Exploring the perspectives of genetic counsellors and patients with limited English proficiency in genetic counselling sessions requiring interpretation services.

by

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ABSTRACT

Genetic counsellors hold unique positions in the health care field. Part of their role involves explaining genetic information to patients in a digestible way in order to empower them to make informed decisions about their genetic health. Medical interpreters are present during appointments with patients who have limited English proficiency (LEP). During these appointments, information is interpreted to the patient in their preferred language. Previous studies in the United States have explored the perspectives of genetic counsellors and interpreters in genetic counseling sessions with medical interpreters. There are currently no studies exploring these perspectives from a Canadian context. Additionally, there have been few studies exploring the point of view of the patients. Six genetic counsellors at the Health Sciences Center in Winnipeg, Manitoba and three patients with LEP were interviewed following genetic counselling appointments that required interpretation services. Semi-structured interviews were utilized to explore the participants' perspectives, expectations, and experiences with medical interpretation. All interviews were transcribed and analyzed using thematic analysis to identify themes under a phenomenological framework. Five major themes were identified from our interviews: 1) Expectations of the providers, 2) Relationships and rapport building, 3) Mode of appointment delivery, 4) Flow of the genetic counselling session, and 5) Patients' lived experiences. Overall, verbatim interpretation was preferred by all genetic counsellors and most patients. Additionally, genetic counsellors did not expect the medical interpreter to know genetic specific terminology and expressed that explaining these terms fell under their own domain and role. All participants preferred in-person to telephone appointments and pointed to visual cues as an important missing factor during phone appointments. Most genetic counsellors described having enough allocated time during appointments with medical interpreters so that all aspects of the genetic counselling appointment were addressed. Some genetic counsellors expressed wanting to learn more about the role of medical interpreters to better understand the medical interpreters' expectations. Lastly, we identified and offered suggestions and recommendations for working with medical interpreters and patients with LEP.

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LIST OF ABBREVIATIONS

LEP: Limited English Proficiency

ESL: English as a second language

ELL: English language learner

CLB: Canadian Level Benchmarks

CELPIP: Canadian English Language Proficiency Index Program

IELTS: International English Language Testing System

WRHA: Winnipeg Regional Health Authority

CHAPTER 1: INTRODUCTION

1.1 Introduction to the Study

The immigrant and refugee population is rising in Canada (Statistics Canada, 2022). As such, a multitude of different languages are being spoken across the country. Given the increasing diversity within Canadian communities, it is reasonable to assume that many Canadians may have limited English proficiency (LEP). It is unsurprising that immigrants may face barriers when accessing healthcare in Canada, with language barriers being one of the main limitations. Subsequently, it is vital that our healthcare systems provide care in the patient's preferred language via medical interpreters. Patients with LEP, like their English proficient counterparts, may require access to various arms within health care such as genetic services. Depending on their indication for referral, they may meet with a genetic counsellor or geneticist for evaluation. Genetic counsellors hold unique positions within health care: they provide education and counselling to patients and their families by translating complex information about genetic conditions and genetic testing into a more patient-friendly context. Interpreters are often utilized in genetic counselling sessions for patients with LEP. Previous studies have explored the perspectives of genetic counsellors and medical interpreters during genetic counselling sessions. However, these studies were completed in the United States where the standard of medical interpretation differs from Canada. Additionally, there are few studies that explore the patient perspective. This study aims to fill this gap within the current literature.

1.2 Research Aims

In this study, three specific aims were addressed:

1. To explore the perspectives of both participant groups (genetic counsellors and patients with LEP) on all aspects of the genetic counselling session involving medical interpretation (contracting, medical and family history intake, information giving,

risk assessment, options for testing, psychosocial counselling, etc.). By exploring each participant's perspective of the appointment, this study aims to gain insight into the expectations of each participant group.

2. To evaluate the participant group's perspectives between each other. This will identify if there were similarities or differences in how participants experienced any part of the genetic counselling session.
3. To obtain feedback and suggestions from both the genetic counsellor and the patient population to identify ways to optimize patient understanding and care in appointments requiring a medical interpreter. Recommendations based on this feedback will help in the development of LEP-friendly patient resources based on their suggestions.

CHAPTER 2: LITERATURE REVIEW

2.1 What is Limited English Proficiency (LEP)

2.1.1 Definition of LEP

“Limited English proficiency” (LEP) is a term used to refer to individuals whose native language is not English and who require additional assistance when communicating in English (Ortega et al., 2022). LEP covers a broad spectrum of individuals, including those who are non-English speaking or have a basic grasp of the English language. LEP encompasses all aspects of language, including both verbal and written English (Ortega et al., 2022). However, it often refers to individuals who require assistance with verbal communication.

The term LEP was first coined in 1975 after a United States Supreme Court ruling (*Lau v Nichols*, 1974) found that the lack of resources in public schools for children with LEP violated the Civil Rights Act of 1964. Since its inception, the term has become predominant over previously used descriptors such as “English as a second language” (ESL).

ESL and LEP are still often used interchangeably; however, ESL is generally used within the context of teaching English to non-native speakers in a country where English is the primary language. The term ESL implies that an individual is being formally, or informally, taught English (Webster & Lu, 2012). However, individuals who are learning English may already be proficient in more than one language. In these cases, ESL does not accurately describe an individual who is learning English as their third, fourth, or fifth language. Inversely, LEP is a broader, more inclusive, and appropriate term for people who require assistance when communicating in English (Ortega et al., 2022). Additionally, the term “English language learner” or “English learner” (ELL/EL) has recently gained popularity as it emphasizes the skill being learned rather than suggesting a deficiency within the individual (Webster & Lu, 2012).

2.1.2 LEP in English-speaking countries

It is important to keep the geographical context in mind when discussing LEP. When referring to an individual with LEP, we typically assume that they are living in a country where English is the primary or official language. While this may be true, an individual can still have LEP outside of countries where English is the official language. English is one of the most widely spoken languages in the world. However, it is the official and/or primary language in 67 countries (Assi, 2022). Approximately 1.5 billion people in the world speak some level of English, but only 400 million people in this group are native English speakers (Szmierga, 2022). This means that the vast majority of individuals who speak English are non-native speakers, and may fall under the definition of having LEP. It stands to reason that there are individuals in countries with and without English as their primary language that have LEP.

If we consider countries like the United States, there are large populations of people who are non-native English speakers that range in their level of English proficiency. 41 million individuals in the United States over the age of 5 identify as Spanish speakers, with half of those individuals also being proficient in English (American Community Survey, 2019). Additionally, about 1 in 10 working-age Americans have LEP (Wilson, 2014). Similar approximations have been made for other primarily English-speaking countries like Canada (Statistics Canada, 2022).

Canada has two official languages: English and French. When considering LEP in Canada, it is crucial to consider what the language of the majority is in the region. The language of majority in the province of Quebec is French. A primarily English speaking person in Quebec may face difficulties communicating in Quebec. However, for example, the same person would not face the same communication barriers in other cities like Toronto, Ontario, where the majority of the population speaks English. Therefore, language proficiency in Canada may be broadened for individuals who require extra assistance when communicating with the region-specific majority.

2.1.3 Immigration and English proficiency in Canada

Individuals who have LEP in majority English-speaking countries may be first-generation immigrants, born to parents of immigrants, or refugees from other countries. English may not have been the primary or official language of the individual's country of origin. Since 1980, Canada has classified immigrants under four different classes (Statistics Canada, 2019). The first covers economic immigrants who are selected to enter Canada due to labour market needs or their ability to begin a business in Canada. Economic immigrants are further divided into three categories: skilled workers, "Canadian experience," and business class. Skilled workers are individuals who have occupational skills, experience, or education that is deemed desirable by the Canadian labour market. The "Canadian experience" category refers to individuals who currently live in Canada, and have temporary immigrant status, such as those who are foreign workers or students. Business class refers to individuals who are entrepreneurs, self-employed, or investors who have the funds, skills, or experience necessary to take part in the Canadian labour market. The second class of immigrants are are family sponsored-immigrants. Refugee status immigrants are the third class of immigrants who require protection or are unable to safely return to their home country. The final class includes all immigrants that do not fit into the other categories. This may include immigration for humanitarian/compassionate reasons, which are reviewed on a case-by-case basis. They are typically granted to avoid negative consequences or because it is in the best interest of the applicant's children.

Of the four different classes of immigration, only economic immigrants require an English/French language proficiency test as part of their immigration application (Government of Canada, 2021a, 2022b). Although English/French proficiency is necessary for Canadian citizenship, it is not required for those seeking refugee status (Government of Canada, 2022b). For an economic immigrant, the Canadian government requires a pass level of 4/10 or "fluent basic" on the Canadian Level Benchmarks (CLB) from an approved language proficiency test (Government of Canada, 2021a). The two tests recognized by Canadian Immigration are the Canadian English Language Proficiency Index Program (CELPIP) or the International English

Language Testing System (IELTS) (Government of Canada, 2022a). Both tests assess an individual’s ability to read, write, comprehend, and speak English. At the “fluent basic” level, individuals are deemed able to communicate basic spoken information, understand simple communication of familiar topics, and construct short, simple texts (Government of Canada, 2022a). It is then reasonable to assume that many individuals that have immigrated to Canada may have LEP.

2.1.4 Indigenous Languages in Canada

Canada is a colonized country, with the first settlers arriving in the 17th century. Before the colonization of this land, many Indigenous bands and tribes had lived within the modern-day Canadian borders for generations. Each Indigenous community celebrates their customs, traditions, spirituality, and language. Following the Seven Years’ War in 1763, Canada was officially colonized by Great Britain as part of the British Empire (Eccles, 2006). France, who lost the war, was granted land and sovereignty in Quebec (Eccles, 2006). As part of the colonization process and the mistreatment that followed, Indigenous people had their culture and language forcibly taken from them through various means (MacDonald & Steenbeek, 2015). The establishment of residential schools is a prominent example that prompted and lead to the loss of many Indigenous languages.

It is impossible to discuss the accessibility needs of individuals with LEP in Canada without addressing Canada’s history of colonization. Unlike English and French, Indigenous languages are not official languages in Canada and do not carry the same legal status (Kirkness, 1998; Leitch, 2006). This creates differences in accessibility for primary English/French speakers and primary Indigenous language speakers. Francophones have the legal right to have services like health care and education provided to them in French in regions where English is the majority language. Additionally, government literature is provided in both English and French irrespective of the majority language in the region. However, government literature in Indigenous languages is not available. To illustrate, in regions such as Inuit Nunangat, 84% of the population primarily speaks an Inuit language, such as Inuktitut (Statistics Canada, 2017). People from Inuit Nunangat or other regions in Nunavut (or other territories) may need to travel to other provinces, where English is the primary language, to receive health care services otherwise unavailable in their home territory. These individuals may encounter language barriers when accessing healthcare and other services, despite being native to Canada. Therefore, the term LEP is not only applicable to immigrants and refugees, but can also apply to Indigenous populations.

2.1.5 Statistics and Linguistics Review

The first large wave of immigrants to Canada from non-Anglophone or Francophone countries began in the late 19th century. Since then, the immigrant and refugee population in Canada has been steadily increasing. In 2016, it was estimated that 22% of the Canadian population was foreign-born (Statistics Canada, 2016). Since 1980, over 7 million individuals have immigrated to Canada, with more than half of these individuals being economic immigrants (Statistics Canada, 2016; Statistics Canada, 2017c). Between 2017 to 2018, immigration accounted for 80% of Canada's population growth (Chagnon et al., 2019). More recently in 2021, Canada welcomed over 400,000 immigrants – the largest number of immigrants accepted in a single year in the country's history (Government of Canada, 2021b). Most immigrants live in Ontario (3.8 million), British Columbia (1.2 million), and Quebec (1 million) as most immigrants typically settle in large urban centres (such as Toronto, Ontario, Vancouver, British Columbia, and Montreal, Quebec) (Statistics Canada, 2017a). However, there is also a steady increase in immigration to other Canadian provinces and territories. In Manitoba, there was an increase from 23,000 immigrants between 2001-2005 to over 63,000 between 2011-2016 (Statistics Canada, 2016c).

Interestingly, there are areas in Canada with high rates of immigration of people from the same country, who therefore may speak the same language. Richmond Hill, Ontario has a high concentration of Chinese-Canadians, who comprise over 30% of the region's population (Statistics Canada, 2016a). Although most individuals in Richmond Hill speak English as their first language, native Cantonese and Mandarin speakers make up over 20% of the population (11.6% and 11.1%, respectively). This phenomenon is also seen in suburbs around Vancouver, British Columbia. In Surrey (part of Metro Vancouver), over 32% of the population is of South Asian descent (Statistics Canada, 2016b). Over 20% of individuals in Surrey speak Punjabi as their first language.

As of 2021, non-native English and French speakers account for approximately 9 million Canadians (23% of the Canadian population), with 12.7% of all Canadians predominantly speaking a language that is not English or French at home (Statistics Canada, 2022). The five most common immigrant languages include Mandarin (1.8% of population), Cantonese (1.7% of population), Punjabi (1.6% of population), Tagalog (1.5% of population), and Spanish (1.4% of population) (Statistics Canada, 2011b). Canada's history of immigration allows for greater diversity and a multitude of languages being spoken across the country. With the increasing immigration rate, many Canadians are likely to be learning English as an additional language and living with LEP. These individuals may require language accommodations when integrating to a new community, and require assistance when accessing necessities such as healthcare services.

2.2 Language Outcomes for Individuals with LEP

2.2.1 Integration to a New Country

Immigrants with LEP face unique barriers when integrating into English-speaking countries. Watkins et al. (2012) state that language barriers and barriers to communication are the greatest obstacles to an individual's well-being and integration into a new society. These barriers arise due to the difficulties in communicating in a new language, which can create obstacles to accessing information (Martzoukou & Burnett, 2018). Without the ability to effectively participate in the new socio-economic landscape, many immigrants face difficulties integrating into the culture of the country they are now living in (Lloyd et al., 2013). As a result, individuals with LEP will rely on family, friends, and volunteers/services to provide them with general information (Martzoukou & Burnett, 2018).

Economic immigrants are required to have at least a “fluent basic” level of English or French to immigrate to Canada. Even with this basic level of language proficiency, there can be difficulties with effective communication. Many new immigrants struggle with everyday activities, including obtaining necessities such as groceries or navigating workplace conversations (Holmes & Riddiford, 2009; Moffat et al., 2017). This can be due to reasons beyond language proficiency or literacy, including the pace of speech, regional accents, or the use of difficult words including informal terms such as shortened language, or “slang,” that the individual has not previously heard before (Skjeggestad et al., 2017).

2.2.2 Barriers Within Healthcare

Language barriers are one of the greatest challenges for individuals with LEP when accessing healthcare (Ali & Watson, 2018). Patients with LEP face more significant difficulties than native-English speakers do. As a result, individuals with LEP may be detered and less likely to seek health care services than their English-speaking counterparts, and have an increased risk of nonadherence to medical recommendations (Flores, 2006; Ong et al., 2012). These individuals may also have lower health literacy than their English-speaking counterparts. Familiarity with healthcare infrastructures and how to navigate healthcare systems can greatly impact how and when patients with LEP access healthcare services. A study by Duraiswamy et al., (2022) also found that patients with LEP were more likely to be diagnosed with head and neck cancer at a later stage due to barriers in accessing care earlier. As such, these patients were more likely to receive surgical versus non-surgical treatment as their primary cancer management compared to native-English speakers. Additionally, an American study in 2012 looked at a specific Chinese community and barriers preventing their utilization of emergency medical services (Ong et al., 2012). Language difficulties such as not speaking English and not understanding the telephone operator when calling 911 were common reasons for not accessing these services. There were also negative perceptions of, or no previous experience with, the services and perceived costs of using emergency services.

