Pitfalls of Communication in a Genetic Counseling Session when Two Languages are Required

THESIS

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By

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Abstract

The provision of genetic counseling using interpreters remains a largely unexplored area, specifically how it can affect rapport building, verbal listening cues and impacts communication in a genetic counseling session. This study explored how both language and cultural differences contribute to how information is communicated and understood when genetic counseling is provided to Latino patients of low English proficiency. We hypothesized that there is a difference in the information that is passed in an English-speaking session when compared to a Spanish-speaking session medicated by an interpreter.

In our study, we focused on Spanish-speaking patients with low-English proficiency that identify with the Latino population. We explored how both language and cultural differences contribute to how information is communicated and understood in a Latino bilingual genetic counseling session. Utilizing a sample \( n=14 \) of prenatal patients who received genetic counseling because of their advanced maternal age, we show that that there are fundamental, qualitative differences in communication by both genetic counselor and patient in Latino bilingual sessions, as compared to English-speaking control sessions.
Genetic counseling sessions that were English-speaking were compared with recorded Spanish-speaking session with patients of low-English proficiency by using a quantitative communication analysis. The patients were asked to provide demographic information (verbally or in writing) and answer questions assessing understanding of the information discussed during the genetic counseling session (Appendix A). To achieve the latter, the patients were asked to repeat the main points of the session in their own words. The free response portion was offered as either written or spoken response based on patient comfort and offered at the end of the session. The study was approved by The Ohio State University Institutional Review Board (Protocol number: 2016B0147).

This study has shown that there is a difference in genetic counseling provision when comparing sessions where both the genetic counselor and the patient English with sessions where the genetic counselor speaks English and the patient primarily speaks Spanish and an interpreter is used to mediate. We have shown that there is importance for further evaluation and improving genetic counselling sessions when Spanish interpreters are involved. Our understanding of genetics will continue to grow along with greater utility of testing and decisions that need to be made based on test results. Genetic counselors will continue to find themselves in sessions where they do not share a common language with their patient, so the ability to work effectively with an interpreter is imperative to helping patients to receive the best health care possible. Language does not need to be a barrier in health care communication and patient care. By understanding the limits to our ability to fully provide genetic counseling services in multilingual sessions, we can seek ways to improve as a profession.
Dedication

This document is dedicated to my parents, John and Lynda, and my husband, Russell.
Acknowledgments

I would first like to thank my thesis advisor, Dr. Martinez, for his expertise and input throughout the process. Thank you to Allison Spitale for helping me formulate my study methods and spearheading the data collection. Thank you to Ana Morales for her assistance with writing and editing. Thank you also to Cassie Stratton, who transcribed and translated the Spanish transcripts. A special thanks to my supportive husband, Russell, who provided statistical analysis and assisted in editing. I am grateful for the patients, interpreters and genetic counselors at the OSU Maternal Fetal Medicine Clinic who participated in this study. Without their help, this project would not have been possible. I am also thankful for the support from my parents, Lynda and John who assisted in editing and the continued support of the rest of my wonderful family, Greg, Marie, Dallin, Aaron and Sterling, throughout this journey.
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Fields of Study

Major Field: Genetic Counseling
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A genetic counselor may be called upon for a wide range of activities, but an essential feature of any genetic counseling session is communication (Elwyn, Gray, & Clarke, 2000; Epstein et al., 1975). Effective communication is more than communicating a predetermined set of facts transmitted from the genetic counselor to the patient; it is instead communicating information tailored to the patient, their understanding, value system and needs at that time (Elwyn et al., 2000). Studies have found that the main elements of a genetic counseling session are education and counseling (Ellington et al., 2006). In 2011, Ellington analyzed a national sample of verbal health communication showing that effective genetic counseling sessions go beyond accurate explanations of complex medical history, requiring the counselor to respond to patient emotions and “understand communication behaviors” of the patient (Ellington, Kelly, Reblin, Latimer, & Roter, 2011). Genetic counselors are trained to address both health concerns and the psychosocial factors that go into decision making and the impact that a genetic condition may have on an individual, family and society (Epstein et al., 1975; Resta et al., 2006). Genetic counselors are important for patient decision making. They give patients the information necessary to make a decision that will be best medically and emotionally for
the patient (Elwyn et al., 2000). A strong emphasis in genetic counseling training is that of being non-directive, giving the patient the information needed to make a decision and feel satisfied knowing that they play an active role in their own health care. (Elwyn et al., 2000; Pieterse, van Dulmen, Ausems, Beemer, & Bensing, 2005). This is not a simple process. Much of it depends on the rapport that is developed through the session between genetic counselor and patient. This rapport allows the patient to feel that they are understood and that they are capable of making complex health decisions. Rapport is built early on in a conversation by the exchange of “pleasantries or chit-chat” before beginning to take the patient’s history or the medical physical exam (Medina, 2009). Disruption of that relationship can create a barrier in decision making. When patient and genetic counselor do not speak the same language, it is necessary to bring in an interpreter to facilitate communication. This removes the genetic counselor one step from the patient, and additional effort is required to reach an engaged level of communication with the patient.

Interpreters in Healthcare

In the United States, there are a growing number of patients in the healthcare system who are non-native English speakers (Hadziabdic & Hjelm, 2014). The 2015 US Census reports that there are over 350 different languages spoken in homes in the United States. Of the 291,484,482-total people surveyed, 60,361,574 (20%) report speaking another language than English at home. Moreover, 25,148,900 report speaking English “less than well”. Diversity in culture and language add a level of complexity to daily communication, and this complexity is magnified in communication pertaining to health
care and medical decisions. Importantly, it is predicted that more than 31 million Americans do not speak the same language as their primary health care provider (Woloshin, Bickell, Schwartz, Gany, & Welch, 1995). It is obvious that differences in language can create linguistic barriers in effective communication but it is not always equally recognized how the cultural differences can impact the effectiveness of communication in the health care setting.

Federal laws have been enacted with cultural and linguistic requirements for hospitals. The Civil Rights Act of 1964 states, “No person in the United States shall, on ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance” (Department of Justice, 1964). This includes exclusion or discrimination of care based on the language status of the individual. If a hospital receives funding from the government, it must provide interpreter services to patients. Patients, however, do have the right to refuse professional interpretation, and they can also elect to instead have a family member or friend interpret for them. (Office for Civil Rights, 2008). The Office of Minority Health created “National Standards on Culturally and Linguistically Appropriate Services” as a guide to help hospitals and healthcare providers ensure quality care to all within the diverse population of the United States (The Department of Health and Human Services, 2013). In addition, the Joint Commission on Accreditation of Healthcare Organizations has created a guide for hospitals to provide a more universal standard of care despite culturally and linguistically diverse patient populations (Wilson-Stronks & Galvez, 2007).
Many have suggested that to reach this goal we need to increase the number of bilingual health care professionals. They propose that this will improve the patient care that low-English proficiency speakers receive in the health care system (Ngo-Metzger et al., 2007). While this may be a solution in certain areas that have large populations of one or two immigration communities and languages, it is not currently feasible with over 350 languages spoken in the United States to staff each hospital with enough providers for every language that they may be required to serve. To bridge this gap, medical interpreters are used.

