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LANGUAGE INTERPRETERS' PERSPECTIVE OF THE INTERPRETER-GENETIC
COUNSELOR WORKING ALLIANCE

by

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ABSTRACT

Interpreters are an asset to the genetic counseling process as they help to bridge both cultural and linguistic gaps. For various reasons, their ability to accurately render the often-complex information discussed in genetic counseling sessions is likely dependent on their ability to establish a working alliance and collaborate with genetic counselors to overcome any challenges. Studies in other healthcare fields document the elements crucial to forming a working alliance between interpreter and healthcare provider, but little research has been done specifically investigating how to form a working alliance in the context of the specialized nature of genetic counseling. The goal of this study was to characterize the experience interpreters have had while working with genetic counselors and determine which factors are most important in establishing a working alliance. A total of 180 interpreters were recruited from ten interpreter industry associations and participated in this study. The study involved an online questionnaire and optional follow up phone interview. The majority of study participants characterized their overall experience working with genetic counselors as good or very good (98%). The vast majority of participants (95%) thought it was important that genetic counselors create an environment that allows both the interpreter and the patient to feel comfortable asking questions, followed by speaking at a moderate pace, pausing often to allow the interpreter to easily interpret the information to the patient (93%), and using simple language and avoiding jargon or at least providing a clear explanation of the terms when talking to the patient (91%). A pre-session to discuss sensitive topics that may come up, review

technical terminology, and the patient's reason for the appointment is something that 81% of participants viewed as important but only 15% of participants experience often. Participants also valued sharing with genetic counselors mutual trust, respect, and an understanding of each other's roles. The results of this study may provide guidance on establishing guidelines on how to work with interpreters in the genetic counseling setting.

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1.1 Complexity of the Genetic Counseling Process

During a genetic counseling session, a genetic counselor will typically gather

patient information in the form of family and medical history, perform a risk assessment

for the patient, educate the patient about pertinent medical genetic information, discuss

genetic testing options and implications, and facilitate decision-making, all while

determining and addressing any psychosocial concerns the patient may be experiencing

(Resta et al., 2006; Uhlmann et al., 2011). As education is integral to the genetic

counseling process and genetic counselors must provide certain information to all

patients, a large proportion of the allotted time for genetic counseling sessions may be

spent educating the patient (Meiser et al., 2008). Educational opportunities arise at

various points throughout the session, when the genetic counselor can "present new

information, correct misconceptions, reinforce information, or lay the foundation for

future patient education" (Uhlmann et al., 2011, p. 256; Weil, 2000, p. 107).

Overall, the information provided by a genetic counselor must be accurate and

correctly portray all aspects and considerations of genetic testing, both positive and

negative. As part of the genetic counseling code of ethics, it is important that this

information be presented in an un-biased, balanced manner and be free of coercion. It

must be presented in a way that is respectful of "clients' beliefs, inclinations,

circumstances, feelings, family relationships, sexual orientation, religion, gender identity,

and cultural traditions" (National Society of Genetic Counselors Code of Ethics, 2017).

Additionally, this information must be discussed at a level appropriate for the patient's

current educational and emotional needs and cognitive abilities, merging the educational

with the psychosocial domain of the session (Weil, 2000). Such meticulous phrasing of

information is done to ensure that patients fully understand the information presented to

them, so that by the end of the process they are able to provide truly informed consent.

Although it is crucial for the patient to have a complete understanding of the

information in order to provide informed consent, this can be difficult to achieve given

the complex nature of medical genetic information. Describing concepts such as

"inheritance, testing, management, prevention, resources, and research" (Resta et al.,

2006, p. 77) requires the use of highly specialized terminology that the general public

may already have some familiarity with, but with which most people are unfamiliar (Lea

et al., 2011; Roter et al., 2007). The terminology must be used in order to convey both

general genetics and complex genetic concepts relevant to a patient's health, so it is

important that a genetic counselor spend time presenting and explaining the terminology

(Meiser et al., 2008; Weil, 2000). To add another layer of complexity and confusion,

there are times when multiple terms describe the same situation or condition as well as

terms that have different technical or scientific meaning compared to lay usage (Weil,

2000). For example, Down Syndrome and Trisomy 21 describe the same genetic

condition and an "uneventful pregnancy" is a term that genetic counselors and healthcare

professionals use to describe a situation differently than a counselee might.

To ensure that all necessary information is being clearly conveyed to the patient,

genetic counselors typically spend more time speaking during the session than the patient

does, one study quoting an average of 2/3 of the total allotted time, sometimes making the session feel exclusively didactic (Butow & Lobb, 2004; Meiser et al., 2008; Roter et al., 2007). Often more focused on education rather than psychosocial issues, sessions tend to get "informationally and conceptually dense" (Roter et al., 2007, p. 3; Meiser et al., 2008; Paul et al., 2015). To break up dense material the genetic counselor will typically present information in a stepwise fashion and pause after each step to assess patient understanding and answer questions, but the information provided in each step often tends to be more than a typical person is able to retain (Roter et al., 2007; Weil, 2000). To understand and retain all the information presented would require the patient to have a high level of health literacy prior to the session; unfortunately, this is generally not the case, as only 12% of Americans have proficient health literacy (Kutner et al., 2006). As a result, a large proportion of information given is frequently "lost to recall and subject to confusion and misunderstanding" (Roter et al., 2007, p. 3). Pertinent to genetic counseling, understanding and retention of the information given in a genetic counseling session is especially difficult for individuals who have recently received a "new diagnosis or are in a stressful medical situation" (Joseph et al., 2017, p. 1101) regardless of their literacy level (Department of Health and Human Services; Kutner et al., 2006). A critical skill genetic counselors must possess then, is the ability to communicate information in a way that makes it relevant to the patient and facilitates understanding. Additionally, they must also navigate psychosocial issues that arise, making the session more involved and placing emphasis on how and when information is presented.

1.2 Language and Health Literacy Barriers in Genetic Counseling

An obvious barrier to communicating and facilitating patient understanding exists when there is a language barrier between a genetic counselor and patient. This is a frequent issue, considering that 86% of the linguistically and culturally homogenous task force of practicing genetic counselors in the US is fluent only in English (NSGC Professional Status Survey, 2019). Although generally people in the United States do speak English, the 2019 American Community Survey 5 Year Estimate predicts that 8.4% of Americans will self-rate their ability to speak English as less than "very well" (U.S. Census Bureau, 2019). Individuals who speak English less than "very well" are considered to be limited English-proficient (LEP), defined as "Individuals who do not speak English as their primary language and who have a limited ability to read, speak, write, or understand English" ("Commonly Asked Questions," 2011). Additionally, 36% of Americans have basic or below basic health literacy, which is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Kutner et al., 2006; Ratzan & Parker, 2000). Low health literacy disproportionately affects individuals who have lower levels of formal education, whose incomes are below the official poverty level, who have no insurance or publicly provided insurance, and who belong to certain racial and ethnic groups such as Hispanic or Black. Although speaking limited English is not a predictor of low health literacy, the proportion of Americans who are considered to have low health literacy happens to overlap considerably with the population that is considered to be LEP (Joseph et al., 2017; Kutner et al., 2006).

Historically, LEP individuals have faced many disparities in healthcare due to the language barrier they frequently face and low health literacy has been shown to act synergistically with language status (Institute of Medicine Committee on Health, 2004; Jacobs et al., 2003; Kutner et al., 2006). In addition to unequal access to healthcare, individuals who are LEP often experience a low quality of healthcare which often results in poor health outcomes (Jacobs et al., 2003).

Over the past 50 years, a growing body of legislation and regulations have been put in place to overcome communicative barriers to healthcare. A 1974 Supreme Court interpretation of Title VI of the 1964 Civil Rights Act - a law that prohibits discrimination based on race, color, or national origin on part of any program receiving federal funding - specifically recognized language as an aspect of country of national origin. Executive Order 13166 signed by President Clinton in 2000 then required all federal agencies to assure the same equal access to their own programs that Title VI required of recipients of their funding. Finally, in 2010, the Affordable Care Act formalized language protection services into law (Affordable Care Act of 2010; Office for Civil Rights, n.d.). The language of this growing body of legal directives began to echo throughout the healthcare field; for example, the National Society of Genetic Counselors (NSGC)'s 2017 Code of Ethics includes language requiring Genetic Counselors to strive to improve access to genetic counseling by providing services to patients "regardless of their abilities, age, culture, religion, ethnicity, language, sexual orientation and gender identity" (NSGC Code of Ethics, 2017). Additionally, NSGC helped fund the development of Lexigene® (www.lexigene.com), an online repository of Spanish and French translations of vocabulary terms frequently used in genetic

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counseling sessions to provide medical interpreters with a supplemental resource. As a result, more LEP individuals are gaining access to healthcare, genetics services included, and many genetic counseling sessions are now being facilitated through the use of medical interpreters.

1.3 Use of Interpreters in Genetic Counseling

Through the involvement of medical interpreters, LEP patients are able to receive a higher quality of care (Jacobs et al., 2003). More specifically, through the involvement of an interpreter, LEP patients have an increased utilization of healthcare services, therapeutic and preventative services, and experience lower rates of medical complications with overall better health and a higher satisfaction with their care (Jacobs et al., 2001; Karliner et al., 2007). Additionally, interpreters have the potential to improve rapport between provider and patient by allowing communication to be almost seamless. Some interpreters will also provide emotional support, clarifying technical terms, and softening the provider's language to make it less abrupt or confrontational, although this behavior is controversial within the interpreting profession (Pham et al., 2008). This increase in quality of care is especially realized when the interpreter is professionally trained, as opposed to ad hoc or untrained (Flores et al., 2003; Flores et al., 2012; Hunt & de Voogd, 2007; Karliner et al., 2007; Larrison et al., 2010).

According to the National Council on Interpreting in Healthcare (NCIHC), interpreters must "render all messages accurately and completely, without adding, omitting, or substituting" (National Council on Interpreting in Healthcare, 2005). Therefore, working with a professionally trained interpreter greatly improves the accuracy of the communication between patient and genetic counselor. However, this

system is not perfect. How well an interpreter is able to preserve the original meaning of information given is dependent on how well the interpreter understands what was spoken by the genetic counselor. Studies show that interpreters who have previously received genetic counseling-related education achieve higher scores when tested on their knowledge and those who receive additional genetic counseling-specific training improve upon their knowledge and understanding of genetics, but the amount of training most interpreters receive specifically related to genetic counseling is minimal (Delgado-Hodges, 2015; Donelan et al., 2009; Langford, 2011). The American College of Medical Genetics (ACMG), acting as the National Coordinating Center for the Regional Genetics Networks with a grant from HRSA, has created training for interpreters in both prenatal and pediatric genetics to help improve access to genetics-related interpretation training (Roat & Joseph, n.d.).

As a result of minimal genetics-related training, many interpreters may be uncomfortable using medical genetic terminology in the genetic counseling session due to a general lack of familiarity with the terms (Donelan et al., 2009; Langford, 2011; Saleh et al., 2009). Those who are less familiar with the terminology are more likely to make mistakes when interpreting (Flores et al., 2003; Flores et al., 2012; Gutierrez et al., 2017; Hallford et al., 2019; Hunt & de Voogd, 2007). Exacerbating the potential for error, many medical genetics terms have no cultural or linguistic equivalents in other languages, making verbatim interpretation difficult and sometimes impossible (Agather et al., 2017). Additionally, genetic counselors sometimes use analogies or American English colloquiums to help patients understand complex genetic concepts, which pose an extra challenge to interpreters as hypothetical and futuristic phrasing may be difficult to

interpret and for patients to understand (Joseph et al., 2017; Joseph & Guerra, 2015; Kamara et al., 2018).

1.4 Conflicting Views on the Role of the Interpreter

Various studies in multiple fields of medicine demonstrate conflicting opinions on what the exact role of an interpreter should be in the context of the patient encounter (Brisset et al., 2013; Hallford et al., 2019; Kamara et al., 2018; Lara-Otero et al., 2019; Leanza et al., 2015; Tam et al., 2020). Brisset et al. (2013) describes the various responsibilities of the interpreter as a continuum like that of Habermas's System and Life-world, where the life-world end of the spectrum focuses on social and personal factors such as culture while the system end of the spectrum focuses on strategic actions that benefit organizations or institutions (Habermas, 1991). The interpreter's role on the continuum is not static but oscillates between strictly serving the needs of the system and serving the needs of the patient (Brisset et al., 2013).

The interpreter may interpret as close to verbatim as possible but may be forced to create word pictures for terms that have no linguistic equivalent or even to intervene to inform the speaker if the source speech is in too high a register (that is, too technical or formal), if it is culturally offensive, or if it is clear to the interpreter that the listener does not comprehend. At the same time, the interpreter must be careful to "not allow personal judgements or cultural values to influence objectivity" (NCIHC, 2005). One particular role of the interpreter that is up for debate is that of a cultural broker, defined as someone who participates in the act of "bridging, linking or mediating between groups or persons of different cultural backgrounds to effect change" (Jezewski, 1990, p. 497). Although it is the interpreter's responsibility to inform the speaker of any important cultural factors,

acting as a cultural broker often requires the interpreter to speak outside of their strictly verbatim or conduit style of interpretation (NCIHC, 2005). In the genetic counseling setting where wording is meticulously chosen, changing the phrasing may significantly alter the meaning of the message, which is where the debate stems. This makes it especially important for the genetic counselor and interpreter to meet before the genetic counseling session and explicitly go over what each of their roles will be and set any boundaries, as demonstrated by research in the psychotherapy realm (Kuay et al., 2015; Tribe & Morrissey, 2004; Tribe & Thompson, 2011).

