmer et al., 2009). Palmer et al. found that 130 culturally

hearing parents who underwent genetic counseling about *GJB2* and *GJB6* genetic testing for their deaf infants showed that all of the parents found genetic counseling beneficial (2009). Despite a greater proportion of negative perceptions towards genetic testing developments, 15% of the d/Deaf participants in one study stated they would be interested in using genetics for prenatal diagnosis of deafness and of those 29% said that they would rather have a deaf child than a hearing child (Middleton et al., 1998). In a more recent study, d/Deaf participants mentioned that there were aspects of new genetic technology that they were excited about, such as selecting for deafness through preimplantation genetic diagnosis (PGD) or potentially restoring hearing (Middleton, Emery, & Turner, 2010). However, other participants were concerned that genetics would eventually lead to the resurgence of a eugenics movement and a third believed that a goal of genetic counseling was to reduce the deaf population. The study also provided evidence that the lack of genetic counseling uptake in the d/Deaf community was due to lack of knowledge about how to obtain a referral more than an aversion to genetic counseling or lack of knowledge about genetic counseling itself.

Another recent study showed that d/Deaf adults were interested in genetic testing to contribute to research and to find the etiology of their deafness, but not to decide whether or not to have children (Boudreault et al., 2010). Association with the Deaf community was positively correlated with a desire to use genetic testing to learn the chances of having a child with deafness and using that information to choose between natural reproduction and adoption of a deaf child. Deaf parents and hearing parents differed markedly concerning whether they would use genetic testing in their children to determine whether assistive hearing devices would improve hearing; specifically Deaf

parents disagreed with using genetic testing for this purpose. Also, when comparing d/Deaf parents and hearing parents of deaf children, d/Deaf parents were more inclined to communicate with their health providers through email, which highlights the important differences in communication preferences for d/Deaf patients (Withrow, Burton, Arnos, Kalfoglou, & Pandya, 2008). In the same study, more than 95% of d/Deaf parents believed that the provider disclosing the genetic testing results should be familiar with Deaf culture. The studies highlight the importance of cultural competency during prenatal genetic counseling with Deaf patients.

Deaf participants who visited genetic counselors trained in Deaf culture and who used certified ASL/English sign language interpreters demonstrated a significant increase in genetics knowledge (Baldwin et al., 2012). This study also demonstrated that the deaf participants requiring an interpreter had significantly less genetics knowledge prior to genetic counseling than the deaf participants that did not require an interpreter. Another study showed that genetic counselors who had friends who were d/Deaf or who had more d/Deaf patients had a more positive attitude about d/Deaf people in general (Enns, Boudreault, & Palmer, 2010). Those genetic counselors with a more positive attitude felt more comfortable discussing and offering genetic testing for genetic mutations associated with deafness. This study shows that increased knowledge of Deaf culture among genetic counselors may lead to more complete counseling. The benefits of a genetic counselor being knowledgeable about Deaf culture may be apparent to their Deaf patients, as one study showed that 95.4% of Deaf participants believed that the healthcare provider discussing genetic testing for deafness should be knowledgeable about Deaf culture (Withrow et al., 2009).

Gender roles and marital expectations vary by culture and can impact a genetic counseling session as well. A study of prenatal counseling for recurrence risks of genetic conditions in British Pakistani individuals found cultural nuances that impacted how the patients interacted with the genetic counselors (Shaw, 2011). One mother was willing to continue trying to get pregnant after experiencing two miscarriages and the death of one infant because her husband's parents were pressuring him to divorce her. She felt that if they had one healthy child, she would not need to worry about her husband leaving her. This sentiment was not isolated: another husband revealed that his wife was ashamed that she could not have a healthy child, which is a woman's role in Muslim culture. She felt that if she could not carry out her purpose, that her life was meaningless. Feelings on medical termination also differed from those observed in the Caucasian population. Some couples would not consider medical termination at all, because of religious interpretation of the Koran forbidding any type of termination, while others found that some Islamic teachings allow termination for fatal conditions and would consider this option. A study comparing native Palestinians and Palestinians living in America also found cultural differences between these two groups which impacted their prenatal genetic counseling (Awwad et al., 2008). The native Palestinians were more likely to avoid marrying someone with a family history of intellectual disability and to prefer arranged marriage to dating before marriage. Eight of the 17 native Palestinians viewed the genetic counseling as directive while only one of the 14 Palestinian Americans viewed it as directive. When making a decision about termination, if a joint decision could not be reached, native Palestinians felt that the man should make the final decision whereas American Palestinians felt that the woman should. Also, the native Palestinians were more

concerned about societal perceptions of either having no children or having unhealthy children, and were more concerned that the woman would be blamed for these outcomes than Palestinian Americans in this study (Awwad et al., 2008).

In India cultural differences in prenatal care exist due to disability and gender perceptions. Gupta (2010) interviewed mothers who had undergone genetic counseling in India and showed that genetic testing for sex selection is common practice and prenatal genetic testing is often felt to be an anxiety-causing obligation. The mothers in the study wanted to ensure the health of their child, but were frustrated by the limitations and risks associated with genetic testing. Giving birth to healthy children is an important role for women in India, and birth abnormalities or genetic syndromes are thought to be the result of past misdeeds or bad *karma* (Gupta, 2010). One participant had a child with a clubfoot and aborted the following pregnancy for fear that it would also be affected. Another couple decided to terminate a pregnancy after finding a 2% chance for Down syndrome after prenatal testing explaining, “It is the height of stupidity to knowingly bring a disabled child into the world. We don’t want the child cursing us” (Gupta, 2010, p. 196). The perspective of disability in India may stem from social stigma, lack of social services for the disabled, or the high cost of medical care. Also, information from genetic counselors is nondirective and many Indian patients seek directive advice (Gupta, 2010). This study is another example of how cultural beliefs can impact a prenatal genetic counseling session.

1.2.3 Pediatric. It is important to recognize that disability may be viewed differently in different cultures. In cultures, such as the Native American culture, where physical strength is valued more highly than intellect, physical abnormalities in a child

may cause greater concern to the parents than intellectual disabilities (Hauck & Knoki-Wilson, 1996). In Mexico, most families will hide a family member with Down syndrome from the outside world because the person will be discriminated against and the mother will be blamed for their condition (Sheets, Baty, Vazquez, Carey, & Hobson, 2012). Sheets et al. (2012) examined how Hispanic mothers living in the United States reacted to the news that their newborn had Down syndrome showed that the mothers wished that they had been told in a more positive way. Upon learning that people in the U.S. have different perceptions of Down syndrome, Hispanic mothers were relieved and began to see their child more positively. Whereas Mexican culture would lay blame on the mother for some past sin and see Down syndrome as a punishment from God, these mothers saw their children as blessings (Sheets et al., 2012). After birth, many of the mothers experienced having their babies taken out of the room by medical staff almost immediately. Mothers saw concern from the staff and not being able to understand English, some thought that their babies had died. Upon receiving the diagnosis, mothers had varied perceptions about the causes of Down syndrome. Some believed that teratogens were the cause, while one mother felt that it was because her husband used to pick on children with Down syndrome when he was young. Most wished that their physicians had given them more information about the disorder with less medical jargon (Sheets et al., 2012). This study shows how understanding and the implications of a pediatric genetic diagnosis can vary by culture.

1.2.4 Cancer. Perceptions about the etiology of cancer vary by culture. One study identifying barriers to genetic counseling in an ethnically diverse population of breast and ovarian cancer survivors found that there were low levels of knowledge about how breast

cancer is inherited in this population (Glenn, Chawla, & Bastani, 2012). The authors found that different barriers inhibited different ethnic groups from seeking genetic testing. African Americans were disturbed by the possibility of misuse of genetic information, Asians were unaware of Western preventative medicine practices, and Latina women practiced *familismo* by prioritizing the needs of their family over their own (Glenn et al., 2012; Perez-Stable, 1987). So while minorities have less access to genetic testing for cancer susceptibility, the reasons they have less genetic testing varies by cultural affiliation.

A study in England examining cancer knowledge among six ethnic groups also found significant differences in knowledge between the groups and the general population, and between the groups themselves (Marlow, Robb, Simon, Waller, & Wardle, 2012). All of the ethnic groups mentioned diet and exercise as risk factors for cancer significantly less than previously found in general population studies in the UK. Also, knowledge of genetic risk factors differed between groups, with Chinese participants mentioning genetics more often than Indian, Pakistani, or Bangladeshi participants. Another study showed similar results: that different ethnic groups have varied degrees of knowledge concerning genetic testing for inherited cancer susceptibility (Halbert, Kessler, & Mitchell, 2005). This showed that while knowledge about breast cancer genetics was low in African Americans compared to Caucasians, the expectations concerning genetic testing were high (Halbert et al., 2005). In summary, while minorities had less knowledge about the etiology of cancer, their knowledge varied according to their cultural affiliation.

Lack of knowledge about how cancer can be inherited can lead to lack of care. Hispanics with a personal or family history of breast and/or ovarian cancer in New York City have been shown to be less likely to receive genetic testing for a hereditary breast or ovarian cancer in comparison to other minority populations (Sussner, Jandorf, Thompson, & Valdimarsdottir, 2010). The participants did not have much knowledge regarding genetic testing for cancer susceptibility and believed that genetic counseling would cause worry and distress by informing them of the cancer risks for themselves and their families. In regards to genetic counseling, some Hispanics do not worry about genetic concerns as much as a genetic counselor would expect, due to the fact that they face considerable life stressors (Penchaszadeh, 2001). Nearly a third of Hispanics living in the United States have recently immigrated and many of those were fleeing war or political repression. In the face of their past and present challenges, genetic issues may not be a priority. In a study evaluating Hispanic attitudes towards *BRCA1* and *BRCA2* (*BRCA1/2*) testing, none of the 51 participants had ever heard of genetic testing for *BRCA1/2* (Kinney, Gammon, Coxworth, Simonsen, & Arce-Laretta, 2010). Participants explained that many Hispanics would not even want their close friends or family to know if they ever received a cancer diagnosis, which could make obtaining a pedigree challenging for cancer genetic counselors (Kinney et al., 2010).

Barriers to cancer prevention services in Hispanics were similar to those seen for general healthcare in other studies and included cost, lack of insurance, discrimination, embarrassment, lack of education about preventative services, secrecy, fear due to immigrant status, fatalism, and procrastination (Derose et al., 2007; Kinney et al., 2010; Simmons et al., 2011). Another study examining Hispanic beliefs about cancer showed

that a third of women believed that injuries could induce cancer (Vadaparampil, McIntyre, & Quinn, 2010). In fact, one Hispanic woman took the underwire out of her bras for fear that they would cause breast cancer. The women in the study either had a personal or family history of breast cancer before the age of 50. They described that they had little or no knowledge what genetic testing for cancer was, and most had never been referred for it. When given choices for the wording of a genetic testing recommendation from a provider, 51 of the 53 women chose directive instead of nondirective recommendations, which has also been observed in other studies (Browner et al., 2003; Penchaszadeh, 2001). Specifically, it has been reported that nondirective recommendations could be misinterpreted as indicating that the appointment is extraneous (Browner et al., 2003).