Medical interpreters are a specialized group of professionals. In the United States the number of employed interpreters is 61,000 according to the Bureau of Labor Statistics, part of the United States Department of Labor (U.S. Bureau of Labor Statistics, 2015). With the total number of U.S registered hospitals according to the AHA at 5,564, (“Fast Facts on US Hospitals,” 2017), there are 10 interpreters on average per major hospital. Interpreters are few in number and as such their job description requires them to interpret innumerable different medical interactions in the course of their career. There simply are not enough of them to specialize within medical fields. Healthcare providers must learn to relate and communicate effectively with the patient through the interpreter despite this challenge (Angelelli, 2004).

It is well-studied that interpreters do improve access to healthcare for patients with low-English proficiency in the United States by bridging a gap that is created by a language barrier (Eamranond, Davis, Phillips, & Wee, 2011; Flores, 2005; Karliner, Jacobs, Chen, & Mutha, 2007). However, a trained interpreter alone is not enough. The provider must
also communicate proficiently with the patient in this setting (Angelelli, 2004; Diamond & Jacobs, 2010; Hsieh, 2010).

Quantitative analysis of interpreter-mediated consultations in many specialties and different provider-patient interactions have been performed, though most extensively in the physician-patient interaction (Flores, 2000; Hadziabdic & Hjelm, 2014; Hudelson et al., 2013). These studies have revealed difficulties that can arise in a session where an interpreter is used to convey important information about treatments for medical conditions. In 2006, Browner studied the negative effects of poor communication in interpreter-facilitated genetic counseling sessions, concluding that many patients who have immigrated to the United States from Mexico do not participate in prenatal diagnostic or screening testing because of misunderstandings that occur.

Many studies have linked discordance in the provider and patient’s language with absence of meaningful or trusting relationships between provider and patient (Dunlap et al., 2015; Flores, 2005; Hsieh, 2010). When there is little trust established, patients are less inclined to ask questions (Dunlap et al., 2015) and often will not admit confusion over complicated terms or options presented by the provider. Absence of trust can result in further testing ordered by the provider that the patient neither understands nor wants (Bhogal & Brunger, 2010). This results in frustration on the part of the patient, and the provider remains unaware of the patient’s confusion.

Several studies have highlighted how clinicians often do not feel sufficiently trained to communicate with patients with low-English proficiency and as a result they do not effectively work with the interpreters in such sessions (Hsieh, 2010; Jacobs, Diamond, &
Stevak, 2010). Because of a lower comfort level in sessions that include an interpreter, topics of discussion like life-style choices can be left out (Eamranond et al., 2011), clinicians are less likely to talk in detail about risk numbers and screening plans (Dunlap et al., 2015) and clinicians are less likely to provide a referral to another specialty (Sarver & Baker, 2000). Providers are more comfortable talking in their native language about health issues not directly connected to the primary reason for the visit. Clearly, linguistic and cultural differences can create a barrier in health care (Escarce & Kapur, 2006).

Latino Culture

A cultural group is made up of individuals that share common beliefs, attitudes, values and behaviors. Individuals in this group can follow the group norm to different degrees. The way that a patient approaches their own health care is influenced by their personal experiences and the cultures with which they identify (Pérez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992). The parts of culture that impact health care can include language, values, beliefs of illness and treatment, and views of the role of a healthcare provider (Flores, 2000). Many studies of cross-cultural healthcare interactions focus on the cultural differences that influence patients’ decisions and the outcome of a healthcare visit (Hudelson, Dominicé Dao, Junod Perron, & Bischoff, 2013; Ngo-Metzger et al., 2007).

The term Latino refers to a diverse population of Latin American descendants including many nationalities and races. In 2009 Latinos made up nearly 16% of the U.S. population and were the largest minority group (Juckett, 2013). In a study conducted at the New York State Psychiatric Institute (NYSPI), which looked at a patient’s preferences for
making treatment decisions using the Control Preferences Scale and Problem Solving Decision Making Scale, it was found that those from the Latino-culture often take a passive role in decision making in their own healthcare interactions. (Patel & Bakken, 2010) According to the study, they tend to treat the medical provider as the authority on the subject, asking few questions and allowing the health care provider to make the ultimate decision (Juckett, 2013; Medina, 2009; Patel & Bakken, 2010). In a healthcare quality survey administered by the Department of Health Policy at George Washington University they found that compared to white Americans and African Americans, Latinos report feeling less understood by their doctors as well as less able to understand their doctors (Mead, Cartwright-Smith, Jones, Ramos, & Siegal, 2008; Peterson-lyer, 2008). Moreover, the study reported that they are two times as likely to leave the visit with unasked questions (Peterson-lyer, 2008). It has also been noted that responses of silence and noncompliance are not uncommon because when a patient is presented with a difficult health care option, they would rather maintain a polite relationship with the provider than disagree with the doctor’s advice or plan. (Baxley & Ibitayo, 2015; Peterson-lyer, 2008).

Another strong Latino cultural belief is that of fatalism. Fatalism is the belief that individuals cannot do much to alter their own fate (Chong, 2002; Flores, 2000). In a survey of 844 Latino adults and 510 Anglos adults discussing knowledge and attitudes towards a cancer diagnosis in both Latino and Anglo adults, it was shown that Latinos who receive a cancer diagnosis are more likely than Anglos to believe that cancer is a death sentence and that cancer is a punishment from God (Pérez-Stable, Sabogal, Otero-
Sabogal, Hiatt, & McPhee, 1992). Of the Latino patients surveyed in the study, 35% stated that they would prefer not to know if they had cancer and that they believe there is little a person can do to prevent cancer (Pérez-Stable et al., 1992). This belief can cause a passive response or cause the patient to feel powerless when faced with disease or disability (Medina, 2009). Another key cultural belief on Latinos that manifests in healthcare interactions is that of respect. In the words of Flores, “deferential behavior is expected on the basis of a position of authority, age, gender, social position, or economic statutes” (Flores, 2000). Health care providers are viewed as authority figures to which respect is due (Medina, 2009; Peterson-lyer, 2008). This respect may lead to fewer questions asked in a session and decreased verbal interaction when the provider is speaking, because questioning or interrupting an authority figure may be viewed as disrespectful (Flores, 2000).

In a Latino culture pregnancy is seen as a natural and respected occurrence, life is seen as a gift (Browner & Preloran, 2000) (Chong, 2002). This can cause Latino patients to not seek prenatal care until later in a pregnancy (Browner, Mabel Preloran, Casado, Bass, & Walker, 2003; Browner & Preloran, 2000) and to refuse prenatal testing at a higher rate than other cultural groups in the United States (Browner, Preloran, & Cox, 1999). The belief that pregnancy is natural, along with the belief of fatalism and respect can impact communication in a health care setting between a Latino patient and a provider.