1.5 Need for More Training on Working with Interpreters

The Accreditation Council for Genetic Counseling (ACGC) Practice Based Competencies for genetic counseling training programs states that a training program must "employ strategies for successful communication when working with interpreters" (ACGC, 2019), but how this training is implemented, and the quality of the training is dependent on each program and the patient population with which each works. In 2009, with funding from the Jane Engelberg Memorial Fellowship (JEMF) award, Nancy Warren developed the online genetic counseling Cultural Competency Toolkit (Warren, 2010). One of the six sections specifically addresses working with interpreters and provides tips from practicing genetic counselors on how to work effectively with interpreters, but these are not meant to define the standards of practice. Unlike other medical professions, no genetic counseling-specific clinical guidelines have explicitly been defined or published. This absence of specific guidelines and likely minimal training in working with interpreters may be what contributes to the results of multiple studies that indicate it would be beneficial for genetic counselors to acquire more

experience related to working with interpreters (Agather et al., 2017; Delgado-Hodges, 2015; Rosenbaum et al., 2020).

1.6 What is a Working Alliance?

Although the term 'working alliance' was originally developed to describe the relationship formed between therapist and patient, Bordin speculated in 1979 that it could be defined and elaborated in terms that would make it universally applicable (Bordin, 1979; Doran, 2016). Historically, research has been done that looked at the collaboration between interpreters and various healthcare providers, which over time has led to the usage of the term working alliance in these contexts (Freed, 1998; Labun, 1999; Raval, 1996). Loosely, the working alliance between an interpreter and healthcare provider can be described as a collaboration in which the two individuals "work together as a collaborate team in therapy" (Dubus, 2009; Raval, 2005; Robertson, 2014, p. 7). The National Standards of Practice for Interpreters in Health Care also states that interpreters are members of the treating team, which further enforces the need to establish a working alliance and make them feel part of the team (NCIHC, 2005). This research has been exclusive of the field of genetic counseling, but considering the often-therapeutic nature of genetic counseling, it's likely that this description can also be applied to the working alliance that interpreters may experience when working with genetic counselors.

1.7 How is a Working Alliance Established?

An abundance of research has been dedicated to characterizing the challenges and successes that result while working with interpreters specifically in the mental health setting (Hadziabdic & Hjelm, 2013; Leanza et al., 2015; Raval, 1996; Raval, 2005; Robertson, 2014; Searight & Searight, 2009; Tribe & Morrissey, 2004). This has led to

the development of practice guidelines and recommendations (Tribe & Lane, 2009; Tribe & Thompson, 2011). It's likely that following these guidelines and knowing how to work effectively with an interpreter can contribute to establishing a working alliance. For example, meeting with the interpreter before the patient encounter can actually improve interpreter accuracy if they are presented with an overview of what will happen in the session and if their tasks are clearly stated (Raval, 2005). During the encounter, it is important to look directly at the patient when talking and speak at a moderate pace while avoiding as much as possible the use of technical terminology (Hadziabdic & Hjelm, 2013; Tribe & Morrissey, 2004). In some circumstances, it may also be helpful to meet with the interpreter following the conclusion of the encounter to debrief about any emotions, clarify any misunderstandings, and provide feedback for each other (Raval, 2005; Searight & Searight, 2009; Tribe & Morrissey, 2004). In addition to the above, establishing "mutual trust, recognition, and respect for each other's work" and creating an environment where everyone feels comfortable asking questions are just as important in establishing a working alliance (Krieger et al., 2018; Labun, 1999; Leanza et al., 2015, p. 358). While sometimes occurring over a short period of time, the establishment of a good working alliance often requires the ability to work together over time and multiple encounters, which is not always feasible in the genetic counseling setting (Delgado-Hodges, 2015; Labun, 1999; Leanza et al., 2015; Raval, 2005; Robertson, 2014).

1.8 Rationale

The ability of interpreters to succeed in the genetic counseling setting is a reflection of their ability to work together and collaborate with genetic counselors to overcome challenges that come with interpreting highly specialized terminology and

making information culturally sensitive while still accurately rendering the original meaning of the message. Some of the methods that genetic counselors are using that are likely helpful in establishing this working alliance and helping interpreters to succeed in the genetic counseling setting are known, but it is also known that not all genetic counselors are proficient in these skills or working with interpreters in general as many interpreters perceive that genetic counselors need more training in regards to working with interpreters (Agather et al., 2017; Delgado-Hodges, 2015; Rosenbaum et al., 2020; Schmitz et al., 2008).

Knowing how to work effectively with interpreters is important in establishing and maintaining a working alliance, which itself is important as it affects the patient's overall experience during the encounter (Bolton, 2002; Lara-Otero et al., 2019; Leanza et al., 2015; Raval, 1996; Schmitz et al., 2008). An abundance of mental health literature outlines the challenges and successes of working with interpreters which has led to the development of guidelines (Hadziabdic & Hjelm, 2013; Leanza et al., 2015; Raval, 1996; Raval, 2005; Robertson, 2014; Searight & Searight, 2009; Tribe & Lane, 2009; Tribe & Morrissey, 2009; Tribe & Thompson, 2011). Although genetic counseling likely shares many similarities with mental healthcare, there are bound to also be many differences due to the unique and complex nature of what is discussed in genetic counseling sessions. Thus, it is important to determine if interpreters feel that genetic counselors are able to establish a working alliance with them when providing care to patients with limited English proficiency and to also determine what elements are most important in establishing this alliance and whether these elements are occurring.

1.9 Purpose of Current Study

The purpose of this study is to characterize the experiences interpreters have had while interpreting in genetic counseling. More specifically, this study will assess the quality of the working alliance interpreters experience with genetic counselors and determine the specific elements that impact that relationship. It will also determine whether interpreters are experiencing these elements in their work with genetic counselors. Leanza and colleagues' (2015) study conclude that it is important that interpreters and the healthcare provider share "mutual trust, recognition, and respect for each other's work" to establish a good working alliance, so this study will also try to determine if interpreters feel that these needs are being met (Leanza et al., 2015). The objectives of this study are to characterize what elements interpreters view as important in being able to work effectively with genetic counselors, determine whether interpreters are experiencing these elements they view as important in their work with genetic counselors, and to characterize the working alliance that interpreters have experienced while working with genetic counselors.

CHAPTER 2: LANGUAGE INTERPRETERS' PERSPECTIVE OF THE INTERPRETER-GENETIC COUNSELOR WORKING ALLIANCE[1]

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2.1 Abstract

Interpreters are an asset to the genetic counseling process as they help to bridge both cultural and linguistic gaps. For various reasons, their ability to accurately render the often-complex information discussed in genetic counseling sessions is likely dependent on their ability to establish a working alliance and collaborate with genetic counselors to overcome any challenges. Studies in other healthcare fields document the elements crucial to forming a working alliance between interpreter and healthcare provider, but little research has been done specifically investigating how to form a working alliance in the context of the specialized nature of genetic counseling. The goal of this study was to characterize the experience interpreters have had while working with genetic counselors and determine which factors are most important in establishing a working alliance. A total of 180 interpreters were recruited from ten interpreter industry associations and participated in this study. The study involved an online questionnaire and optional follow up phone interview. The majority of study participants characterized their overall experience working with genetic counselors as good or very good (98%). The vast majority of participants (95%) thought it was important that genetic counselors create an environment that allows both the interpreter and the patient to feel comfortable asking questions, followed by speaking at a moderate pace, pausing often to allow the interpreter to easily interpret the information to the patient (93%), and using simple language and avoiding jargon or at least providing a clear explanation of the terms when talking to the patient (91%). A pre-session to discuss sensitive topics that may come up, review technical terminology, and the patient's reason for the appointment is something that 81% of participants viewed as important but only 15% of participants experience often.

Participants also valued sharing with genetic counselors mutual trust, respect, and an understanding of each other's roles. The results of this study may provide guidance on establishing guidelines on how to work with interpreters in the genetic counseling setting.

2.2 Introduction

The highly complex, specialized nature of the information discussed in a genetic counseling session can alone be sufficient to create a barrier to achieving informed consent due to its demand for patients to have a high health literacy, defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000). An additional factor that impacts a patient's ability to understand and fully participate in a genetic counseling session is a language barrier between the patient and healthcare provider, which if not addressed appropriately can further impede achieving informed consent. The 2019 American Community Survey 5 Year Estimate predicts that 8.4% of Americans will self-rate their ability to speak English as less than "very well" (U.S. Census Bureau, 2019). Individuals who speak English less than "very well" are considered to be limited English-proficient (LEP), defined as "Individuals who do not speak English as their primary language and who have a limited ability to read, speak, write, or understand English" ("Commonly Asked Questions," 2011).

Over the past 50 years, a growing body of legislation and regulations have been put in place to overcome communicative barriers to healthcare. In 2011, the Affordable Care Act formalized language protection services into Executive Order 13166 of 2000 which required all federal agencies to assure the same equal access to their own programs that Title VI required of recipients of their funding (Affordable Care Act of 2010; Office

for Civil Rights, n.d.). The National Society of Genetic Counselors (NSGC) also recognizes the importance of providing services to patients "regardless of their abilities, age, culture, religion, ethnicity, language, sexual orientation and gender identity" (NSGC Code of Ethics, 2017). Subsequently, as more LEP patients receive genetic counseling services, language discordance becomes more frequent as 86% of the culturally and linguistically homogenous task force of practicing genetic counselors in the United States are fluent only in English (NSGC Professional Status Survey, 2019). As a result, medical interpreters have begun to play an invaluable role in the genetic counseling session in bridging both cultural and language gaps.

Bridging these gaps and so improving the quality of the care that LEP patients receive is most successful when interpreters are professionally trained, as opposed to being ad hoc or untrained (Flores et al., 2003; Flores et al., 2012; Hunt & de Voogd, 2007; Karliner et al., 2007; Larrison et al., 2010). An interpreter's ability to "render all messages accurately and completely, without adding, omitting, or substituting" (National Council on Interpreting in Healthcare, 2005) is highly dependent on their familiarity and comfort with the terminology used in the genetic counseling session (Donelan et al., 2009; Flores et al., 2003; Flores et al., 2012; Gutierrez et al., 2017; Hallford et al., 2019; Hunt & de Voogd, 2007; Langford, 2011; National Council on Interpreting in Healthcare, 2005; Saleh et al., 2009). As expected, studies show that interpreters who have received genetic counseling-related education achieve higher scores when tested on their knowledge and understanding of genetics, but the amount of training most interpreters receive specifically related to genetic counseling is minimal and not memorable (Delgado-Hodges, 2015; Donelan et al., 2009; Langford, 2011). Those who are less

familiar with the terminology are more likely to make mistakes when interpreting, as many genetics terms have no cultural or linguistic equivalents in other languages, making verbatim interpretation difficult and sometimes impossible and exacerbating the potential for error (Agather et al., 2017; Flores et al., 2003; Flores et al., 2012; Gutierrez et al., 2017; Hallford et al., 2019; Hunt & de Voogd, 2007).

In the absence of adequate genetics-related training, the ability of an interpreter to convey accurate information to a patient in a genetic counseling session then in part comes down to their ability to collaborate with the genetic counselor and overcome such challenges together. For example, as part of their standards of practice, interpreters are to ask for clarification in situations in which they don't understand what was said by the provider or patient. They are also expected to "alert all parties to any significant cultural misunderstanding that arises", or in other words, act as a cultural broker or someone who "bridges, links or mediates between groups or persons of different cultural backgrounds to effect change" (Jezewski, 1990, p. 497; NCIHC, 2005). In order to meet these standards of practice, the interpreter must feel comfortable speaking up during the session and the genetic counselor must be receptive and welcoming of such interventions. Lack of agreement regarding the role of the interpreter, particularly in regard to the interpreter acting as a cultural broker will likely affect the dynamic between provider and interpreter, causing the interpreter to not feel comfortable speaking up to ask for clarification or alert the parties of a cultural misunderstanding (Brisset et al., 2013; Hallford et al., 2019; Kamara et al., 2018; Lara-Otero et al., 2019; Leanza et al., 2015; Raval, 1996; Raval, 2005; Tam et al., 2020). This negatively impacts the accuracy of the communication

between the genetic counselor and the patient and so likely the quality of care the patient receives.