When people of different ethnicities move to America, their perceptions of how cancer is inherited can change. Previous studies have shown that awareness of genetic testing for inherited cancer predisposition is positively correlated with acculturation, which was measured by competency in the English language (Vadaparampil, Wideroff, Breen, & Trapido, 2006). Hispanics may also have less knowledge about their family history of cancer because there are cultural barriers to discussing cancer within a family (Kinney et al., 2010; Quinn, McIntyre, & Vadaparampil, 2011). In one study, the participants' views of cancer varied greatly from Western views (Kinney et al., 2010). They had fatalistic attitudes towards cancer, secrecy and shame surrounded the topic of cancer as it is a taboo in Hispanic culture, and some thought that cancer was contagious.

How familial relationships are defined differs greatly between Eastern and Western cultures. A study on cancer genetic counseling in Chinese-Australians showed

communication barriers that genetic counselors may face when discussing inheritance and other beliefs surrounding cancer (Barlow-Stewart et al., 2006). For example, the concept of inheritance in Chinese culture was paternalistic. Paternal cousins were considered to be brothers and sisters because they shared the same last name, whereas maternal cousins were considered to be in different families. In this way, someone could marry their maternal cousin, because they are not family, but they could not marry their paternal cousin.

Also, inherited factors in Chinese culture were believed to come more from the males in the family than the females. If a female had an unusual trait she would be cast out, making it less likely for her to transmit the same trait (Barlow-Stewart et al., 2006). Illness was perceived as a weakness resulting from punishment for past actions. In arranged marriages, the woman's family would be checked for any such 'weaknesses', but only in the males in her family. One man explained that, "it was believed that males were genetically stronger and the bloodline was greatest there, as traditionally Chinese males carry the family line... males can inherit property and can also inherit illnesses and can pass down to future generations." (Barlow-Stewart et al., 2012, p. 27).

In regards to cancer, younger participants were more aware that cancer could be hereditary while their elders believed that cancer came from fate or wrongdoings from an ancestor (Barlow-Stewart et al., 2006). Also, the Chinese participants reported that talking about cancer, even within the family, was considered taboo and thought to bring bad luck. Fear that discussing cancer would bring it about and fatalistic views if cancer did occur created a barrier to cancer genetic counseling. A study in Singapore showed that avoiding bad news was a major barrier to cancer genetic counseling in Asians (Chin et

al., 2005). Another barrier was lack of perceived benefit, as more than half of the breast cancer patients were unaware that they were at increased risk for additional breast cancer (Chin et al., 2005).

1.3 Improving Cultural Competency in Genetic Counseling

The patient's preconceived notions can impact the outcome of the genetic counseling session. In some cultures, healthcare providers are thought to be in a higher class than the patients they serve, so rapport-building can be crucial to developing an open relationship with the patient (Bhogal & Brunger, 2010). In small communities, the patient may worry about their privacy if the interpreter is known to them, which could also limit the patient's ability to speak freely. If a person has emigrated from a country that is politically or otherwise oppressed, they may mistrust medical professionals. For these reasons, it is important to identify whether there are any barriers between the patient and the healthcare provider that will affect the productivity of the session. Genetic counselors should also reassure the patient that they are only there to facilitate their decision-making, and not to make decisions for them.

Research has given healthcare providers insight into how to better overcome language barriers with patients. Recommendations for the Deaf community include inquiring about the patient's cultural affiliation, their language preference, and their beliefs surrounding why they are deaf (Baldwin et al., 2012). Providers should utilize visual aids while educating their d/Deaf patients since their cognition is likely to be more visual than in hearing patients (Baldwin et al., 2012). Another study showed how language barriers can impact risk understanding in Hispanics (Eichmeyer et al., 2005). In the study, 7.8% of Caucasians compared to 71.4% of Hispanics did not understand risks

pertaining to prenatal genetic counseling scenarios. Hispanics best understood risk when it was conveyed in either fractions or pictures and least understood risk when it was conveyed through descriptive language (Eichmeyer et al., 2005). When English is not a patient's first language, it may be difficult for the patient to assign meaning to risk that is described qualitatively.

Understanding Eastern traditions can aid genetic counselors in connecting with their patients who hold these values. In Chinese culture, since family honor is of paramount importance, it may be detrimental to discuss a gene mutation running through a family without discussing the fact that every family and every person has genetic changes and mutations (Barlow-Stewart et al., 2006). In order to incorporate Chinese belief systems, it may be easier for a patient to understand testing for "bad luck" or "*zhung*" (an imbalance of *ying* and *yang*) in a person, rather than a gene mutation. Genetic counselors should recognize that the identification of a gene mutation in an unmarried patient may make that patient a less desirable spouse when considering arranged marriages and be prepared to counsel on such issues.

Cultural competency does not solely come from understanding the patient's culture. In order to understand how culture affects others, healthcare providers must first understand how culture affects themselves and how their culture has impacted their own perceptions (Lewis, 2002). Middleton et al. offer practical recommendations for improving cultural competency by tailoring genetic information to patients' cultures (2005). They argue that it would be impossible to learn every medically pertinent fact about every culture and that striving for cultural competence may simply mean knowing which questions are important, being aware of cultural differences, and being empathic to

them. Weil (2001) describes these ideals as, “establishing and maintaining trust, the essential need to respect the counselee’s healthcare beliefs and practices, and the necessity of understanding the impact of culture on the process of decision making and on counselee’s responses to nondirective counseling” (p. 143). Other authors agree with this strategy and recommend simply asking the patient what they believe while remaining nonjudgmental and counseling that there are many valid belief systems (Barlow-Stewart et al., 2006). These strategies can be helpful not only when there are obvious cultural differences between the counselor and the patient, but with any patient-counselor relationship since small cultural nuances are sure to exist. Cultural competence will continue to improve by educating healthcare professionals and supporting research aimed at identifying ways to reduce disparities in healthcare between cultural minorities and the general population (Nelson, 2002).

1.4 Rationale

The ABGC acknowledges the value of cultural competency in its description of genetic counseling. The ABGC states, “The genetic counselor communicates genetic, medical, and technical information in a comprehensive, understandable, nondirective manner with knowledge of and insight into the psychosocial and ethno-cultural experiences important to each client and family” (ABGC, 2010). Genetic counselors must not only be able to communicate information to people of different cultures, but also understand how a patient’s cultural background may influence their interpretation of that information and their decision-making process. Since genetic counselors are a predominantly homogenous population serving a diverse population (Mittman & Downs, 2008) it is essential that ongoing research identifies areas for professional learning and

growth with the goal of better serving patients who seek genetic services. In everyday practice, the perspective of a patient from a minority community may differ from that of his or her prenatal genetic counselor. As genetic counselors become more culturally competent they are better equipped to serve their patients' needs by reducing cultural discrepancies.

1.5 Purpose

The purpose of this study is to gain a better understanding of how genetic counselors incorporate cultural issues into their counseling and how they rank cultural issues against clinical issues in clinical case scenarios. Understanding different cultures is vital to genetic counseling because cultural and ethnic beliefs can impact how genetic information is perceived and acted upon (Weil, 2001). A patient's culture not only can alter the meaning of the genetic information being given, but can also affect how that patient makes medical decisions (Weil, 2000). Although research has been conducted on how genetic counselors conduct sessions with patients from minority communities and how those patients interpret the genetic counseling sessions, no prior research study has determined how genetic counselors rank cultural issues against the medical or emotional issues they encounter in clinical settings. The results of this study will benefit genetic counselors and culturally diverse patients counsel by identifying if cultural issues are recognized, how they are ranked against other clinical issues, and how genetic counselors perceive cultural issues impact the genetic counseling process.

This research project may culminate in a better understanding of the thought processes of genetic counselors and how they perceive cultural issues affect their genetic counseling sessions. The data obtained from this research may increase the flow of ideas

about culturally sensitive topics and spark discussion among genetic counselors. Genetic counselors have long been intrigued by the ethical and cultural dilemmas they encounter and this study may provide important insights about how counselors rank complex cultural issues in prenatal genetic counseling.

1.6 Hypothesis

We hypothesize that, although genetic counselors are trained in the importance of cultural sensitivity, prenatal genetic counselors are prioritizing the medical elements of the session over the cultural issues present. We hope to understand the factors that contribute to the respective ranking of clinical concerns versus cultural competency. We expect to find a number of different responses to how genetic counselors viewed the hypothetical sessions.

Chapter 2: Manuscript

A Qualitative Study on How Prenatal Genetic Counselors Prioritize Cultural Issues When Counseling Patients¹

2.1 Abstract

The genetic counseling community has long recognized that the successful outcome of a session with a patient whose cultural background differs from the genetic counselor's is best achieved through recognition of the cultural differences and implementation of specific skills to overcome cultural barriers. Although research has examined the need and effects of cultural competency in genetic counseling, no prior study has evaluated how genetic counselors perceive the importance of addressing cultural issues in a genetic counseling session. Prenatal genetic counselors were recruited by emailing all NSGC members. For this study, sixteen prenatal genetic counselors were interviewed and asked to prioritize issues based on three hypothetical case examples in which the patients belonged to different cultural groups: Deaf, Hispanic, and Asian Indian. Study participants mentioned educational elements of the session more frequently than how cultural issues might impact the perception of that education. Participants recognized how cultural beliefs could affect the session but instead of relying on personal biases they favored strategies that highlighted patient individualization such as empathizing, asking pertinent questions, and showing respect. Several potential barriers to discussing patient culture were identified including concern of personal biases, concern about offending the patient, and feeling uncomfortable when the patients' cultural views are different from their own, for example gender roles and perception of assigning fault to the mother of a

¹ Berry, D. K., Vincent, V., Belk, R., Vadaparampil, S., & Warren, N. S. To be submitted to *Journal of Genetic Counseling*

child with a birth defect. Further research is needed to explore the skills used by genetic counselors in cross cultural genetic counseling sessions, and their perceived comfort and limitations.

2.2 Introduction

How effectively healthcare providers recognize and respond to cultural differences among their patients is a measure of their cultural competence. Cultural competence is defined by Dr. Linwood Lewis as, “the ability to provide skilled treatment to members of diverging cultural backgrounds through the use and knowledge of differing cultures, and self-awareness of one’s attitudes, beliefs, behaviors, and biases linked to culture and cultural differences” (Leroy, Veach, & Bartels, 2010, p. 143). The Institute of Medicine (IOM) highlights the importance of cross-cultural education to reduce the ethnic and racial disparities that still exist in the healthcare system (Nelson, 2002).

Cultural competence is an important component in genetic counseling. The ABGC in their description of the profession states, “The genetic counselor communicates genetic, medical, and technical information in a comprehensive, understandable, nondirective manner with knowledge of and insight into the psychosocial and ethno-cultural experiences important to each client and family” (American Board of Genetic Counseling, Inc., 2010). Therefore, genetic counselors must not only be able to provide information to people of different cultures, but also recognize how a patient’s cultural background may influence their interpretation of that information and their decision-making process. Since genetic counselors are a homogenous population serving a diverse population (Mittman & Downs, 2008) it is essential that ongoing research identifies areas

for professional learning and growth with the goal of better serving patients who seek genetic services.