The provision of genetic counseling using interpreters remains a largely unexplored area, specifically how it can affect rapport building, verbal listening cues and impacts communication in a genetic counseling session. This study explored how both language
and cultural differences contribute to how information is communicated and understood when genetic counseling is provided to Latino patients of low English proficiency. We hypothesized that there is a difference in the information that is passed in an English-speaking session when compared to a Spanish-speaking session mediated by an interpreter.
Chapter 2: Methods

Study Design

Genetic counseling sessions that were English-speaking were compared with recorded Spanish-speaking session with patients of low-English proficiency by using a quantitative communication analysis. The patients were asked to provide demographic information (verbally or in writing) and answer questions assessing understanding of the information discussed during the genetic counseling session (Appendix A). To achieve the latter, the patients were asked to repeat the main points of the session in their own words. The free response portion was offered as either written or spoken response based on patient comfort and offered at the end of the session. The study was approved by The Ohio State University Institutional Review Board (Protocol number: 2016B0147).

Study Participants

Participants for this study were consented at the time of their prenatal genetic counseling appointment at the Ohio State University Fetal and Maternal Medicine Clinic. Participants had to be 18 years or older and pregnant at the time of the appointment. Both English and Spanish speaking participants were consented for the study. Our sample size consisted of seven Spanish participants and seven English participants. Other quantitative communication analyses in a literature search show that 13 (Hadziabdic 2014), 12-24
(Seale 2013) and 8 (Hudelson 2013) recorded and analyzed sessions have provided sufficient data to draw appropriate conclusions. Thus, this sample size falls within the sizes shown in literature to be sufficient for data collection.

Measures

Each participant was offered the opportunity to participate before the session began. They were given a written consent form in their native language and the form was reviewed with the participant with the counselor and interpreter as needed. There was time for questions and clarification. If they declined, the session proceeded normally. If they consented and they signed the consent form, a recorder was turned on and the session proceeded normally. At the end of each session the participant was given the demographics and assessment of genetic counseling session understanding survey in their native language and then given time alone to complete the survey either in writing or verbally, by speaking their answer into the audio recorder that was provided for that purpose.

These audio files were then collected and transcribed for ease of analysis. The sessions were transcribed and the Spanish portions were translated.

Data Analysis

Dialogue Analysis

The dialogues were analyzed in regards to how clearly information was passed and received by the participant. The sessions were also evaluated for content and questions asked during the session. Common themes in each session were noted along with the length of phrases, time spent in a session and words spoken during the session. An
analysis of back-channeling, where the listener responds (verbally or non-verbally) without taking over the flow of conversation from the current speaker (Lambertz, 2011), was used during the genetic counseling sessions to evaluate the level of engagement that each party, both genetic counselor and patient, were participating. As our data was collected in audio-form, the evaluation took place only on verbal back-channels. We analyzed the three known back-channeling categories for this study: vocalized sounds with little or no meaning, like “mhm or uhaha”; expressions of agreement or evaluation, like “right” or “really”; and repeating or clarifying the statements the listener hears (Gardner, 2001; Lambertz, 2011).

Survey Analysis

The information from the assessment of genetic counseling session was important for understanding the effectiveness of the information that was given by the provider and what was understood by the patient. Statistical analysis consisted of t-tests comparing English-speaking and Spanish-speaking sessions in a two-sample model assuming unequal variances.
Chapter 3: Results

Patients were offered the chance to participate upon arriving at the genetic counseling session, 14 women during our period of data collection agreed to participate in the study. In their survey responses, six participants wrote the answers to the long response and nine vocally responded into the recorders for their answers. We had a 100% compliance in those recruited to participate.

We analyzed 14 genetic counseling sessions. Seven of the recorded sessions included an English speaking genetic counselor and a Spanish speaking patient with an interpreter mediating. The other seven sessions included an English speaking genetic counselor and an English-speaking patient. All 14 sessions were physician referrals for women who were known to be pregnant. All the women in the study had been referred for advanced maternal age, during which information on potential pregnancy risks based on age and testing options to personalize those risk figures for the current pregnancy were discussed.

Demographic Results
Demographic survey data is provided in Table 1. All participants at the time of the study were living in and planning on delivering their child in the United States. The majority of Spanish-speaking participants recorded Mexico as their country of origin, while five of the English-speaking session participants had lived in the United States their entire lives.
For thirteen of the fourteen participants, this was not the first pregnancy. For two of the Spanish-speaking sessions this was the first child that would be born in the United States.

There was a difference in marital status of the participants: 71.4% of the Spanish-speaking participants reported being currently married while only 28.6% of the English-speaking participants reported currently being married. The majority of English-speaking participants (42.9%) reported that they have never been married.
Lived in the United States for:< 1 year     1  1  0
1-5 years         1  1  0
5-10 years        4  3  1
>10 years         3  2  1
All their life     5  0  5

Number of children born in the United States: This the first is
1                          3  1  2
2                          3  1  2
3                          3  3  0
4                          1  0  1

Highest grade or year of school completed: Elementary     1  1  0
Some High School         1  1  0
High School graduate     6  3  3
Some college or technical school     3  1  2
College graduate         2  1  1
Graduate school          1  0  1
Married                  7  5  2
Separated                3  2  1
Never been married       3  0  3
Divorced                 1  0  1
Employed for wages       9  5  4
Out of work more than a year     1  1  0
Out of work less than a year     1  0  1
Homemaker                3  1  2

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Figure 2: Demographics of the Participants

Participants had a similar distribution of education in both the English and Spanish-speaking session. The majority of our participants (85.7%) graduated high school, with three Spanish-speaking participants and three English-speaking participants noting this as their highest level of education. There were two Spanish-speaking participants who had
not graduated from high school, and one of these three reported having attended some high school.

A similar working background was also noted, with 64.2% identifying as “working for wages.” Among these participants, five were Spanish and four English speakers. There was a small number (n=5) of Spanish and English participants who considered their work “homemaking” or identified themselves as “out of work”.

Main Study Themes

Four main themes arose from the data regarding communication: (a) Rapport Building, (b) Information Sharing, (c) Decision Making, and (d) Conversational Engagement.