There can be challenges with accessing services as a whole, as well as more nuanced issues such as communicating test results to patients with LEP and gauging patient comprehension (Marcus et al., 2014). In a study conducted by Marcus et al., (2014), when patients with LEP received mammogram results by letter (instead of in-person or by phone), they were less likely to understand their results as the letter was written at a higher English reading level. Additionally, children of individuals with LEP in the United States were found to have less regular preventative medical appointments and were more likely to have “poor” to “fair” perceived level of health than their native-English speaking counterparts (Goenka, 2016). Similarly, mothers with LEP experience frustration when accessing services for their children, specifically over navigating an unknown healthcare system, negative experiences with their healthcare providers, and inadequate language accommodations such as medical interpreter services (Steinberg et al., 2016).

Finally, studies have shown that patients with LEP receive a lower quality of healthcare and have increased risks to patient safety compared to native-English speakers. A meta-analysis by Shamsi et al., (2020) found that language barriers resulting in miscommunication and decreased patient satisfaction had a direct impact on the quality of healthcare. Furthermore, patients with LEP are less satisfied with the care that they received when accessing emergency services and were less likely to return to the same site in the event of another emergency (Carrasquillo et al., 1999). Having LEP is also correlated with difficulties such as transportation, knowledge of how the healthcare system operates in a given country, or financial factors (Timmins, 2002).

To expand on the transportation difficulties noted above, transportation is another major barrier to accessing healthcare for individuals with LEP (Yeheskel & Rawal, 2019). Some healthcare facilities are far from where the individual is living, or not easy to get to due to the lack of accessible infrastructures such as public transit or walkability issues (Flores et al., 2005;

Silver et al., 2012). When individuals with LEP need to use public transit and service is readily available to and from medical centres, it may be difficult to find and understand information about transit routes and schedules (Silver et al., 2012). Thus, individuals with LEP may rely on family members or friends to take them to their medical appointments (Silver et al., 2012). In these instances, coordination and timing may be difficult to arrange for all parties involved. As a result, individuals with LEP may not be able to access services or take part in follow-up visits as easily as folks who are native-English speakers.

2.2.3 Healthcare Outcomes

Patient safety refers to the use of best practices and reduction of unsafe acts within the healthcare system resulting in more favourable patient outcomes (Bowen, 2015). Two aspects of patient safety include adverse events and medication errors. Language barriers can increase the risk for an adverse event to occur resulting in physical harm to the patient (Bowen, 2015). Children of parents who have LEP are twice as likely to have a serious medical event and have a hospital stay that is five times longer than children of English-speaking parents (Cohen et al., 2005; Lion et al., 2013). Additionally, patients with LEP are more likely to have complications when taking medications and be less adherent to the prescribed dosage and schedule (Bowen, 2015). Patients with LEP are also less likely to understand the purpose and category of their medication and not have side effects explained to them (Barton et al., 2013; David & Rhee, 1998; Karliner et al., 2012).

Beyond increased risks to patient safety, individuals with LEP have poorer health outcomes in comparison to native-English speakers. The aforementioned factors undoubtedly play a role in these outcomes. Overall, those with LEP have reported lower self-perceived physical and emotional health compared to their English proficient counterparts (Kim et al., 2011). When looking at specific medical conditions, such as diabetes mellitus type 2, patients with LEP tend to have worse outcomes (Alvidrez & Pérez-Stable, 2017; Njeru et al., 2018). This may be a result of LEP patients' reduced level of participation in the decision-making process, and misunderstanding of what role these factors play in the management of their condition (Alvidrez & Pérez-Stable, 2017; Levinson et al., 2005; Njeru et al., 2018).

Qureshi et. al (2014), who studied outcomes for head and neck cancers, found that patients with LEP underwent chemoradiation less frequently than English proficient patients. Additionally, patients with LEP had inferior post-treatment endpoints, which often led to significant morbidity and functional limitations (Qureshi et al., 2014). The authors speculated that communication challenges when discussing treatment options, information about medication, and adherence to post-treatment management of the condition were reasons for poorer outcomes.

Overall, these studies show that having LEP can significantly impact a person's medical care at all stages. Although patients with LEP are a heterogeneous group and cannot be generalized, it is clear that barriers to access and communication can prohibit a person from receiving appropriate and timely medical care. To mitigate the negative consequences, it is often recommended to have a medical interpreter present during these appointments to improve patient-provider communication and patient comprehension.

2.2.4 Reliance on Family Members for Interpretation

Individuals with LEP may rely on family, friends, and volunteer services for guidance when integrating into their new society. This is also true when accessing healthcare. Often, family members such as children or siblings may be present during medical appointments to help with communication between the patient with LEP and their healthcare provider. To this patient, a child who learned English in school and can speak the parent's native tongue may be an optimal choice to bring to a medical appointment. Married women may also rely on their husbands to help interpret (Gerrish et al., 2004). There may also be a perceived obligation to rely on oneself or family members rather than using formal services such as a medical interpreter (Aroian et al., 2005). Although it is not generally recommended to utilize family members as medical interpreters (Juckett & Unger, 2014), in reality, this is a common occurrence. Associated risks may include miscommunications due to lack of training with medical terminology and potential traumitization of the family member by being exposed to a complex medical condition (Juckett & Unger, 2014; Rimmer, 2020). As well, family members may not disclose all the medical information given, in order to protect the patient from feelings of despair and hopelessness (Mostafazadeh-Bora & Zarghami, 2016). Despite these reasons, patients with LEP seem to prefer having family or friends act as interpreters during their medical appointments (Ho, 2008). This may be because family and friends speak the same dialect as the patient, and it is therefore easier to understand the interpretation (Aroian et al., 2005; Hadziabdic & Hjelm, 2013). Additionally, the patient may feel more comfortable having a family member present during their appointment (Gray et al., 2011; Ho, 2008).

2.3 Medical Interpretation

2.3.1 Role of Medical Interpretation in Healthcare

Typically, professional interpreters fall into one of five categories: medical, legal, sign language, conference, and guide interpreters (Professional Interpreting Canada Language Service Providers, 2021).

It is often recommended that medical interpreters are utilized during appointments with patients with LEP (Basu et al., 2017; Juckett & Unger, 2014). The role of a professional interpreter varies depending on the setting. Medical interpreters help bridge the linguistic gap between patients with LEP and healthcare providers by communicating back and forth between English and the patient’s native language. Having a medical interpreter present can not only ensure that the patient understands what is said by the healthcare provider, but also allow the healthcare provider to understand the patient (Juckett & Unger, 2014).

During a medical appointment with the interpreter, it is usually recommended that the healthcare provider speak directly to the patient, while the medical interpreter interprets the information in the patient's preferred language (Health Interpretation Network, 2007). Using a professional interpreter helps to reduce communication errors and protect patient confidentiality (Gray et al., 2011; Rosenberg et al., 2007). Typically, medical interpreters receive specific training in general medical terminology to accurately interpret information that the healthcare provider is giving to the patient. This ensures that medical information is appropriately and accurately relayed in the patient’s preferred language.

2.3.2 Medical Interpretation in Canada and the United States

The standard of medical interpretation is different in every country. We will review and compare medical interpretation in the United States and Canada as the majority of the literature regarding the use of medical interpretation is from the United States. Although there is some research done on the impact and role of medical interpretation in Canada, it is important to be aware of the different interpretation styles between the two countries.

In the United States, medical interpreters are typically required to have certification from either the Certification Commission of Healthcare Interpreters or the National Board of Certification for Medical Interpreters (Arocha & Joyce, 2013; Youdelman, 2013). Both organizations provide formal training to ensure adequate knowledge of medical terminology, standard practices, role boundaries, and ethical obligations. Certification streamlines the process of medical interpretation and ensures that patients are receiving a high quality of care across the United States. The Centre for Disease Control and Prevention in the United States stipulates that medical interpreters have three basic responsibilities: professionalism and confidentiality, accuracy and completeness, and cultural bridge and knowing limits (Centre for Disease Control, 2006). Regarding accuracy and completeness, medical interpreters are trained to interpret verbatim, even if what is being said seems irrelevant. Additionally, in the United States, medical interpreters can serve as a cultural bridge between patients and healthcare providers. This is referred to as “cultural brokerage”. Cultural brokering involves advocating for patients and their families by providing the social and cultural context of the medical condition (Gustafsson et al., 2013). Interpreters may include relevant or essential cultural information when necessary to help clarify what each person is saying (Sleptsova et al., 2014). Cultural brokerage can be done for both the patient with LEP and the healthcare provider. This allows the medical interpreter to deviate away from direct verbatim interpretation when necessary to provide further context into a conversation (Gustafsson et al., 2013).

Medical interpretation in Canada is similar to the United States when it comes to professionalism, confidentiality, and accuracy. Canadian medical interpreters require certification via the Canadian Translators, Terminologists, and Interpreters Council to ensure that the highest quality service is provided to patients (Canadian Translators, Terminologists, and Interpreters Council, n.d.). However, medical interpretation in Canada and the United States differ in their allowance of cultural brokering. According to the National Standard Guide for Community Interpreting Services and Winnipeg Regional Health Authority (WRHA) Language Access Services, it is required that medical interpretation is verbatim, and the interpreter is expected to maintain a neutral role (Health Interpretation Network, 2007; Winnipeg Regional Health Authority, 2021). As per the National Standard for Community Interpreting Services, “the interpreter must be able to understand and convey cultural nuances without assuming the role of advocate or cultural broker” (Health Interpretation Network, 2007).

Indigenous language interpreters are exceptions to this guideline in Canada. Cultural brokerage in Indigenous languages ensures that medical interpretation is done in a way that promotes patient well-being in a safe, culturally sensitive manner (Kaufert & Koolage, 1984). Certain anatomical terms may not exist in some Indigenous languages, therefore the interpreter cannot provide a verbatim interpretation, and must modify their translation to convey a similar message. Knowledge of cultural values and traditions can help provide context to the healthcare provider about how to best manage a condition (Kaufert & Koolage, 1984).

2.3.3 Cultural Brokerage

Cultural brokerage in healthcare can affect patient treatment, management, and healthcare outcomes. It can also help facilitate informed consent and decision-making. There are specific situations where cultural brokerage may be necessary during medical appointments. For example, a medical interpreter assuming the role of a cultural broker can help identify when “cultural bumps” occur during an appointment. A cultural bump is defined as “a phenomenon that occurs when an individual has expectations about another person's behavior within a particular situation but encounters a different behavior in that situation when interacting with an individual from a different culture” (Archer & Nickson, 2012). Cultural brokerage can benefit both the healthcare provider and patient by providing cultural information when there is confusion or a misunderstanding. It may include explaining why a medication schedule or follow-up appointment may not work for a patient due to a religious or cultural holiday, exploring different treatment options that align with a patient’s cultural values, or providing the context for why a patient may react in a specific manner to information that may be taboo in their culture.

There is debate about whether cultural brokering during medical interpretation is beneficial. People from the same country or culture can have widely different beliefs and values (Hanel et al., 2018; Kaufert & Putsch, 1997). Even though the medical interpreter and the patient share the same language, this does not mean that the interpreter holds the same views or values as the patient. For example, Arabic is spoken in many countries, however these countries may hold very different cultural norms, religious beliefs, and values. In these cases, it may be inappropriate for a medical interpreter to play the role of a cultural broker and provide cultural context – the cultural context may not be the same for the patient and can lead to miscommunication.

2.3.4 Healthcare Outcomes with Medical Interpretation

Regardless of whether a medical interpreter provides verbatim translation or plays the role of a cultural broker, the use of professional interpreters increases the quality of care for patients with LEP (Hsieh, 2013; Karliner et al., 2007). Ngo-Metzger et al., (2007) found that patients with LEP who received care from a provider who spoke the same language were more likely to understand their medical situation and proper medication use. This study also showed that utilizing medical interpreters can help achieve the same positive result when there is language discordance between the provider and patient. One meta-analysis from 2005 reviewed the literature regarding the utilization of medical interpreters published between 1966 and 2005, finding that medical interpreters improved clinical care when compared to interpretation done by family and friends (Flores, 2005). Medical interpreters increased the quality of care provided to those with LEP to a similar level of care provided to those without language barriers. Another meta-analysis from 2006 found that patient satisfaction and clinical outcomes are better when a trained medical interpreter is utilized during medical appointments (Karliner et al., 2007). This study revealed that there were fewer interpretation errors when trained professionals were used, which led to a higher rate of patient understanding and involvement in their healthcare.

Lastly, medical interpreters have been shown to improve patient health education and health literacy. When comparing language discordant medical appointments with and without interpreters, patients receive more health education when an interpreter is present (Flores, 2005; Ngo-Metzger et al., 2007). When an interpreter was not present, there was limited health education given and understood by the patient due to language barriers (Ngo-Metzger et al., 2007). The presence of a medical interpreter can help patients better understand their health information and make autonomous decisions as they receive health education in their preferred language and are more likely to comprehend the information. It has been shown that patients feel more empowered during provider interactions to effectively communicate their healthcare needs when an interpreter is utilized (Hsieh, 2013). By bridging linguistic gaps, medical interpreters help patients to better understand their health information in order to make informed and suitable medical decisions. Overall, this leads to better health outcomes for patients with LEP.

2.4 Genetic Counselling

2.4.1 Role of a Genetic Counsellor

Genetic counsellors hold unique positions within the healthcare field. They provide counselling to patients about their genetic information, and work alongside geneticists and other medical professionals. Patients requiring genetic counselling services may have a genetic condition themselves or have a family history of a genetic condition. Genetic counsellors work in many different specialties including prenatal, cancer, and pediatrics. Part of the genetic counsellor's role is to educate patients on their genetic health by taking complex genetic information and translating it into digestible language. Details about the genetic condition in question, recurrence risks, and genetic testing must be communicated in patient-friendly language to allow patients to make informed decisions about their genetic health and facilitate genetic testing.

Genetic counselling appointments typically involve contracting with the patient about the expectations and/or schedule of the appointment, taking a personal medical and family history, providing information about the genetic condition in question, and if applicable, reviewing the patient's options for genetic testing. Contracting involves setting a mutual agenda between the patient and genetic counsellor – the genetic counsellor reviews their goals and plans for the appointment and the patient has an opportunity to discuss their expectations and concerns (Uhlmann et al., 2010). Contracting at the beginning of an appointment allows patients to be more involved in the session and for genetic counsellors to better understand their patient's concerns. Genetic counsellors take personal medical and family histories to assess recurrence risks for the patient and other family members. To illustrate, a patient who is experiencing symptoms of Huntington's disease may report when their symptoms began, what their symptoms are, and whether other family members have experienced similar symptoms. Knowing these details is important when determining a patient's risk of having the condition and can help the genetic counsellor guide testing options.