Research has provided the medical community insight on how to best serve patients who belong to specific cultural groups. Since the Hispanic population is growing rapidly in the United States, there has been a significant amount of research performed concerning how their culture can impact their medical care and how they interact with medical providers (DeNavas-Walt et al., 2011). Since Hispanics in the U.S. are a diverse group of people originating from many countries, with various levels of acculturation and cultural backgrounds, like any cultural group the characteristics provided here are meant to serve as a guide but are not to be assumed simply based on Hispanic ethnicity.

Hispanics are strongly connected to their extended family and believe that the good of the family bears greater priority than the good of the individual, called *familismo* (Perez-Stable, 1987). Also, while Hispanic men believe that showing weakness, illness, or emotion to physicians is shameful, called *machismo*, Hispanic women believe that acting calm after receiving bad news is shameful (Perez-Stable, 1987). Hispanic women, therefore, tend to react in a very open and emotional way. Hispanics expect their doctors to be friendly and to share a similar relationship with them as they do with their priests, called *personalismo*. A doctor who is impersonal may be regarded as a poor physician, despite his or her medical expertise. Hispanics, and other ethnic groups, may misinterpret a genetic counselor's nondirective style of counseling as a professional or personality flaw (Awwad et al., 2008; Penchaszadeh, 2001). Hispanics are accustomed to direct recommendations from their healthcare professionals, and nondirective counseling can be understood as a lack of knowledge, apathy, or even unfriendliness (Penchaszadeh,

2001). Therefore, Hispanic patients may react differently to unexpected news, may expect familiarity from their healthcare provider and may make medical decisions based on the greatest benefit to the family unit instead of the individual.

Miscommunication between Hispanic patients and prenatal genetic counselors can impact the outcome of a genetic counseling session. One study showed that when determining whether Hispanic patients with a positive maternal serum alpha-fetoprotein (MSAFP) screen would like to have their AFP levels measured through amniocentesis, many patients did not understand the difference between alpha-fetoprotein (AFP) and the “protein” coming from their diet (Browner et al., 2003). Therefore, when patients were asked if they would like to proceed with amniocentesis, many refused, responding that they would simply eat more protein to correct the imbalance. One genetic counselor in that study avoided correcting this misconception because she did not want to offend her culturally-different patients. Other sources of misinformation in that study resulted from lack of trust, truncated translation of the patient’s thoughts by the interpreter, and the patient misunderstanding the counselor’s nondirective counseling.

In India cultural differences in prenatal care exist due to disability and gender perceptions. Giving birth to healthy children is an important role for women in India, and birth abnormalities or genetic syndromes are thought to be the result of past misdeeds or bad *karma* (Gupta, 2010). Gupta (2010) interviewed mothers who had undergone genetic counseling in India. One participant had a child with a clubfoot and aborted the following pregnancy for fear that it would also be affected. Another couple decided to terminate a pregnancy after finding a 2% chance for Down syndrome after prenatal screening explaining, “It is the height of stupidity to knowingly bring a disabled child into the

world. We don't want the child cursing us." The perspective of disability in India may stem from social stigma, lack of social services for the disabled, or the high cost of medical care.

Since hearing people may overlook the cultural needs of people who are Deaf because they do not belong to an easily identifiable ethnic minority, individuals from the Deaf community also face barriers to receiving proper healthcare. For this paper the word "deaf" with a lower-case "d" will refer to the medical condition of audiologically-measurable deafness while "Deaf" with an upper-case "D" will refer to the culture of those who associate themselves with the Deaf community regardless of whether they are medically deaf (though some level of deafness is an important factor in being accepted as part of the Deaf community). Individuals who are Deaf share a similar language, belief system, values, historically attended deaf schools (though less so in recent years), and political structure (Swanson, 1997; Woodward, 1972).

People who are culturally Deaf have different perceptions of genetic counseling than the general population. In a study that evaluated attitudes of d/Deaf people towards genetics and interest in prenatal testing for deafness, many d/Deaf participants had a negative perspective of genetic testing for deafness susceptibility (Middleton et al., 1998). These feelings may stem from past experiences of discrimination against the d/Deaf community, including being the target of genocide in WWII and the perception that modern genetic counseling services still have eugenic roots (Emery et al., 2008; Lane, 2005). Despite a greater proportion of negative perceptions towards genetic testing developments, 15% of the d/Deaf participants in one study stated they would be interested in using genetics for prenatal diagnosis of deafness and of those 29% said that

they would rather have a deaf child than a hearing child (Middleton et al., 1998). In a more recent study, d/Deaf and hard of hearing participants mentioned that there were aspects of new genetic technology that they were excited about, such as selecting for deafness through preimplantation genetic diagnosis (PGD) or potentially restoring hearing loss (Middleton et al., 2010). However, other participants were concerned that genetics would eventually lead to the resurgence of a eugenics movement and a third believed that a goal of genetic counseling was to reduce the d/Deaf population. The study also provided evidence that the lack of genetic counseling uptake in the d/Deaf community was due to lack of knowledge about how to obtain a referral more than an aversion to genetic counseling or lack of knowledge about genetic counseling itself (Middleton et al., 2010). Deaf people are also interested in having genetic testing to contribute to research and to find the etiology of their deafness (Boudreault et al., 2010).

Language provides a significant barrier to providing medical care in the U.S. when a patient does not speak English fluently. Research has given healthcare providers insight into how to overcome language barriers with patients. Recommendations for the Deaf community include inquiring about the patient's cultural affiliation, their language preference, and their beliefs surrounding why they are deaf (Baldwin et al., 2012). Providers should utilize visual aids while educating their deaf patients since they learn visually (Baldwin et al., 2012). Another study showed how language barriers can impact risk understanding in Hispanics (Eichmeyer et al., 2005). In the study, 7.8% of Caucasians compared to 71.4% of Hispanics did not understand risks pertaining to prenatal genetic counseling scenarios (Eichmeyer et al., 2005). Hispanics best understood risk when it was conveyed in either fractions or pictures and least understood risk when it

was described qualitatively. When English is not a patient's first language, it may be difficult to assign meaning to risk that is described qualitatively.

The purpose of this study was to gain a better understanding of how genetic counselors incorporate cultural issues into their counseling and how they rank cultural issues against clinical issues in clinical case scenarios. Understanding different cultures is vital to genetic counseling because cultural and ethnic beliefs can impact how genetic information is perceived and acted upon (Weil, 2001). A patient's culture can not only alter the meaning of the genetic information being given, but can also affect how that patient makes medical decisions (Weil, 2000). Although research has been conducted on how genetic counselors conduct sessions with patients from minority communities and how those patients interpret the genetic counseling sessions (Baldwin et al., 2012; Barlow-Stewart et al., 2006; Browner et al., 2003; Eichmeyer et al., 2005; Middleton et al., 2005; Weil, 2001), no prior research study has determined how genetic counselors rank cultural issues against the medical or emotional issues they encounter in clinical settings. The results of this study will benefit genetic counselors and culturally diverse patients by identifying if cultural issues are recognized, how they are ranked against other clinical issues, and how genetic counselors perceive how cultural issues impact the genetic counseling process.

2.3 Methods

2.3.1 Participants and design. Participants were invited through an invitational letter sent by email to members of NSGC (Appendix A). The invitational letter was entitled, "How Prenatal Genetic Counselors Organize Complex Clinical Issues". In order to reduce potential bias of counselors reporting socially desirable responses regarding

cultural sensitivity, the investigator did not disclose that the primary focus of the survey was to assess how genetic counselors rank cultural issues. Those prenatal genetic counselors who responded to the invitational email agreed to a verbal consent form before beginning the phone interview (Appendix B). A pilot study was first conducted to ensure the flow and completeness of the survey. Three prenatal genetic counselors, who were known to a committee member, were contacted by the principal investigator and asked to take part in a phone interview for the pilot study. The interview consisted of three prenatal genetic counseling case scenarios. The pilot study data was not used in the study. The survey flow and clarity were revised based on feedback from pilot survey participants.

All members of NSGC (2,847 people) were emailed the invitational letter and a subsequent reminder letter. In order to take part in the study, participants had to be members of NSGC, and currently practicing as prenatal genetic counselors. The phone interviews were conducted by the first author and recorded to make transcription possible and to ensure that the quality of the data could be monitored. The recordings were transcribed manually by the first author without any identifying information other than the responses to demographic questions.

Both phases of the study (the pilot and the main study) were approved by the Institutional Review Board at the University of South Carolina in August, 2012.

2.3.2 Survey instrument. The survey was created by the principal investigator with discussion from the committee after reviewing the pertinent literature. Interviews averaged approximately 30 minutes during which time the principal investigator took notes on participant responses with which to guide the discussion. The survey consisted

of demographic questions followed by three hypothetical prenatal case examples (Appendix C). The case examples contained cultural issues in the Deaf, Hispanic, and Indian cultures along with clinical prenatal genetic counseling issues. In the first case example participants were asked to identify what issues were important in an advanced maternal age (AMA) session, where the patient was concerned about the risk for Down syndrome, is in the first trimester, and both parents were Deaf. In the second case participants were asked what issues were important when counseling a 22 year-old Mexican woman who had a 1 in 8 risk for Trisomy 18 after second trimester screening. In the third case multiple soft signs for Down syndrome are found during a second trimester ultrasound in a 25 year-old patient from India. The patient refuses further testing because she is afraid of being blamed by her husband and family if the pregnancy is affected with Down syndrome. The patient says she will not tell her husband about the increased chance for Down syndrome.

For each case, study participants were asked to rank which issues were important to include in the agenda of the session. These responses determined if cultural issues were ‘important’ and how participants ranked cultural issues against clinical issues. After the three case examples, it was revealed that the focus of the study was how genetic counselors view the importance and impact of cultural issues. Follow-up questions after the three case examples asked questions concerning how cultural competency influenced participant interaction with culturally-different patients.

2.3.3 Data analysis. Since it was most important to seek a wide range of perspectives to gain insight into complex views, a qualitative approach was chosen. Responses were grouped by case example and follow-up question and coded by

participant number to identify which themes occurred with the highest frequency through descriptive analysis. Interviews as a whole were analyzed by the principal investigator to formulate themes manually and pertinent quotes were extracted to illustrate those themes. A committee member verified the analysis by reviewing the interview transcripts. A general thematic approach along the grounds described by Braun and Clarke was employed to identify themes in order to analyze the qualitative interviews (Braun & Clarke, 2006). Thematic analysis is a widely used, flexible method for detecting and analyzing themes in qualitative data (Braun & Clarke, 2006). Each interview was analyzed by question and each question response was compared across all participants. Topics that emerged within the answers became a category, and entire interviews from all participants were analyzed for similar topics. Topics that emerged as a pattern in the data became a theme. Two themes were sub-divided into sub-themes for clarity of analysis. Topics that emerged less frequently than themes were either included as a point within a theme or became their own sub-theme, depending on the frequency of the topic. Identifying if cultural issues were recognized and how they ranked against other clinical issues was accomplished through descriptive analysis by determining the frequency of each issue mentioned and by asking participants what the most important issue to address in each case was. Determining how genetic counselors perceive how cultural issues impact the genetic counseling process was accomplished through general thematic approach.