Rapport Building

We evaluated the beginning of each session for the first question asked of the participant to gauge the information that each patient came in with and to see how the opening question affected the rest of the session. All of the participants came into the session knowing that they were getting an ultrasound. As graph 2 shows, only six, two Spanish-speaking and four English-speaking participants, of fourteen (40%) knew that they were there because they were over 35 years old. Only one Spanish-speaking participant and two English-speaking participants knew that along with age, another purpose of the session was to talk about other testing options (Graph 3).
Percent of patients who knew they were referred because they were over 35 years old

- Didn’t know 57%
- Knew 43%

- Spanish
- English

Figure 3: Patients who Knew they were Referred for being over the Age of 35
Figure 4: Patients who Knew they were Referred to Talk about Testing Options

As part of contracting, six of seven Spanish-speaking participants were asked in the beginning of the session why they had come to the appointment that day or what their doctor had told them about the visit. Spanish-speaking participant MC2 was asked, “What's your understanding about what we're going to talk with you about today?” UA10, also Spanish-speaking, was asked, “I just wanted to start by hearing from you what your doctor told you about why you would be meeting with genetics today.” In only one of the English-speaking sessions did the participant get asked if she understood why she had come. In that session, the patient had already received an abnormal quad-screen result and was coming in to discuss those results.
On the other hand, questions about the patient’s understanding of the reason for the visit were less frequent in the English-speaking sessions. In these sessions, (71%) of the sessions began with questions on how the pregnancy was going. Four of the Spanish-speaking sessions did not include a direct question inquiring about how their pregnancy was going during the entire session.

This excerpt from the beginning of English-speaking session UA1 show how this open-ended question allows the participant to tell a story:

GC: So how is the pregnancy going so far?
Patient: Pretty good so far, in the beginning I was a lot more nauseous than I was with him [speaking of son in the room]
GC: Ok
Patient: And this one is calmer than he was, sometimes it scares me cuz I was so use [sic] to him. He was awake like every 2 hours and I mean from with him I started feeling him move like at 12 weeks it felt like a little fishy is moving in you, little kind of butterflies

GC: Ahuh
Patient: And then he'd be all over me, this one I feel him move or like the little sometime it'll be a strong feeling right up there rolling or something

The following excerpt from the beginning of a Spanish-speaking session UA10 show how the opening question does not invite the same kind of story telling response from the patient:
GC: I just want to start by hearing from you, what your doctor told you about why you would be meeting with genetics today

Interpreter: Sólo quiero escuchar de Usted de que le dijo el médico de porque se va a reunir hoy

Patient: Oh, por me van hacer um, el ultrasonido

Interpreter: ¿Cómo?

Patient: Me van hacer ultrasonido

Interpreter: They're going to do an ultrasound

GC: Ok, did your doctor talk to you at all about screening for chromosome problems?

Interpreter: ¿El médico le ha hablado de detecciones de problemas de cromosoma?

Patient: No

Interpreter: No

GC: Okay

The patient is asked questions to ascertain facts. Storytelling is not solicited as it is in the English-speaking session, and she responds with short, factual answers for the questions she was asked. The opening question in the English-speaking session is open ended while the Spanish-speaking session opening question is not open ended.

*Information Sharing*

There was no statistically significant difference in the length of the sessions between Spanish-speaking (mean 34.88 minutes) and English-speaking sessions (mean 29.88 minutes) (p>0.05). While the session length was comparable, the amount of information exchanged was not. The English-speaking sessions had a mean of 4798 words a session while the Spanish-speaking sessions had a mean of 2524 words in a session. By
comparing the total number of words spoken in English during a session with a Spanish speaker, English-speaking sessions involved significantly more words exchanged over the course of the conversation than Spanish-speaking sessions (p<0.001).

When we isolate the number of English words that were spoken by the patient in the English-speaking sessions and compare that to the number of English words the interpreter spoke on behalf of the patient during the Spanish-speaking sessions, the word count is significantly greater in the English-speaking sessions (p<0.05). The number of words spoken by a genetic counselor in the English-speaking sessions is significantly greater than in the Spanish-speaking sessions (p<0.0005). The percentage of words spoken by the genetic counselor compared to the total number of words spoken in a session is not statistically significant between the English-speaking and Spanish-speaking sessions. Genetic counselors speak the same percent of the time during both Spanish-speaking and English-speaking sessions, but they say more words and give more information in the English-speaking sessions.

Circumlocution is the presentation of an explanation after a term or concept is introduced. This technique is used with more frequency in the English-speaking sessions. An example of the genetic counselor introducing trisomy 13 and 18 in both a Spanish-speaking session and then an English-speaking session shows this difference below:

UA8-Spanish-speaking session;

GC: Besides this chromosome 21, the blood test also looks at the number 13 and 18
Interpreter: Menos la [sic] cromosoma 21, el estudio de sangre mira a número trece y dieciocho
GC: Some babies will get an extra copy of those chromosomes and these conditions are a lot more serious

Interpreter: Algunos bebés también pueden recibir una [sic] cromosoma extra y estas condiciones que son más complicados [sic].

GC: Most of these babies don't survive very long

Interpreter: La mayoría de estos bebés no viven, no sobreviven por mucho tiempo

GC: But they are pretty rare, definitely less than 1%

Interpreter: Pero son definitivamente raras, menos que un porcentaje.

GC: And then lastly the test will look at X and Y chromosomes

UA4 – English-speaking;

GC: um so yeah so the other numbered chromosomes that we look for are. So this is trisomy 18

Patient: Ok

GC: So there are three here at 18 and sometimes it is called Edwards syndrome.

Patient: Ok

GC: or Patau syndrome at 13 and these are the serious ones.

Patient: Ok

GC: So, babies with these usually don’t survive very long after birth if they make it through the pregnancy.

Patient: Ok

GC: So a normal ultrasound for these is much more reassuring because they are much more serious. We usually do see things on a scan.

Patient: What kinds of things do you usually see on a scan?

GC: All kinds of things anything from growth problems in the baby …
Patient: Ok

GC: Heart defect brain abnormalities, clefts in the brain clefts in the lips, clubbed, clenched hands. I mean there are a whole range of things.

Patient: Gotcha

GC: Most babies have multiple things.

Patient: Ok

GC: They don’t look typical but it is usually the birth problems like the heart and the brain problem why[sic] they don’t survive very long after birth

Patient: Gotcha

GC: There are a few that do, but they have serious delays and medical issues after birth. Those are the big ones that we screen for.

Patient: Ok

GC: Sometimes sex chromosomes abnormalities can happen…

Both sessions inform the patient that there are other conditions they are looking for that are more severe than Down syndrome but in the English-speaking session the genetic counselor gives a greater breadth of information, expounding on what trisomy 13 and 18 are called and what is looked for in an ultrasound with these conditions. In the Spanish-speaking session, the two conditions are introduced to the patient but no questions are asked by the patient and only basic information is volunteered by the genetic counselor before moving on to the next topic of conversation.

In the English-speaking sessions, the genetic counselor spoke in longer phrases than in the Spanish-speaking sessions. This can be seen in graph 4, by taking the longest phrase spoken by the genetic counselor in a session, we found that the longest phrases in the
English-speaking sessions were significantly longer than those in the Spanish interpreted sessions (p<0.05) (Graph 4).