During the appointment, the genetic counsellor provides information about the genetic condition to the patient, including information about the inheritance pattern, chance to be affected or a carrier of the condition, general management, and treatment recommendations. The genetic counsellor breaks down complex information into concise, lay-level language that is patient-friendly. This aspect of the appointment is paramount for a patient to make an informed and autonomous decision. The genetic counsellor will then review what, if any, genetic testing is available and best suited for the patient based on the patient's concerns, personal values and belief, and preferences. According to Rantanen et al., (2008), the ideal genetic counsellor has nine qualities: 1) is appropriately trained on genetics and ethical implications, 2) provides relevant and objective information, 3) assures that the patient understands the information, 4) provides psychological support, 5) ensures informed consent is provided, 6) upholds the confidentiality of genetic information, 7) considers familial implications of genetic testing, 8) appropriately handles and navigates discrimination of genetic testing, and 9) assures autonomous decision making of the patient.

2.4.2 Informed Decision Making and Empowerment

Facilitating informed and autonomous decision-making is an important part of a genetic counsellor's role. An informed decision in a medical setting requires sufficient information about a procedure or test to be comprehended by the patient for a confident decision to be made (Uhlmann et al., 2010). Since there are many personal, familial, and ethical considerations when undergoing genetic testing, a patient should be aware of all the relevant factors before making decisions regarding genetic testing (Uhlmann et al., 2010). To make an informed decision, the patient needs to understand the possible test outcomes, the potential impacts of the genetic test results on their health management, how the results may impact their family's health, as well as information on the confidentiality and privacy of their genetic information. It is part of the genetic counsellor's role to educate the patient on these topics.

Often, consent forms are provided to patients outlining the risks, benefits, and limitations of genetic testing to help facilitate an informed decision. At the end of the appointment, the patient (if they have the legal capacity) or the parent/guardian can provide informed consent.

Part of making an informed decision is empowerment. Empowerment is the process of becoming stronger and more confident in controlling one's life and claiming one's rights (McAllister & Dearing, 2015). Empowerment in a clinical genetic setting encompasses five main dimensions: cognitive control, decisional control, behavioural control, emotional regulation and hope (McAllister et al., 2011). McAllister & Dearing (2015) define these dimensions as follows:

1. <u>Cognitive control</u> is having sufficient knowledge and understanding about the condition, including risks to oneself and other relatives.
2. <u>Decisional control</u> involves having options or feeling able to make informed decisions between options for managing risk.
3. <u>Behavioral control</u> is feeling able to use the health and social care systems effectively to reduce harm/improve life for oneself and other relatives.
4. <u>Emotional regulation</u> is feeling able to effectively manage emotional consequences of genetic information.
5. <u>Hope</u> for a fulfilling family life for oneself, relatives, and future descendants.

When patients feel empowered in these five aspects, they feel more control in autonomous decision-making (McAllister & Dearing, 2015). It is the genetic counsellor's role to place an emphasis on patient autonomy in decision-making, and to empower patients to make the decision that is most appropriate for them based on their personal, familial, and cultural values.

2.4.3 Cultural Competency

Cultural competency is the ability to understand, appreciate, and interact with people from cultures or belief systems that are different from one's own (DeAngelis, 2015). Cultural competence stems from the idea that a culturally sensitive individual is aware that cultural variances exist between individuals, but they do not reserve any biases towards the differences and similarities (DeAngelis, 2015). However, cultural competency includes having knowledge and understanding of cultural norms. Cultural humility goes further to say that “an individual must take an interpersonal stance that is open to the other concerning aspects of cultural identity that are most important to the person” (Hook et al., 2013). It does not necessitate having knowledge of different cultural values. Cultural humility allows an individual to be open to other peoples’ preferences through empathy and inquiry while being self-reflective of their own preferences (Hughes et al., 2020). Finally, cultural safety requires healthcare practitioners to engage in ongoing examination of themselves, their biases, and prejudices, and the potential impact of their own culture on clinical interactions and healthcare service delivery (Curtis et al., 2019). When healthcare providers apply these principles, it ensures that they are providing the most appropriate and culturally safe care to their patients.

Genetic counsellors are trained in cultural competency, humility, and safety, as they are invaluable skills to aid in providing culturally appropriate care to their patients (Accreditation Council for Genetic Counseling, 2015). This training allows genetic counsellors to understand cultural influences that may be present when a patient is making decisions about genetic testing or management of their genetic conditions. For example, individuals from certain cultures may prefer not to disclose distressing information to family members to protect them from feelings of anxiety, distress, or sadness (Carrese & Rhodes, 1995; Mostafazadeh-Bora & Zarghami, 2016). As such, some individuals may feel less comfortable sharing medical information with other family members, even when it could have an impact on them (Xue et al., 2013). However, someone originating from a specific country or speaking a certain language does not mean that the individual shares the same beliefs or cultural norms as other individuals from the region. Part of cultural safety and humility is recognizing that everyone has their viewpoints; these viewpoints can also be influenced by an acceptance, or rejection, of their native culture. Knowing and recognizing the patient’s individuality can help genetic counsellors be more effective when counselling their patients (Uhlmann et al., 2010).

2.4.4 Mode of Appointment and COVID-19

Genetic counselling sessions can occur through different modalities such as in-person, over the telephone, or by videoconferencing/telemedicine. Providers have utilized virtual appointments to provide services to individuals who are unable to attend appointments in-person. Reasons for virtual appointments can include distant geographical locations, limited access to transportation, or a disability that makes it difficult to travel to the clinic. Prior to the COVID-19 pandemic, most genetic counselling appointments occurred in person and virtual appointments were only booked when necessary (Uhlmann et al., 2021). However, due to COVID-19 related lockdowns and safety regulations, many genetics clinics rapidly switched to only offering virtual appointments. Recent studies were done to assess the efficacy of virtual appointments and the impact of the pandemic on the genetic counselling profession. In general, virtual appointments were found to be on par with in-person appointments and were shown to have similar levels of patient satisfaction in a genetic counselling context (Brown et al., 2021; Christian et al., 2022; Gonzalez et al., 2022). Videoconferencing was preferable to telephone appointments for most genetic counsellors as genetic counsellors could use visual aids and catch the patient’s visual cues (Brown et al., 2021; Uhlmann et al., 2021). Furthermore, it allows the opportunity to see multiple family members at once (Ahimaz et al., 2021). Difficulties with virtual appointments include arranging for genetic samples to be obtained and testing coordination, technical difficulties, and rapport building with patient, as well as access to devices such as computers and telephones (Ahimaz et al., 2021). Despite these difficulties, it is likely that the uptake of virtual genetic counselling appointments will persist post-pandemic due to the convenience it provides to patients (Uhlmann et al., 2021).

2.5 Medical Interpretation and Genetic Counselling

2.5.1 Medical Interpretation and Genetic Counselling

Genetic counsellors often work with medical interpreters during appointments with patients who have LEP. A medical interpreter can be requested by the referring provider, by the patient, or be offered by the genetics clinic staff. The patient typically makes the final decision on whether an interpreter is necessary.

In a study done by Kamara et al., (2018) 24 cancer genetic counselling sessions for Latina women who required medical interpreters were recorded and analyzed. The analysis was completed by bilingual Spanish-English researchers to determine linguistic and cultural challenges in shared decision-making. The authors of this study found that there was a lack of participation by the Latina patients in the decision-making process due to reduced information comprehension and information overload. From the recorded appointments, future-oriented hypothetical explanations, such as possible test results, were difficult for interpreters to understand and interpret effectively. It was also found that misinterpretations by the medical interpreter occurred often, especially when discussing genetic terminology and concepts due to specific terminology not existing in the language or the interpreter not knowing the interpretation of the word. These misinterpretations, whether they were miscommunications or omissions of crucial information, can impact a patient’s ability to make an informed decision, and will often go unnoticed by both the patient and the genetic counsellor.

Due to the unique nature of genetic counselling and the content matter involved, it can be difficult to have a medical interpreter that is familiar with genetic terminology. Training to become a medical interpreter includes learning specific medical terminology, but it does not necessarily involve terms that are commonly used in a genetics setting. As the immigration rate increases in Canada more individuals with LEP may require genetics services. Therefore, genetic counsellors and medical interpreters must work together to provide optimal care to patients with LEP.

2.5.2 Genetic Counsellor Perspectives

Previous research has explored genetic counsellors’ experiences working with medical interpreters. Schmitz et al., (2018) interviewed 15 genetic counsellors across the United States about their experience working with medical interpreters. The results of this study showed that there was a preference for in-person medical interpretation, as opposed to telephone or virtual interpretation. Terminology issues frequently arose when either the medical interpreter did not know the specific genetic term or if the word did not exist in the target language. Finally, time constraints occurred more frequently when an appointment required medical interpretation. Genetic counsellors noted different strategies and techniques that they used during appointments with interpreters, including the avoidance of complex terminology, and debriefing with the medical interpreter after the appointment to provide information for future genetic counselling appointments.

Hurtado-de-Mendoza et al., (2018) explored providers' perceptions of barriers and facilitators when working with Latina populations in a genetic cancer risk counselling setting. Twenty health care providers, including genetic counsellors, were interviewed and it was found that language was a main barrier to accessing genetic cancer risk counselling. The genetic counsellors in the study noted that using medical interpreters was helpful overall when communicating with patients who have LEP, however it does not come without its difficulties. The genetic counsellors reported that using interpreters can hinder rapport building with patients, add extra time to appointments, and create uncertainty about the information being interpreted. Some bilingual genetic counsellors found that interpreters summarize and cut off key points of information, while others stated that incorrect translations of words were used. Additionally, bilingual genetic counsellors found that misinterpretations occurred when the medical interpreter was not familiar with the nuances of genetic terminology or became emotionally involved with the appointment and did not want to upset the patient.

2.5.3 Medical Interpreter Perspectives

The perspectives of genetic counsellors are invaluable in identifying successes and difficulties when working with medical interpreters. The medical interpreters' perspectives are equally valuable to obtain a complete understanding of these difficulties and successes. Each person involved in the appointment plays a specific role and have expectations for how the appointment will proceed. A genetic counsellor may be focused on providing information to the patient, and a medical interpreter may be more focused on the pacing of the appointment or interpreting the information in a way that is intelligible to the patient.

Rosenbaum et al., (2020) interviewed medical interpreters to explore their perceptions of cultural bumps during genetic counselling appointments. Eleven Spanish and Polish-speaking medical interpreters from the Chicago area were interviewed about their experiences with genetic counselling appointments. The authors of this study found that there were cultural bumps in five major themes: 1) assumptions about the patient's health literacy, 2) norms regarding family roles, relationships, and decision-making, 3) patient faith and beliefs, 4) impact of cultural competency on genetic counselling sessions, and 5) maintaining and improving cultural competency. These results showed that cultural bumps occurred when the genetic counsellor provided information to the patient and can impact patient decision-making. Rapport building with the patient was found to be dependent on the cultural competency of the genetic counsellor, with improvement in patient-provider relations when the genetic counsellor was more culturally competent.

Krieger et al., (2018) explored the experiences and perspectives of medical interpreters working with the Hmong population in genetic counselling sessions. Six interpreters were interviewed about their perceptions of their role, unique challenges of genetic sessions, knowledge genetics providers require when working with Hmong patients and interpreters, and what support and training are required for medical interpreters to effectively interpret in a genetics setting. The results showed that most interpreters view their primary role as providing verbatim interpretations of what the provider and patient are saying. However, some interpreters believed that providing the same message with substitutions for some words is appropriate and other interpreters viewed their role as a cultural broker during the appointment. Interpreters also noted time pressures during appointments, preferred when visual aids were used, felt that it was the genetic counsellor’s role to be culturally competent, and preferred when genetic counsellors knew how to effectively work with medical interpreters.

2.5.4 Genetic Counsellor and Medical Interpreter Perspectives

Having both the genetic counsellors’ and medical interpreters’ perspectives provides a more detailed, nuanaced, and complete picture of what occurs during an appointment with LEP patients. Having both perspectives can also elucidate areas of improvement. Lara-Otero et al. (2019) explored both the genetic counsellors’ and medical interpreters’ perspectives on the medical interpreter’s role during genetic counselling appointments. This study interviewed 10 genetic counsellors and 11 medical interpreters at two different cancer counselling clinics in California. Most interpreters viewed their role as being a patient advocate, cultural broker, and emotional support; this exceeded the scope of direct interpretation. Interpreters described difficulties including technical difficulties when providing interpretation over telephone or teleconferencing platforms, terminology difficulties, and the emotional aspects of the job. Given the geographical region where this study took place, some genetic counsellors spoke and/or understood Spanish. Some genetic counsellors would correct the medical interpreter when they felt that information was being miscommunicated. This was referenced by medical interpreters as being a point of tension, as the interpreters felt that the genetic counsellor was overstepping and not allowing the interpreter to do their job. Finally, the authors of this study found that there was distrust between both genetic counsellors and medical interpreters. Many of the interpreters stated that there was either explicit or implicit distrust from the genetic counsellors in the interpreter’s ability to appropriately interpret. The genetic counsellors in this study stated that they valued literal and neutral interpretation of information, and when they felt that this was not occurring, they would question the interpreter’s competence and ability to provide an accurate interpretation. This study highlights the importance of trust in a working relationship between the genetic counsellor and interpreter, and how it can impact the genetic counselling session.

2.5.5 Patient Perspectives

The use of medical interpreters in other healthcare settings have been explored from the patient perspective. Although genetic counselling is unique in terms of the style of medical appointment and terminology that is used, these studies provide a foundation for how a genetic counselling session may be perceived by patients with LEP. There are few studies assessing the patient perspective of using medical interpreters (Hughson et al., 2016).

Joseph & Guerra (2015) observed twenty hereditary breast cancer genetic counselling appointments attended by Latina patients and interviewed ten patients about their experience of the appointment. During the interviews, some patients had difficulties with understanding and explaining the specific genetic information that was provided to them during the appointment, but were able to recall the purpose of genetic testing. Some patients also described feelings of embarassment when answering the genetic counsellor’s questions about family and personal history. It was observed that medical interpreters were unfamiliar with genetic counselling, including the hour-long appointment format, specific terminology, and the nature of genetic information as difficulties during the appointment.

Hadziabdic & Hjelm (2014) interviewed 13 Arabic-speaking patients to explore their experiences using medical interpreters during primary healthcare appointments. The authors of this study found that participants equated good interpretation with an interpreter’s knowledge of terminology and ability to maintain objectivity throughout the appointment. Face-to-face interpretation was preferred over telephone appointments when complex topics were discussed. Finally, participants stated that it is preferred when they share the same region of origin, dialect, gender, and political views as the interpreter, implying the ulitiy of cultural brokerage for some.

One study by Schwei et al., (2017) looked at when patients with LEP believed a medical interpreter was required, and how the decision to utilize medical interpretation is made. This study interviewed 20 patients with LEP in Spanish and Hmong-speaking communities. It was found that the patient's decision to utilize medical interpretation was based on their perceived level of English proficiency, how complex they anticipated the information to be, and how easy it was to access interpretation services.

Another study quantitatively assessed patients with LEP perspectives on the quality of medical interpretation provided in a primary care setting (Pathak et al., 2021). Medical interpretation was provided across different modalities (in-person, videoconferencing, and telephone) while the provider and patient were in-person during the appointment. Survey questions reviewed the patient's general experience with the interpreter, including how well the interpreter listened to the patient, communicated the information provided by the doctor, whether they helped the patient understand their medical condition, test results, and the treatment plan, and the patient's overall experience. The results showed that patients had a generally positive experience with medical interpretation and that there were no significant differences between the different interpretation modalities across the survey questions.