2.4 Results

Seventeen prenatal genetic counselors responded to the email and sixteen took part in the phone interview ($N = 16$). The demographic information of the participants is included in

Table 2.1. All participants except one were female and all were of Caucasian ethnicity. Fifty-six percent of the participants had been practicing as prenatal genetic counselors for less than 10 years and 44% had been practicing for 10 or more years. On average, participants reported that an average of 38% of the patients they saw in prenatal genetics clinic belonged to a minority community (were not Caucasian), and an average of 16% of their patients did not speak English as their first language. Participants were also asked their comfort level with addressing cultural issues measured on a scale of 1-10, where 1 is uncomfortable and 10 is very comfortable. The participants' comfort level in recognizing cultural issues with patients in their clinic ranged from 5 to 10 with an average of 7.4.

Table 2.1 Participant Characteristics (N = 16)

Characteristics	<i>n</i> (%)
Age	
20-30	4 (25%)
31-40	7 (44%)
41-50	1 (6%)
50 +	4 (25%)
Gender	
Female	15 (94%)
Male	1 (6%)
Ethnicity	
Caucasian	16 (100%)
Years in Practice	
0-4	5 (31%)
5-9	4 (25%)
10-19	3 (19%)
20+	4 (25%)
Years in Prenatal Practice	
0-4	5 (31%)
5-9	4 (25%)
10-19	4 (25%)
20+	3 (19%)
Geographic Region	
1	1 (6%)
2	6 (38%)
3	3 (19%)
4	3 (19%)
5	0 (0%)
6	3 (19%)
% Minority Patients	
0-20	2 (13%)
21-40	8 (50%)
41-60	4 (25%)
61-80	2 (13%)
% Patients Whose First Language Was Not English	
0-10	8 (50%)
11-20	3 (19%)
21-30	4 (25%)
31-40	1 (6%)

Table 2.2 Important Issues to Address in Case Examples (N = 16)

Responses	<i>n</i>
Case 1	
Age-associated risk for chromosome abnormalities	15
Possible genetic contribution to deafness	15
Prenatal testing	12
Pedigree	9
If the parents' knew the cause of their deafness	9
Ethnic-based carrier screening	5
Parents' feelings about having a deaf child (Deaf culture)	4
Parents' feelings about their own deafness (Deaf culture)	2
Ultrasound	2
Newborn hearing screen	1
Advanced paternal age	1
Decision-making	1
Pregnancy continuation or termination options	1
Case 2	
Second trimester screen results	12
Further testing options	11
Decision-making	7
Ultrasound	7
Pregnancy continuation or termination options	6
Education about Trisomy 18	3
Pedigree	2
Ethnic-based carrier screening	2
Psychosocial issues	2
Case 3	
Testing options	8
Psychosocial issues	8
Etiology of Down syndrome	6
Ultrasound findings	6
Offering to speak with the husband	5
Risk estimate	5
Pregnancy continuation or termination options	3
Patient's cultural beliefs	3
Patient autonomy	2
Patient's feelings about a pregnancy with Down syndrome	1

When asked their concerns when counseling patients from cultural minorities, participants most often mentioned the challenges of working with non-English speaking patients (Table 2.3). Participants worried that the interpreter may not convey the information accurately, that the ideas would not translate well, and that the patient would not ‘get it’. Participants wanted to ensure that patients who did not speak English understood the information being conveyed so that they could make well-informed decisions. The second most frequent concern was the participant’s own biases about how a patient’s culture could lead to incorrect assumptions about the patient’s perception of the medical information.

Table 2.3 Concerns When Counseling Patients from a Cultural Minority (N = 16)

Concern	<i>n</i>
Language/interpreter barrier/ misunderstanding information	10
Avoiding personal biases	6
Not offending the patient	4
Cultural Barrier	2
Patient’s education level	2
Building rapport	2
True informed consent is obtained	2
Considering the patient’s religion	1

Five over-arching themes were identified from the analysis of the interview transcripts: the crux of the session, the significance of culture within a session, recognizing culture, connecting to the patient, and identifying the source of misunderstandings.

The Crux of the Session

Table 2.2 and Figure 2.1 show that in all three cases, educating the patient about their indication was the most frequent response. In the first case, only four participants mentioned discussing the patients’ feelings about deafness, and in the third case only

three participants mentioned addressing the patient’s Indian beliefs. No one mentioned addressing the patient’s Hispanic cultural beliefs in the second case. In the first case educational issues were mentioned 52 times while cultural issues were mentioned six times, and in the third case educational issues were mentioned 28 times and cultural issues were mentioned three times. After education, the most common responses were related to psychosocial issues, pedigree and medical history collection, and cultural issues, respectively (Fig. 2.1).

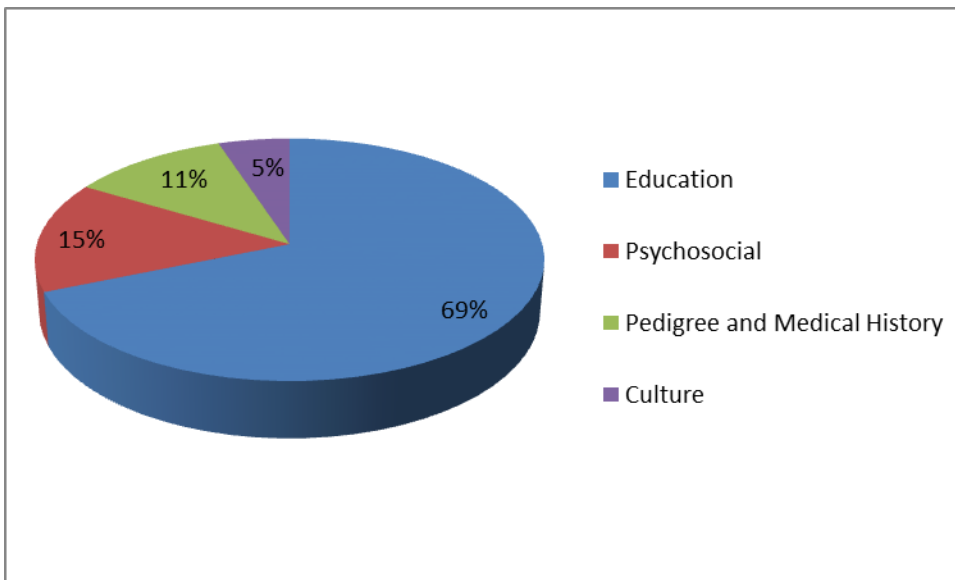


Figure 2.1 Distribution of types of participant responses regarding case examples.

Participants were asked what the most important issue to address in the three cases. In the first case, fourteen participants responded that the referral reason was the most important issue, which was also the patient’s concern (the age-related risk for Down syndrome). In the second case, ten participants responded that understanding the results of the second trimester screen was the most important issue. Participant #2 summarized, “Always the main reason, the main goal is to make sure they understand why they’re there”. Participant #6 answered, “My concerns are only what the patient’s concerns are. I

would address it in order of what the patient's biggest concerns are." In the third case, the most common response was addressing psychosocial issues. Participants realized that the patient must have already been educated about her options in order to come to a decision about her medical management and so psychosocial issues ranked the highest.

The Significance of Culture within the Session

Participants mentioned ways in which a patient having a different cultural background than the counselor would impact how the session was conducted. For example, in the third case, three of the participants mentioned exploring the patient's cultural beliefs, and two believed that it would be the most important aspect of the session.

I would probably want to explore the relationship between the wife and the husband and whether or not that's a normal attitude or thought-process in the culture, probably primarily, I think that would be my first concern... Explore her feelings of guilt and if that is typically in the culture and then say, well what would happen if the baby really does have a problem, would the feelings of guilt or blame be worse than it would be now? Would they want to stop the pregnancy? What would it actually mean for them to have a baby with Down syndrome? Because I know in an Indian culture, oftentimes disease is not viewed well, it's often a little bit shameful in the culture. So I'd want to make sure she focused not only on how she's going to feel during the pregnancy with this news, but what if the baby actually had a problem, how would she feel then, because then she has to take care of a child, especially for a lifetime (Participant #12).

Participant #14 felt that lacking knowledge about a patient's culture could negatively impact a session.

If you completely miss the mark and you're trying to educate them on something, if you miss the mark, they may not trust you or they may not understand you, or something is going to happen where there could be an adverse effect (Participant #14).

Two sub-themes were identified within the theme 'the significance of culture within the session': patient individualization and reasons not to address a patient's culture.

Patient Individualization

Several participants responded that there was little or no difference when counseling a patient from an ethnic or cultural minority. These participants recognized that every patient is unique and that culture is only one aspect of every person's individuality that needs to be appreciated when counseling.

I don't really feel like my concerns for counseling people in a minority population are any different than counseling any patient. My concern is that they understand everything that's going on, all the different testing and the different repercussions for their family of the tests, and to help them make the best decision for them... I feel like every session is a little bit different because every patient is a little bit different and that includes personalities, culture, age, intellect, and anything else that you want to throw in there. So culture is just one of those things that make people a little bit different (Participant #7).

Participant #9 put it this way:

Caucasians are not an ethnicity, and there are multiple ethnicities in the Caucasian population, so I can't say Caucasian Italian versus Caucasian Polish, you know they're all different, so I consider everybody is some sort of culture and I'm not up on, the only culture I truly understand is my own, which is a sub-Caucasian culture, so to say oh Caucasians would react like this and Asians would react like this and Hispanics would react like this, there's lots of different cultures that go into Hispanic and lots of different cultures that go into Asian.

Participant #2 did not believe that counseling someone from a cultural minority altered the way she counseled. "I think everybody's cultural beliefs are important to their decisions (Participant #2)." Participant #16 explained, "... It [understanding a patient's culture] can only take you so far and then every family is different. You can't necessarily make assumptions... so sometimes that's helpful a little bit, but I think it's very individual family to family".

Reasons Not to Address a Patient's Culture

Some participants believed that the issues in the case examples were not cultural and so culture did not need to be addressed. For example, in the second case, participants were asked if their concerns about speaking to the mother-in-law would be different if she were Caucasian instead of Mexican. Fourteen participants responded that their concerns would be the same while only two said they would be altered. As Participant #6 noted, "There are crazy mother-in-laws from all ethnic backgrounds" and Participant #7 reasoned, "Her concerns aren't related to her ethnic background, her concerns are based

on the findings and the risks associated with that and the procedure [amniocentesis]”. When discussing if addressing culture was important in the third case with the Indian patient, Participant #10 expressed “No. Because if a woman is in a relationship where she feels like her family or her husband’s family would blame her for birth defects then, that doesn’t make any difference what ethnic background you’re from.”