Figure 5: Number of Words Spoken and Time of Sessions

Therefore, in the English-speaking sessions there was a greater expansion of concepts and ideas conveyed at one time. This is shown in instances like the description of Trisomy 21 or Down syndrome in English-speaking session UA7 and Spanish-speaking session UA8:

GC speaking to participant UA7:
So with something like Down syndrome, it is caused by an extra chromosome. So there are three copies of chromosome number 21 instead of two, and the body doesn't know quite what to do with that, so we get some extra learning disabilities and some health issues that can go along with that…

GC speaking to participant UA8:

GC: So Down syndrome is caused by three copies of chromosome number 21 instead of two
Interpreter: La [sic] síndrome de Down es causado por una copia de tres veces de la [sic] cromosoma 21 en vez de solamente dos
GC: That extra genetic material is what causes some of the learning delays and health concerns that we see in kids with Down syndrome
Interpreter: Entonces material genético es lo que causa la falta de desarrollo para [sic] esos niños

The same information is given but in the Spanish-speaking session it is much more factual information while the English-speaking session allows for a more personalized approach to the words, for example, “the body doesn’t know quite what to do with that…”

Graph 5 shows that seven of the women (50%) had heard of Down syndrome before: two Spanish-speaking participants and five English-speaking participants. Six of the participants stated that they had previously heard of the different types of testing offered: three Spanish-speaking participants and three English-speaking participants (Graph 6). Over half of the participants (64.2%) knew that being over the age of 35 increased the
risk of having a chromosomal issue in their pregnancy: four Spanish-speaking participants and five English-speaking participants (Graph 7).

Figure 6: Prior Knowledge of Down Syndrome

Figure 7: Prior Knowledge of Testing Options
Participants in the English-speaking sessions were more inclined to ask questions to the genetic counselor than those who were in the Spanish-speaking sessions. In sessions where a relative, who had accompanied the patient, asked a question it was counted along with the patient’s questions for a total of all questions that were asked to the genetic counselor. With this quantification, in 57% of Spanish-speaking sessions, one or no questions were asked of the genetic counselor while 42.8% of the English-speaking sessions show the genetic counselor being asked 5 or more questions (Graph 8).
In English-speaking session UA4 we see questions asked for further explanation on chromosome abnormalities that may occur and information on what potential ultrasound findings would make health professionals suspicious of a chromosomal condition.

Patient: so, to be Down syndrome is it only on the… on this [gesturing to chromosome 21 on the picture]?

GC: the 21st

Patient: yeah the 21st. So if it was a third [chromosome] somewhere else it would be something else?

... 

GC: A normal ultrasound for these [conditions] is much more reassuring and because they are much more serious. We usually do see things on a scan.

Patient: What kinds of things do you usually see on a scan?
In English-speaking session UA6, the patient asks questions to interpret her result number better, allowing the genetic counselor to know her concerns and help fill in the information that the patient is seeking:

GC: Is that better than you were thinking, worse than you were thinking?
Patient: I don’t know, what is a good number?

Genetic counselors universally talked about the different chromosome conditions for which a pregnancy of a woman over 35 is at an increased risk, but the level of detail is different between English-speaking and Spanish-speaking sessions. This can be seen in comparing the conveyance of age related risk between English-speaking session MC4 and Spanish-speaking session UA2:

GC speaking to participant MC4 – English-speaking,

If we look at 133 women that are all 37 [years old] when they have babies, we think that one of them would have a baby with Down syndrome. So less than 1% chance for Down syndrome. We think that about 1 in 66, so a little less than 2% would have a baby with any chromosome condition.

GC speaking to participant UA2-Spanish-speaking,

At 41, the chance for the baby to have Down syndrome or any chromosome change is about 1 in 35, which is about 3% chance.
Both cover the risk number at that age in pregnancy, but the Spanish-speaking session is very fact-based in the description whereas the English is expanded and presents the information in a less formal, more personal manner.

Decision Making

Near the beginning of each session, all participants were asked if they planned on doing further testing. Before counseling there were eight patients who wanted no further testing beyond ultrasound, five Spanish-speaking participants and three English-speaking participants (Graph 9). Four participants came to genetic counseling already desiring to do further testing, one Spanish-speaking participant and three English-speaking participants. Two of seven English-speaking participants stated that they had had further testing with their past pregnancies.

At the conclusion of the session participants were again asked if they wanted to pursue any further testing during the pregnancy. Graph 10 shows that post-counseling there were eight patients who decided on just the ultrasound: five Spanish-speaking participants and three English-speaking participants. Two of the English-speaking participants had already undergone additional testing ordered by their primary care provider before the session: one received the Quad screen and the other cell free fetal DNA testing. Four of the participants opted for both an ultrasound and cell free fetal DNA testing: two Spanish-speaking participants and two English-speaking participants. Two English-speaking participants opted for an ultrasound with the first trimester screen.
Figure 10: Feelings towards Testing Before the Session

Figure 11: Final Testing Decisions

In the surveys collected, all participants noted that they had no further questions, or that all questions they previously had were addressed in the session. When asked what, they...
had learned, both the English-speaking and Spanish-speaking participants stated that they had learned about risks for their pregnancy, what was being looked for in testing or they had learned more about further testing for the pregnancy (Graph 11).

Figure 12: Survey Responses of what Patients Learned in the Session

**Conversational Engagement**

The number of back-channeling responses from the patient and GC were significantly greater in the English-speaking sessions compared to the Spanish-speaking sessions (p value 0.05) (Graph 12).
In an excerpt from the UA3 English-speaking session and the UA8.5 Spanish-speaking session, we see an example of this back-channeling and engagement or lack of engagement shown in the dialogue. The back-channels are identified with a box around them:

From session UA3-English;
GC: The blood test that you had kind of looked at that and then it also looked at [sic] some babies will get an extra chromosome 13 or 18 that can cause a lot more serious health problems. Most of those babies don’t survive very long after they are born but all of those extra chromosomes … those are still relatively rare. After 35 they are just a little bit more common.

Patient: Yeah

GC: What they did on this blood test here of yours is basically there are little bits and pieces of your baby’s chromosome material that float around in your blood.

Patient: Yeah

GC: They draw some blood from your arm and look at all the little bits and pieces and essentially they are trying to see, are there’re extra pieces of chromosomes 21, 18 and 13? And then they also look at the sex chromosomes the X and Ys there.

Patient: Ahuh

GC: And they are not seeing any concerns. They said based on the levels that they are seeing your risk for each of those health conditions was less than 1 in 10000 for this pregnancy, so super low.

Patient: Yeah

GC: This type of blood test is never going to be able to come back and say there is absolutely zero risk.

Patient: Ahuh

From session UA8.5-Spanish;

GC: We can also do a blood test that gives us some additional information if you want.
Interpreter: Si desea también nos podemos [sic] hacer un estudio de sangre que nos da un poco de información adicional.

GC: This is a blood test for you where we draw your blood.

Interpreter: Es un estudio de sangre para Usted donde sacamos su sangre.