Knowing how to work effectively with interpreters is critical in avoiding such challenges. It is also important in establishing and maintaining a working alliance, loosely defined as when two individuals "work together as a collaborate team in therapy" (Robertson, 2014, p. 7; Dubus, 2009; Raval, 2005). Establishing a good working alliance is important as it affects the patient's overall experience during the encounter (Bolton, 2002; Lara-Otero et al., 2019; Leanza et al., 2015; Raval, 1996; Schmitz et al., 2008). An abundance of mental health literature outlines challenges and successes in working with interpreters (Hadziabdic & Hjelm, 2013; Leanza et al., 2015; Raval, 1996; Raval, 2005; Robertson, 2014; Searight & Searight, 2009; Tribe & Morrissey, 2004). This has led to the development of specific guidelines for working with interpreters within mental health practice (Tribe & Lane, 2009; Tribe & Thompson, 2011). Although literature related to this in genetic counseling is sparse, some of the methods used by genetic counselors are likely helpful in establishing a working alliance and helping interpreters succeed in the genetic counseling setting (Schmitz et al., 2008). Conversely, not all genetic counselors are proficient in these methods or in working with interpreters in general, as many interpreters perceive that genetic counselors need more training related to working with interpreters (Agather et al., 2017; Delgado-Hodges, 2015; Rosenbaum et al., 2020).

Working with interpreters in genetic counseling likely shares many similarities with mental healthcare, but there are bound to also be many differences due to the unique and complex nature of information discussed. Therefore, the goal of this project was to characterize the experience interpreters have had while working with genetic counselors,

determine which elements are most important in establishing a working alliance, and determine how often these elements occur in genetic counseling sessions.

2.3 Materials and Methods

2.3.1 Participants

Participants for this study included individuals 18 years of age and older who have been practicing as a spoken language interpreter for one or more years and have interpreted for at least one genetic counseling session. Participants were recruited through interpreter industry associations, including the National Council on Interpreting in Healthcare (NCIHC), 7 state interpreter associations, the Certification Commission for Healthcare Interpreters (CCHI), and remote interpreting company Certified Languages International (CLI). A study recruitment advertisement was sent out through each associations' electronic mailing list or posted on the respective association's social media page. The advertisement included a brief description of the study and an anonymous link to the online survey (Appendix A). Participation was voluntary and those who completed the online survey had the option to be entered into a raffle to win access to the Health Care Interpreter Network (HCIN) online course, *Interpreting for Prenatal Genetic Counseling*. Participants also had the option to participate in a follow-up phone interview. The University of South Carolina Institutional Review Board (IRB) deemed this study exempt from review in June 2020 (Pro 00100669).

2.3.2 Materials/Measures

This study utilized a self-applied online questionnaire and a subsequent optional semi-structured interview conducted over the phone by the researcher. The online questionnaire was developed through Qualtrics and incorporated skip logic to tailor the

questions to each participants' personal experiences. The questionnaire contained items about demographics, the respondent's sense of how often various factors occur while working with genetic counselors and how important it is that those factors occur, how often respondents feel that they share mutual trust and respect with genetic counselors and how important it is to experience this, what is being discussed in pre-sessions and what is important to be discussed in pre-sessions, good or bad memorable experiences, and how important it is to speak up to ask for clarification or to act as a cultural broker. Answers were structured as multiple choice, Likert scale, select all that apply, and open-ended text entry questions (Appendix B).

The semi-structured interviews were conducted over the phone by the primary researcher and included approximately 15 questions (Appendix C). Interviewees were asked demographic questions and to elaborate further on some of the questions asked in the online survey, in addition to other questions regarding their experiences working with genetic counselors.

2.3.3 Procedure

The first page of the survey outlined the specific details of the project and pertinent information for the survey. Clicking forward and beginning the survey constituted consent. Participants were able to move back and forth between questions, skip any question, or leave the questionnaire at any time. If participants neglected to answer the questions that determined their eligibility, they were prompted to answer but were able to skip. Following two weeks of inactivity, incomplete surveys were automatically closed and recorded.

Upon completion of the survey, participants had the option to leave their contact information (name, email) in order to participate in a follow-up semi-structured phone interview. The primary investigator (DL) contacted volunteers via email to set up a time to conduct the phone interview. Verbal consent was obtained at the beginning of each interview for participation and recording of the interview. The phone interviews were recorded on the primary investigator's password-protected laptop with Apple Simple Recorder and were transcribed verbatim. Transcripts were given unique number codes and the code key was kept separately to ensure responses remained anonymous. Audio recordings were destroyed upon completion of transcription. Data was collected from June 2020 to October 2020.

2.3.4 Analysis

Data was analyzed from January 2021 to March 2021. Descriptive statistics were used to describe the demographic information, which elements interpreters view as most important in working effectively with genetic counselors as well as which of these elements actually occur while working with genetic counselors. The "Moderately Important" and "Extremely Important" responses were added together to constitute overall importance and the "Frequently" and "Almost Always" responses were also added together to constitute which elements occurred most frequently. The "Not at all important" and "Slightly important" responses were added together to constitute items that were not important to participants and the "Never" and "Occasionally" were also added together to identify which elements occurred least frequently. The questions regarding elements interpreters think are important to experience while working with genetic counselors and actually experience while working with genetic counselors were

also separated out as multiple series of four level ordinal variable scales where an overall score was computed and then summarized as a continuous variable. The scale scores for these questions were run as the outcome variable in a linear regression in which responses to some of the demographic questions were candidate predictor variables. Adjusted R-square values determined how well demographic predictor variables explained the variability in scale scores.

To determine if interpreters are experiencing the elements they view as important in their work with genetic counselors, corresponding sub-items between questions asking about importance of elements versus whether the elements are occurring were arranged in nine 4x4 tables, and a Goodman-Kruskal gamma statistic was computed, along with a p-value under the null hypothesis of no association.

Descriptive statistics were used to describe what interpreters think is important to discuss in pre-sessions with genetic counselors and what is actually discussed with those interpreters who have actually experienced a pre-session. To determine if there are any differences in what was viewed as important to discuss in a pre-session between interpreters who have experienced a pre-session compared to those who haven't, a series of 2x2 tables were created for each of the listed discussion topics provided to participants. Odds ratios were then computed as the measure of association, along with a p-value resulting from a chi-squared or Fisher's exact test as appropriate. Among the interpreters who did experience a pre-session, a chi-squared test of independence was used to determine if there is an association between what they viewed as important to discuss in pre-sessions versus what was actually experienced in pre-sessions.

Descriptive statistics were used to describe responses to questions regarding who typically initiates pre-sessions, reasons for not having a pre-session, overall experience working with genetic counselors, overall ability to work with genetic counselors compared to other healthcare providers, individuals who have had positive and/or negative experiences that were memorable, comfort with genetics terms, participation and comfort speaking up to ask for clarification, and participation and comfort speaking up to act as a cultural broker. The dichotomous responses to questions regarding memorable positive experiences, memorable negative experiences, speaking up to ask for clarification, and speaking up to act as a cultural broker were the outcome variables in separate logistic regression analyses in which responses to some of the demographic questions were candidate predictor variables.

A grounded theory approach was used to analyze the qualitative data from answers to free response survey questions and follow-up interview questions. The primary investigator (DL) and project advisor (VV) individually coded the qualitative responses, determined derived themes, and compared the results until common themes and categories were agreed upon.

2.4 Results

2.4.1 Demographic Information

A total of 180 individuals participated in our study. Because participants were allowed to skip questions, there are discrepancies in the number of responses per question. Demographic characteristics are summarized in Table 2.1. The majority of participants were female (82.58%; n=128) above the age of 30 (85.9%; n=134). The two most common racial and ethnic identities were Hispanic/Latino (35.19%; n=57) and

White/Caucasian (34.57%; n=56). The single most common native language was Spanish (37.01%; n=57) as was the single most common target interpreted language (37.79%; n=65). Most participants reported to be freelance interpreters (49.28%; n=68) and provided services remotely in a wide range of states rather than in specific regions (48.15%; n=65). Participants most frequently reported having completed between 65 and 120 hours of formal interpretation training (42.75%; n=59). While most participants have not completed training specifically on interpreting in genetics (69.7%; n=92), for those that did, the average number of hours of training was 20.95 hours (range 1-50 hours). The average amount of time participants had been working as interpreters was 12.26 years (range 1 to 50 years; median 10 years). A little over half of the participants were certified medical interpreters (52.17%; n=72) with about two thirds holding a Certified Healthcare Interpreter (CHI) credential (61.9%; n=39). The most common modality of interpretation was over the phone (44.1%; n=86) followed by in person (35.38%; n=69). Almost half of participants had interpreted for over 15 genetic counseling sessions (42.96%; n=58) while one third of participants had interpreted just one to five sessions (34.07%; n=46). The most commonly selected genetic counseling setting that participants had interpreted in was prenatal/OB/preconception (35.47%; n=83) followed by pediatric (25.21%; n=59). The majority of participants indicated that they work with each genetic counselor only once or a few times (61.35%; n=73) while the remainder of participants indicated that they tend to work repeatedly with the same genetic counselor(s) (38.65%; n=46). Respondents who worked at a healthcare facility indicated more frequently that they worked repeatedly with the same genetic counselor(s) (61%; n=14) than did those who

worked at a language services company (35%; n=12) or as a freelance interpreter (30%; n=17).

2.4.2 Pre-Session with a Genetic Counselor

Almost two thirds of participants have never experienced a pre-session discussion with a genetic counselor (60%; n=66). The most common indicated reasons for not having a pre-session were that there was not enough time (42.42%; n=29) and that the genetic counselor did not want to (43.94%; n=29). Genetic counselors and interpreters are evenly split in terms of who usually initiates the pre-session (50%; n=21). The study participants that have had a pre-session with a genetic counselor reported that the three most commonly discussed items in pre-sessions were the patient's reason for the appointment (69.05%; n=29), sensitive topics that may come up during the session (52.38%; n=22), and what to expect in the session (47.62%; n=20) (Figure 1). Regardless of whether participants have actually had a pre-session with a genetic counselor, participants believed it would be most important to discuss sensitive topics that may come up in the session (59.62%; n=62), review of technical terminology that will be used in the session (58.65%; n=61), and what to expect in the session (56.73%; n=59) (Table 2.2).

2.4.3 Interpreter Experiences Working with Genetic Counselors

The majority of participants characterized their overall experience working with genetic counselors as either very good (51.46%; n=53) or good (46.60%; n=48). Compared to working with other healthcare providers, most interpreters thought working with genetic counselors was either the same as other healthcare providers (48.04%; n=49) or a little bit more difficult than with other healthcare providers (37.25%; n=38). Over

half of the respondents said they had a memorable experience that was positive while working with a genetic counselor (57.28%; n=59) while the majority of participants (69.39%; n=68) said they did not have a memorable experience that was negative while working with a genetic counselor. The majority of interpreters felt some level of comfort with the terms that come up in genetic counseling sessions: 58.59% (n=58) felt very comfortable and 31.31% (n=31) felt comfortable. The majority of respondents have spoken up to ask for clarification during a genetic counseling session (87.13%; n=88) and most felt very comfortable when doing so (73.49%; n=61). Less than half of participants have spoken up during a genetic counseling session to act as a cultural broker (44%; n=44), but out of those that have, the majority felt very comfortable when doing so (62.79%; n=27).

Interpreters who worked at a healthcare facility were 4.58 times more likely to have a memorable positive experience working with a genetic counselor compared to the referent level (p-value=0.025) (Table 2.3). Out of the demographic characteristics included in analysis, none made a significant difference on whether interpreters had a memorable negative experience while working with genetic counselors, although interpreters who worked at a healthcare facility were 3.7 times more likely and interpreters whose main modality of interpretation was over video were 2.8 times more likely to have a memorable negative experience (Table 2.4). Out of the demographic characteristics included in analysis, none made a significant difference on whether interpreters spoke up during a genetic counseling session to ask for clarification. Although they didn't reach clinical significance, interpreters who worked at a healthcare facility were 5.1 times more likely and interpreters who worked with each genetic

counselor only once were 4.6 times more likely to speak up during a genetic counseling session and ask for clarification compared to the respective referent levels (Table 2.5). Interpreters who worked at a language services company were significantly less likely to speak up during a genetic counseling session and act as a cultural broker (OR= 0.306; p-value=0.04). Interpreters who interpreted over 15 genetic counseling sessions were 5.4 times more likely to speak up and act as a cultural broker (p-value=0.024). Although it didn't reach clinical significance, interpreters who worked with one genetic counselor a couple times were 4.3 times more likely, interpreters who worked with one genetic counselor once were 3.8 times more likely, and interpreters who worked repeatedly with many different genetic counselors were 3.8 times more likely to speak up and act as a cultural broker during a genetic counseling session as compared to the referent level of working only once with many different genetic counselors (Table 2.6).