2.6 Study Rationale

Currently, there are limited studies that explore the patients' perspectives of genetic counselling appointments with a medical interpreter and none that explore the Canadian experience with medical interpretation to our knowledge. This limits our understanding to the American context, which set different expectations of medical interpreter. Our study intends to focus on exploring the perspectives of both genetic counsellors and patients to develop a richer understanding of their experiences. First, this exploratory study is necessary to bring into view the perspectives of our patients with LEP. Secondly, this study is needed to understand the perspectives of the patients and genetic counsellors involved in genetic counselling of LEP patients within the Canadian context. The findings from this study will offer insight to the similarities and differences in the experiences of the participants, which may have implications for our current standards of care. This will allow a basis for providing recommendations on how to improve the genetic counselling experience that is better suited to patients with LEP.

CHAPTER 3: METHODS

3.1 Study Design

A qualitative, phenomenological methodology was utilized to better understand participants' lived experiences during a genetic counselling session that utilized medical interpretation services. To explore and deepen our understanding, we based this study using a phenomenological framework as this methodology seeks to understand the ways people experience and make meaning of events (Neubauer et al., 2019; Wojnar & Swanson, 2007). The phenomena in question are genetic counselling sessions that required medical interpretation. This is an exploratory study that utilized semi-structured, one-on-one interviews with patients with LEP and genetic counsellors to capture their unique perspectives on their genetic counselling appointment. Each interview was transcribed and analyzed for overarching themes within and between data sets. Data was analyzed using Braun & Clarke (2006) thematic analysis. This method of analysis was chosen due to its flexible approach to qualitative data analysis that includes recognizing the researcher's own subjectivity as a key resource in the analysis process. While individual counselling sessions were unique, the phenomenological methodology allowed for the identification of similar themes within each genetic counselling session with a medical interpreter. An overview of the study methods is outlined below in Figure 1.

This study was approved by the Research Ethics Board at the University of Manitoba under approval number H2021:194 (HS24922) and the Shared Health Approval Committee for Privacy, Impact, and Access in Research under approval number SH2021:089.

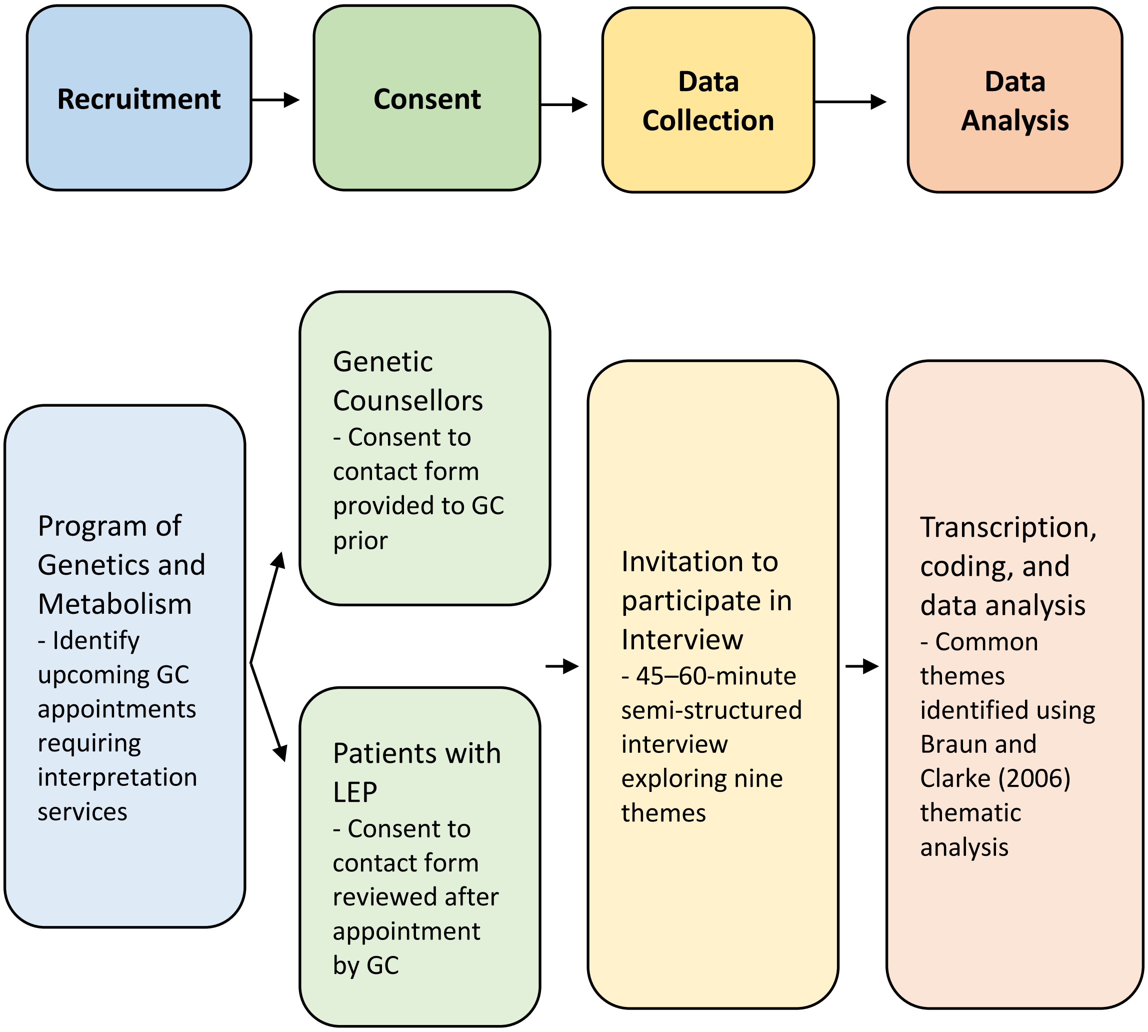

Figure 1. Workflow of the study design and methods.

3.2 Interviews

3.2.1 Study participants

Two participant groups were recruited for this study: genetic counsellors and patients with LEP who had a genetic counselling appointment that required medical interpretation. Recruitment of both participant groups occurred at the department of Genetics and Metabolism at the Health Sciences Centre in Winnipeg, Manitoba, Canada. In order to capture the largest study population as possible, we recruited patients and genetic counsellors from all available specialties including prenatal, cancer, metabolics, general genetics, and multidisciplinary clinics that involved a genetic counsellor in a subspeciality clinic such as cardiology, ophthalmology, movement disorders, etc. Participants were invited to join the study based on the following inclusion and exclusion criteria (Table 1 & Table 2). Patients requiring interpretation for Indigenous languages were not included in this study. This was due to the difference in interpretation style as Indigenous interpreters serve as cultural brokers and advocates.

Initially, we aimed to recruit medical interpreters as a third participant group. We worked with the staff at the WRHA Language Access Interpretation Services and were approved to recruit medical interpreters through their services. WRHA Language Access Interpretation Services provides in-hospital, in-patient medical interpretation services at Health Sciences Centre in Winnipeg, Manitoba. Due to the COVID-19 pandemic, the majority of genetic counselling appointments occurred either by videoconferencing or telephone. The medical interpreters that took part in most of the department’s genetic counselling appointments were through an approved third-party interpretation service, MCIS Language Solutions. When creating the study design, it was anticipated that WRHA Language Interpretation Services would be providing interpreters for genetic counselling sessions. Unfortunately, this was only discovered by the principal investigator months after recruitment began, therefore MCIS Language Solutions was not engaged prior to recruitment to gauge interest or ethics approval. Due to time constraints for study completion, MCIS Language Solutions was not contacted for this study and subsequent ethic amendments were not submitted. As such, medical interpreters were not recruited for our study.

Table 1. Inclusion and exclusion criteria for patients.

To participate in the study, you must meet all the criteria:	You cannot participate in this study if you meet one or more of the following:
✓ At least 18 years old ✓ You have limited English proficiency ✓ You or your child were referred to, and attended, a genetic counselling appointment at the Program of Genetics & Metabolism in Winnipeg, Manitoba. ✓ Your appointment involved the use of a medical interpreter ✓ The appointment was with a genetic counsellor ✓ Your appointment was by virtual, telephone or in-person	☒ You accompanied someone that you are not the parent or guardian of to their genetic counselling appointment

Table 2. Inclusion and exclusion criteria for genetic counsellors.

To participate in the study, you must meet all the criteria:	You cannot participate in this study if you meet one or more of the following:
✓ Board certified, or board eligible, genetic counsellor at the Program of Genetics & Metabolism at Health Sciences Centre (Winnipeg, MB) ✓ Only you counselled the patient with the use of a medical interpreter during the appointment e.g. genetic counselling students are excluded.	☒ You are involved as an advisor or committee member for this research study.

3.2.2 Recruitment

Recruitment occurred through the Program of Genetics and Metabolism at Health Sciences Centre from August 2021 to March 2022. Prospective participants included patients with self-identified LEP referred to the Program of Genetics and Metabolism for a genetic counselling appointment, genetic counsellors working within the program, and medical interpreters who attended the appointment.

Prior to recruitment, we engaged genetic counsellors working within the department to gauge interest in participating in the study through a virtual meeting. During the meeting, we provided information about our study, and outlined the recruitment process for both the genetic counsellors and patients with LEP. We provided ample opportunities within the meeting for our prospective genetic counsellor participants to ask questions. Overall, the genetic counsellors group expressed interest in participating in interviews and was generally well received.

In order to recruit genetic counsellors to our study, we explained to the genetic counselling group that an initial email with detailed information about the study would be sent to all genetic counsellors in the department. If the genetic counsellor had an appointment with a patient that required a medical interpreter, and elected to participate in the study, they were directed to complete the “Consent to Participate in Research” form (Appendix B) attached to the email and send it back to the researcher. A date and time for the interview was arranged with the genetic counsellor participants once consent was obtained.

Due to the COVID-19 pandemic, safety precautions and restrictions were placed on the Genetics department. All genetic counsellors were required to work from home for most of the work week. As such, the majority of genetic counselling appointments that took place during our recruitment period were virtual (i.e., over the phone, videoconferencing, etc). To recruit patients with LEP, we asked the genetic counsellor participants to provide the “consent to contact" forms to their patients and return to the principal investigator. An email was sent to the genetic counsellors in the department that outlined the inclusion/exclusion criteria for both participant groups, along with a copy of the "Consent to Contact" form (Appendix A) for the patients and a "Consent to Participate in Research" form (Appendix B) for the genetic counsellors.

When a genetic counsellor had an appointment requiring medical interpretation, the genetic counsellor involved reviewed the Consent to Contact form with the patient. The consent to contact form requested the patient's preferred language, method of contact, dates/times to be contacted, and whether they would like an interpreter to be present when contacted. If a patient provided consent to contact, the principal investigator contacted the potential participant to review the "consent to participate" form. An interpreter who spoke the patient's preferred language was present at the time of contact for all potential participants who requested it. Interpretation services were provided by MCIS Language Solutions. Once consent was received, the researcher arranged a follow-up session to interview the participant. Of note, the interpreter utilized for initial contact with the potential patient participant was different from the one present for the interview due to differences in the type of interpretation provided (i.e.: community interpreters, not medical interpreters, were present during interviews).

3.2.3 Study Instruments

We developed an interview guide based on findings from previous studies exploring similar topics and the 24 item Genetic Counselling Outcome Scale (GCOS-24) (Hansen, 2019; Hudelson, 2005; Kotovicz et al., 2018; Krieger et al., 2018; McAllister, Wood, et al., 2011). The GCOS-24 is a patient reported outcome measure that has been validated for clinical genetics service. This scale includes questions exploring patient empowerment, informed decision making, understanding genetic information, and the psychosocial impact of a genetic counselling appointment (McAllister, Wood, et al., 2011). We adapted questions from the GCOS-24 to explore similar concepts of patient empowerment, informed decision making, etc. within the context of working with medical interpreters. We included additional questions addressing factors found from previous studies that affected genetic counselling appointments with an interpreter. These factors included: logistical constraints, terminology, and rapport building. We designed our interview guide to best capture and explore the experiences and perceptions of participants, while building from previous knowledge.

The interview guide consisted of 8-10 open-ended questions and multiple follow up questions exploring the participants' experiences. Areas of focus included:

1. General impressions of the appointment.
2. Successes/positive aspects of the appointment.
3. Difficulties/challenging aspects of the appointment.
4. Informed decision making.
5. Patient empowerment.
6. Experience with medical interpretation.
7. Perception of the medical interpreter's role.
8. Time constraints.
9. Suggestions for improvement.

We tailored our questions for each participant group while aiming to address the same area of focus. For example, when assessing patient informed decision making, the principal investigator asked the genetic counsellor, "do you feel that the patient made an informed decision about the genetic test?" Conversely, the patient was asked "do you feel that you had enough information to make an informed decision about your genetic test?". Following this structure, an initial question would be asked exploring a focus area and follow up questions were asked for further elaboration based on the participants' responses. By utilizing a semi-structured interview, the interviewer was able to modify their interview questions ad hoc to delve into what the participants wished to speak about. Participants were free to address topics that were the most important to them and allowed participants to introduce new topics related to the interview questions, which gave a more holistic account of their experiences. Additionally, this allowed for opportunities to explore novel and unique concepts that were not anticipated. Sample interview guides can be found in Appendix C and D.

The interview guide was approved for use by the Research Ethics Board. The principal investigator and supervisor completed practice interviews prior to recruitment of participants to ensure proper interview techniques were used.

3.2.4 Interviewing and Data Collection

Once we received consent to participate from our study participants, individual interviews were scheduled. Interviews were scheduled for one hour and participants had the option of doing the interview by telephone or videoconferencing. All videoconferencing interviews were completed over the video communication application BlueJeans^{TM}. If a patient participant indicated that they required interpretation services, an “on-demand” community language interpreter was accessed through MCIS Language Solutions. All interviews were audio recorded, with videoconferencing interviews also being video recorded. We transcribed each interview from the audio recordings. All study participants received a $10 virtual gift card to a big box store to thank them for their participation in the study.

3.3 Data Analysis

3.3.1 Transcription

A total of ten interviews were completed, audio recorded, and transcribed. Interviews occurring over videoconferencing platforms were transcribed using only the audio recording. The principal investigator transcribed seven of the ten interviews, including two interviews that required interpretation services. The remaining three interviews were transcribed via a third-party transcription service, TranscriptHeroes^{TM}. The principal investigator audio-checked the three interviews transcribed by TranscriptHeroes^{TM} to ensure accuracy. Transcripts of interviews requiring interpretation only included the English responses provided by the interpreters. Due to funding limitations, the patient participants' responses in their preferred language were not translated. For this same reason, it was not possible to verify the participants' responses.

All audio-recordings were initially transcribed verbatim. The principal investigator then edited the transcripts to remove any filler words (such as "like", "ah", "um", etc.) to improve readability. We removed any names or potential identifiers that were in the audio recordings and replaced with the participant's unique identification number to protect their privacy and confidentiality. If there were any sections of the audio recording that were inaudible or unintelligible, they were marked as [unintelligible] and the transcription continued once the audio was clear.

3.3.2 Coding and Analysis

Data analysis was done using Braun & Clarke (2006) thematic analysis. Thematic analysis lends well to phenomenology, as it allows researchers to examine the different factors that lead to the experience of a phenomenon. Thematic analysis involves six phases: familiarizing yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Thematic analysis posits that themes do not "emerge" from the data, rather, themes are conceptualized by the researcher based on the data. For this study, an inductive approach to thematic analysis focusing on latent theme development was utilized. Inductive coding involves the generation of codes as the data is analyzed, as the goal of our study is to better understand the unique experience of each participant, inductive coding allows us to analyze the data based on the participant responses rather than preconceived notions of what the data will show. Similarly, latent theme development allows us to capture underlying ideas, patterns, and assumptions beyond what is directly stated in the interview transcripts.