GC: We can actually look at the genetic information that comes from the baby that is in your blood while you are pregnant.

Interpreter: Podemos actualmente mirar a la información genética de [sic] que viene del bebé de su sangre.

GC: So all these conditions that I'm talking about involve changes in the amount of genetic information a baby has.

Interpreter: Porque todas estas condiciones genéticas de que estoy hablando es un cambio genético que el bebé tiene.

GC: It is more accurate at finding Down syndrome than the ultrasound is.

Interpreter: Es más seguro a encontrar algo de síndrome de Down que el ultrasonido.

In the above Spanish-speaking session there are is no back-channeling occurring from the patient, interpreter or genetic counselor. This is a pattern seen throughout the majority of each Spanish-speaking session.

Beyond back-channeling, the genetic counselor in the English-speaking sessions also more frequently followed up on statements made by the patient. For example, in UA1, when termination is brought up, the counselor is able to clarify what the patient is hinting at:

Spouse: And there's a few people that choose not to just deal with it…

Patient: I could never do that to my child.
GC: Ok you're talking about not continuing with the pregnancy?
Spouse: Yeah
GC: Right and some people do make that decision, but some people would just want to be better prepared to raise a child.
Patient: Yes
GC: Ok, sounds like that's what you would be interested in?
Spouse: Yeah

And later in the same session, when the patient comments on trying to lose weight the statement is validated by the genetic counselor and provides encouragement for the patient to expand on the idea:

Patient: My height I believe is 5'5" or 5'6" I can't remember.
GC: That's ok well just round up.
Patient: Just did mine [weight] it is 309, I'm trying to drop it I've been walking with him in the evening a lot and trying to be careful cuz [the] doctor said try and get down a little bit because I have to have surgery again cuz I had a cesarean with him [speaking of her son in the room].
GC: Yeah it's good to get your exercise.
Patient: So, I've been walking with him in the evening, we walk around, don't we bud? [addressing the child], while Daddy is at work put him in the stroller and walk through the neighborhood.

The same follow up to patient statements was not seen as frequently in the Spanish-speaking sessions. For example, in session UA8 Spanish-speaking the patient is noted to
have shaken her head, but there is no follow up to find out what she is shaking her head at:

GC: It is very good, the only way to know 100% is with this invasive test.
Interpreter: Pero si quisiera saber cien por ciento seguro, se hace esta prueba invasiva.
GC: I see you shaking your head.
Interpreter: Yo veo que mueve la cabeza que no
GC: With this test when they take some fluid from around the baby we can make this full picture and know for sure, but that test has a small risk of complications.
Interpreter: Con el otro estudio le sacamos una cantidad pequeña de líquido que nos da un dibujo entero de esto, pero esa prueba tiene una complicación pequeña*

*known translation error of this phrase

The genetic counselor notes the shaking of the head but continues on with information that needs to be covered instead of addressing the cause of this non-verbal cue.

Nine of the patients came by themselves, six Spanish-speaking sessions and three English-speaking sessions. In Graph 13 we see that five patients were accompanied by a relative in the session. One Spanish-speaking participant was accompanied by her husband, and four of the English-speaking participants were accompanied by one or more people. Two English-speaking participants came with their husband and one or two children, one came with her mother and another female relative, and one came with her sister and another female relative. In the single Spanish-speaking session where the patient was accompanied by her husband, he did not participate in the session beyond answering direct questions about his health history. He was not vocal in the decision making process or in the information seeking portion of the session. This was also true in
one of the English-speaking sessions, with the husband only responding when a direct question was asked of him. In the other three English-speaking sessions with the family members present, there was active participation during the session asking questions and providing information.

![Attended the English-speaking session](chart1.png)

![Attended the Spanish-speaking session](chart2.png)

Figure 14: Number of People who Attended the Session with the Patient
Chapter 4: Discussion

Beyond showing that bilingual sessions have a linguistic and cultural filter that can affect the information that the patient understands when an interpreter mediates the session, our data shows that the level of engaged communication that occurs between the genetic counselor and patient is affected when there is an interpreter mediating the session. Our data show that there are differences in genetic counseling sessions when comparing English-speaking sessions and Spanish-speaking sessions. The women who participated in our study came from similar education and working backgrounds, thus there was not an education or work bias that needed to be accounted for in the study analysis. We see that knowing beforehand why they are coming in for testing is not common for women in a genetic counseling session. Both English and Spanish women come in at similar levels of understanding. As shown by the opening question of the session, we see that genetic counselors do not approach a session the same way. When approaching a Spanish-speaking session the genetic counselor engages in a much lower level of nonessential dialog. The session is fact-based, with an exchange of needed information, such as dates, conditions and expectations. This is shown in the opening of each session, where the patient is asked if their doctor told them why they were coming in or if they knew the purpose of the visit. When the participant is asked this opening question it establishes the
tone of the session to be one of information seeking and giving. This type of statement has a specific answer and does not lend itself to embellishment or storytelling from the patient (Apodaca et al., 2016). Throughout the Spanish-speaking session we see this collection of facts and information and not as many open-ended questions. With the need to have each statement translated, the genetic counselors use descriptions and information that is very factual. Assessing if the patient has been told the purpose of the visit is an important question in a genetic counseling session. This question assesses a starting point and lets the counselor know where the patient stands in relation to the information that needs to be covered (Klitzman, 2010). This question is used in both English-speaking and Spanish-speaking sessions but it is used differently based on the patient’s language. As an opening question, it sets a fact-seeking tone to the session instead of the open-ended questions that is asked in the English-speaking sessions. Open ended questions allow the patient to tell their story (Apodaca et al., 2016), as shown by above mentioned English-speaking patient UA1, who stated that, “[Pregnancy feels] like a little fishy is moving in you”. In the English-speaking sessions storytelling is solicited from the opening question at the beginning, and with continued open ended questions and opportunities for fluid dialogue, the patients in these sessions are much more likely to talk. By leading with an open question that evaluates feelings, it opens up an opportunity for a steady flow of dialogue between the genetic counselor and the patient (Engestrom, 1995).