Participants discussed several reasons to avoid discussing cultural influences with a patient. When referring to the first case with the Deaf couple Participant #14 said that she would not address any cultural issues, “because they’ve lived in that world, that’s what they’re used to and I think they know more about that than I do.” This participant believed that she would not be able to add anything to the couples’ counseling experience by discussing Deaf culture since they clearly had a deeper understanding of Deaf culture than she did.

In some cases, participants did not seem to recognize that a patient’s response may have been influenced by their cultural beliefs so the participant did not feel the need to address it. At the end of the second case, the participants were told that the patient declined diagnostic testing saying, ‘if you aren’t recommending the testing, it must not be very important’. This example was used to see if participants would recognize that patients from different cultures may expect their healthcare providers to be directive about their medical management. Fourteen participants responded that they would review their nondirective role with the patient, while two responded that they would accept the patient’s decision to decline testing without further discussion.

Well, maybe that’s what her decision is. That may have given her an out, like giving her permission to say what she’s thinking she wants to do.

Giving her permission to act on her own feelings. Maybe she's looking for approval. I wouldn't argue with her (Participant #2).

Recognizing Culture

Participants appropriately recognized patient cultural beliefs and values in the case examples. Many participants recognized Deaf culture even though most did not specify discussing cultural beliefs as an important issue to include in their agenda. Six participants noted that there is a Deaf culture and four said that many Deaf individuals want deaf children and they would want to explore the parents' feelings about having a deaf child versus having a hearing child. Three participants mentioned that their Deaf patients typically did not want prenatal testing for deafness.

Five sub-themes were identified within the theme 'recognizing culture': family dynamics, role of providers in other cultures, acceptance or discomfort with patient culture, overcoming personal biases, and our role as genetic counselors in addressing culture.

Family Dynamics

Participants recognized how familial roles and relationships could differ between cultures. When the participants were asked if they would consider the role of family in decision-making important when responding to the mother-in-law in the second case, one participant mentioned the possible influence of the patient's Mexican cultural background. Participant #8 responded, "Yes, because I know that culturally there are a lot of people who rely on their parents, even when they are married, to help them with decisions or make decisions for them..."

Participant #4 said that she would have different concerns if the mother-in-law were Caucasian and mentioned the influence of Mexican culture. She responded, “She [the patient] may be more likely to consult other family members when making a decision compared to a Caucasian family (Participant #4).”

In the third case participants were asked if they would handle the case differently if the patient were Caucasian instead of Indian. Thirteen answered that they would not handle the case any differently, while three thought they might be surprised at that type of response in a Caucasian individual and would explore her feelings more. Participant #11 reasoned, “I would try a little bit harder I think with a Caucasian to make sure she’s not in an abusive relationship and that she’s secure, whereas I wouldn’t have thought to do that with an Indian couple”.

Role of Providers in Other Cultures

Four participants recognized the expectation in some cultures that the role of the healthcare provider is to be directive. “I think in my experience that’s more of a cultural thing, because I know in Hispanic cultures they rely more on directive management of medical cases, they look to the paternalists, because that’s what their medical system is, it’s very paternalistic (Participant #12).”

Acceptance or Discomfort with Patient Culture

While some participants discussed a cultural belief and how they would counsel within the parameters of that belief, others seemed uncomfortable with certain patient beliefs or values without trying to explore further. One participant mentioned that she was not always confident that she knew what the woman wanted to do if the man was the family’s decision maker.

...In Indian families... culturally often the husband is the decision-maker in the situation... I'm not always sure they [wives] acquiesce with [to] their husband's decision and I always encourage them to feel free to speak if there is something they would like to pursue, but I guess my point is that I'm not always sure again that I know their heart of hearts because I think that what they show me is not really what they've been discussing in the office because they'll lapse into Indian or some Asian language and have a conversation privately amongst themselves and then the husband announces what the decision is, so I'm not always privy to the whole conversation (Participant #11).

Another participant felt that part of being culturally sensitive meant allowing the husband to speak for his wife if that is part of the patients' culture.

I think you have to recognize it when you come to Middle Eastern, families who are Muslim. And this is where you see a lot of the decision-making is from the man, that he is talking for her and he is the one asking you questions and things like this. This is a very unique time that's pretty common as well in the genetic counseling session where you must take into account the cultural aspect that the man is in essence in charge, is the primary decision-maker. Because if you don't, you aren't going to get anywhere. You won't be able to provide care because they're not going to listen to you, they aren't going to take any of the information that you provide. You won't be able to do genetic counseling unless you have an understanding that culturally this is how their family is, this is how their

family dynamics interact, and you have to work within that of course
(Participant #3).

Participant #10 agreed, saying, “Instead of thinking he’s being dominant and controlling of her, thinking this is how they were raised and this is how we need to do this session”.

One participant felt uncomfortable that some of her female patients did not vocalize more during a session.

Sometimes, husbands will come in very religious couples and they’ll do all the talking and you’re trying to get the woman to talk to you and it’s very difficult. She’s being oppressed right there in front of you in the room and you just have to try to do the best you can in those situations to make sure that the patients are understanding what you are saying (Participant #8).

Some participants mentioned ‘changing’ or ‘curing’ their patients’ cultural beliefs. “Her beliefs are important, you can’t discuss her beliefs and you obviously can’t change what her husband believes (Participant #7).” Participant #8 referred to how women belonging to an Indian culture can be blamed for having a child with a disability. “This is been something that’s centuries old, it’s not something that we can cure in one session.”

Another participant went so far to accept her patient’s culture that she did not correct scientific misinformation. The participants were told that the patient in the second case had been eating more meat in order to decrease the chance of Trisomy 18 in the pregnancy. While 15 participants answered that they would correct this misinformation, one participant mentioned that she would not:

I wouldn't want to discount the idea that doing something or eating something could prevent Trisomy 18 in the baby. I wouldn't want to kind of break that belief system... but I would want to be sensitive and have her realize what the risks and benefits of diagnostic testing would be given that there is a real possibility (Participant #4).

Overcoming Personal Biases

Participants mentioned being aware of common cultural beliefs, but some seemed reluctant to discuss these with patients in case the participant's personal bias did not reflect the patient's cultural beliefs. In the second case some participants were concerned about relying on their own biases about Mexican culture and advocated for treating every case individually.

There certainly is a stereotype and a bias... especially with Mexican ancestry that the culture is more of a family-driven dynamic, and this is true to some extent, but you really have to take every case for what it is and you have to throw out these biases to some extent... Maybe in the back of my mind I have a different understanding that this family is going through a lot of this together which is more stereotypical of their culture in Mexico, but no, it wouldn't change how I actually interact with them... You have biases and then you have understanding and biases I refer to that in kind of a negative connotation, like people who are Mexican they're Roman Catholic and they're not going to consider termination of pregnancy. This would be a bias that would affect how you counsel a patient, inappropriately I think (Participant #3).

Our Role as Genetic Counselors in Addressing Culture

Participants viewed their role as a genetic counselor differently in regards to understanding a patient's culture. Some participants felt that an integral part of genetic counseling lay in being able to understand patients from different cultures.

One of the big things as far as what genetic counselors can uniquely provide to medicine in general really has to do with not necessarily information but how the information is provided, how we counsel people. So, obviously you know doctors counsel people about a test or this or that, but really genetic counselors are experts or quite skilled at providing the information in such a way that patients can understand and process and make decisions on... there're a lot of smart people out there who can provide the information. But really the genetic counselor's true skill lies in how the information is provided taking into account culture, the complexities that are there and things like this. I think that's really where we, as a field, provide something that nobody else can, at least not as good as we do (Participant #3).

Participant # 12 stated, "I think part of our job as a genetic counselor is decision-counseling and decision-counseling can really only be done when you truly understand the thought-process that they have, and to know what their goal is with the decision-making process."

Another participant provided a nearly opposite perspective. When discussing how she would counsel the Indian patient in the third case who indicated that she would be blamed if her baby had an abnormality, Participant #9 said that she would refer the

patient to a social worker because this would be a long term issue and the social worker would have better tools to address it than a single genetic counseling session would.

Connecting to the Patient

Participants mentioned several strategies they would use to build rapport and trust with their patient if they were from a different cultural background than their own. Six participants felt that understanding a patient's culture helped them to better understand the patient's thought process and facilitated decision making. One participant felt that it help build rapport. There were four sub-themes identified in the theme 'connecting to the patient': empathy, asking questions, speaking the patient's language, and patient-driven agenda.

Empathy

Several participants felt that empathy was a valuable tool in connecting to the patient if they were not knowledgeable about a patient's culture.

I feel like having a genuinely open heart and making sure that patients know that they're supported and that I'll work with them carries a lot even though it might not be considered a cultural issue. I think the fact that they sense that I am interested and eager and trying to engage with them and to make sure that we are providing the best service to them, while I may not be privy to all of their cultural issues, I think sometimes they then will share that with me and I will learn more by the end of it (Participant #11). Because some of these people's lives are so difficult that we're just a drop in the bucket to the difficulties in their lives. We're just one small part of the whole, I mean they want healthy babies, there's no question,

desperately want healthy babies and I think that they see that we're trying to get them there (Participant #8).

Asking Questions

Three participants mentioned that it was impossible to understand everyone's cultural background, so knowing which questions to ask was important to understand the patient's perspective.

I don't think we can know everything... I try to understand as much as I can about other cultures... I can just ask open-ended questions to the patient and have them explain different things to me about what their life in their country was like and I try to just get information from them, nonthreatening, I try to just let them talk to me about their life and their culture and ... I find that helpful just to try and understand where they're coming from (Participant #8).

Participant #12 answered:

When I am talking to a culture that I am unfamiliar with, or where I know there are some differences that are significant from my own beliefs and cultures, I try to ask instantly and just be curious and say tell me more about why you feel that way.

Speaking the Patient's Language

Three participants mentioned that they were able to counsel in Spanish. I'm really glad I speak Spanish. It just helps to be able to make sure the patients are really understanding and getting all the information and they

feel comfortable asking me questions and just to be able to speak in their own language (Participant #5).

Patient-driven Agenda

A few participants mentioned that they would let the patient guide the agenda of the session in order to ensure that their concerns were being addressed and to avoid discussing information that the patient was not interested in. When referring to the first case Participant #11 said that she would guide her session and how much she discussed either the chance for deafness or achondroplasia based on the parents' "cultural concerns". Participant #7 said, "Any session I'm in I let the couple guide me for what they want the most information on". Participant #3 expressed a similar sentiment:

It really would be patient driven. Especially with deafness because people obviously don't die, you know you don't have miscarriages because of congenital deafness and both of them are quite unique patients simply because there's community, the Deaf community as well as Little People. There are organizations out there that stereotypically are fine people like themselves, so that has I think ramifications as well. And with the Deaf community you especially hear how this is not viewed as a disability, it's more of just a difference and so they may not be very interested in discussing the recurrence risk or genetic testing for deafness because this is just how they've lived their life and some people who are deaf hope to have a child who is deaf as well.