The principal investigator familiarized themselves with the data by reviewing each audio-recording, memo-ing, and directly transcribing six of the ten interviews. All transcripts were uploaded to an online qualitative data software, Dedoose (Dedoose Version 9.0.54 Web Application for Managing, Analyzing, and Presenting Qualitative and Mixed Method Research Data., 2022), for analyzing and storage. During initial coding, the principal investigator used inductive thematic analysis to review each transcript and develop codes. We developed a codebook containing all the latent codes identified in each transcript. The supervisor reviewed the codebook and transcripts with the principal investigator to ensure rigor and validity of the codes. Thematic analysis posits that there is no one “accurate” way to code data, and therefore inter-rater reliability is not necessary for this type of analysis. However, by having an independent second coder, this ensures that any discrepancies or nuances in the codes are identified, discussed, and resolved. Following initial coding, the principal investigator reviewed the codebook and conceptualized major themes and subthemes based on patterns, frequency, and commonalities between the initial codes. All themes were again reviewed with the co-investigator to ensure that these conceptualized themes accurately described and addressed the collected data.

3.3.3 Positionality and Reflexivity

Positionality in qualitative research assumes that a researcher’s beliefs, assumptions, and experience have influence on the data sets that they are working with. Reflexivity refers to a researcher’s positionality and how one must be aware of these biases and acknowledge its role in the research process. When working with any data, it is important to be actively aware and reflective of how one’s positionality affects the results.

To state our positionality, the principal investigator is a genetic counselling student, a first-generation immigrant to Canada who has family members with LEP and has never personally required medical interpretation. All these factors have an influence on how interviews are administered, how the transcripts are analyzed, and how themes were formulated. To illustrate, the principal investigator is familiar with the general outline of a genetic counselling session as she is a genetic counselling student. This experience influences their understanding of how a session “should” flow and what factors are important to address with the patient; all of which a patient may not be as familiar with. Furthermore, the principal investigator within the genetic counselling context previously worked with medical interpreters, but only as the training healthcare provider, never as the patient. Additionally, during the interview process the principal investigator was aware of power dynamics between herself and the genetic counsellor participants. All of the participating genetic counsellors have been previous supervisors of the principal investigator and was reflective of how this affected questions and responses during the interview, as well as the conclusions drawn from the data. Therefore, the beliefs and experiences with medical interpretation have always been from the perspective of a training health care professional. Finally, being a bilingual, first-generation immigrant influences the researcher’s role in this study. The principal investigator having family members who require interpretation and translation services was a motivating factor for pursuing this work. This also created a bias towards patient populations and focusing on their perspectives during data analysis. This bias was based in wanting to provide exceptional care for patients and may have influenced the resulting themes and recommendations of this study.

Biases will always exist in qualitative research. However, the goal is not to eliminate these biases, but rather to be aware of them throughout the research process. By addressing these biases before the recruitment process, researchers can incorporate how their positions may affect how the data is analyzed and how conclusions are drawn from the data. In order to acknowledge their biases, the principal investigator completed memo-ing before and after each interview and took detailed field notes during the interviews which were kept in a reflexivity journal for reflection. As well, the principal investigator ensured that the semi-structured interview guide was followed in a way that allowed participants to elaborate on their experiences but also ensured the same initial questions were being asked in each interview. Memo-ing was done throughout initial coding and theme development on the Dedoose^{TM} software. Additionally, the student researcher frequently spoke with the supervisor and her committee about these biases and how they may have influenced collection and analysis of the data. By taking these steps towards practicing reflexivity and being aware of the researcher's positionality, this study has taken the researcher bias into account when drawing conclusions from this study.

CHAPTER 4: QUALITATIVE RESULTS

4.1 Overview

A total of ten interviews were completed and analyzed in this study. Eight patients completed the Consent to Contact forms and six genetic counsellors completed the Consent to Participate in Research forms. Seven genetic counselling interviews were completed, with one genetic counsellor completing two interviews based on two separate appointments. Of the eight patients who completed a consent to contact form, two of the prospective participants declined being interviewed and three were lost to follow-up. The remaining three patients were interviewed. Four interviews were completed over BlueJeans^{TM} teleconferencing and six were completed over the phone. Medical interpreters were present for two of the three patient interviews. Interviews ranged from 37-56 minutes, with an average of 46.4 minutes (Figure 2). The average interview length for the genetic counsellor participant group was 45 minutes, compared to 50 minutes for the patient participant group. Data saturation was achieved for the genetic counselling participant group after five interviews when no novel codes or themes were identified. Data saturation was not achieved for the patient participant group due to recruitment difficulties and time constraints for study completion. However, similar ideas and themes were discussed by all patient participants and these findings were complementary to the findings in the genetic counselling group. Additionally, we saw that the patient interviews provided new, invaluable perspectives to the field which has not been previously explored.

We identified five major themes using thematic analysis seen in Figure 3. These themes included: 1) expectations of the providers, 2) relationship and rapport building, 3) mode of appointment, 4) flow of the genetic counselling session, and 5) lived experience of the patient. Suggestions and recommendations provided by participants is summarized at the end of the chapter.

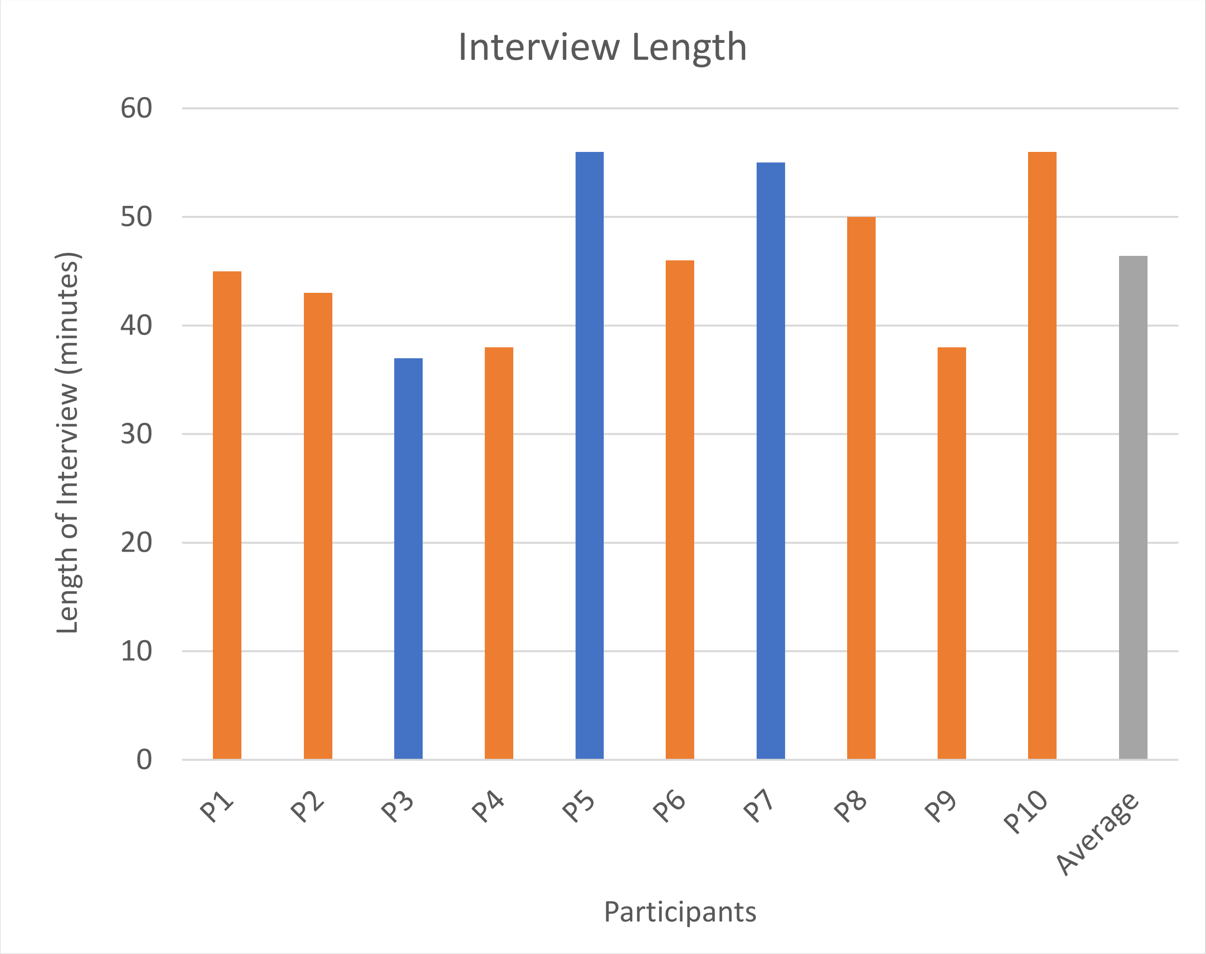

Figure 2. Average interview length. Orange bars represent genetic counsellor interview length, while blue bars represent patient interview length.

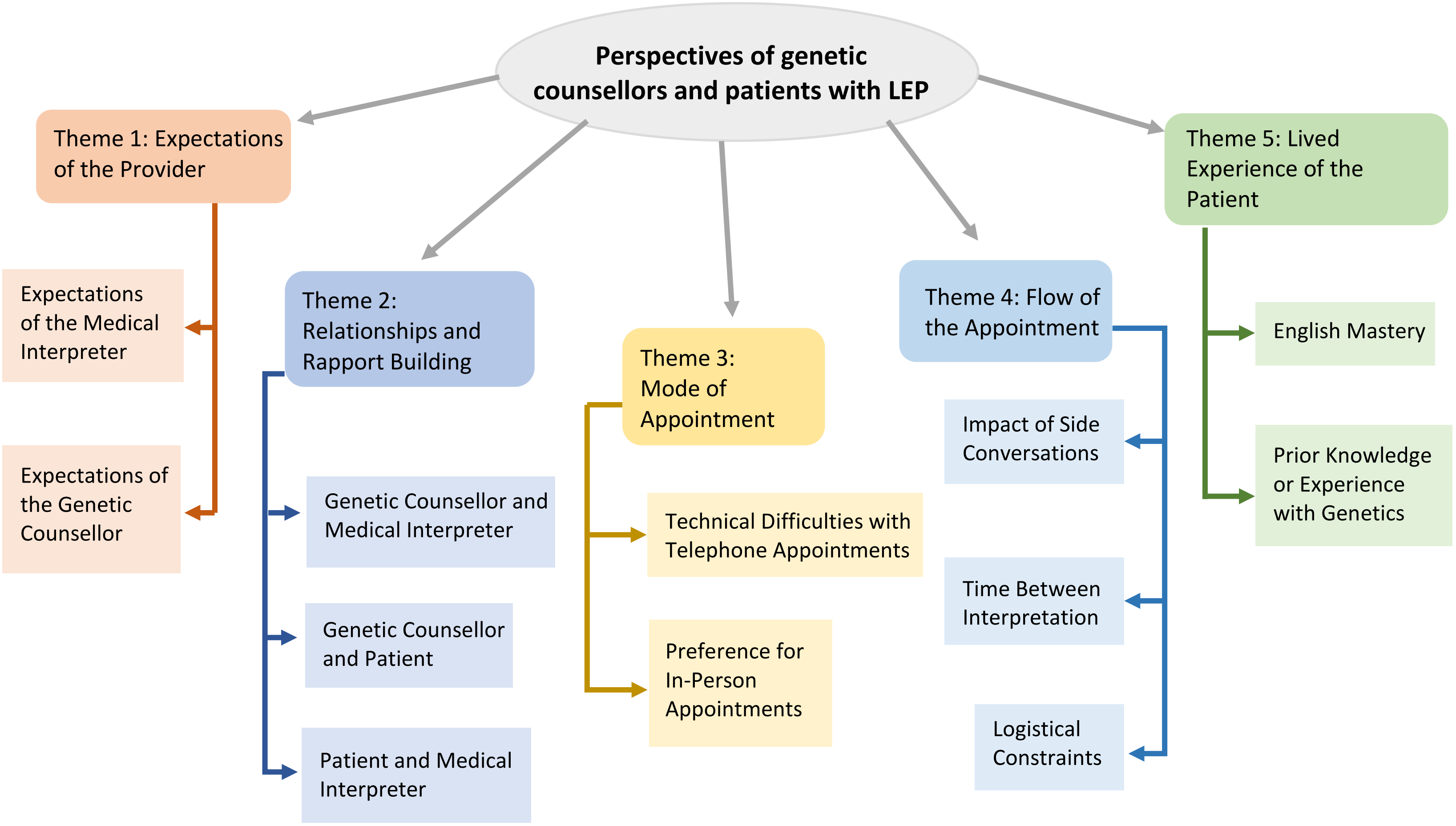

Figure 3. Overview of results of thematic analysis.

4.2 Participants

Basic demographic information was obtained during each interview. We interviewed genetic counsellors from different areas of practice. In order to preserve our participants' privacy and confidentiality, area of practice is not included in these results as there were only 10 genetic counsellors in the department at time of data collection. All participants were female. Experience working as a genetic counsellor ranged from 8 months to over 20 years. All genetic counsellors reported having worked with medical interpreters previously. Two out of three patient participants had medical interpreters present at previous medical appointments. Two of the three patient participants reported that this was their first appointment with a genetic counsellor or genetics professional. The third participant reported seeing a genetics professional prior to moving to Canada. The genetic counsellor participant group reported the following languages being spoken during the appointment including Punjabi (3), Vietnamese (1), Arabic (1), Mandarin (1), Portuguese (1), and two undisclosed languages (Figure 4). Of the patient participants, two spoke Arabic and one spoke Portuguese. Nine participants attended telephone genetic counselling appointments, with the exception of one genetic counsellor who attended a videoconferencing appointment. There were two "duos", a patient and a genetic counsellor who attended the same appointment, that completed interviews.