The frequency of genetic counselor actions that interpreters viewed as important are summarized in Table 2.7. The top three genetic counselor actions that interpreters thought were important were that the genetic counselor creates an environment that allows both the interpreter and the patient to feel comfortable asking questions (95.24%; n=100), the genetic counselor speaks at a moderate pace, pausing often to allow the interpreter to easily interpret the information to the patient (93.33%; n=98), and the genetic counselor uses simple language and avoids jargon or at least provides a clear explanation of the terms when talking to the patient (91.43%; n=96). The frequency of genetic counselor actions that interpreters actually experienced while working with genetic counselors are summarized in Table 2.8. The three most commonly experienced actions were the genetic counselor speaks in first person and addresses the patient

directly when speaking to them (83.93%; n=94), the genetic counselor creates an environment that allows both the interpreter and the patient to feel comfortable asking questions (66.96%; n=75), and the genetic counselor speaks at a moderate pace, pausing often to allow the interpreter to easily interpret the information to the patient (65.79%; n=75). A visual comparison of the importance and frequency of genetic counselor actions are displayed in Figure 2.2.

The frequency of feelings shared with genetic counselors that interpreters viewed as important are summarized in Table 2.9. The top three important shared feelings with genetic counselors were that the genetic counselor trust the interpreters (100%; n= 100), that the genetic counselor understand the complexities of the interpreters' work (98%; n=98), and that interpreters also understand the complexities of what it is that genetic counselors do (98%; n=98). The frequency of shared feelings with genetic counselors that interpreters actually experienced while working with genetic counselors are summarized in Table 2.10. The three most commonly experienced shared feelings were that interpreters understood the complexities of what it is that genetic counselors do (98.08%; n=102), interpreters respect the work that genetic counselors do (97.12%; n=101), and that the genetic counselor and interpreter shared mutual trust (94.12%; n=96). A visual comparison of the importance and frequency of interpreter feelings are displayed in Figure 2.3.

2.4.4 Qualitative Results

Qualitative results were analyzed from open-text questions within the questionnaire and six semi-structured phone interviews. Phone interviews lasted an average of 29 minutes (range 20 to 45 minutes). Emergent themes were associated with

establishing a working relationship, navigating complex genetic information, and a cultural broker role.

Establishing a Working Alliance. Two major themes emerged related to interpreters and genetic counselors establishing a working alliance. The first major theme was that mutual respect is important in establishing a good working alliance. Interpreters claimed to have experienced good working alliances with genetic counselors who understood that interpreters aren't genetics experts and were patient with them if they disclosed their knowledge gap and needed to ask questions to understand what they were being asked to interpret. One survey participant said:

> I was interpreting during a genetic consult for a young boy. He was diagnosed with an ultra-rare genetic disorder, so I struggled with some of the vocabulary and asked for a moment to look up a word (the name of his syndrome). The genetic counselor was very gracious and reassured me that since there are only 32 people diagnosed with this condition in the world, they did not expect me to know the name off the top of my head.

Likewise, interpreters felt they were unable to establish a good working alliance when genetic counselors expected them to have a complete understanding of genetics, became impatient or frustrated when they needed clarification, or requests for clarification were pushed aside or weren't answered effectively. Another survey participant noted that when this occurs, it "sets a bit of a negative tone and it's emotional and makes you think do they think I'm stupid."

The second major theme was that it was beneficial for an interpreter to have worked with a specific genetic counselor multiple times or to work with genetic

counselors who have prior experience working with interpreters. Interpreters stated that they were better able to establish a working alliance with genetic counselors with whom they had worked multiple times. With these genetic counselors, they knew what to expect in terms of how the genetic counselor presented information and, in some instances, even learned or developed body language cues to allow for seamless communication during the session. A participant explained:

> I think it was really helpful to work with people who I knew how they worked and they knew how I worked as well; just having a familiarity with their cadence and their mannerisms and knowing they were going to be pausing frequently to check for comprehension made everything a whole lot smoother.

Even in the absence of multiple interactions, it was evident to interpreters which genetic counselors had prior experience working with interpreters and which did not. In particular, participants perceived genetic counseling students and genetic counselors new to the workforce to be the least comfortable working with interpreters and felt that they struggled to establish a working alliance with these genetic counselors.

Navigating Complex Genetic Information. Several themes emerged related to navigating the complex information that comes up in genetic counseling sessions. The first theme was related to the genetic counselor helping the interpreter prepare for the session. Many interpreters stated that it was helpful to have a pre-session in which the genetic counselor disclosed what was going to be discussed in the session and any sensitive topics that were likely to come up. One participant stated:

> If they give me that heads up then I'm ready with my dictionaries and my glossaries and websites and I'm able to get information right away if I need to or

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if there's a word that I don't understand I already have my dictionaries and

glossaries ready here at home on video, so that helps a lot.

It was helpful for interpreters to have prior training in genetics or knowledge about

genetics, but they also appreciated when genetic counselors gave the interpreter literature

or materials about specific conditions that were going to be discussed in the session.

Multiple participants indicated they think it's important that interpreters understand the

material they interpret because "understanding creates effective communication" and "if

the interpreter is confused obviously the whole interpretation is going to be really

confusing" (interview participants 4 and 6). Some challenges that interpreters faced

related to this theme were that the genetic terminology and information was hard to

understand because it is so complex. In addition, it was often challenging to find

equivalent terminology in the non-English language. Finally, respondents struggled to

find information on rare conditions.

A second theme was related to how the genetic counselor presented information

to the patient. Interpreters appreciated when genetic counselors presented information

clearly, completely, and in plain language, at a moderate pace with frequent pauses. They

also appreciated the use of visual aids. It was challenging when genetic counselors used

technical terminology, talked quickly without frequent pauses, didn't use visual aids, and

when complex mathematical concepts were discussed, although some participants

recognized these concepts were unavoidable. Some participants also believed that genetic

counselors overestimate patient education levels and talk at too high of a register.

Interpreters also perceived a difference in how genetic counselors helped patients make

decisions about testing, some presenting the pertinent information in a non-biased manner

while others perceived the genetic counselor used data to "scare or force patients to get testing done," particularly in the prenatal setting.

An additional theme was related to how attentive the genetic counselor was during the session. Participants appreciated when genetic counselors checked in with how well both the patient and interpreter were understanding. They especially appreciated genetic counselors' efforts to answer all patient and interpreter questions. Interpreters were also able to tell when genetic counselors were in tune with the patient's emotions and helped them to emotionally process the information. Recognizing the complexity of the information discussed, interpreters were uncomfortable with genetic counselors who didn't stop to check for patient understanding, didn't explain the information differently when it clearly would have helped the patient understand, and discussed sensitive material non-empathetically. One survey participant explained:

> The counselor used complex terminology and mathematical concepts. I (transparently) explained that I was struggling to understand and interpret accurately, and the patient confirmed that she herself was having trouble understanding, and yet the counselor did not lower her register or even shorten her (very long) utterances. It was a real struggle. In the end, I was exhausted and the patient and provider both seemed frustrated.

Cultural Broker Role. An interview question asked participants to discuss their opinion on the role of the interpreter being a cultural broker. The majority of participants (83%) stated that they did believe being a cultural broker was within their role as an interpreter because interpreters "speak not only with language but also with an understanding of where the people come from." For those interpreters who have acted as

a cultural broker in a genetic counseling session, most stated that genetic counselors were receptive to the information they provided. Genetic counselors even adjusted their explanations based on what the interpreter disclosed, one participant saying, "I told the provider I had the feeling the patient was not understanding the conversation and then the provider did a very good job at lowering the register and explaining genetics in an understandable fashion," but some genetic counselors were better at doing this than others. In particular, some participants noted that genetic counseling students were slightly less receptive in receiving this information. One participant said,

> Some of the students I worked with in the past I think were a little bit less receptive. I don't think it was intended to be received poorly, I think it was kind of just overall feeling a little bit flustered about working with an interpreter and trying to find different ways of wording things that were not very textbook.

Multiple participants thought it was best to utilize this role of cultural broker when sensitive subjects were being discussed or in other extreme situations, but one participant stressed that "interpreters really need to caution themselves because just because you speak that language or were raised in the same culture that doesn't necessarily mean that you automatically have the same standards and the same perception of the world."

2.5 Discussion

2.5.1 Working Alliance

Previous research has demonstrated that the quality of care a patient receives in language-discordant psychiatric and genetic counseling healthcare settings is influenced by the relationship between the provider and the interpreter used to bridge the language barrier (Bolton, 2002; Bordin, 1979; Lara-Otero et al., 2019; Raval, 1996; Schmitz,

2018). Two individuals "who work together as a collaborate team in therapy" (Robertson, 2014, p. 7) loosely defines a working alliance, which can be used to describe the relationship between interpreter and genetic counselor (Dubus, 2009; Raval, 2005). Elements that foster a working alliance that the current study was able to address include working together over time, practicing helpful techniques when working together, and developing "mutual trust, recognition, and respect for each other's work" (Leanza et al., 2015, p. 358).

An important factor in building a working alliance is working together regularly over time (Delgado-Hodges, 2015; Labun, 1999; Leanza et al., 2015; Raval, 2005; Robertson, 2014). This is not something that participants in this study experienced frequently as over half of study participants indicated that they only work with each genetic counselor once or just a few times. Yet, in this study, it seemed that those who did work repeatedly with each genetic counselor were better able to build a working alliance than those who only worked with each genetic counselor once or just a few times. Just over half of participants stated that they had at least one memorable positive experience, and these experiences were more likely to occur if the interpreter worked at a healthcare facility. Looking at the specific subset of participants who work at a healthcare facility, 61% did indeed work repeatedly with each genetic counselor. Working together over time may lead to better experiences and likely a good working alliance. One of the participants even stated, "I think the positive experiences I have had working with genetic counselors have largely been for the reason that we knew each other."

It is also possible that in addition to working together over time, working together in person helps contribute to positive experiences and building a working alliance. More

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than half of participants who work at a healthcare facility also indicated they work completely onsite. It has been demonstrated before that working with in-person interpreters is preferred by genetic counselors as working with remote interpreters provides more challenges, and this study supports that interpreters also have a better experience when in person (Joseph & Guerra, 2015; Schmitz, 2018).

Interestingly, interpreters who worked at a healthcare facility were also 3.7 times more likely to have a memorable negative experience. This study did not investigate whether this may be due to their relationship with the genetic counselor or due to the nature of the visit as they may have more direct contact with strong patient emotions if the majority of these interpreters are working in person.

Similarly, around one third of participants believed that working with genetic counselors is a little bit more difficult than working with other healthcare providers. It's possible that participants attributed their response to this question to the complex nature of information discussed in genetic counseling sessions or the sensitive situations that this information elicits. One participant stated, "I would say 80-90% of the time you deal with concepts and situations that you are unfamiliar with, so that is what makes it more difficult."

Despite not working together repeatedly, nearly all participants (98%) characterized their overall experience working with genetic counselors as good or very good, indicating there must be other factors that influence the relationship between interpreter and genetic counselor. Leanza et al. (2015) showed that sharing trust, respect, and a mutual understanding of each other's work are important in establishing a working alliance, and this has been observed in the genetic counseling setting as well (Lara-Otero

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et al., 2019). The majority of participants viewed these shared feelings with genetic counselors as important and indicated that they frequently experience most of these feelings as well. Nearly all interpreters (98%) understand what it is that genetic counselors do, while only 68% of participants indicated that they frequently feel that genetic counselors understand the complexities of what it is that interpreters do. Interpreters may have a good grasp on what genetic counselors do because genetic counselors often explain their role and their agenda at the beginning of each genetic counseling session with patients. Conversely, it has been documented that healthcare providers could benefit from more training on working with interpreters, and genetic counselors aren't excluded from this (Delgado-Hodges, 2015; Hsieh, 2010; Pinto Taylor et al. 2019). Having a better knowledge of how to work with and the utility of interpreters may help interpreters feel better appreciated and understood by the genetic counselors with whom they work.

Recognizing what genetic counselors are doing well while working with interpreters is also important. Using the recommendations provided to mental healthcare providers as a guide, study participants were asked how often they experience various provider actions that were found to be helpful when working with interpreters in the mental healthcare setting (Hadziabdic & Hjelm, 2013; Searight & Searight, 2009; Tribe & Lane, 2009; Tribe & Morrissey, 2004; Tribe & Thompson, 2011). In general, the actions that interpreters viewed as important are experienced fairly frequently, including that the genetic counselor creates an environment that allows both the interpreter and the patient to feel comfortable asking questions, the genetic counselor speaks at a moderate pace, pausing often to allow the interpreter to easily interpret the information to the

patient, the genetic counselor uses simple language and avoids jargon or at least provides a clear explanation of the terms when talking to the patient, and the genetic counselor speaks in first person and addresses the patient directly when speaking to them. Although these actions are experienced somewhat frequently, genetic counselors could work toward making sure these actions are experienced by interpreters in every session. Establishing genetic counseling specific guidelines on how to best work with interpreters may be helpful in accomplishing this as well as helping genetic counselors and interpreters build better working alliances.

2.5.2 Genetics Terminology

The material discussed in genetic counseling sessions is inherently complex and difficult to understand without a strong background in it or experience working with it. Previous studies have demonstrated that interpreters struggle with understanding this material and are more likely to make interpretation errors when they don't understand (Donelan et al,. 2009; Hallford et al., 2019; Joseph & Guerra, 2015; Saleh et al., 2009; Schmitz, 2018). This is particularly true due to the fact that the information discussed often involves specialized terminology, analogies, hypotheticals, and mathematical concepts (Joseph et al., 2017; Kamara et al., 2018). Interestingly, the majority of participants in this study felt some level of comfort with the terms that come up in genetic counseling sessions. No specific genetics terms were provided in this study, but when Langford (2011) provided interpreters with a quiz regarding specific genetics terms, some terms proved to be problematic but overall, most interpreters had high knowledge scores. Despite this, it seems that interpreters may still benefit from more genetics-related

training as those with more experience interpreting in genetic counseling felt more comfortable with the terms.