Identifying the Source of Misunderstanding

Since participants were not as knowledgeable about the culture of someone with a different background from themselves, they were not always sure about where to attribute misunderstandings or misinformation. Participants mentioned that they were not confident whether the misunderstanding had cultural origins or not. One participant that said she would have different concerns if the mother-in-law in the second case were Caucasian because she had less understanding of Hispanic culture than Caucasian culture.

I would feel like there's less room for misinterpretation certainly with both the language barrier and the culture barrier, because I think I would feel more comfortable if they were Caucasian... an incomplete understanding of her intentions may confound the problem, like it may just be that this is the way things happen in their culture, so I may feel, I might not have that uncertainty with a Caucasian family (Participant #12).

Another participant mentioned similar uncertainty when facing misinformation.

It'd be very difficult to say here is precisely where it's coming from... the misinformation could be from the culture, could be from yourself meaning your dealing with an interpreter so it could be a misinterpretation. So we use a word and it could be a word that doesn't quite mean the same thing in Spanish as it does in English. It could be misinformation from the internet, friends, [or] family. Again, it's hard to pinpoint where this underlying misconception is coming from. You can ask, you can say who told you or where did you hear this (Participant #3)?

2.5 Discussion

The ABGC description of the profession states that genetic counselors must recognize how a patient's cultural background influences their interpretation of the information provided and how that interpretation impacts their decision-making (ABGC, 2010). The purpose of this study was to gain a better understanding of how genetic counselors incorporate cultural issues into their counseling and how they rank cultural issues against clinical issues in clinical case scenarios. Study participants prioritized educating about the medical elements of the session higher than addressing how cultural issues might impact the perception of that education and listed educational elements of the session more frequently than addressing cultural influences. Participants recognized how cultural issues could affect the session but instead of relying on personal biases about culture, favored strategies that highlighted patient individualization. Several potential barriers to discussing patient culture were identified including concern of personal biases, concern about offending the patient, and feeling uncomfortable when the patients' cultural views are different from their own, for example gender roles and perception of assigning fault to the mother of a child with a birth defect.

The majority of participant responses to the first and second case example aligned more closely with Kessler's teaching model than Kessler's counseling model (Kessler, 1997). However, in the third case, when the patient had already expressed that she did not want further testing, participant responses more closely aligned with Kessler's counseling model by responding that psychosocial and cultural elements were important to explore in understanding how the patient came to that decision. In this case, participants perceived that education issues had likely already been explored with the patient in order

for her to decline testing. This demonstrates that the participants valued both elements of the teaching and counseling model, but that participants believed education should precede counseling so that the patient understands why they have been referred to genetic counseling. The teaching model espouses that cultural issues are secondary to the medical issues, unless the patient's culture directly impacts communication with the counselor or the client's genetic risk factors while the counseling model of practice emphasizes the emotional impact created by the information discussed in the session (Kessler, 1997). A genetic counselor using the teaching model may believe, regardless of cultural background, the client will make an informed decision if properly educated by the counselor (Lewis, 2002). Some counselors may feel that as long as they are open and genuine with their patients and they provide an emotionally non-threatening environment to discuss their feelings, that addressing the patient's cultural background may not be necessary. A genetic counselor using the counseling model strives to understand the client's cultural perspective in order to help a patient arrive at an informed decision. Education is not the end goal, but rather a means to help the patient incorporate the information into their own belief system (Kessler, 1997).

Our participants recognized that cultural competency does not solely come from understanding a patient's culture. Participants mentioned strategies for connecting with their patients that were similar to those espoused by Middleton et al. (2005) and Barlow-Stewart et al. (2006). These authors and our participants expressed that it would be impossible to learn every medically pertinent fact about every culture and that striving for cultural competence may simply mean knowing which questions are important, being aware of cultural differences, and being empathic to them. This method of gaining a

patient's insight mitigates the risk of offending a patient by assuming incorrect information and genetic counselors can gain personal insight into their patients' experiences instead of relying on cultural generalizations. Weil describes these ideals as, "establishing and maintaining trust, the essential need to respect the counselee's healthcare beliefs and practices, and the necessity of understanding the impact of culture on the process of decision making and on counselee's responses to nondirective counseling" (Weil, 2001, p. 143). Several participants mentioned these strategies and found them helpful because detailed prior knowledge of the patient's culture was not essential and so a genetic counselor could build rapport with a patient from any culture.

Participants mentioned several reasons why they would not discuss culture with a patient. A few participants mentioned that they considered the patients' familial interactions to be independent of their culture and so discussing culture was irrelevant to these relationships. As introduced early in this thesis, the term culture can be defined as the values, goals, expectations, beliefs, perceptions and behaviors of a group of people who share similar origins, customs, and styles of living (Randall-David, 1989). Some of the participant responses provide evidence that genetic counselors may be overlooking the cultural influences of a patient since familial values are a part of a person's culture. When referring to the Deaf couple, another participant expressed that she did not want to appear to teach the couple something that they were experts of and that what the participant could discuss about Deaf culture would not be of any help to the couple. However, what this participant perceived as a barrier could be an opportunity for personal growth by asking the couple questions about their feelings about deafness and their chance for having a deaf child. Although the couple is bound to know more about Deaf

culture than the genetic counselor, genetic counselors have the skills and training to counsel the couple on their feelings regarding their perceptions of deafness.

Participants mentioned being aware of common cultural beliefs, but some seemed reluctant to raise these beliefs for discussion in case the patient did not share those beliefs. Participants recognized the dangers of personal biases such as those described by Hunt & de Voogd (2005) where providers who assumed Hispanic patients would never terminate a pregnancy provided incomplete information about the option of amniocentesis. This concern about personal biases may have been a barrier because participants may have worried that if their understanding of the culture was incorrect or if a certain cultural belief was not held by their patient, they may damage their rapport or offend the patient. This barrier was also seen when participants were told that a patient had been eating more meat in order to decrease the chance of Trisomy 18 in the pregnancy. As in the study by Browner et al. (2003), one genetic counselor in our study advocated against correcting the patient for fear that she would, “break that belief system”. Browner et al noted, “Counselors are wary of addressing the mistaken beliefs of their clients when those misapprehensions appear to be rooted in the client’s ethnic or cultural background” (Browner et al, 2003, p. 1939). The authors later argue that, while counselors may be hesitant to challenge a patient’s cultural belief for fear of harming their rapport, rapport is only a tool used to meet the goals of the genetic counseling session which include education and correcting misconceptions (Browner et al., 2003).

Another barrier to cultural competency may be a discomfort with cultural beliefs that are in contrast to the counselor’s value system. Specific examples included husbands who are expected to fulfill a decision-making role in the marital relationship, which may

be in conflict with the value of patient autonomy, or where mothers are blamed for unexpected pregnancy outcomes by their spouses and families. Three participants used negative language when describing familial interactions and cultural beliefs including “she’s being oppressed”, “you can’t change”, and “it’s not something we can cure” which are contrary to Weil’s (2001) ideals for cultural competency. The difference between gender roles in Caucasian and Middle Eastern cultures specifically seemed to present an emotional conflict for several counselors.

There were several limitations to this study. Only 16 prenatal genetic counselors were interviewed and their responses may not be representative of the opinions of the whole field. Whether the findings were representative of the wider genetic counseling community could be tested in a larger quantitative study at a later time. The participant sample was rather homogenous, with only one male and no participants from racial-ethnic minority populations. However, the genetic counseling community in the U.S. is also quite homogenous so the sample may be representative in this respect. Additionally, the participants were not responding to actual cases, but hypothetical cases without conducting an actual session. It is possible that elements would have been addressed in actual sessions that were not mentioned as important in response to the hypothetical cases. However, these findings are still valuable in showing the differences in the amount of consideration given to cultural and non-cultural issues. Since only three cultures were used in the case examples, the response data is for the most part limited to these cultures.

One strength of the study was that the primary focus of the survey was to assess how genetic counselors rank cultural issues was not disclosed until the end of the study, so potential bias of counselors reporting socially desirable responses regarding culturally

sensitivity was avoided. Another strength was the range in the levels of experience in the participants and the diversity of their geographic locations.

Several participants showed recognition of their limitations and room for professional growth in cultural competence. At the end of the interview Participant #4 disclosed, “After this survey, I feel like I should pay a little more close attention”. Participant #9 remarked, “I’m going to be honest, I think there’s some cultural stuff that I totally miss”. These comments and the results obtained demonstrate that further research is needed to explore the skills used by genetic counselors in cross cultural genetic counseling sessions, and their perceived comfort and limitations. In addition, further research is needed to explore the perceptions of clients as to whether their cultural needs are being met within the context of genetic counseling sessions. This research could observe actual cases with a greater number of participants and receive feedback from patients. Cultural competence will continue to improve by continuing to educate our healthcare professionals and by supporting research aimed at identifying ways to reduce disparities between cultural minorities (Nelson, 2002).

2.6 Conclusions

The goal of the study was to determine how prenatal genetic counselors perceive the importance of cultural influences in prenatal genetic counseling. Participants listed educating about the patient indication more frequently than addressing cultural issues when they were asked what issues they would deem important to include in each hypothetical prenatal case example. Many participants recognized the potential cultural influence in the case examples and favored strategies that did not rely on their own assumptions about a patient’s culture such as establishing trust, empathizing, showing

respect for the patient's culture, and asking pertinent questions in order to gain insight into how a patient's culture may impact their medical decision-making. The strategies mentioned focused on patient individualization instead of assuming the patient's cultural beliefs based solely on belonging to a particular minority population. Of course, these are tools genetic counselors use with all patients regardless of a patient's cultural background. Many times participants did recognize cultural issues in the case examples, but concerns about personal biases of cultural beliefs not aligning with the actual beliefs of the patient and about offending the patient were barriers to discussing culture with the patient. Sometimes culture was not discussed because the participant did not realize the patient's responses reflected a cultural belief. This study demonstrates that further research is needed to explore the skills used by genetic counselors in cross cultural genetic counseling sessions, and their perceived comfort and limitations. In addition, further research is needed to explore the perceptions of clients as to whether their cultural needs are being met within the context of genetic counseling sessions.

Chapter 3: Conclusions

The goal of the study was to determine how prenatal genetic counselors perceive the importance of cultural influences in prenatal genetic counseling. Participants listed educating about the patient indication more frequently than addressing cultural issues when they were asked what issues they would deem important to include in each hypothetical prenatal case example. Many participants recognized the potential cultural influence in the case examples and favored strategies that did not rely on their own assumptions about a patient's culture such as establishing trust, empathizing, showing respect for the patient's culture, and asking pertinent questions in order to gain insight into how a patient's culture may impact their medical decision-making. The strategies mentioned focused on patient individualization instead of assuming the patient's cultural beliefs based solely on belonging to a particular minority population. Of course, these are tools genetic counselors use with all patients regardless of a patient's cultural background. Many times participants did recognize cultural issues in the case examples, but concerns about personal biases of cultural beliefs not aligning with the actual beliefs of the patient and about offending the patient were barriers to discussing culture with the patient. Sometimes culture was not discussed because the participant did not realize the patient's responses reflected a cultural belief. This study demonstrates that further research is needed to explore the skills used by genetic counselors in cross cultural genetic counseling sessions, and their perceived comfort and limitations. In addition,

further research is needed to explore the perceptions of clients as to whether their cultural needs are being met within the context of genetic counseling sessions.