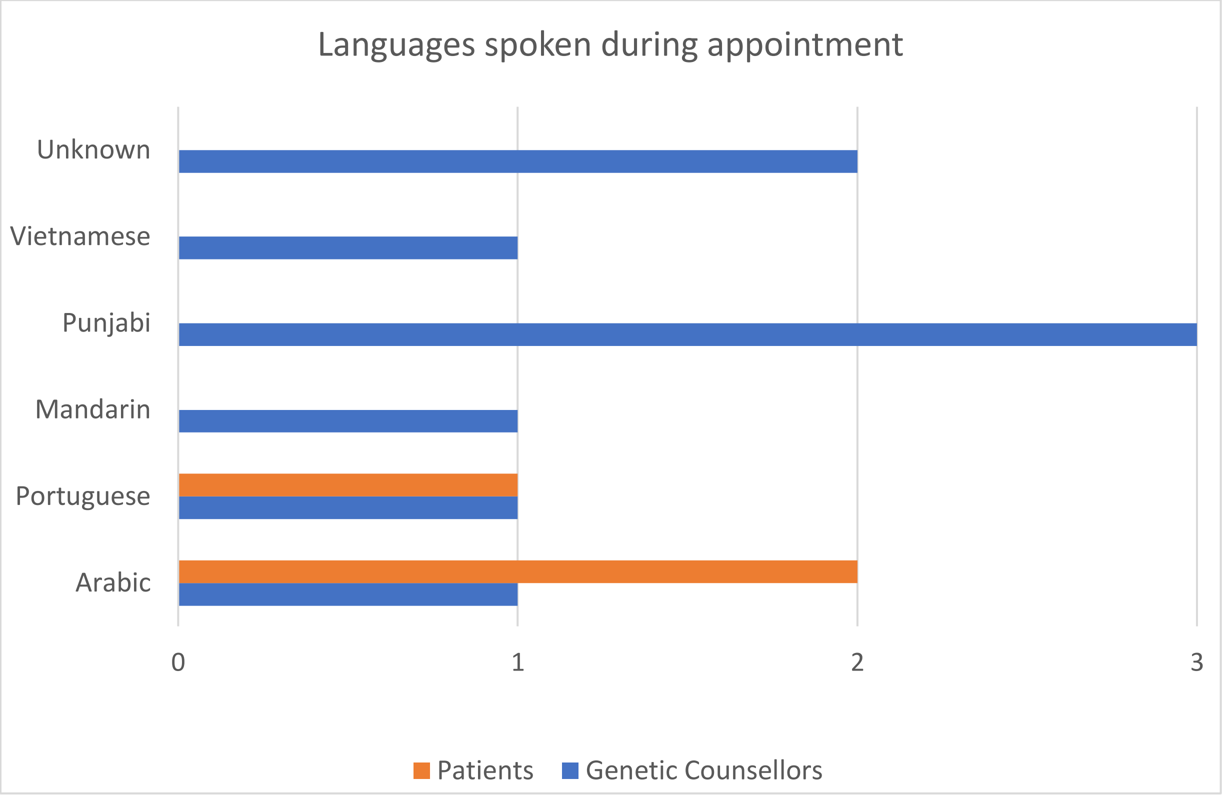

Figure 4. Languages spoken during the appointment.

4.3 Theme 1: Expectations of the Providers

Expectations held by the participants for the medical interpreter and the genetic counsellor was identified as a major theme. First, this theme captured how both participant groups viewed the medical interpreter's role during their appointment. These expectations included: style of interpretation, knowledge of terminology, and clarifications. Secondly, all participants reflected on their expectations of the genetic counsellor, including the genetic counselling participants. Most genetic counsellors expressed that it was a part of their role to explain things clearly, gauge patient understanding, and address miscommunications or misunderstandings. Overall, the genetic counselling participants viewed it as "their job" to address all aspects of the session and that the medical interpreter was present only to help bridge the linguistic gap.

4.3.1 Expectations of the Medical Interpreter

Interpretation Style

Genetic counsellor participants and the majority of patient participants expressed that they expected, and preferred, when medical interpreters provided direct, verbatim interpretation. The genetic counsellors stated that this was the most ideal scenario.

> *"In an ideal setting your interpreter really should be repeating everything you say verbatim*."
>
> - Participant #1, genetic counsellor

> *"I really prefer just a very direct interpretation like, word for word what I am saying and what the patient is saying."*
>
> - Participant #8, genetic counsellor

> *"What makes me comfortable is just to send my message exactly how I want to the [genetic counsellor], and he gave me what the doctors say exactly. So, just direct, direct. [sic]"*
>
> - Participant #7, patient

One patient participant indicated that she spoke English and was able to understand the English interpretation the interpreter provided. This participant equated good interpretation with direct translation. Additionally, when verbatim translation was given, it was void of the interpreter's own viewpoints and opinions.

> *"She translated every word, so I knew she was doing a good job. And she wasn't maybe judging me or giving her opinion instead of just translating what I want to say, or what I needed."*
>
> - Participant #5, patient

Although verbatim interpretation was preferred, two genetic counsellors indicated that they were comfortable if the essence of their statement was being conveyed. These participants noted that there may be linguistic differences between English and the patient's preferred language and that it was more important to interpret what is being said in a way that makes sense, rather than ensuring that every word is interpreted.

> *"I think ultimately it's getting the message across… I think the translator is to be verbatim but with interpretation added on, it's to make sure that the information that is coming across is actually making sense… like, okay I hear what you're say [sic], but would I actually say this to someone else? Would it still make sense? Would it still be the same message?"*
>
> - Participant #8, genetic counsellor

However, one patient participant indicated that they would prefer for the medical interpreter to take on the role of a cultural broker. The following quote by this participant speaks to how it may be helpful for the interpreter to act as an advocate for the patient and explain the cultural context of what was being said.

> *"No, it would be better if the interpreter would also be advocating the culture. Explaining things to him. For instance, I am a Muslim… The interpreter can act as an advocate in this case because the interpreter can understand my background. So, things like this can be explained or advocated by the interpreter? [sic] That would be much more better."*
>
> - Participant #3, patient

Overall, most participants expected that the medical interpreters provided verbatim interpretations whenever possible. If direct interpretation was not possible due to linguistic constraints, close approximations that conveyed the same message were acceptable. The genetic counsellor group did not favour the idea of the medical interpreter taking on the role of a cultural broker. However, there may be a place for this from the patient perspective. As one patient participant exemplified, cultural brokerage involves advocating for the patient's cultural viewpoints which may be necessary or clarifying in some scenarios.

Terminology

Participants had expectations of what terminology the medical interpreter should or should not be familiar with. All genetic counsellor participants expected the medical interpreter to have a baseline understanding of general medical terms. However, they did not expect the interpreter to be as familiar with genetics specific terminology. The genetic counsellors noted that genetic terminology is uncommon and may not be known by English speaking patients either:

> *"When you just think of some of the [genetic] terms we use like chromosome and then some of the terms we use even to define chromosome changes like*

> *translocation, rearrangement, isodicentric, centromeric, those aren't terms that people are familiar with, right? As a general rule, regardless of what language you're speaking, it gets a little bit more difficult."*
>
> - Participant #1, genetic counsellor

One participant compared their expectations of the medical interpreter to know genetics terminology to their experience with other healthcare providers:

> *"I mean in the ideal world, yes, the interpreter would understand all of those [genetic] concepts to be able to interpret them… I think about the providers that we work with on a regular basis that are medically trained professionals that sometimes don't know what these [genetic] concepts mean. So, I'm not sure how we would expect interpreters who aren't necessarily trained in the medical field to understand what these concepts are. It just seems a little unrealistic."*
>
> Participant #9, genetic counsellor

However, there was a clear shift in expectations of the medical interpreter when it came to knowing general medical terminology. Multiple participants stated that they expected the medical interpreter to be familiar with and able to interpret commonly used medical terms. Two genetic counsellor participants described their previous difficulties with interpreters.

> *"I'm happy to explain [genetic] terms and conditions and those sorts of things, but there's been one or two times where just some, what I would assume to be more basic things, that if you're a trained medical interpreter, I would have hoped that they would have had some of that knowledge. So, it took a lot of time explaining things to the interpreter and less for the interaction with the patient, which wasn't my favourite."*
>
> Participant #4, genetic counsellor

> *"He asked me to repeat what I had said several times, because he didn't understand the terminology... He didn't know terms like mammograms or gynecological organs and things like that, which I found a bit surprising."*
>
> - Participant #6, genetic counsellor

The majority of genetic counsellors expressed that the medical interpreter's role was to have knowledge and familiarity with common, general medical terms. The genetic counsellors did not expect medical interpreters to know and be familiar with genetic terminology. The patient participants did not comment on their expectations of the medical interpreter in this regard.

Clarifications

Genetic counsellors also stated that they expected the medical interpreter to ask for clarifications when a statement was not understood. However, these clarifications were only appreciated when it was to ensure that the medical interpreter was understanding certain terms or phrasing correctly. When clarifications occurred too frequently, it was less acceptable. Additionally, genetic counsellors pointed to their expectation that the medical interpreter does not need to comprehend what is being said for their own knowledge, but rather just enough to interpret the information to the patient. There was a fine balance for when and how clarifications occurred during the appointment. Generally, the medical interpreter's role was viewed solely as a linguistic aide in this sense.

> *"This [interpreter] was clarifying everything like, you know, when I said that all cancer is genetic. "Well, what do you mean" I'm like "what… you're not supposed to ask me that!" You're just supposed to tell the patient that."*
>
> - Participant #2, genetic counsellor

> *"I don't think you can expect that of the interpreter because their job is really to interpret right? They're not there to necessarily understand or comprehend*

> *everything that's going on I mean to the level that they need to interpret things."*
>
> \- Participant #1, genetic counsellor

From the patient perspective, all participants noted positive interactions with the medical interpreter and had no comments about clarifications specifically.

4.3.2 Expectations of the Genetic Counsellor: "That's my job!"

All the genetic counsellor participants expressed the expectations that they had of themselves and their own role during the appointment. Every genetic counsellor spoke of their responsibility as the main health care provider to address any miscommunications or misunderstandings, explain terminology, and be culturally competent when working with patients with LEP.

> *"Well, there may be a lot of missed and misinformation in genetics in terms of things… I feel like it's part of my role, is to dismantle some of that and make sure that they have the correct information for when they go home and talk to their relatives."*
>
> \- Participant #4, genetic counsellor

> *"I think it's my job, because if it is a cultural taboo, I should be able to kind of pick up on that and ask about that and acknowledge that maybe there is some discomfort or that they haven't talked about that before and try to create a safe space so that they can talk about it with me. I definitely do think that it is on us."*
>
> \- Participant #8, genetic counsellor

When asked about cultural competency, one participant pointed to the concept of cultural humility, and recognizing that individuals of the same culture may not have the same beliefs and values. This participant expressed that it was part of the counsellor's role to be aware of cultural differences, but to be mindful that each patient is unique:

> *"If my job is to try and educate this person, or whatever the point of the appointment is, yes, it's more useful for me to have background knowledge that in a particular culture this is how people might perceive it... But that also makes sweeping generalizations about people in that culture – they don't all feel the same way."*
>
> - Participant #6, genetic counsellor

A few participants also explained how it was the genetic counsellor's job to explain genetic terms in a digestible, patient-friendly way:

> *"That is ultimately my job. [The medical interpreter's] job is to relay information. So, I would say my job is to give that information to the interpreter to relay. I think it helps they have [the terminology], but I think, ultimately, that is my job."*
>
> - Participant #10, genetic counsellor

> *"If I'm using a term that an interpreter doesn't understand, there's a good chance my patient doesn't understand it either. So, chances are I'm using the wrong terms to begin with."*
>
> - Participant #6, genetic counsellor

4.4 Theme 2: Relationships and Rapport building

Another major theme that was seen was the relationships between the three parties involved in the session. The genetic counsellors discussed building rapport with their patients and the medical interpreters. All participants spoke about the relationships between themselves and the medical interpreters and how these relationships were built. Lastly, patient participants viewed their relationships with the genetic counsellors in a generally positive way.

4.4.1 Relationship Between the Genetic Counsellor and the Medical Interpreter

When asked about rapport building with medical interpreters, most genetic counsellors had not considered how they built rapport with the interpreter. Generally, the relationship was seen as a professional partnership to provide the best quality of care to patients with LEP, rather than focusing on building rapport with the medical interpreter specifically. Genetic counsellors viewed this professional partnership as a friendly, positive relationship, but as one participant stated, is different from “rapport in the traditional sense”:

> *“I’ve never really thought about my rapport with an interpreter per se… It’s not something that's been at the forefront of my mind… My relationship with the interpreter doesn't having [sic] a bearing on the session, and it's their role, in my mind, to make sure that the patient understands the information or I guess relays what I’m saying to the patient. So, I had never thought about it in terms of myself and the interpreter having to have any kind of rapport in the traditional sense, I guess.”*
>
> \- Participant #9, genetic counsellor

> *“I would I like it that we could be more of a partnership. I don't know if that's the word, but yeah, just part of the team. I often don't feel that especially when it's over the phone.”*

- Participant #2, genetic counsellor

One participant spoke to rapport building with the medical interpreter as "basic human niceness" – or how one would treat any other individual:

> *"I mean I think it's important to build rapport with an interpreter as well, mainly just from a basic human niceness standpoint. They're obviously there, I don't want to ignore them. I've had a couple of interpreters, like the ones that I've had a couple times, where I'll chat and be like "Oh, we've met last week" or whatever and like "how are you doing" stuff like that. So yeah, in the vast majority they've all been very nice. Yeah, I mean I think that's just basic human kindness."*

- Participant #10, genetic counsellor

Although rapport building is not formal with the medical interpreter, most genetic counsellors view their relationship with medical interpreters in a friendly, professional manner. Genetic counsellors do not see rapport building between them and medical interpreter as necessary to meet the goals of a genetic counselling session.

However, in general, genetic counsellors felt that their ability to trust the interpreter and their interpretation could influence their relationship with the medical interpreter. Genetic counsellors felt that if the interpretations provided were accurate, there was a greater sense of trust and, therefore, a more positive relationship with the interpreter. Some genetic counsellors offered their reflections on their experiences working with medical interpreters, and what factors made their interpretations trustworthy. A few genetic counsellors pointed to the medical interpreter asking for appropriate clarifications and patient questions to gauge whether they trusted the medical interpreter/their interpretations:

> *"I do trust it [the interpretation] because I find that most of the time the conversation makes sense like the answers that I am getting back are the questions that I was asking. Even in the times when it is just a yes or no it is harder to gauge. I think based on my other experiences, they have all been very positive. I've never had an experience where I felt like I was not able to [have] that trust."*
>
> - Participant #8, genetic counsellor

> *"I guess I would say I trusted him [the interpreter] because this was clear to me… I could tell by his comments, and I could tell – like he did ask me – he said, "Oh I don't understand that word". So, then I do trust him, because he has been honest with me and he's told me that he has a limitation, so then we tried to work around it, right. So then yes, I do trust him – I guess I have to right?"*
>
> - Participant #6, genetic counsellor

Though trust can be built through interactions and experiences, sometimes trust can be afforded to an individual based on expectations of their role. One genetic counsellor participant described having to put faith in the interpreter, despite not understanding the situation. By having this faith, the genetic counsellor trusted that the medical interpreter was doing all aspects of their perceived role:

> *"I feel as a provider sometimes I feel at a loss because I literally cannot understand anything that's going on… I have to put my faith in the interpreter, that they are doing everything correctly and they're interpreting concepts correctly, they are not putting in that bias, and that if a problem does arise, that they're letting me know right away so I can kind of deal with it*."
>
> Participant #10, genetic counsellor

4.4.2 Relationship Between the Genetic Counsellor and the Patient

Building rapport and trust with the patient is an important part of the genetic counselling appointment. Genetic counsellors were asked whether they were able to build rapport with their patients and what factors affected their rapport building. Generally, participants stated that they were able to build rapport and there were no major differences between rapport building with patients with LEP and their English-speaking counterparts. However, factors that influenced their rapport building with the patient included mode of the appointment, visual cues (discussed further under Section 4.5 – Theme 3: Mode of Appointment), potential cultural differences, and the presence of an interpreter:

> *"I find with all patients, some you'll connect with more and some you won't. And I find patients of different cultural backgrounds may speak more or less and may sort of answer yes, no questions, regardless if English is their first language or not. But I think sort of apart from that, yes, I think for the most part I'm able to build rapport."*
>
> - Participant #4, genetic counsellor

> *"When you're using an interpreter, you don't speak to the interpreter you speak to the patient, and you act almost as if the interpreter is not in the room… but I've been in some instances where it's the interpreter who's addressed and not the patient, which I think makes it harder to build up that rapport."*
>
> - Participant #10, genetic counsellor

All three patient participants stated that they had positive experiences with their genetic counsellors and were able to build a relationship with them. One patient stated that the language the genetic counsellor used and the empathy that they expressed during the appointment helped to build rapport:

> *"She was using appropriate words with me, and she was respecting me, and she is doing her job. Sometimes the bad news came from when she's doing her job. But no, she was good. I could tell she is a good person with me. [sic]"*
>
> - Participant #7, patient

4.4.3 Relationship Between the Patient and the Medical Interpreter

Both genetic counsellors and patients were asked about their perception of the relationship built between the patient and the medical interpreter. Genetic counsellors were able to provide a "third-party" perspective and discussed different aspects of the appointment that informed them about the relationship between the patient and interpreter. Patients were asked directly about how they perceived their relationship with the interpreter. Both the genetic counsellors and patient groups discussed the cultural and linguistic bond that was inherently present during an appointment and how that helped build rapport. Both participant groups also mentioned instances where the medical interpreter was a support person for the patient and how that created a positive relationship between all parties. Finally, one patient discussed how trusting the interpretation provided positively influenced her experience with the medical interpreter.