The interpreter standards of practice state that interpreters must ask for clarification when they don't understand something, but genetic counselors should still ensure they create an environment where the interpreter feels comfortable doing so (NCIHC, 2005). Although it wasn't statistically significant, interpreters who work at a healthcare facility were 5.1 times more likely to speak up and ask for clarification and more than half of these individuals work repeatedly with each genetic counselor. Having more experience working with genetic counselors may allow interpreters and genetic counselors to build a better working alliance so that interpreters feel more comfortable asking for clarification during a session. Additionally, 85% of participants think it's important that the genetic counselor encourages the interpreter to speak up and ask for clarification if they don't understand something during the genetic counseling session, but only 39% of participants indicated that they experience this often. If the genetic counselor and interpreter don't already have experience working together, this is something that can easily be stated at the beginning of the session to make the interpreter more comfortable and help build a better working alliance.

2.5.3 Cultural Broker Role

As outlined by the interpreter standards of practice, interpreters must "alert all parties to any significant cultural misunderstanding that arises," or essentially act as a cultural broker in situations viewed by the interpreter to have a significant impact (Jezewski, 1990; NCIHC, 2005). Less than half of the study participants, though, have actually spoken up to act as a cultural broker. This study did not assess reasons for this,

such as these situations not having come up in a session for over half of study participants or that participants don't feel comfortable speaking up when these situations do occur. Bauer and Alegria (2010) suggest that less comfort around this interpreter role could potentially be due to external conflict on whether an interpreter should take on this role and, if so, to what extent.

Participants who interpreted for over 15 genetic counseling sessions were much more likely to speak up and act as a cultural broker during genetic counseling sessions. This could indicate that interpreters who work more often in the genetic counseling setting feel more comfortable about what their exact role is in a genetic counseling session. Additionally, 63% of those who indicated they are very comfortable acting as a cultural broker indicated that they work repeatedly with each genetic counselor. Furthermore, the frequency of individuals who feel very comfortable acting as a cultural broker increases as the frequency of how much they work with each genetic counselor increases, which could indicate that a working alliance or good relationship with a genetic counselor helps the interpreters to feel comfortable acting as a cultural broker. The general experience noted by study participants was that genetic counselors are typically very receptive and open to receiving information from them regarding cultural misunderstandings which also likely is experienced as interpreters work more frequently in genetic counseling and with each genetic counselor more often.

Interestingly, interpreters who indicated that they work for a language services company were significantly less likely to speak up and act as a cultural broker in genetic counseling sessions, with only 43% indicating that they feel very comfortable with this role. Many interpreters at language service companies work completely remotely,

compared to those who work onsite and those who work a mixture of both. Working

virtually may provide challenges to interpreters in establishing their role in the genetic

counseling setting. Also, only 30% of interpreters at language service companies work

repeatedly with each genetic counselor, so working remotely may be a barrier or

limitation to building a good working alliance with genetic counselors and refining their

role in that context.

Overall, the present study and previous studies suggest there is a need for better

communication regarding the expectations and role of the interpreter in the genetic

counseling session (Agather et al., 2017; Brisset et al., 2013; Leanza et al., 2015). To

ensure genetic counselors provide more culturally competent care, it may also be

important to encourage interpreters to speak up in situations where cultural awareness is

lacking (Kamara et al., 2018; Lara-Otero et al., 2019). Further proving this point, 81% of

study participants indicated they think it's important to be encouraged to inform the

genetic counselor if potential cultural conflicts or important cultural differences come up

in the genetic counseling session while only 27% of participants indicated that they

experience this often. Similar to encouraging the interpreter to speak up to ask for

clarification when needed, a simple sentence before the session begins to encourage

interpreters to speak up when cultural misunderstandings arise may go a long way in

building a working alliance with interpreters and allowing the interpreter to feel

comfortable in the cultural broker role.

2.5.4 Pre-Sessions

Holding a brief meeting between the provider and interpreter before an

appointment is a successful technique in helping to build a working alliance and may

actually help interpreters provide more accurate interpretations (Bolton, 2002; Delgado-Hodges, 2015; Raval, 2005; Saleh et al., 2009; Schmitz, 2018; Searight & Searight, 2009). Interpreters have previously demonstrated a desire for pre-sessions before genetic counseling sessions and in this study, most participants indicated that pre-sessions are important (Delgado-Hodges, 2015). Unfortunately, this seems to be one of the actions that genetic counselors are most lacking as only 13% of participants indicated that they often experience pre-sessions, with not enough time being one of the most common reasons for being unable to have one. This may be an easy adjustment to make as interpreters seem to want just a quick overview:

> It was literally maybe like 5 or 6 sentences; it wasn't much but it gave me such a good overview and I think sometimes providers would benefit greatly from just giving interpreters that 30 second to one-minute prep so that we have an overview of what we're even talking about rather than just jumping into it.

Additionally, having a single sentence about encouraging interpreters to speak up to ask for clarification or inform the genetic counselor if potential cultural conflicts or important cultural differences come up in the session may help the interpreter feel more comfortable carrying out tasks that are required of them by their standards of practice and also contribute to establishing a working alliance.

2.5.5 Strengths and Limitations

A major strength of this study is that there are not many others of its kind. Few studies have been done that specifically look at the relationship between interpreters and genetic counselors to determine how to best encourage a good working alliance. Additionally, this study was able to recruit a large, diverse sample that represents

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interpreters from across the United States and beyond who are practicing in a variety of settings via a variety of modalities.

The majority of study participants in this study were females whose native language is Spanish, so the results of this study may not be generalizable to the entire practicing population of interpreters. Because each language and each culture have their own intricacies, it is likely that the experience for interpreters of each is slightly different. Additionally, because the genetic counseling task force is largely female, male interpreters likely have a different experience than female interpreters, and these differences were unable to be captured in this study due to the small sample size of male interpreters.

Another limitation of this study is that it cannot be known for sure if and how much study participants attributed their answers regarding their working relationship with genetic counselors to the complex information that is often discussed in genetic counseling sessions. It seemed that many study participants focused more on the difficulty of the information discussed rather than the actual relationship they shared with the genetic counselors with whom they worked, which may indicate that helping interpreters better understand this information may lead to better working alliances.

Lastly, there was the potential for several biases in this study. Interpreters who viewed their genetic counseling encounters as more positive were potentially more likely to participate in the study. To our knowledge there were no validated sets of questions that specifically addressed our research questions so novel questions had to be generated, which could have potentially introduced informational biases. It is also possible that there

are other confounding variables that could explain some of the results but were not specifically measured in this study.

2.5.6 Future Directions

More work needs to be done to clearly define the role of the interpreter in the genetic counseling setting. To do this, it may be helpful to focus on interpreters who work repeatedly with genetic counselors to assess which roles are most often expected of them in genetic counseling sessions and how those roles align with what they perceive their roles to be. It may also be helpful to ask these same questions to genetic counselors who frequently work with interpreters to find the specific roles that reflect the wants and needs of both interpreters and genetic counselors.

In general, interpreters and genetic counselors could both benefit from more education regarding what elements would help to foster good working alliances. Interpreters in the study felt that the genetic counselor creating an environment that allows the interpreter and patient to feel comfortable asking questions, speaking at a moderate pace with frequent pauses to allow the interpreter to easily interpret the information, using simple language and providing a clear explanation of terms when jargon is unavoidable, having a pre-session, and establishing mutual trust, respect, and recognition of each other's work are most helpful when working with genetic counselors. These are elements which should be emphasized in training and continuing education of genetic counselors.

Lastly, this study found that a potentially important element of building a good working alliance between interpreter and genetic counselor is working together multiple times. It also determined which genetic counselor actions were viewed as most important

when working with interpreters, but this study can't say definitively that these are the only factors. Future studies should address whether there are any other elements not listed in this study that are important in building a good working alliance and if it is possible to build a working alliance during just a single interaction.

2.5.7 Conclusion

Interpreters play a pivotal role in genetic counseling sessions as they help to bridge language and cultural barriers that often arise due to the linguistic and culturally homogenous nature of the genetic counseling task force. Working together over time seems to be a strong predictor of having positive experiences and building a good working alliance, but this isn't always possible in the genetic counseling setting where interpreters most often interact with each genetic counselor once or just a few times. In the absence of working together multiple times, there are other things that may be helpful in building a good working alliance. This includes things like trusting and respecting each other as well as understanding the intricacies of each other's work. Additionally, it seems that knowing how to work with interpreters also goes a long way in building a good working alliance. This study documents which actions interpreters view as most important and also demonstrates that genetic counselors could work on carrying out these actions more consistently. Speaking at a moderate pace, pausing frequently, using simple language, addressing the patient directly, encouraging the interpreter to speak up during times of misunderstanding or when information is culturally insensitive, and holding a pre-session are examples of some of these actions. Lastly, this study demonstrated the importance of taking time before or at the beginning of the genetic counseling session to

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have a brief pre-session with the interpreter. This study may also guide what exactly

needs to be discussed in the pre-session.

CHAPTER 3: CONCLUSION

Interpreters play a pivotal role in genetic counseling sessions as they help to bridge language and cultural barriers that often arise due to the linguistic and culturally homogenous nature of the genetic counseling task force. Working together over time seems to be a strong predictor of having positive experiences and building a good working alliance, but this isn't always possible in the genetic counseling setting where interpreters most often interact with each genetic counselor once or just a few times. In the absence of working together multiple times, there are other things that may be helpful in building a good working alliance. This includes things like trusting and respecting each other as well as understanding the intricacies of each other's work. Additionally, it seems that knowing how to work with interpreters also goes a long way in building a good working alliance. This study documents which actions interpreters view as most important and also demonstrates that genetic counselors could work on carrying out these actions more consistently. Speaking at a moderate pace, pausing frequently, using simple language, addressing the patient directly, encouraging the interpreter to speak up during times of misunderstanding or when information is culturally insensitive, and holding a pre-session are examples of some of these actions. Lastly, this study demonstrated the importance of taking time before or at the beginning of the genetic counseling session to have a brief pre-session with the interpreter. This study may also guide what exactly needs to be discussed in the pre-session.

Table 2.1 Demographics of Participants

Characteristic	n	%
Gender (N=155)		
Male	25	16.13
Female	128	82.58
Other	2	1.29
Age (N=156)		
18-30	22	14.10
31-50	65	41.67
51 or older	69	44.23
Racial and Ethnic Identity (N=162)		
White/Caucasian	56	34.57
Black/African American	8	4.94
Hispanic/Latino	57	35.19
Asian/Asian American	27	16.67
American Indian/Alaska Native	1	0.62
Other	13	8.02
Native Language Spoken* (N=154)		
Spanish	57	37.01
English	23	14.94
Russian	10	6.49
Arabic	9	5.84
Interpreting Service Languages Provided,+ (N=136)**		
Spanish	65	47.79
French	12	8.82
Russian	10	7.35
Arabic	9	6.62
Working Arrangement (N=138)		
FT or PT staff interpreter at a healthcare facility	24	17.39
FT or PT staff interpreter at a language services company	38	27.54
Freelance interpreter	68	49.28
Retired interpreter	1	0.72
Other	7	5.07
Regions Interpretation Services are Provided* (N=135)**		
Western States	17	12.59
Mountain States	7	5.19
Heartland States	6	4.44
Midwestern States	22	16.30
Southern States	6	4.44
New York / Mid-Atlantic States	9	6.67
New England	3	2.22
I work as a remote interpreter serving a wide range of states	65	48.15
Amount of Formal Training (N=138)		

None	5	3.62
<40 hours	15	10.87
40-64 hours	30	21.74
65-120 hours	59	42.75
Associates degree in translation and interpreting	16	11.59
Master's degree in translation and interpreting	13	9.42
Training on interpreting for genetics (N=132)		
Yes	40	30.30
No	92	69.70
Certified Medical Interpreter (N=138)		
Yes	72	52.17
No	66	47.83
Credential Held (N=63)		
CHI	39	61.90
CMI	19	30.16
Washington State DSHS Medical Interpreter	5	7.94
Interpretation Modalities[+] (N=136)		
In person (onsite)	69	50.74
Over the phone	86	63.24
Over videoconference	40	29.41
Number of Genetic Counseling Sessions Interpreted For (N=135)		
0	9	6.67
1-5	46	34.07
6-15	22	16.30
Over 15	58	42.96
Genetic Counseling Settings Previously Interpreted in[+] (N=119)		
Clinic that sees adult-onset conditions	36	30.25
Clinic that sees pediatric and/or adult cancers	42	35.29
Clinic that sees pediatric conditions	59	49.58
Clinic that sees prenatal/OB/preconception conditions	83	69.75
Not sure	14	11.76
Experience Working with Genetic Counselors (N=119)		
Worked with one genetic counselor once	12	10.08
Worked with one genetic counselor a couple times	17	14.29
Tends to work only once with many different genetic counselors	22	18.49
Tends to work just a little with many different genetic counselors	22	18.49
Tends to work repeatedly with only one or a few genetic counselors	7	5.88
Tends to work repeatedly with many different genetic counselors	39	32.77

[+] Participants were instructed to select all that apply, allowing the percentage to add up to more than 100.