References

- ABGC. (2010). Required criteria for graduate programs in genetic counseling seeking accreditation by the American Board of Genetic Counseling. 1-26. Retrieved from http://www.abgc.net/docs/REQUIRED_CRITERIA_final_5-18-10.pdf
- Adams-Spink, G. (2004). NHS 'failing' deaf patients. Retrieved from <http://news.bbc.co.uk/1/hi/health/3527099.stm>
- Awwad, R., Veach, P. M., Bartels, D. M., & LeRoy, B. S. (2008). Culture and acculturation influences on Palestinian perceptions of prenatal genetic counseling. *Journal of Genetic Counseling, 17*(1), 101-116. doi: 10.1007/s10897-007-9131-2
- Baldwin, E. E., Boudreault, P., Fox, M., Sinsheimer, J. S., & Palmer, C. G. (2012). Effect of pre-test genetic counseling for deaf adults on knowledge of genetic testing. *Journal of Genetic Counseling, 21*(2), 256-272. doi: 10.1007/s10897-011-9398-1
- Barlow-Stewart, K., Yeo, S. S., Meiser, B., Goldstein, D., Tucker, K., & Eisenbruch, M. (2006). Toward cultural competence in cancer genetic counseling and genetics education: lessons learned from Chinese-Australians. *Genetics in Medicine, 8*(1), 24-32. doi: 10.109701.gim.0000195884.86201.a0
- Barnett, S., & Franks, P. (2002). Health care utilization and adults who are deaf: Relationship with age at onset of deafness. *Health Services Research, 37*(1), 103-118.
- Bhokal, A. K., & Brunger, F. (2010). Prenatal genetic counseling in cross-cultural medicine: A framework for family physicians. *Canadian Family Physician, 56*(10), 993-999.
- Boudreault, P., Baldwin, E. E., Fox, M., Dutton, L., Tullis, L., Linden, J., . . . Palmer, C. G. (2010). Deaf adults' reasons for genetic testing depend on cultural affiliation: results from a prospective, longitudinal genetic counseling and testing study. *Journal of Deaf Studies and Deaf Education, 15*(3), 209-227. doi: 10.1093/deafed/enq012
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

- Browner, C. H., Preloran, H. M., Casado, M. C., Bass, H. N., & Walker, A. P. (2003). Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients. *Social Science & Medicine*, *56*(9), 1933-1946.
- Chin, T. M., Tan, S. H., Lim, S. E., Iau, P., Yong, W. P., Wong, S. W., & Lee, S. C. (2005). Acceptance, motivators, and barriers in attending breast cancer genetic counseling in Asians. *Cancer Detection and Prevention*, *29*(5), 412-418. doi: 10.1016/j.cdp.2005.06.009
- DeNavas-Walt, Carmen, Proctor, B., & Smith, J. (2011). *Income, Poverty, and Health Insurance Coverage in the United States: 2010*. Washington, DC: U.S. Government Printing Office.
- Derose, K. P., & Baker, D. W. (2000). Limited English proficiency and Latinos' use of physician services. *Medical Care Research and Review*, *57*(1), 76-91.
- Derose, K. P., Escarce, J. J., & Lurie, N. (2007). Immigrants and health care: sources of vulnerability. *Health Affairs (Millwood)*, *26*(5), 1258-1268. doi: 10.1377/hlthaff.26.5.1258
- Eichmeyer, J. N., Northrup, H., Assel, M. A., Goka, T. J., Johnston, D. A., & Williams, A. T. (2005). An assessment of risk understanding in Hispanic genetic counseling patients. *Journal of Genetic Counseling*, *14*(4), 319-328. doi: 10.1007/s10897-005-0759-5
- Emery, S., Burke, T. B., Middleton, A., Belk, R., & Turner, G. (2008). Reproductive liberty and deafness: Clause 14(4)(9) of embryo bill should be amended or deleted. *BMJ*, *336*(7651), 976. doi: 10.1136/bmj.39563.495741.80
- Enns, E. E., Boudreault, P., & Palmer, C. G. (2010). Examining the relationship between genetic counselors' attitudes toward deaf people and the genetic counseling session. *Journal of Genetic Counseling*, *19*(2), 161-173. doi: 10.1007/s10897-009-9272-6
- Glenn, B. A., Chawla, N., & Bastani, R. (2012). Barriers to genetic testing for breast cancer risk among ethnic minority women: an exploratory study. *Ethnicity & Disease*, *22*(3), 267-273.
- Gupta, J. A. (2010). Exploring Indian women's reproductive decision-making regarding prenatal testing. *Culture, Health & Sexuality*, *12*(2), 191-204. doi: 10.1080/13691050903429316
- Halbert, C. H., Kessler, L. J., & Mitchell, E. (2005). Genetic testing for inherited breast cancer risk in African Americans. *Cancer Investigation*, *23*(4), 285-295.

- Harris, J., & Bamford, C. (2001). The uphill struggle: Services for deaf and hard of hearing people- issues of equality, participation and access. *Disability and Society*, 16(7), 969-979.
- Hauck, L., & Knoki-Wilson, U. M. (1996). *Culture of Native Americans of the Southwest*. Baltimore: Johns Hopkins University Press.
- Hunt, L. M., & de Voogd, K. B. (2005). Clinical myths of the cultural "other": implications for Latino patient care. *Academic Medicine: Journal of the Association of American Medical Colleges*, 80(10), 918-924.
- Julliard, K., Vivar, J., Delgado, C., Cruz, E., Kabak, J., & Sabers, H. (2008). What Latina patients don't tell their doctors: a qualitative study. *Annals of Family Medicine*, 6(6), 543-549. doi: 10.1370/afm.912
- Kessler, S. (1997). Psychological aspects of genetic counseling. XI. Nondirectiveness revisited. *American Journal of Medical Genetics*, 72(2), 164-171.
- Kessler, S. (2001). Psychological aspects of genetic counseling. XIV. Nondirectiveness and counseling skills. *Genetic Testing*, 5(3), 187-191. doi: 10.1089/10906570152742227
- Kinney, A. Y., Gammon, A., Coxworth, J., Simonsen, S. E., & Arce-Laretta, M. (2010). Exploring attitudes, beliefs, and communication preferences of Latino community members regarding *BRCA1/2* mutation testing and preventive strategies. *Genetics in Medicine*, 12(2), 105-115. doi: 10.1097/GIM.0b013e3181c9af2d
- Koenig, C. J., Dutta, M. J., Kandula, N., & Palaniappan, L. (2012). "All of those things we don't eat": a culture-centered approach to dietary health meanings for Asian Indians living in the United States. *Health Communication*, 27(8), 818-828. doi: 10.1080/10410236.2011.651708
- Lane, H. (2005). Ethnicity, ethics, and the deaf-world. *Journal of Deaf Studies & Deaf Education*, 10(3), 291-310. doi: 10.1093/deafed/eni030
- Leroy, B., Veach, P. M., & Bartels, D. M. (Eds.). (2010). *Genetic Counseling Practice: Advanced Concepts and Skills*. Hoboken, NJ: John Wiley & Sons, Inc.
- Lewis, L. J. (2002). Models of genetic counseling and their effects on multicultural genetic counseling. *Journal of Genetic Counseling*, 11(3), 193-212.
- Marlow, L. A., Robb, K. A., Simon, A. E., Waller, J., & Wardle, J. (2012). Awareness of cancer risk factors among ethnic minority groups in England. *Public Health*, 126(8), 702-709. doi: 10.1016/j.puhe.2012.05.005

- Middleton, A., Ahmed, M., & Levene, S. (2005). Tailoring genetic information and services to clients' culture, knowledge and language level. *Nursing Standard*, 20(2), 52-56.
- Middleton, A., Emery, S., & Turner, G. (2010). Views, knowledge and beliefs about genetics and genetic counseling among deaf people. *Sign Language Studies*, 10(2), 170-196.
- Middleton, A., Hewison, J., & Mueller, R. F. (1998). Attitudes of deaf adults toward genetic testing for hereditary deafness. *American Journal of Human Genetics*, 63(4), 1175-1180. doi: 10.1086/302060
- Misra, R., Balagopal, P., Klatt, M., & Geraghty, M. (2010). Complementary and alternative medicine use among Asian Indians in the United States: a national study. *Journal of Alternative and Complementary Medicine*, 16(8), 843-852. doi: 10.1089/acm.2009.0517
- Mittman, I. S., & Downs, K. (2008). Diversity in genetic counseling: past, present and future. *Journal of Genetic Counseling*, 17(4), 301-313. doi: 10.1007/s10897-008-9160-5
- Modell, B., Harris, R., Lane, B., Khan, M., Darlison, M., Petrou, M., . . . Varnavides, L. (2000). Informed choice in genetic screening for thalassaemia during pregnancy: audit from a national confidential inquiry. *BMJ*, 320(7231), 337-341.
- Nelson, A. (2002). Unequal treatment: confronting racial and ethnic disparities in health care. *Journal of the National Medical Association*, 94(8), 666-668.
- NSGC. (2012). Professional Status Survey 2012 Complete Salary and Benefits Report. <http://www.nsgc.org/MemberCenter/LeadershipCenter/tabid/190/Default.aspx?EntryId=4245>.
- NSGC code of ethics. (1992). *Journal of Genetic Counseling*, 1(1), 41-43.
- Palmer, C. G., Martinez, A., Fox, M., Zhou, J., Shapiro, N., Sininger, Y., . . . Schimmenti, L. A. (2009). A prospective, longitudinal study of the impact of GJB2/GJB6 genetic testing on the beliefs and attitudes of parents of deaf and hard-of-hearing infants. *American Journal of Medical Genetics*, 149A(6), 1169-1182. doi: 10.1002/ajmg.a.32853
- Penchaszadeh, V. B. (2001). Genetic counseling issues in Latinos. *Genetic Testing*, 5(3), 193-200. doi: 10.1089/10906570152742236
- Perez-Stable, E. (1987). Issues in Latino health care. *The Western Journal of Medicine*, 146(2), 213-218.