A part of a genetic counselor’s training is to educate by explaining technically difficult concepts to a broad range of people with an even broader range of backgrounds and education in order to help them make decisions regarding their health (Fraser, 1974). A
portion of every genetic counseling session is spent sharing information and educating the patient. Without more time for Spanish-speaking sessions, we see that the same topics are addressed as in the English-speaking sessions but they are much more condensed. In Browner’s 2006 study they found that many Latino patients do not participate in prenatal diagnostic or screening testing because of misunderstandings that occur during the genetic counseling sessions with an interpreter mediating. This is why it is so important for a genetic counselor to work effectively with an interpreter so that misunderstandings can be cleared up and the patient has the information necessary to make the right decision for their life. Circumlocution is used in the English-speaking sessions to take a concept and expound upon it. In the Spanish-speaking sessions we see the same concepts introduced, but they are not given the same clarifications or explanations. One-worded back-channel responses including, “mm”, “yeah”, “ahuh”, etc. are considered tokens of conversational engagement. Back-channeling responses are a good measure of the engagement of either party in the conversation. These sessions were not video recorded so we do not have the nonverbal cues. We cannot rule out the possibilities of head nods or other nonverbal cues from the patient. Verbal back-channels during the session show that the level of conversational engagement is much greater in the English-speaking sessions. In the Spanish-speaking sessions, both the genetic counselor and the patient give far fewer cues that they are listening or engaged in the information being presented. There is turn taking in the control of the conversation, but neither party looks for ways to engage when they are not in control of the dialogue. This could affect the rapport between the genetic counselor and the patient if both parties do not feel like the other is
engaging in the information presented (Apodaca et al., 2016; Lambertz, 2011). Part of this lack of engagement could stem from the cultural belief of respect, believing that contradicting or interrupting a health care provider is disrespectful. This may further be addressed in a study analyzing the engagement between a Spanish-speaking genetic counselor and a Spanish-speaking patient.

Our findings contribute to the current literature by further documenting differences that exist in healthcare sessions with low-English proficiency (Browner et al., 2003; Butow et al., 2011; Dysart-Gale, 2007; Eamranond, Davis, Phillips, & Wee, 2011). While all of the same types of information is covered, there is less interaction between the patient and the provider when the session is mediated by an interpreter. Both sides seem to edit their speech when there is a mediator. The patient asks fewer questions and the genetic counselor speaks in shorter phrases and condensed ideas. Without both sides active verbally there is a tendency for the session to take on a lecture-based feel with little time for questions or flow of dialogue to have engaged communication with the patient when an interpreter is present and mediating the session. More is said in English-speaking sessions over the same time constraints because there is a greater amount of detail or explanation delivered. There is a lot of information that needs to be covered in a genetic counseling session and this is seen in the number of words that are spoken by the genetic counselor. Other participants speak far less, but the Spanish-speaking sessions show a dramatic decrease in dialogue from the patient. The conversation is much more one sided than it is in the English-speaking sessions. This could be an example of the cultural belief
of respect where the patient does not wish to be disrespectful by verbally interrupting the flow of dialog.

This same cultural belief may also be at play in the decision making of the session. The few Spanish-speaking sessions that concluded with further testing were because the woman came in knowing that their doctor sent them for this testing. All of the other Spanish-speaking sessions came in not wanting further testing, although on the after visit surveys they stated learning about their risks and the purpose of testing. All patients came in with a limited knowledge of the conditions and testing that were being addressed in the session. When new material is introduced it is natural for questions to be asked by the listener, which shows they are engaged in the exchange and clarifying unclear concepts or ideas that are presented (Graham & Brookey, 2008). It also helps the presenter of the information focus on the information that is of most importance to the listener. We show that the number of questions asked of the genetic counselor during a session are few, with Spanish-speaking participants asking the least. This is interesting because our survey data shows that all participants, both English-speaking and Spanish-speaking, stated that they had no further questions at the conclusion of the session or that all of their questions were addressed in the session. This seems unlikely as very few questions were asked during the sessions. When asked at the end of the session what they learned or what they understood after the genetic counseling session, the Spanish-speaking patients’ answers had a broad range, showing that participants did not grasp all that was covered in the session or what was hoped they would get out of the session. Part of this may come from the Latino cultural belief of fatalism. This belief
individuals cannot do much to alter fate (Flores, 2000), and that pregnancy is a gift, lends itself to not asking questions because there is no belief that answers could help or change the circumstance and the baby is wanted. As shown in the Perez-Stable study of cancer diagnosis of Latino patients, our results could also reflect, through the lack of testing after genetic counseling, that patients would prefer not to know health conditions when they believe nothing can be done to affect the outcome and not anything that the patient would choose to do if a condition was identified. This is an area that merits further study.

Limitations and Considerations for Future Studies

There were several limitations in this study that are mentioned and should be taken into consideration for future studies of communication in interpreted genetic counseling sessions. First, all our sessions were based in the prenatal setting. Genetic counseling is an extensive field that covers many different medical specialties, and in order to fully understand where our difficulties lie as a profession, we need to look at the interactions of genetic counselors, interpreters and patients in other fields, too. This study could easily be replicated in cancer, pediatric, cardiovascular, and other medical specialties in which genetic counselors are involved.

We also only focused on one language, Spanish, while there are hundreds of other languages that require interpreters in a health setting. Studying languages that are not as prevalent in the United States may shed greater light on the difficulties of conveying complex information in languages that, unlike Spanish, do not have correlating vocabulary for genetic terms. We believe that as we explore other populations with low-English proficiency, we will find that the more removed one culture is from an English
based culture, the greater the discrepancies that will occur in an interpreted session. Because there are not any fluent Spanish counselors in the prenatal genetic counseling profession here in the Columbus, Ohio area, we limited our study to two types of sessions, English speaking provider with English speaking patient and English speaking provider with an interpreter and Spanish speaking patient. In future studies it would be helpful to add a third group of Spanish speaking providers with Spanish speaking patients in order to provide another control. A Spanish speaking provider with a translator and English speaking patient would add another interesting aspect to translated genetic counseling sessions.

We looked at only fourteen sessions. While we believe from the literature that this is a sufficient number of sessions to use in a dialogue analysis, more numerous sessions would give an even greater sense of the patterns that have been observed. We encourage future researchers to look at a greater sample size for further exploration of this question. Our data was collected over a seven-month period, but a longer period of collection would allow for a larger number of patients and give a greater data set to be evaluated.

It is important to note that not all of our English speaking patients were from the United States. One of our patients was from Nigeria and the culture bias from a non-Spanish speaking foreign culture was not considered in this study. Our study design assumed that the English-speaking participants to be native English speakers, so these two participants who are not native English speakers could have a confounding effect when evaluating understanding of the genetic information presented and on understanding cultural factors that affect the decision to test or not in a genetic counseling session. Future studies
should either account for or exclude these patients from control groups because they add another confounding factor to the analysis.

The majority of the sessions were conducted as initial advanced maternal age appointments and took place before the patient had gone through prenatal testing, including ultrasound or any blood tests, but this is not true of all of our sessions. One session was post ultrasound, one had completed first trimester screening, one had completed cell free DNA, and two participants had completed carrier screening. Two of our English participants had prenatal testing done in previous pregnancies which may have biased them towards repeating testing in their current pregnancy. One of our patients came in for results of testing that had been ordered and come back abnormal from another provider. Three of the patients were repeats due to advanced maternal age in a previous pregnancy. This may have affected their background knowledge of the conditions and testing and could have impacted the decision to go forward with testing because they had previous experiences with genetic counselors. In future studies with a greater time frame for the collection of data, we would encourage an exclusion criterion that would allow for patients in the same state of pregnancy and testing to be evaluated across the board.