* The top four native languages are listed. Other native languages include Albanian (n=2), Bengali (n=3), Cantonese (n=1), Farsi (n=3), French (n=6), Greek (n=1), Hebrew (n=1), Hindi (n=1), Hmong (n=1), Italian (n=2), Japanese (n=2), Korean (n=1), Mandarin (n=5), Polish (n=1), Portuguese (n=5), Punjabi (n=1), Romanian (n=2), Somali (n=2), Swahili (n=1), Tagalog (n=1), Vietnamese (n=1), Other (n=11).

** The top four languages provided in interpretation services are listed. Other interpreted language serves include Bengali (n=2), Burmese (n=1), Cantonese (n=2), Farsi (n=4), Hindi (n=8), Hmong (n=1), Italian (n=4), Japanese (n=2), Korean (n=1), Malay (n=1), Mandarin (n=7), Nepali (n=1), Portuguese (n=6), Punjabi (n=2), Romanian (n=1), Somali (n=2), Vietnamese (n=1).

*** Western States: Washington, Oregon, California, Idaho, Alaska, Hawaii; Mountain States: Montana, Wyoming, Nevada, Utah, Colorado, Arizona, New Mexico, Texas; Heartland States: North Dakota, South Dakota, Nebraska, Iowa, Kansas, Missouri, Oklahoma, Arkansas; Midwestern States: Minnesota, Wisconsin, Michigan, Illinois, Indiana, Ohio, Kentucky; Southern States: Tennessee, North Carolina, Louisiana, Mississippi, Alabama, Georgia, South Carolina, Florida; New York / Mid-Atlantic States: New York, Pennsylvania, West Virginia, Virginia, Maryland, Delaware, DC, New Jersey; New England: Massachusetts, Vermont, New Hampshire, Rhode Island, Connecticut, Maine.

Table 2.2 Topics all Participants View as Important to Discuss in a Pre-Session (N=104)

Topic	n	Percentage (%)
Sensitive topics that may come up	62	59.62
Technical terminology	61	58.65
What to expect in the session	59	56.73
Patient's reason for the appointment	58	55.77
How to best communicate with patient	40	38.46
Review of genetic counseling process	39	37.5
Ground rules for using an interpreter	36	34.62
Interpreter role/tasks in session	35	33.65
Information on patient's culture	33	31.73
Interpreter's interpretation style	32	30.77
Genetic counselor's role/tasks in session	28	26.92
Confidentiality issues	28	26.92

Table 2.3 Logistic Regression Using Memorable Positive Experience as the Outcome

Demographic	OR	LCL	UCL	p-value
WorkInterpreter at a HC facility	4.579	1.201	21.47	0.025
WorkInterpreter at a language scvs co	0.884	0.332	2.332	0.802
WorkOther	1.868	0.339	13.49	0.480
Number.genetic.sessions6-15	1.429	0.363	5.83	0.610
Number.genetic.sessionsOver 15	1.262	0.372	4.31	0.707
ExperienceJust a little with many different gcs	0.857	0.25	2.922	0.804
ExperienceRepeatedly with only one or a few gcs	0.873	0.117	7.536	0.895
ExperienceRepeatedly with many different gcs	0.703	0.208	2.313	0.562
ExperienceWith one gc once	1.067	0.156	7.902	0.947
ExperienceWith one gc a couple times	0.59	0.095	3.33	0.552
PhoneYes	1.443	0.546	3.875	0.458
VideoYes	1.329	0.538	3.355	0.538
Settings.adultYes	0.613	0.236	1.562	0.306
Settings.prenatalYes	0.66	0.195	2.071	0.480
Settings.not.sureYes	0.367	0.055	2.17	0.270

Table 2.4 Logistic Regression Using Memorable Negative Experiences as the Outcome

Demographic	OR	LCL	UCL	p-value
WorkInterpreter at a HC facility	3.732	0.941	16.34	0.061
WorkInterpreter at a language scvs co	1.027	0.294	3.462	0.965
WorkOther	0.113	0.001	1.205	0.076
Number.genetic.sessions6-15	0.484	0.09	2.476	0.382
Number.genetic.sessionsOver 15	0.6	0.117	2.94	0.527
ExperienceJust a little with many different gcs	0.576	0.122	2.637	0.474
ExperienceRepeatedly with only one or a few gcs	1.269	0.143	11.29	0.828
ExperienceRepeatedly with many different gcs	1.227	0.306	5.326	0.775
ExperienceWith one gc once	0.586	0.043	6.378	0.661
ExperienceWith one gc a couple times	0.027	0	0.429	0.008
PhoneYes	0.541	0.171	1.673	0.284
VideoYes	2.831	0.961	8.875	0.059
Settings.adultYes	0.374	0.109	1.154	0.088
Settings.prenatalYes	1.963	0.502	8.857	0.337
Settings.not.sureYes	3.823	0.225	60.62	0.327

Table 2.5 Logistic Regression Using Asking for Clarification in a Session as the Outcome

Demographic	OR	LCL	UCL	p-value
WorkInterpreter at a HC facility	5.07	0.622	96.51	0.138
WorkInterpreter at a language scvs co	1.332	0.311	6.587	0.701
WorkOther	0.159	0.009	1.554	0.114
Number.genetic.sessions6-15	1.541	0.226	12.01	0.657
Number.genetic.sessionsOver 15	1.125	0.179	6.263	0.896
ExperienceJust a little with many different gcs	1.442	0.255	8.641	0.675
ExperienceRepeatedly with only one or a few gcs	0.195	0.012	2.273	0.191
ExperienceRepeatedly with many different gcs	1.608	0.297	9.487	0.574
ExperienceWith one gc once	4.606	0.2	1181	0.380
ExperienceWith one gc a couple times	2.871	0.189	437.3	0.486
PhoneYes	1.791	0.41	7.804	0.428
VideoYes	1.152	0.287	5.163	0.843
Settings.adultYes	0.492	0.115	1.883	0.299
Settings.prenatalYes	1.131	0.173	5.365	0.883
Settings.not.sureYes	5.17	0.202	1568	0.368

Table 2.6 Logistic Regression Using Acting as a Cultural Broker as the Outcome

Demographic	OR	LCL	UCL	p-value
WorkInterpreter at a HC facility	0.806	0.203	3.202	0.756
WorkInterpreter at a language scvs co	0.306	0.088	0.937	0.038
WorkOther	0.253	0.034	1.551	0.138
Number.genetic.sessions6-15	2.399	0.527	12.71	0.262
Number.genetic.sessionsOver 15	5.35	1.236	29.16	0.024
ExperienceJust a little with many different gcs	2.389	0.576	11.01	0.233
ExperienceRepeatedly with only one or a few gcs	2.52	0.322	20.21	0.373
ExperienceRepeatedly with many different gcs	3.811	0.986	17.11	0.052
ExperienceWith one gc once	3.848	0.342	43.78	0.268
ExperienceWith one gc a couple times	4.331	0.532	40.16	0.171
PhoneYes	0.88	0.301	2.551	0.813
VideoYes	1.999	0.737	5.764	0.175
Settings.adultYes	0.993	0.354	2.717	0.989
Settings.prenatalYes	0.43	0.117	1.485	0.182
Settings.not.sureYes	0.79	0.105	5.794	0.815

Table 2.7 Importance of Genetic Counselor Actions

Action	Important (n)	Percentage (%)
GC creates comfortable environment (N=105)	100	95.24
Moderate pace with pauses (N=105)	98	93.33
Simple language (N=105)	96	91.43
GC addresses patient directly (N=104)	94	90.38
GC encourages me to ask for clarification (N=105)	89	84.76
GC encourages me to inform of cultural conflicts (N=105)	85	80.95
Pre-session (N=105)	81	77.14
GC values my feedback (N=104)	71	68.27
Post-session (N=104)	44	42.31

Table 2.8 Frequency of Experience of Genetic Counselor Actions

Action	Often (n)	Percentage (%)
GC addresses patient directly (N=112)	94	83.93
GC creates comfortable environment (N=112)	75	66.96
Moderate pace with pauses (N=114)	75	65.79
Simple language (N=113)	69	61.06
GC encourages me to ask for clarification (N=112)	44	39.29
GC values my feedback (N=112)	36	32.14
GC encourages me to inform of cultural conflicts (N=110)	30	27.27
Post-session (N=111)	17	15.32
Pre-session (N=112)	15	13.39

Table 2.9 Importance of Shared Feelings with Genetic Counselors

Action	Important (n)	Percentage (%)
The GC trusts me (N=100)	100	100
GCs understand what I do (N=100)	98	98
I understand what GCs do (N=100)	98	98
GCs respect my work (N=100)	97	97
I respect GC's work (N=100)	91	91
I trust the GC (N=100)	86	86

Table 2.10 Frequency of Experience of Shared Feelings with Genetic Counselors

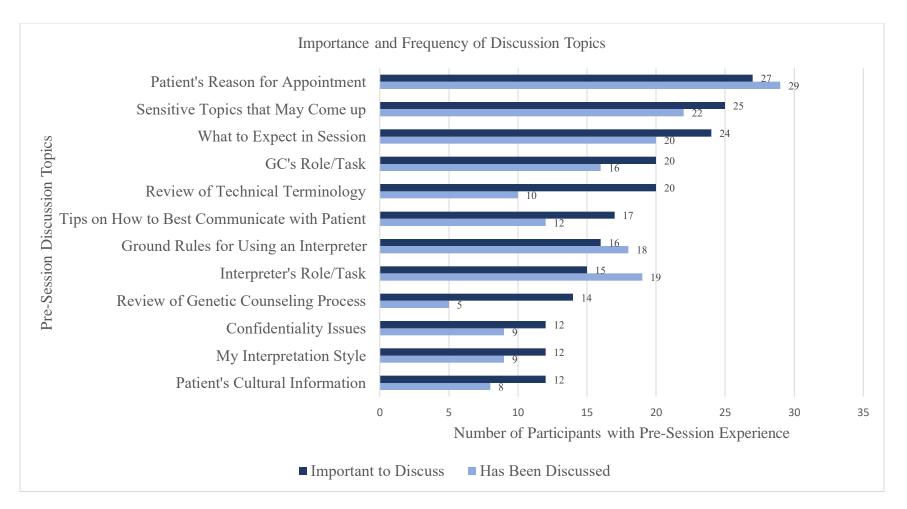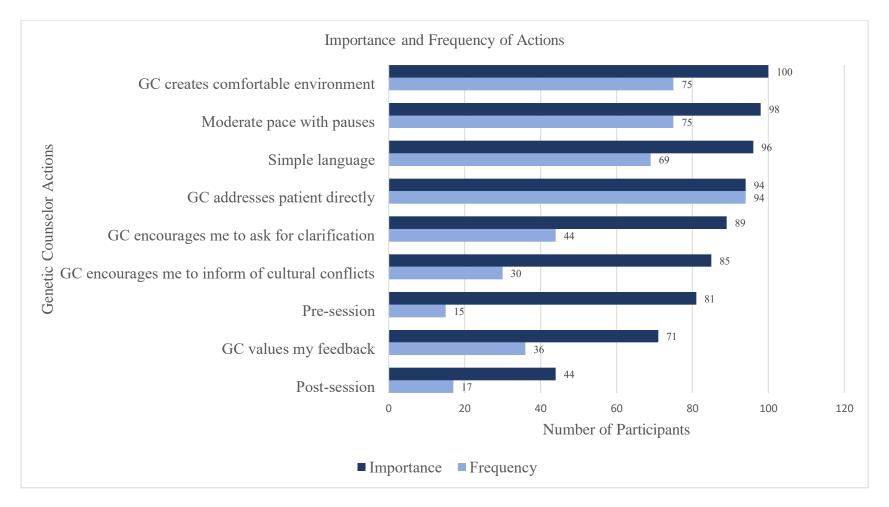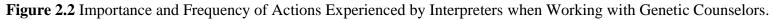| Action	Often (n)	Percentage (%)
I understand what GCs do (N=104)	102	98.08
I respect GC's work (N=104)	101	97.12
I trust the GC (N=102)	96	94.12
The GC trusts me (N=102)	96	94.12
GCs respect my work (N=102)	93	91.18
GCs understand what I do (N=103)	70	67.96

Figure 2.1 Importance (N=39) and Frequency (N=42) of Discussion Topics in a Pre-Session According to Participants who have Experienced a Pre-Session.
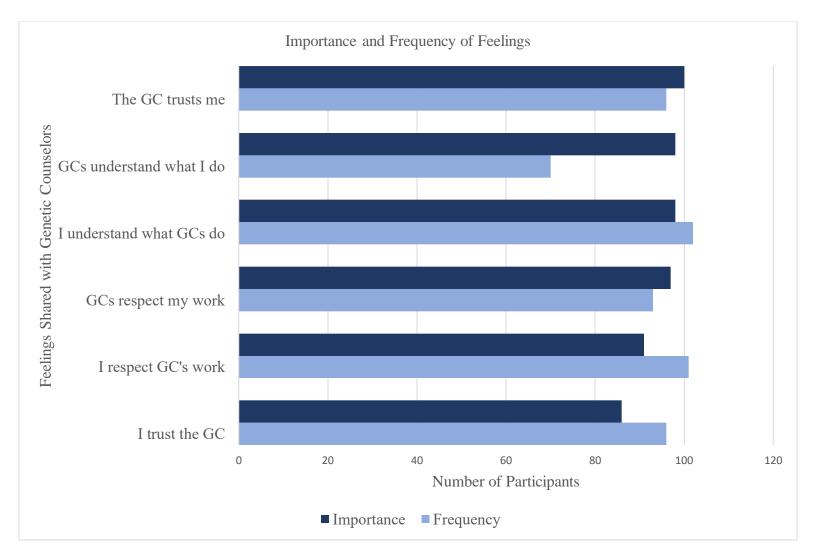
Figure 2.2 Importance and Frequency of Actions Experienced by Interpreters when Working with Genetic Counselors.