- Quinn, G. P., McIntyre, J. Q., & Vadaparampil, S. T. (2011). Challenges in recruiting Mexican women for cancer genetics research. *Journal of Community Genetics*, 2(1), 43-47. doi: 10.1007/s12687-010-0032-y
- Randall-David, E. (1989). *Strategies for Working with Culturally Diverse Communities and Clients*. Bethesda: Association for the Care of Children's Health.
- Shaw, A. (2011). Risk and reproductive decisions: British Pakistani couples' responses to genetic counselling. *Social Science & Medicine*, 73(1), 111-120. doi: 10.1016/j.socscimed.2011.04.011
- Sheets, K. M., Baty, B. J., Vazquez, J. C., Carey, J. C., & Hobson, W. L. (2012). Breaking difficult news in a cross-cultural setting: a qualitative study about Latina mothers of children with down syndrome. *Journal of Genetic Counseling*, 21(4), 582-590. doi: 10.1007/s10897-011-9425-2
- Simmons, V. N., Jimenez, J. C., Castro, E., Litvin, E. B., Gwede, C. K., Vadaparampil, S. T., . . . Quinn, G. P. (2011). Initial efforts in community engagement with health care providers: perceptions of barriers to care for cancer patients in Puerto Rico. *Puerto Rico Health Sciences Journal*, 30(1), 28-34.
- Steinberg, A. G., Barnett, S., Meador, H. E., Wiggins, E. A., & Zazove, P. (2006). Health care system accessibility. Experiences and perceptions of deaf people. *Journal of General Internal Medicine*, 21(3), 260-266. doi: 10.1111/j.1525-1497.2006.00340_1.x
- Sussner, K. M., Jandorf, L., Thompson, H. S., & Valdimarsdottir, H. B. (2010). Interest and beliefs about *BRCA* genetic counseling among at-risk Latinas in New York City. *Journal of Genetic Counseling*, 19(3), 255-268. doi: 10.1007/s10897-010-9282-4
- Swanson, L. (1997). Cochlear implants: The head-on collision with medical technology and the right to be deaf. *Canadian Medical Association Journal*, 157, 929-932.
- Vadaparampil, S. T., McIntyre, J., & Quinn, G. P. (2010). Awareness, perceptions, and provider recommendation related to genetic testing for hereditary breast cancer risk among at-risk Hispanic women: similarities and variations by sub-ethnicity. *Journal of Genetic Counseling*, 19(6), 618-629. doi: 10.1007/s10897-010-9316-y
- Vadaparampil, S. T., Wideroff, L., Breen, N., & Trapido, E. (2006). The impact of acculturation on awareness of genetic testing for increased cancer risk among Hispanics in the year 2000 National Health Interview Survey. *Cancer Epidemiology, Biomarkers & Prevention*, 15(4), 618-623. doi: 10.1158/1055-9965.epi-05-0378

- Weil, J. (2000). *Psychosocial Genetic Counseling*. New York, NY: Oxford University Press.
- Weil, J. (2001). Multicultural education and genetic counseling. *Clinical Genetics*, 59(3), 143-149.
- Withrow, K. A., Burton, S., Arnos, K. S., Kalfoglou, A., & Pandya, A. (2008). Consumer motivations for pursuing genotyping testing and their preferences for the provision of genetic services for hearing loss. *Journal of Genetic Counseling*, 17, 252-260.
- Withrow, K. A., Tracy, K. A., Burton, S. K., Norris, V. W., Maes, H. H., Arnos, K. S., & Pandya, A. (2009). Provision of genetic services for hearing loss: results from a national survey and comparison to insights obtained from previous focus group discussions. *Journal of Genetic Counseling*, 18(6), 618-621. doi: 10.1007/s10897-009-9246-8
- Woodward, J. (1972). Implications for sociolinguistics research among the deaf. *Sign Language Studies*, 1, 1-7.

Appendices

Appendix A: Invitation Letter

Invitation to Participate: How Prenatal Genetic Counselors Organize Complex Clinical Issues

Dear Prenatal Genetic Counselor,

My name is Darcy Berry and I am a second year genetic counseling student at the University of South Carolina's School of Medicine. You are being invited to participate in a research study we are conducting for my graduate thesis project. The objective of this study is to assess and understand how prenatal genetic counselors organize and rank the clinical issues that they encounter.

This study is intended to benefit genetic counselors by analyzing how counselors organize their sessions with patients. It will reveal themes about how prenatal genetic counselors view various clinical issues and how they counsel cases that have several complex components. We believe that the study results will demonstrate how experienced prenatal genetic counselors organize the complex elements of a case into a cohesive session. As many genetic counselors have their own unique styles, we expect to encounter a variety of perspectives and organization models.

If you decide to participate, you will be asked to complete an anonymous qualitative survey over the phone asking a series of questions about how you rank various issues that you may encounter in clinic. Your verbal consent will be obtained before the survey begins. The survey should take approximately 30 minutes to complete. You do not have to answer any questions that you do not wish to answer and you can stop taking the survey at any time. The phone interview will be recorded to ensure accuracy and all identifying information will be deleted after the interview.

If you would like to participate in this survey, please call (727-251-3613) or email (berrydk2@email.sc.edu) me to schedule an appointment.

If you have any questions, or would like more information, please contact me (or my faculty advisor, Victoria Vincent), using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at 803-777-7095. Thank you for considering participating in my research project. Your input is invaluable, and we appreciate your time!

Darcy Berry, B.S.
Genetic Counseling Intern
University of South Carolina
School of Medicine
Genetic Counseling Program
2 Medical Park, Suite 103

Victoria Vincent, M.S.
Genetic Counselor
University of South Carolina
School of Medicine
Genetic Counseling Program
2 Medical Park, Suite 103

Columbia, SC 29203
phone: (727) 251-3613
berrydk2@email.sc.edu

Columbia, SC 29203
phone: (803) 545-5727
Victoria.Vincent@uscmed.sc.edu

Appendix B: Verbal Consent Form

Verbal Consent Form: How Prenatal Genetic Counselors Organize Complex Clinical Issues

Attn: Prenatal Genetic Counselor,

You are being invited to participate in an anonymous research study we are conducting for my graduate thesis project at the University of South Carolina's School of Medicine. The results of this project will be coded in such a way that your identity will not be attached to the final form of this study. This phone interview will be recorded. Your participation is voluntary. You may skip any questions that you do not feel comfortable answering and may stop participating at any time. The survey should take approximately thirty minutes. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at 803-777-7095. Do you consent to participate in this study?

Yes/No

Appendix C:

Demographics

Number of years in practice as a genetic counselor:

Number of years in prenatal practice:

Ethnicity: Caucasian, African American or Black, Hispanic or Latino, Asian, American Indian or Alaskan Native, Native Hawaiian or other Pacific Islander

Location of practice: State

Setting of practice: university medical center, hospital, private practice, industry

Age:

Case #1

A Caucasian couple who have both been deaf since birth come to the prenatal genetics clinic to discuss first trimester screening, with the aid of a sign language interpreter. The mother is prima gravid, 38 years old, and is in the first trimester. The mother is worried that her age will cause the baby to be at a higher risk for Down syndrome. The family history appears unremarkable and no one else in the family has any level of deafness.

What issues are most important to include in the agenda of the session?

Rank by which issues are most important in the session (the issues you would spend the greatest amount of time discussing with the patients).

What makes this issue have a higher ranking than this issue (cultural issue/psychosocial issue vs. non-cultural issue)?

Would your concerns be different if the couple had achondroplasia instead of deafness? In what ways (which issues would be most important)?

Rank by which issues are most important in the session (the issues you would spend the greatest amount of time discussing with the patients).

Case #2

A woman comes into prenatal clinic who is a 22 year old, G2P1 from Mexico. She was referred because her second trimester screen revealed a 1/8 risk of trisomy 18. She did not know why she was referred and is very upset about the news. You tell her, with an interpreter, about amniocentesis, and she is concerned about the risk of miscarriage. You discuss the benefits, limitations, and risks of diagnostic testing and her options if the test results were positive. She does not know what she would do if the test

came back positive and wished that her husband had taken off of work so that he could help her make this decision. She says she needs to go home and discuss her options with him. You set up a follow-up appointment in two days so that she can bring her husband.

What issues are most important to include in the agenda of the session?

Rank by which issues are most important in the session (the issues you would spend the greatest amount of time discussing with the patients).

What makes this issue have a higher ranking than this issue?

Two hours later you receive a phone call from the patient's mother-in-law in broken English. She is distressed and asks if the patient is going to, "kill her grandchild". You tell her that you are not at liberty to discuss any patient's case without their permission and the mother-in-law becomes angry. She wants to know the details of trisomy 18 and of the diagnostic tests.

What issues are most important when considering your response to the mother-in-law?

Rank by which issues are most important (the issues that will most impact how you respond to the mother-in-law).

What makes this issue have a higher ranking than this issue?

Do you consider the role of family in decision-making or patient rapport important when responding to the mother-in-law?

Would your concerns about your response to the mother-in-law be different if the family were a different culture, for example Caucasian? In what ways?

At the follow-up session she says that she has been eating more meat in order to increase her protein levels. She believes that this action is enough to decrease the chance of trisomy 18 in the pregnancy. To what do you attribute her course of action?

You explain the meaning of the low serum proteins to her and her husband with an interpreter. You ask her if this information changes her feelings about having diagnostic testing. She asks if you are recommending diagnostic testing, and you respond

that you are informing her of her options and want her to make the decision that is best for her and her family. She says that if you aren't recommending the testing, it must not be very important, and she decides not to pursue it. To what do you attribute her line of reasoning?

Case #3

A woman comes into prenatal clinic who is prima gravid, 25 years old, in the second trimester, and from India. She is referred to you for after finding multiple soft signs for Down syndrome including increased nuchal fold, intracardiac echogenic focus, and single umbilical artery. You give her the diagnostic testing options for aneuploidy and she responds that she just wants to wait and see when the child is born. You ask her how she came to this decision. She responds that if her husband finds out that there is something wrong with the baby, he will blame it on her and her family back in India will be ashamed of her. She says that the child could still be healthy and that she will not tell her husband of the ultrasound results.

Rank by which issues are most important in the session (the issues you would spend the greatest amount of time discussing with the patient).

What makes this issue have a higher ranking than this issue?

What issues do you think are the most important in the patient's decision not to have diagnostic testing?

What cultural beliefs do you consider to be important to her decision?

Would your response be different if she were Caucasian instead of Indian? How?

Other Questions:

Are any cultural issues important to discuss in the first case?

Are any cultural issues important to discuss in the second case?

Approximately, what percentage of patients do you counsel who are from a minority population (not Caucasian)?

Approximately, what percentage of patients do you counsel where English is not their first language?

What is your biggest concern when counseling patients from a minority population?

How much does understanding a patient's culture impact your ability to provide effective genetic counseling?

In what ways does understanding a patient's culture not impact your effectiveness as a genetic counselor?

What would you say your comfort level is in recognizing cultural issues with patients in your clinic on a scale of 1 to 10?

Comments:

Appendix D:

Table D.1

NSGC Regions

Region Number	Geographic Area
1	CT, MA, ME, NH, RI, VT, CN, Maritime Provinces
2	DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec
3	AL, FL, GA, KY, LA, MS, NC, SC, TN
4	AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario
5	AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask.
6	AK, CA, HI, ID, NV, OR, WA, British Columbia

(NSGC, 2012)