Our interpreters were both male and female. This could be a confounding factor in a prenatal session when a woman is disclosing health information that is very personal about her pregnancy and prenatal history. Just as the gender of the interpreter could play a role in the type of information and questions a patient feels comfortable answering, two of the Spanish sessions also had a genetic counseling student present. In one Spanish-
speaking and four English-speaking sessions, there were family members that accompanied the participant to the session. These family members included spouses, mothers, sisters and children. We would hope that if the family member was brought to a prenatal session that the patient felt comfortable sharing personal information or asking questions in front of them, but this was not assessed and could play a role in a patient feeling that they were able to get all of the information they needed from the sessions with the genetic counselor.

The survey was administered at the end of the session and often there was a quick turnaround to get the patient from the session to their ultrasound. This meant that not all of the surveys were filled out in the detail expected. All of the multiple demographic questions were answered but the free response, even in the cases where they chose to vocally record their answers, were short and not as specific as we had to receive. This could be avoided by asking only multiple choice questions or by giving the survey to the patient to take home and mail the responses back, giving adequate time to look at and answer the questions.

Future Directions

We can see from this study that genetic counseling sessions with a translator present can be different. When an interpreter is present in a session, both the counselor and the patient treat a session differently. We have identified differences in the approach to the session, different levels of engagement on both sides of the conversation and a different depth of discussion was addressed between the two types of sessions.
We can’t expect interpreted sessions to follow the same pattern as a session without one. Two-participant conversations are a different style of communication than three-participant conversations and need to be seen for their differences so that we can then work to make both styles equally effective for the patients that are seen in a genetic counseling session. We propose to accomplish this by including a special training module teaching how to approach sessions with an interpreter and different communication skills to employ when counseling with a patient who speaks a different language than the genetic counselor. Our hope is to take training for genetic counselors beyond just cultural sensitivity and understanding of personal cultural bias that is taught in a standard genetic counseling program, to include training on how to approach interpreted sessions. This training would be most effective if developed as a joint-specialty module involving professional health interpreters. The International Medical Interpreters Association Guide on Working with Medical Interpreters is provided as a resource for genetic counselors on the National Society of Genetic Counselors tool kit for working with medical interpreters (International Medical Interpreters Association, 2016). This guide is an example of how tools marketed towards health care professionals do not address the communication issues found in this study. It does not address how to build rapport or emotional engage with a patient through an interpreter. This is a portion of genetic counseling training that would benefit from a focused curriculum. The interpreters could provide the genetic counselors with insight on the best way to prepare for a session with an interpreter present and how to evaluate with their interpreter how after the session the information is being conveyed to the patient. The genetic counselors
in turn can provide a framework for the key parts or information covered in a session, helping the interpreters understand the goals and objectives of this aspect of a patient’s healthcare. By opening the dialogue between these two professions it will allow for adjustments to be made by both parties so that the patient receives the best care possible. It also will allow understanding of the role of each professional in a session and help to resolve issues that may arise in a session. The most effective way of addressing these differences this study noted between Spanish-speaking and English-speaking session is to strengthen the relationships between genetic counselors and the interpreters.

With further study into genetic counseling sessions where the genetic counselor speaks a different language than the patient and uses an interpreter to mediate will continue to show differences and give additional data to the main discrepancies when compared to sessions where both the genetic counselor and the patient speak the same language. When genetic counselors and interpreters work together to help each other understand the purpose each professional holds in a session we can begin to remedy these differences.

With a determination to provide linguistically and culturally accurate information, we believe that language does not need to be a continued barrier in affected healthcare communication and patient care in a genetic counseling session.

Furthermore, to address the number of patients, both English-speaking and Spanish-translated, that do not understand the purpose of a genetic counseling appointment and are often under the opinion that they are just coming for an ultrasound, perhaps a pamphlet could be developed and distributed to the referring physicians explaining what will be covered in a genetic counseling visit. Many studies have looked at the impact of
pamphlets given to patients at the end of a visit (Shank, Murphy, & Schulte-Mowry, 1991) or given to patients to pass along to family members (Vetto, Dubois, & Vetto, 1996), but we would be looking at giving patients pamphlets before the visit. Providing literature in Spanish or English to the patient with some of the more basic information of why they are coming in could help them to have an understanding before the session, allowing allow more of the session to be devoted to decision making instead of only covering information. This will allow for discussion that will help with the decisions that need to be made. In patients undergoing cancer treatment, it was found that over 50% found the pamphlets given provided important information for decision making about treatment options (Vetto et al., 1996). A pamphlet will help women decide if counseling is what would be most beneficial at this stage in their pregnancy. The Spanish-speaking sessions had a very high rate of women coming in and not wanting testing and still not wanting testing at the end. By understanding the purpose of the visit beforehand it could help them not only make the best decision for them and their family, but also help them come with questions prepared for the visit.

Another possible accommodation would be to allow for more time in a session that is to be interpreted. This would take the time pressure off of the counselor and allow more time to dialogue with the patient instead of lecture them. This is not always feasible when the hospital structure allots a certain amount of time for each patient and scheduling is not arranged by the counselor.
Conclusion

This study has shown that there is a difference in genetic counseling provision when comparing sessions where both the genetic counselor and the patient English with sessions where the genetic counselor speaks English and the patient primarily speaks Spanish and an interpreter is used to mediate. We have shown that there is importance for further evaluation and improving genetic counselling sessions when Spanish interpreters are involved. Our understanding of genetics will continue to grow along with greater utility of testing and decisions that need to be made based on test results. Genetic counselors will continue to find themselves in sessions where they do not share a common language with their patient, so the ability to work effectively with an interpreter is imperative to helping patients to receive the best health care possible. Language does not need to be a barrier in health care communication and patient care. By understanding the limits to our ability to fully provide genetic counseling services in multilingual sessions, we can seek ways to improve as a profession.
References


Appendix A: Survey-English

1. Can you tell me why you came in today?

2. After your visit today, what do you understand about how this applies to your pregnancy?

3. Will this information affect what you will do, if yes then how?

4. Do you intend to discuss this with your spouse? If so how would you explain to them what you understood?

   To your mother/father

   To your sister/brother

   To your children?

5. Are there others you intend to discuss these results with? If so who? (examples)

6. Did you get all of your questions answered during the session? If no, what questions still remain

   □ Check if you would like the genetic counselor to call and address these questions
Appendix B: Survey-Spanish

1. ¿Puede usted resumir el motivo de su consulta hoy?

2. ¿Cuáles son las opciones que usted tiene según lo que entendió de la consejera?

3. ¿Qué hará usted debido a la información que recibió hoy?

4. ¿Piensa usted conversar con su esposo/pareja de lo que aprendió hoy!? ¿Cómo se lo explicaría?
   Madre/padre
   Hermano/hermana

   ¿Otras personas, quién?

5. ¿Tiene todavía alguna pregunta?

   □ Check si desea que la consejera le llame para responder a estas preguntas