Figure 2.3 Importance and Frequency of Feelings Experienced by Interpreters when Working with Genetic Counselors.

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APPENDIX A: STUDY RECRUITMENT LETTER

Dear Interpreter,

You are invited to participate in a graduate research study focusing on the experience interpreters have had while working with genetic counselors. My name is Dacia Lipkea and I am a graduate student studying for a Masters degree in genetic counseling at the University of South Carolina. All spoken language medical interpreters who are over the age of 18 and have interpreted for at least one genetic counseling session are eligible and encouraged to take this survey. The survey is open now and will be available through **September 15, 2020**. The link to the survey can be found below.

Participation in this survey is voluntary and will take most participants 20-30 minutes to complete. Responses to this survey will be anonymous. By completing the survey, you are agreeing to participate in the study. Those who qualify and complete the online survey will have the option to be entered into a raffle to win free access to an interactive Health Care Interpreter Network (HCIN) course, *Interpreting for Prenatal Genetic Counseling*. At the end of the survey, you will have the option to leave your contact information to potentially be contacted for a follow-up phone interview that will take between 30-45 minutes. The interview will be audio recorded so that what is discussed can be accurately transcribed. The recordings will only be reviewed by members of the research team and will be destroyed upon completion of the study. All responses will remain confidential.

Survey participants will experience no direct benefits from completing the survey, although indirect benefits may be appreciated in the future through improvements in how medical interpreters and genetic counselors collaborate during patient encounters. There is no risk associated with participation in this study. We intend to share the results of this study. At the end of the survey, you will be prompted to indicate whether you are interested in receiving a brief fact sheet highlighting the major results of the study. This study has been approved by the University of South Carolina Institutional Review Board. Thank you for your time and for sharing your experiences with us. We greatly appreciate your participation in this study. If you have any questions about the survey or the study, please contact Dacia Lipkea at dacia.lipkea@uscmed.sc.edu.

Survey Link: https://uofsc.co1.qualtrics.com/jfe/form/SV_2hlO2GXNeL7djPn

Sincerely,

Dacia Lipkea
Genetic Counselor Candidate

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USC Genetic Counseling Program
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Columbia, SC 29203
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APPENDIX B: STUDY QUESTIONAIRE

Thank you for participating in this study of interpreter experiences working with genetic counselors. Please review the study details below prior to completing the survey. You are invited to participate in a graduate research study focusing on the experience interpreters have had while working with genetic counselors. My name is Dacia Lipkea and I am a graduate student studying for a Masters degree in genetic counseling at the University of South Carolina. As part of my degree program, I am conducting research in collaboration with Victoria Vincent (MS, CGC), Cynthia Roat (MPH), and Myriam Torres (PhD, MSPH). All spoken language medical interpreters who are over the age of 18 and have interpreted for at least one genetic counseling session are eligible and encouraged to take this survey. The survey is open now and will be available through **September 15, 2020**. Participation in this study is completely voluntary. If you agree to participate, you will be asked to fill out an online survey that will take most participants approximately 20-30 minutes to complete. Responses to this survey will be made anonymous. Once you click on the link and begin the survey, you may exit the survey at any time. Completion of the survey constitutes consent, indicating that you have read through the above information and agree to participate in the study. At the end of the survey, you will have the option to leave your contact information to potentially be contacted for a follow-up phone interview that will take between 30-45 minutes. The interview will be audio recorded so that what is discussed can be accurately transcribed. The recordings will only be reviewed by members of the research team and will be destroyed upon completion of the study. All responses will remain confidential.

Those who qualify and complete the online survey will have the option to be entered into a raffle to win free access to an interactive Health Care Interpreter Network (HCIN) course, *Interpreting for Prenatal Genetic Counseling*. If you wish to enter the raffle, click on the link provided at the end of the survey which will take you to a separate page to enter your contact information. We intend to share the results of this study. At the end of the survey, you will be prompted to indicate whether you are interested in receiving a brief fact sheet highlighting the major results of the study.

Survey participants will experience no direct benefits from completing the survey, although indirect benefits may be appreciated in the future through improvements in how medical interpreters and genetic counselors collaborate during patient encounters. There is no risk associated with participation in this study. Thank you for your time and for sharing your experiences with us. We greatly appreciate your participation in this study. If you have any questions about the survey of the study, please contact Dacia Lipkea at dacia.lipkea@uscmed.sc.edu. This study has been approved by the University of South Carolina Institutional Review Board. Please contact the University of South

Carolina's Office of Research Compliance at (803) 777-6670 if you have any questions about your rights as a research subject. Click the forward arrow to continue with the survey.

---

1 What is your current age in years?

○ **Under 18 (1)**

○ **18 - 30 (2)**

○ **31 - 50 (3)**

○ **51 or older (4)**

Skip To: End of Block If What is your current age in years? = Under 18

---

2 What gender do you identify as?

○ **Female (1)**

○ **Male (2)**

○ **Other, please specify: (3)**
_____

---

3 How would you describe your racial and ethnic identity? Please select all that apply.

☐ **White or Caucasian (1)**

☐ **Black or African American (2)**

☐ **Hispanic or Latino (3)**

☐ **Asian or Asian American (4)**

☐ **American Indian or Alaska Native (5)**

☐ **Native Hawaiian or Pacific Islander (6)**

☐ **Other, please specify: (7)**

_____

---

4 What is your native language?

▼ Albanian (1) ... Other (43)

❊

5 How many years have you been practicing as an interpreter? Please round to the nearest year. If you have been working for less than 1 year, please round up to 1.

_____

---

6 In addition to English, in which languages do you provide interpreting services? Please select all that apply.

☐ **Albanian (1)**

☐ **American Sign Language (2)**

☐ **Amharic (3)**

☐ **Arabic (4)**

☐ **Armenian (5)**

☐ **Bengali (6)**

☐ **Bosnian (7)**

☐ **British Sign Language (8)**

☐ **Burmese (9)**

☐ **Cantonese (10)**

☐ **Farsi (11)**

☐ **French (12)**

☐ **German (13)**

☐ **Greek (14)**

☐ **Haitian Creole (15)**

☐ **Hebrew (16)**

☐ **Hindi (17)**

☐ **Hmong (18)**

☐ **Italian (19)**

☐ **Japanese (20)**

☐ **Karen (21)**

☐ **Khmer (22)**

☐ **Korean (23)**

☐ **Laotian (24)**

☐ **Lithuanian (25)**

☐ **Malay (26)**

☐ **Mandarin (27)**

☐ **Nepali (28)**

☐ **Polish (29)**

☐ **Portuguese (30)**

☐ **Punjabi (31)**

☐ **Romanian (32)**

☐ **Russian (33)**

☐ **Somali (34)**

☐ **Spanish (35)**

☐ **Swahili (36)**

☐ **Tagalog (37)**

☐ **Thai (38)**

☐ **Tigrigna (39)**

☐ **Turkish (40)**

☐ **Vietnamese (41)**

☐ **Other, please specify: (42)**

_____

----

7 I provide interpreter services to this region of the United States:

○ **Western States (Washington, Oregon, California, Idaho, Alaska, Hawaii) (1)**

○ **Mountain States (Montana, Wyoming, Nevada, Utah, Colorado, Arizona, New Mexico, Texas) (2)**

○ **Heartland States (North Dakota, South Dakota, Nebraska, Iowa, Kansas, Missouri, Oklahoma, Arkansas) (3)**

○ **Midwestern States (Minnesota, Wisconsin, Michigan, Illinois, Indiana, Ohio, Kentucky) (4)**

○ **Southern States (Tennessee, North Carolina, Louisiana, Mississippi, Alabama, Georgia, South Carolina, Florida) (5)**

○ **New York / Mid-Atlantic States (New York, Pennsylvania, West Virginia, Virginia, Maryland, Delaware, DC, New Jersey) (6)**

○ **New England (Massachusetts, Vermont, New Hampshire, Rhode Island, Connecticut, Maine) (7)**

○ **I work as a remote interpreter serving a wide range of states. (8)**

8 Which of the following best describes your working arrangement?

○ **I am a full-time or part-time staff interpreter at a healthcare facility. (1)**

○ **I am a full-time or part-time staff interpreter at a language services company. (2)**

○ **I am a freelance interpreter. (3)**

○ **I am a retired interpreter. (4)**

○ **Other, please specify: (5)**

_____

9 Which of the following best describes the modality(ies) through which you **most often** interpret? Please select all that apply.

☐ **In person (onsite) (1)**

☐ **Over the phone (2)**

☐ **Over videoconference (3)**

10 How much formal training have you had as an interpreter? (Do not count continuing education classes.)

○ **None (1)**

○ **Less than 40 hours (2)**

○ **40 hours - 64 hours (3)**

○ **65 hours - 120 hours (4)**

○ **Associates degree in Translation and Interpreting (5)**

○ **Masters degree in Translation and Interpreting (6)**

○ **Doctoral degree in Translation and Interpreting (7)**

---

11 Are you certified as a medical interpreter?

○ **Yes (1)**

○ **No (2)**

---

12 What credential do you hold?

○ **CHI (1)**

○ **CMI (2)**

○ **Washington State DSHS Medical Interpreter (3)**

---

13 Have you ever received any training specifically on interpreting for genetics?

○ **Yes (1)**

○ **No (2)**

✳

14 How many hours of training have your received specifically on interpreting for genetics?

_____

---

15 About how many genetic counseling sessions have you interpreted for?

○ **0 (1)**

○ **1-5 (2)**

○ **6-15 (3)**

○ **Over 15 (4)**

Skip To: End of Block If About how many genetic counseling sessions have you interpreted for? = 0

---

16 Which of the following best describes your experience working with genetic counselors?

○ **I have only worked with one genetic counselor once. (1)**

○ **I have only worked with one genetic counselor a couple times. (2)**

○ **I tend to work only once with many different genetic counselors. (3)**

○ **I tend to work just a little with many different genetic counselors. (4)**

○ **I tend to work repeatedly with only one or a few genetic counselors. (5)**

○ **I tend to work repeatedly with many different genetic counselors. (6)**

---

17 In what genetic counseling setting(s) have you interpreted? Please select all that apply.

☐ **A clinic that sees patients with adult onset genetic conditions (1)**

☐ **A clinic that sees pediatric and/or adult cancers (2)**

☐ **A clinic that sees pediatric genetic conditions (3)**

☐ **A clinic that sees prenatal/OB/preconception genetic conditions (4)**

☐ **Not sure (5)**

----

18 Please indicate how often you have experienced the following when working with genetic counselors:

	Never (1)	Occasionally (2)	Frequently (3)	Almost always (4)
The genetic counselor does a brief pre-session with me before each genetic counseling session begins. (1)	○	○	○	○
The genetic counselor speaks at a moderate pace, pausing often to allow me to easily interpret the information to the patient. (2)	○	○	○	○
The genetic counselor uses simple language and avoids jargon or at least provides a clear explanation of the terms when talking to the patient. (3)	○	○	○	○
The genetic counselor speaks in first person and addresses the patients directly when speaking to them. (4)	○	○	○	○
The genetic counselor encourages me to speak up to ask for clarification if I don't understand something during the genetic counseling session. (5)	○	○	○	○

The genetic counselor encourages me to inform them if potential cultural conflicts or important cultural differences come up in the genetic counseling session. (6)	○	○	○	○
The genetic counselor creates an environment that allows both me and the patient to feel comfortable asking questions. (7)	○	○	○	○
I meet with the genetic counselor following the conclusion of the session to talk about things such as my reaction to emotional content and our impressions of the session, to ask for any clarification that is needed, and to give feedback for each other. (8)	○	○	○	○
The genetic counselor welcomes and values my feedback as an interpreter. (9)	○	○	○	○