Cultural and Linguistic Bonds

All the patients touched on the cultural and linguistic connection that they felt with their interpreter. One participant had an interpreter that was from the same country and spoke the same dialect as her. The participant described how this was very meaningful to her and felt that they shared a bond:

> *"I don't know if they knew that, but this interpreter was perfect for me because I think, if I would guess, she is from … and I am too, so we basically speak the same dialect and, yeah, we have the same accent. [sic]"*
>
> - Participant #5, patient

The same participant went on to state that this linguistic connection made her feel more comfortable with the medical interpreter than the genetic counsellor:

> *"Yeah, I think I was comfortable with both of them, but maybe more with the interpreter because she speaks Portuguese. But I know [the GC] was super kind and I felt comfortable with her too, but maybe a little bit more with the interpreter."*
>
> \- Participant #5, patient

The other two patients stated similar sentiments in terms of a shared culture. These patients spoke Arabic and they described feeling a bond with other Arabic speakers. One participant echoed a similar stance as Participant #6 (genetic counsellor) regarding cultural humility and how individuals from the same culture can share different beliefs. This participant still touched on the fact that the interpreter speaking the same language as her and sharing a similar culture was important in building a relationship. Another participant spoke directly to sharing a similar culture as her interpreter and how this aided the rapport that was built between them.

> *"Of course, yes. It would be really great if always someone who can understand you, who to whom you can express yourself freely and can understand you and help you also to understand the other guy in your own way in your own culture and it always great. [sic]"*
>
> \- Participant #3, patient

> "*Every Arabic people they are brothers, and they have the same language, and we understand each other. [sic]"*
>
> \- Participant #7, patient

Finally, one genetic counsellor expressed that she appreciated when the patient and the medical interpreter build rapport as it created a more comfortable atmosphere during the appointment. This participant stated that having a shared language can aid in building rapport as it is easier to communicate with one another:

> *"As long as the rapport is still professional and the interpreter's interpreting correctly, I think that's probably fine if they're comfortable with the interpreter that's probably better for everybody… I think sometimes when you speak the same language as someone it is a little bit easier to build that rapport it just comes more naturally."*
>
> Participant #1, genetic counsellor

Support person

A few genetic counsellors and one patient spoke about how the medical interpreter served as a support person during the session. The patient stated that the empathy shown by the medical interpreter helped build their relationship during the session. The genetic counsellors felt that this was important for the session, as it helped build rapport between the patient and the medical interpreter.

> *"Yes, he was doing a good job, and because he understands the situation, they show me like an emotion [sic], like emotions and understanding how he is sensitive about my situation."*
>
> - Participant #3, patient

> *"This woman* [the interpreter] *served as a support person, because they talk [sic] while they were in the waiting room together. And you know they would, you know, talk when they left, and I think there was a hug. Like it wasn't like she was a close friend, like she wasn't a community friend or family friend."*

- Participant #2, genetic counsellor

> *"I think the patient felt really supported and comfortable with the interpreter and I really appreciated that. It added a lot to the appointment."*
>
> - Participant #8, genetic counsellor

<u>Trusting the interpretation</u>

One of the patient participants spoke English at a conversational level and she stated that she was able to understand what the medical interpreter was interpreting to the genetic counsellor. This participant discussed how the medical interpreter interpreted everything she said word-for-word, even when the patient felt like she was not making sense. This patient also noted how the interpreter used specific words that she had said when interpreting her sentences. This helped the patient gain more trust in the interpreter and build a positive relationship:

> *"The translation word-by-word I think helped. So, I trust her to, just trust like what I was saying, not something else or minimize my experience or the thing that I was trying to say. [sic]"*
>
> - Participant #5, patient

4.5 Theme 3: Mode of Appointment

During the interviews, multiple participants discussed their experiences with different modes of appointments. Some participants stated they had some technical difficulties with telephone appointments. Overall, there was a preference for in-person appointments due to the importance of visual cues. The genetic counsellors discussed how visual cues helped them determine whose turn it was to speak and gauge patient understanding, which can be lost during telephone appointments.

4.5.1 Technical Difficulties with Telephone Appointments

Most telephone appointments that occurred were three-way-calls, with the genetic counsellor, medical interpreter, and the patient. Multiple genetic counsellors reported having technical difficulties during telephone appointments including poor reception, and difficulty hearing the medical interpreter:

> *"I mean the biggest [sic] I find lately with working with interpreters over the phone is sometimes just the level of clarity of the connection right. So, if you have a grainy connection or a lot of feedback, it can really, really impact your ability to understand everybody. It just really puts a whole damper on the whole conversation right because it just adds that one more layer of complexity."*
>
> \- Participant #1, genetic counsellor

> *"I'm not a huge fan of telephone sessions with the interpreters. Also, because I think the connection is always very bad, but I don't really know what can be improved on that. Like if you need that, that's what you need, and if that's the only thing available, that's just what's available, it's better than nothing."*
>
> \- Participant #10, genetic counsellor

> *"I guess he was hard to understand because he muffled a lot – I don't know if it was an audio issue, or just the way he was speaking but I had to ask him to repeat himself several times."*
>
> \- Participant #6, genetic counsellor

4.5.2 Preference for In-Person Appointments

In contrast to telephone appointments, genetic counsellors and patients had a strong preference for in-person appointments. Both participant groups pointed to how in-person appointments feel more comfortable as you can see the person you are speaking with. Generally, both participant groups stated that it was important to be able to see and interact through non-verbal cues during the appointment.

> *"I like to see people's faces. I'm terrible over the phone … Like looking at the person's face [helps] me to understand what she meant, you know? Over the phone you don't have this contact, so I'm terrible at conversations over the phone."*
>
> - Participant #5, patient

One genetic counsellor also mentioned that the nature of in-person appointments made it easier to work with medical interpreters and discuss expectations of the appointment with them:

> *"I find personally because when you're in person you have a chance to have a short meet and greet with the interpreter, talk to them about expectations… and on the phone, it doesn't always happen. Sometimes the patient is already on the line, or you have a poor connection or, it took you so long to get them on the phone… you don't have the same amount of chance to go through some of that necessarily."*
>
> - Participant #1, genetic counsellor

One patient participant had a previous genetics appointment with an in-person medical interpreter. Despite stating that she had a positive experience with telephone interpretation, she preferred in-person medical interpretation.

> *"In person, it's always better… you can fully understand, you're getting everything. So, it is much better in person. You can get the whole thing it is much better… Generally speaking, over the phone, appointments over the phone might be confusing. Generally speaking, sometimes you may not be understand what is said. [sic]"*
>
> - Participant #3, patient

Genetic counsellors reflected on how they relied on visual cues when gauging whose turn it was to speak. Additionally, two genetic counsellors explained how losing these visual cues during telephone appointments affected knowing when to continue versus when to wait for interpretation:

> *"I think it's more clear in-person than it is on the phone when the interpreter should step in because I think there's more of a natural pause."*
>
> - Participant #2, genetic counsellor

> *"When you're all on the phone, it's not totally clear because you missed those cues. And so, then I think that also leads to some of the confusion with who needs to speak when and what we're actually waiting for and whether everything is clear."*
>
> - Participant #1, genetic counsellor

Additionally, a few genetic counsellors stated that they relied on visual cues to gauge patient understanding. Interestingly, two genetic counsellors described a specific actions or facial expressions as indicators that the patient understood what was being said:

> *"I think I can gauge better if someone's understanding by if they are nodding, their body language, their facial expressions "yes this is making sense" and*

> *they are nodding along. If they are on the phone, I think it is a lot harder to gauge."*
>
> Participant #8, genetic counsellor

> *"How I gauge most patient's understanding is kind of those nonverbal cues, like the looks on their faces, if there's confusion, if there's kind of like, "okay, yeah, I get this" look."*
>
> Participant #10, genetic counsellor

4.6 Theme 4: Flow of a Genetic Counselling Session

Genetic counsellors discussed how the "typical" flow of an appointment is impacted by side conversations that occur between the medical interpreter and the patient. Additionally, genetic counsellors communicated how the time it takes to interpret a statement can affect the flow of the appointment. Interpretation time also affected the genetic counsellor's trust of the interpretation given and their ability to provide psychosocial counselling.

4.6.1 Impact of Side Conversations

During appointments, side conversations are between the medical interpreter and the patient in the patient's preferred language, without the inclusion of the genetic counsellor. The genetic counsellors explained that when side conversations occur, the flow of the appointment can be disrupted. Given that the side conversations weren't spoken in English, oftentimes, the genetic counsellors are not privy to these conversations. However, some genetic counsellors stated that they have, and will, ask the medical interpreter to clarify what was said. The participants explained that when side conversations occur and are not explained, it can leave the genetic counsellor feeling uneasy about what was being said:

> *"If it goes on for a minute or two and there's equal talking back and forth between the interpreter and the patient, that's when I start to get nervous almost, I don't understand what's going on. But I don't want to miss anything, and I want to make sure the patient fully understands what the discussion is."*
>
> \- Participant #4, genetic counsellor

> *"Little side conversations that will happen between the interpreter and the families as they're trying to clarify things and… sometimes I think it's something that the interpreter can clarify and doesn't necessarily maybe need to be interpreted back, but then you're always left about little bit of uncertainty about what's being said. So it can be, you know, a little bit frustrating that way at times too."*
>
> \- Participant #1, genetic counsellor

> *"When you do try to have those side explanations or side conversations, there is the risk that if the interpreter misunderstood you, then they sort of interpret that differently or incorrectly back to the patient right. So, I think you try to sort of stick to not doing that."*
>
> \- Participant #9, genetic counsellor

4.6.2 Delay in Interpretation

Genetic counsellors mentioned how the amount of time that it takes to communicate back and forth with the patient impacted the flow of the session. Some participants spoke about how the flow of the appointment is disrupted because the genetic counsellor must speak in short sentences as to not overwhelm the medical interpreter:

> *"It's always a fragmented conversation, because I try to speak in very short chunks and so that, in itself, takes away from some of the counselling aspects."*
>
> - Participant #6, genetic counsellor

Genetic counsellors also used the time between interpretations to determine interpretation accuracy; the length of a statement should be similar to the length of the interpretation. One genetic counsellor described an experience where she felt she could not trust the interpretation because of the amount of time it took to interpret:

> *"I would [say] something that was a complex sentence or two, and I felt like he would say like one or two words to the patient's mother. There's no way that [sic] interpreted properly, like there's no way that I have two sentences, and they're saying essentially two words."*
>
> - Participant #10, genetic counsellor

Finally, one genetic counsellor spoke about how psychosocial counselling feels less natural because of the time between interpretation.

> *"It just feels a little bit less natural when your patient has said something that's maybe very personal for them and now the interpreter has said it to you, and then by the time you say [something], and then the interpreter says it back. This may just be my own personal feeling, but you feel like it loses some of that sincerity by the time it's gone through a third party, so it can be a little bit tricky that way with regards to psychosocial."*
>
> - Participant #1, genetic counsellor

4.6.4 Logistical Constraints

We asked participants about logistical constraints, such as the length of time of the appointments. Most participants relayed that appointments involving interpretation typically take longer compared to appointments with English-speaking patients due to the time needed to interpret. Genetic counsellors were aware of these time constraints during the appointment and had developed strategies to accommodate these constraints. Most genetic counsellors and all patients felt that enough time was allocated for each appointment.

> *"Definitely appointments with interpreters always take longer. I find, because you have the conversation going through a third party, so everything that said [sic] gets said twice. It definitely takes longer, I think as a general rule, we* [the WRHA genetics clinic] *do a good job of accommodating for the extra time needed."*
>
> \- Participant #1, genetic counsellor

> *"For strategies, keeping my phrases short so that they're manageable for both the interpreter but also for the patient. And then just trying to keep really to the point and the most salient points that I want to get across. So rather than lots of background information, which I would avoid for other patients as well – I try to just keep it very clear with what the statements are and what I think are the most important things I want them to understand."*
>
> \- Participant #6, genetic counsellor

4.7 Theme 5: Lived Experience of the Patient

The final theme explores the experiences that each patient brings with them into a genetic counselling appointment. Each patient has prior lived experiences; internal or external factors that influence the session. In a sense, this is what the patient "brings to the table" even before the appointment has begun. In this theme, we explore subthemes of English mastery and prior knowledge or experience with genetics. Although this theme is specific to the patient's lived experience, all study participants discussed how these experiences affected rapport building and the flow of the session.

4.7.1 English Mastery

The level of English proficiency can range widely in patients who have LEP, ranging from little to no verbal English to conversational level English. Patients can request a medical interpreter at their medical appointments. However, in some cases an interpreter is arranged by a healthcare professional. All three patient participants reported that their referring health care provider stated that an interpreter was needed on their referral. Two of the participants stated that they had lower English proficiency and were glad an interpreter was present during their appointments to help them understand what was being said:

> *"It was really helpful. It's always great to have an interpreter. And I know I'm much better than when I first arrived to Canada, like completely unable to understand anything. And now I can understand a little bit, but I still, I can't understand what the [health care provider] would be saying and it can also be great to have an interpreter. [sic]"*
>
> - Participant #3, patient

However, the third patient, who had a higher level of English proficiency, did not request an interpreter to be present for her interview and was not aware that one had been arranged for her by her referring healthcare provider. She stated that she had never required a medical interpreter before, and she had been a longstanding patient with her referring healthcare provider. The patient explained that she was ultimately glad that the interpreter was present at her genetic counselling appointment. However, the healthcare provider's request for an interpreter made her doubt her English proficiency and she described wanting to be involved in the process of requesting an interpreter:

> *“I felt like my English was just garbage. I mean for the nurse had to do this without asking me, I thought oh, my English is garbage; maybe I do need interpreter … I think she should just ask me “Are you OK with interpreter?” … but the way that she did, I don’t agree very much. [sic]”*
>
> - Participant #5, patient

Genetic counsellors also reflected on their experiences with patients with LEP who had some level of English mastery. These patients intermittently responded in English during these sessions. Two genetic counsellors described previous experiences where their patients were able to speak conversational English but still had an interpreter present. In both scenarios, the genetic counsellor stated that it was helpful having the interpreter present when they began explaining medical and genetic concepts:

> *“There were some points where the patients would respond to me in English when I would explain things. But it’s nice to have an interpreter, so if I explain things more complicated, or if there’s terms that the patient doesn’t understand, then there’s sort of a, for sure, it’s been translated into their first language, so there should be less opportunity for there to be sort of a missing link.”*
>
> - Participant #4, genetic counsellor

4.7.2 Prior Knowledge or Experience with Genetics

Genetic counsellors may see members of the same family for the same indication. Often these individuals are knowledgeable about the genetic condition because it “runs in the family”. One patient participant had previously seen a genetics professional in another country prior to her appointment in Winnipeg. She explained that there is a familial genetic condition and sought genetic testing for her children in the past. The appointment that occurred in Winnipeg was arranged to obtain genetic testing for another child. When asked about her recent genetic counselling, she stated that she already had a good understanding of the condition as it had been explained to her previously in her primary language.