19 Please indicate how important it is to you that the following occur to help establish a good working alliance with a genetic counselor.
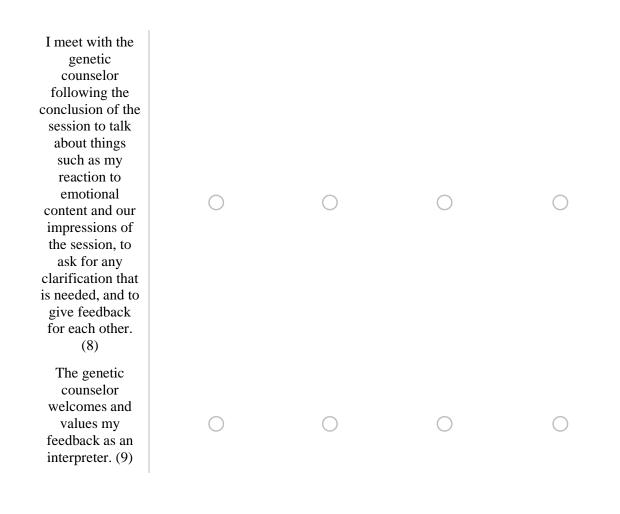
	Not at all important (1)	Slightly important (2)	Moderately important (3)	Extremely important (4)
The genetic counselor does a brief pre-session with me before each genetic counseling session begins. (1)	○	○	○	○
The genetic counselor speaks at a moderate pace, pausing often to allow me to easily interpret the information to the patient. (2)	○	○	○	○
The genetic counselor uses simple language and avoids jargon or at least provides a clear explanation of the terms when talking to the patient. (3)	○	○	○	○
The genetic counselor speaks in first person and addresses the patients directly when speaking to them. (4)	○	○	○	○

The genetic counselor encourages me to speak up to ask for clarification if I don't understand something during the genetic counseling session. (5)	○	○	○	○
The genetic counselor encourages me to inform them if potential cultural conflicts or important cultural differences come up in the genetic counseling session. (6)	○	○	○	○
The genetic counselor creates an environment that allows both me and the patient to feel comfortable asking questions. (7)	○	○	○	○

| I meet with the genetic counselor following the conclusion of the session to talk about things such as my reaction to emotional content and our impressions of the session, to ask for any clarification that is needed, and to give feedback for each other. (8) | ○ | ○ | ○ | ○ |
| The genetic counselor welcomes and values my feedback as an interpreter. (9) | ○ | ○ | ○ | ○ |

---

20 Have you ever had a pre-session with a genetic counselor before the genetic counseling session began?

○ **Yes (1)**

○ **No (2)**

---

21 Who typically initiates the pre-session before a genetic counseling session?

○ **I do (1)**

○ **The genetic counselor does (2)**

---

22 What is typically discussed in the pre-session(s) you've had with a genetic counselor before the genetic counseling session? Please select all that apply.

☐ **The genetic counselor's role or tasks will be in the session (1)**

☐ **My role or tasks will be in the session (2)**

☐ **The ground rules for communicating through an interpreter (3)**

☐ **My interpreting style (e.g. simultaneous or consecutive) (4)**

☐ **The patient's reason for the appointment (5)**

☐ **What to expect in the session (6)**

☐ **Sensitive topics that may be come up (7)**

☐ **Confidentiality issues (8)**

☐ **Review of technical terminology that will be used in the session (9)**

☐ **Review of the genetic counseling process (10)**

☐ **Information on the patient's culture (11)**

☐ **Tips on how to best communicate with the patient (12)**

---

23 What is the most common reason for not having a pre-session with a genetic counselor before the genetic counseling session begins?

○ **I don't think it's important. (1)**

○ **There is no time. (2)**

○ **The genetic counselor does not want to. (3)**

○ **I am not allowed to do so by my employer. (4)**

---

24 Regardless of whether you've had a pre-session with a genetic counselor, what do you think is important to discuss in a pre-session with a genetic counselor before the genetic counseling session? Please select all that apply.

☐ **Nothing (1)**

☐ **The genetic counselor's role or tasks will be in the session (2)**

☐ **My role or tasks will be in the session (3)**

☐ **The ground rules for communicating through an interpreter (4)**

☐ **My interpreting style (e.g. simultaneous or consecutive) (5)**

☐ **The patient's reason for the appointment (6)**

☐ **What to expect in the session (7)**

☐ **Sensitive topics that may be come up (8)**

☐ **Confidentiality issues (9)**

☐ **Review of technical terminology that will be used in the session (10)**

☐ **Review of the genetic counseling process (11)**

☐ **Information on the patient's culture (12)**

☐ **Tips on how to best communicate with the patient (13)**

25 **Please indicate how strongly you agree with the following statements pertaining to your general experience working with genetic counselors:**

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)
I trust the genetic counselor(s) with whom I've worked. (1)	○	○	○	○
The genetic counselor(s) with whom I've worked trust me. (2)	○	○	○	○
I respect the work that genetic counselors do. (3)	○	○	○	○
Genetic counselors respect the work that I do as an interpreter. (4)	○	○	○	○
I understand the complexities of what it is that genetic counselors do. (5)	○	○	○	○
Genetic counselors understand the complexities of my work as an interpreter. (6)	○	○	○	○

26 **Please indicate how important it is to you that the following occur when working with a genetic counselor:**

	Not at all important (1)	Slightly important (2)	Moderately important (3)	Extremely important (4)
I trust the genetic counselor(s) with whom I work. (1)	○	○	○	○
The genetic counselor(s) with whom I work trust me. (2)	○	○	○	○
I respect the work that genetic counselors do. (3)	○	○	○	○
Genetic counselors respect the work that I do as an interpreter. (4)	○	○	○	○
I understand the complexities of what it is that genetic counselors do. (5)	○	○	○	○
Genetic counselors understand the complexities of my work as an interpreter. (6)	○	○	○	○

27 Overall, how would you characterize your experiences working with genetic counselors?

○ **Very good (1)**

○ **Good (2)**

◯ **Bad (3)**

◯ **Very bad (4)**

---

28 Overall, how would you compare your ability to work with genetic counselors compared to other healthcare providers in other healthcare settings?

Working with genetic counselors is generally...

◯ **Much easier. (1)**

◯ **A little bit easier. (2)**

◯ **The same as with other healthcare providers. (3)**

◯ **A little more difficult. (4)**

◯ **Much more difficult. (5)**

---

29 Have you had any memorable experiences working with a genetic counselor that were positive or good?

◯ **Yes (1)**

◯ **No (2)**

Display This Question:

If Have you had any memorable experiences working with a genetic counselor that were positive or good? = Yes

30 What happened in the session to make you feel this way?

_____

_____

_____

_____

_____

---

31 Have you had any memorable experiences working with a genetic counselor that were negative or challenging?

   ○ **Yes (1)**

   ○ **No (2)**

---

32 What happened in the session to make you feel this way?

_____

_____

_____

_____

_____

---

33 Some of the terms and phrases that frequently come up in genetic counseling sessions include chromosome, gene, autosomal recessive inheritance, carrier, and mutation. These words and their underlying concepts are complex and not a part of everyday conversation. How comfortable do you feel with the terms that have come up in any of the genetic counseling sessions you interpreted?
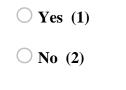
   ○ **Very comfortable (1)**

   ○ **Somewhat comfortable (2)**

   ○ **Somewhat uncomfortable (3)**

   ○ **Very uncomfortable (4)**

34 Have you ever spoken up to ask for clarification from the genetic counselor during a genetic counseling session?

○ **Yes (1)**

○ **No (2)**

35 Generally, how comfortable do you feel speaking up and asking for clarification from the genetic counselor during a genetic counseling session?

○ **Very comfortable (1)**

○ **Somewhat comfortable (2)**

○ **Somewhat uncomfortable (3)**

○ **Very uncomfortable (4)**

36 Have you ever acted as a cultural broker or brought up a potential cultural conflict to the genetic counselor during a genetic counseling session?

○ **Yes (1)**

○ **No (2)**

37 Generally, how comfortable do you feel acting as a cultural broker or bringing up a potential cultural conflict to the genetic counselor during a genetic counseling session?

○ **Very comfortable (1)**

○ **Somewhat comfortable (2)**

○ **Somewhat uncomfortable (3)**

○ **Very uncomfortable (4)**

40 You have reached the end of the survey, but your responses are not yet submitted.

If you would like to talk in more detail about your experience working with genetic counselors, be emailed a fact sheet with the major results of the study, or if you would like to be entered into the raffle for free access to the HCIN course, *Interpreting for Prenatal Genetic Counseling*, please use the link below to enter your contact information in a new browser winder. Please do so **BEFORE** submitting your survey, as the link will not be available to you after you leave this page. Please remember to come back to this page to submit your responses by hitting the blue arrow below.

Link to enter contact information:
https://uofsc.co1.qualtrics.com/jfe/form/SV_0VDNSbllr6mK5md

APPENDIX C: PHONE INTERVIEW QUESTIONS

Introduction:
I first just wanted to thank you for filling out the online survey and volunteering to participate in the follow-up phone interview. Before we get started, I'll just briefly read through our consent form and then ask if you still want to continue. You are invited to participate in a graduate research study focusing on the experience interpreters have had while working with genetic counselors. Once we begin the phone interview it shouldn't take any longer than 30-45 minutes to complete. If at any point you are asked a question that you don't want to answer or feel that you no longer want to continue with the interview that is fine just let me know. The interview will be audio recorded so that what is discussed can be accurately transcribed. The recordings will only be reviewed by members of the research team and will be destroyed upon completion of the study. All interview responses will be de-identified and remain confidential. Do you have any questions? Do you agree to continue?

Demographics:
What is your current age? Which category does your current age fall into, 18-30, 31-50, or over 51?

What gender do you identify as?

How many years have you been practicing as an interpreter?

In addition to English, in which languages do you provide interpreting services?

Which modality(ies) best describes the format you <u>most often</u> interpret? In person, over the phone, video medical interpreting?

Which of the following best describes your working arrangement: full-time or part-time staff interpreter at a healthcare facility, full-time or part-time staff interpreter at a language services company, freelance interpreter, retired interpreter, or other?

Not counting continuing education classes, how much formal training have you had as an interpreter? How many hours?

Have you ever received any training specifically on interpreting for genetics?

About how many genetic counseling sessions have you interpreted? 1-5, 6-15, or over 15?

How would you describe how often you work with each genetic counselor? Do you tend to work only once with many different genetic counselors or work repeatedly with multiple genetic counselors?

Main Questions:
Tell me more about your positive experiences or successes while working with a genetic counselor?

Tell me more about your negative experiences or challenges while working with a genetic counselor?

What makes working with genetic counselors different- that is, easier or harder- than working with other healthcare providers?

What does good collaboration between an interpreter and genetic counselor look like and what can interpreters and genetic counselors do to best encourage this collaboration?

In situations where you spoke up to act as a cultural broker or inform the genetic counselor of any potential cultural conflicts, how did the genetic counselor respond and were they interested in hearing this information?

APPENDIX D: FACT SHEET SENT TO INTERESTED PARTICIPANTS

LANGUAGE INTERPRETERS' PERSPECTIVE OF THE INTERPRETER-GENETIC
COUNSELOR WORKING ALLIANCE
Results Fact Sheet

Summary of Demographics
- 180 participants
- 83% of participants were female
- 86% of participants were above 30 years old
- Spanish was the most common native and target interpreted language
- 43% of participants have interpreted for over 15 genetic counseling sessions
- 61% of participants work with each genetic counselor only once or a few times

Pre-Session
- 60% of participants have experienced a pre-session with a genetic counselor
- 81% of participants viewed having a pre-session as important, but only 15% of participants experience pre-sessions with genetic counselors often
- The three discussion topics that participants thought were most important to discuss in a pre-session were: sensitive topics that may come up in the session, review of technical terminology that will be used in the session, and what to expect in the session

Experience Working with Genetic Counselors
- Most participants characterized their experience working with genetic counselors as either good (51%) or very good (47%)
- Participants who worked at a healthcare facility were 4.58 times more likely to have a memorable positive experience working with a genetic counselor (61% of these participants work with repeatedly with the same genetic counselors)
- Top three genetic counselor actions that participants viewed as important: genetic counselor creates an environment that allows both the interpreter and the patient to feel comfortable asking questions, genetic counselor speaks at a moderate pace pausing often to allow the interpreter to easily interpret the information to the patient, and the genetic counselor uses simple language and avoids jargon or at least provides a clear explanation of the terms when talking to the patient
- Top three important shared feelings with genetic counselors: genetic counselor trust the interpreters, genetic counselor understand the complexities of the interpreters' work, and that interpreters also understand the complexities of what it is that genetic counselors do

- Least often experienced feeling: the genetic counselor understands what interpreters do

Genetics Terminology
- 90% of participants felt comfortable or very comfortable with the terminology used in genetic counseling sessions
- 87% of participants have spoken up to ask for clarification, 73% feel comfortable doing so

Cultural Broker Role
- 44% of participants have spoken up to act as a cultural broker, 63% feel comfortable doing so
- Participants who worked at a language services company were significantly less likely to speak up and act as a cultural broker