> *"I already have experience with the subject or situation. This is not the first [child]. I have two previous [children] with the same situation, same condition. So, I can understand what's going on. I know what she's talking about, I can understand everything based on my past experience. It is something in the family, so I understand what she is talking about. So yes, because I do have experience with the same experience, the same situation. [sic]"*
>
> - Participant #3, patient

Conversely, the other two patients have not had experiences with genetics professionals and did not have as much prior knowledge about their indications. One patient had never heard of the condition she was being seen for. She described how the genetic counsellor spent a lot of time explaining the condition to her:

> *"No, this is the first time [hearing of the condition] … she explained to me everything. She was trying hard to let me know and understand everything. [sic]"*
>
> - Participant #7, patient

The final patient had a personal experience with the condition as a family member was previously affected and had passed away. She described how she attended the appointment with prior knowledge of the condition and how this information played a role in her expectations of the appointment. However, during the appointment she learned that genetic conditions are not as straight-forward as she initially expected:

> *"I was just thinking OK, I'm going to this appointment, and I will get tested and I will know if I will die … or not. But it's not like that. It's not that simple. Yeah. And then [the genetic counsellor] explained the percentages actually and not everybody that has a gene has a disease. And sometimes has the disease and don't have the gene. So, it's not that simple. [sic]"*
>
> \- Participant #5, patient

4.8 Suggestions and Recommendations

Participants were asked about suggestions and recommendations when working with medical interpreters and patients with LEP. Genetic counsellors described techniques that they have found helpful when working with interpreters, such as speaking slower and saying 1-2 sentences at a time:

> *"I do try to speak slowly, and I'm cognizant about that. I also try to speak in like a sentence the time. I think that's probably the biggest modification that I make, and it's also just trying to be more clear and enunciate."*
>
> \- Participant 10, genetic counsellor

One participant explained how she tries to avoid analogies that she typically uses with English speaking patients because the meaning may be lost when interpreted:

> *"I try to avoid analogies as best I can, because they often do not translate. So, some of the really good … analogies to explain it in English, it doesn't necessarily translate to another language."*
>
> \- Participant 2, genetic counsellor

When asked about suggestions to optimize care for patients, two genetic counsellors stated that language-specific resources can be helpful to send to patients after the appointment:

> *"I do think it would be helpful to have some more resources in other languages too. Most of the things that I am familiar with are just in English."*
>
> - Participant #8, genetic counsellor

> *"Where possible, if we could locate language specific resources."*
>
> - Participant #2, genetic counsellor

Finally, some genetic counsellors described receiving training on working with medical interpreters. Two genetic counsellors stated that they did not know a lot about the profession and wanted to learn more about the training and perspectives of medical interpreters:

> *"Yeah, I think it's helpful to know what training they have. Maybe that can lead to some understanding. I guess it would help with my understanding of like "what is your training?"."*
>
> - Participant #10, genetic counsellor
>
> -

> *"Honestly, I don't know a lot about the profession. So, it would be kind of nice for me to know… just like what their day to day looks like. Yeah, I really don't know anything, so it's kind of hard to get a sense of what things are like from their end."*
>
> - Participant #8, genetic counsellor

CHAPTER 5: DISCUSSION

5.1 Overview of the Study

The main goal of this study was to understand the experiences of genetic counsellors and patients with LEP who attended genetic counselling sessions requiring interpretation services. Previous research into the topic of medical interpretation in the genetic counselling field has not yet included the patients' perspectives, which is crucial to furthering our understanding of these experiences. To achieve this goal, our study had three aims. The first aim was to explore the perspective of the participants on the different aspects of a genetic counselling session. By exploring these perspectives, our study gained insight into how both participant groups view the role of the medical interpreter and the genetic counsellor. The second aim was to evaluate the perspectives of both participant groups between each other. Identifying similarities and differences between the genetic counsellors and patients' perspectives builds a better understanding of what factors contributed to the successes and difficulties during their respective appointments. Finally, our last aim was to obtain recommendations and suggestions to ensure patients with LEP receive optimal care.

5.2 Expectations of a Genetic Counselling Appointment with a Medical Interpreter

Participants in this study described the expectations they had of medical interpreters during the genetic counselling appointment. Both participant groups generally preferred verbatim interpretations. A few genetic counsellors stated that it was also acceptable if the interpretation captured the essence of what was said. This preference for verbatim interpretations aligns with the expectations of the National Standard Guide for Community Interpreting Services (Health Interpretation Network, 2007). Previous studies have also described the genetic counsellor's preference for verbatim interpretation (Hurtado-de-Mendoza et al., 2018; Schmitz et al., 2018). Two of the three patients stated that they preferred verbatim interpretations, while the third patient felt strongly about the medical interpreter being a cultural advocate during the appointment. Due to the small sample size of the patient participant group and the discrepancy between preference, we cannot make conclusions about patient preferences for interpretation style. However, the National Standard Guide for Community Interpreting Services deems it appropriate for an interpreter to convey cultural nuances if they do not take the role of a cultural broker (Health Interpretation Network, 2007). In this way, it may be possible to provide verbatim interpretations while still being a support person and cultural advocate for patients. This may involve the medical interpreter asking for clarifications based on cultural or linguistic factors; in this way, they are still providing verbatim interpretations but also providing cultural context.

Our results show that genetic counsellors held expectations of themselves; they felt that it is their responsibility to address all aspects of the appointment, including addressing miscommunications and misunderstandings, explaining genetic specific terminology, and being culturally competent. The expectation for medical interpreters to provide verbatim interpretations may be connected to the genetic counsellor's expectation of themselves and the appointment. As the main healthcare provider, genetic counsellors work with patients to set the appointment agenda and goals to achieve during the appointment. In this sense, genetic counsellors typically have a certain degree of control over an appointment – there are certain goals and aspects that they wish to achieve which is tailored to the patient's needs (Uhlmann et al., 2010). There may be less control when working with patients with LEP because a medical interpreter is required to communicate.

When verbatim interpretation is provided, it allows the genetic counsellor to identify if a miscommunication or misunderstanding has occurred. This may be why genetic counsellors appreciated when medical interpreters asked for clarifications; it allowed potential miscommunications to be caught before they were interpreted to the patient. This was further echoed when genetic counsellors described situations when side conversations occurred and were not explained to them. In these scenarios, it is not clear what was said between the medical interpreter and the patient. Genetic counsellors described feelings of nervousness and frustration when they did not know what was being said. These feelings may stem from not being able to address, or know, if the patient has any concerns, questions, or misunderstandings about the information being given (Wiener & Rivera, 2004). When these side conversations occur, it is possible that some aspects of the genetic counselling session are not being addressed sufficiently, thereby barring the genetic counsellor from fulfilling their expectations of their role and their job.

Our study found that trust was a key component of the relationship built with the interpreter for both the genetic counsellors and the patients. It was previously shown that distrust between genetic counsellors and medical interpreters can exist during appointments (Lara-Otero et al., 2019). This occurs when genetic counsellors feel that the medical interpreter is not meeting their expectations of providing verbatim interpretations. Our study found that genetic counsellors' trust in the medical interpreter is influenced by perceived patient understanding and when clarifications are made. If patients are asking questions that are relevant or responding appropriately to the genetic counsellor, this increases the genetic counsellor's trust that accurate interpretation was provided. Similarly, when medical interpreters ask for clarifications, it shows that they are committed to providing correct interpretations by understanding the statement and avoiding a possible miscommunication (Wiener & Rivera, 2004) although this was not seen as a benefit to all genetic counsellor participants.

Most genetic counsellors desired the relationship between themselves and the medical interpreter to be a partnership. Since there was an expectation that the medical interpreter had a baseline understanding of general medical terminology but did not need to know genetics related terms, genetic counsellors felt that it was their job to explain genetic specific terminology, and work with the medical interpreter in partnership to ensure that the patient understood these terms.

Similarly, the idea of the medical interpreter as a support person for the patient was discussed. Genetic counselling appointments often involve emotionally heavy topics (Uhlmann et al., 2010). When this occurs, the genetic counsellor acts as a support person and attends to the psychosocial needs of the patient. Our results show that the genetic counselling participants appreciate when a medical interpreter also serves as a support person. This goes beyond the role of only providing verbatim interpretation. However, the results of this study also show that genetic counsellors found it acceptable when medical interpreters ask for clarifications and conveyed the meaning of a statement in lieu of a word not existing in the language. Based on these results, there may be leniency in the expectations of the medical interpreter's role toward an interpretation style that is between verbatim interpretation and cultural brokerage. In this way, both the genetic counsellor and the medical interpreter can work in partnership to ensure that the patient not only understands the information being provided, but is comfortable and supported. The idea of working in partnership to achieve the goals of the appointment may help build trust between the genetic counsellor and the medical interpreter (Hsieh et al., 2010).

5.3 Mode of Appointment

We found that the mode of the appointment had an impact on the experiences of both genetic counsellors and patients with LEP. All participants preferred in-person appointments and had difficulties with telephone appointments. Almost all participants in this study had telephone appointments but spoke to previous experiences (both genetic counselling and general medical appointments) when discussing their preference for in-person appointments. The preference for in-person appointments when using medical interpreters aligns with previous research done in this field (Hurtado-de-Mendoza et al., 2018; Schmitz et al., 2018). A common reason for this preference was the ability to see and pick up on visual cues. Most communication is non-verbal and relies on visual cues including body language, tone, and facial expressions (Phutela, 2015). Genetic counsellors pointed to visual cues as a way of identifying when a miscommunication had occurred, as well as identifying who's turn it is to speak. The loss of visual cues during telephone appointments can lead to disruptions in the flow of the appointment, such as cutting one another off, and impacts the relationship with the patient. When you are unable to see someone, these cues cannot be detected or can be easily missed.

Beyond the loss of visual cues, telephone appointments were also difficult due to technical issues. Genetic counsellors described factors such as poor reception and difficulty hearing the patient or medical interpreter. These factors are beyond the control of the parties involved in the session. Although telephone appointments may not be the preferred mode of appointment, one patient participant reported still having an overall positive experience. It is also worth noting that the option of a telephone appointment can help increase accessibility to services (Tutty et al., 2019). As one genetic counsellor stated, sometimes telephone appointments may be the only option available to patients. For some patients, in-person appointments may be difficult to attend due to travelling distance and requiring transportation to get to the clinic. Access to reliable transportation, whether it is public transportation or reliance on friends and family members, can be a barrier for patients with LEP when attending medical appointments (Silver et al., 2012; Yeheskel & Rawal, 2019). Virtual appointments can provide an alternative for those who are unable to easily attend in-person appointments (Christian et al., 2022; Gonzalez et al., 2022). Given the shift to virtual genetic counselling appointments due to the COVID-19 pandemic (Uhlmann et al., 2021), it is possible that virtual appointments will be more common moving forward.

5.4 Lived Experiences Affect the Patient’s Perception of the Appointment

Lived experience refers to the patient’s past experiences which can influence the genetic counselling appointment. This can include factors such as prior experience with and knowledge of genetics, English proficiency, as well as their culture and language. Each patient brings their own unique perspective that has been shaped by these lived experiences to each appointment. One patient participant reported having multiple children affected by the same condition and has attended appointments with other genetics professionals before. As such, she already had background knowledge and understanding of the condition prior to her appointment with a genetic counsellor in our centre. This patient stated that her familiarity with genetics and meeting with genetics professionals before helped her understand what was said during the appointment, as it was all explained to her before. In contrast, one of the patients had never heard of the condition before and the other had a family member that was affected but did not know specifics about the condition. The participants' previous experiences may affect their expectations of the appointment. For example, a patient who has knowledge and experience with a condition may wish to focus the conversation on testing options rather than be given information about the condition. Conversely, a patient who is not familiar with the genetic condition in question may need more time to have their questions answered. This is not limited to patients with LEP.

This lived experience is not unique to patients with LEP; it is true of all patients. As illustrated above, a patient's level of understanding prior to the appointment is important for genetic counsellors to be aware of when assessing a patient's goals for the appointment and setting the appointment agenda (Uhlmann et al., 2010). Prior understanding of genetic concepts or specific conditions can also determine what, if any, genetic terms the patient knows. In our study, knowledge of terminology was mainly discussed in the context of medical interpreters. However, one genetic counsellor described how genetic terminology is uncommon in general conversation. As such, familiarity with genetic terms is not unique to patients with LEP and is important to be aware of for all patients. However, some terms may not have a direct translation in certain languages (Krieger et al., 2018). Being aware of these linguistic differences and having alternate ways of explaining complex genetics terms may be helpful in these scenarios.

Patients with LEP can range widely in their level of English proficiency. This aspect of the patient's lived experience can help determine whether an interpreter is needed, or wanted, during a genetic counselling appointment. The need for a medical interpreter can depend on patient's own perceived level of English proficiency (Schwei et al., 2017). Two of our patient participants had previous experiences with medical interpreters and were aware that one would be present for their appointment. One of the patients spoke to her experiences with gaining English-proficiency since moving to Canada. She explained that her English had improved, but she appreciates when interpreters are present to help her understand medical appointments. The last patient participant had never required interpretation services prior to her genetic counselling appointment and was not aware that an interpreter was requested by her referring healthcare provider. The patient explained that this experience made her question her English proficiency, describing her English as “garbage”. Ultimately, she was glad the interpreter was present to help explain medical and genetic terminology, but the experience negatively impacted her relationship with the referring healthcare provider and her self-image. This patient’s lived experience of being able to communicate at a conversational level in English with others affected her perceived need for an interpreter to be present. From this experience, we see how important it is for the patient to be involved when requesting a medical interpreter to ensure that the service is wanted.

The culture of origin and native language of patients with LEP undeniably affects their worldview. Our results highlight the important bonds that are made when patients and medical interpreters share a common cultural background and language, regardless of worldview. As one genetic counsellor pointed out when discussing the relationship between the patient and interpreter, it is easier to build rapport when you speak the same language as someone. This was echoed by the patient participants as well. One patient explained how she felt more comfortable with her interpreter solely based on the fact she spoke not only the same language, but the same dialect as well. This linguistic, and dialectical, bond can help build connections between individuals in cross-cultural communities (Abdulrahman, 2022; Hadziabdic & Hjelm, 2014). Language is also tied to the culture of an individual. Sharing the same culture can also help create these bonds. The other two patients explained how speaking Arabic connected them to their interpreter culturally. As one patient described, all Arabic people are like family and understand each other.

These cultural bonds help build positive relationships between the patient and interpreter, but also make an argument for cultural competency and humility of the genetic counsellors. Previous studies have found that culturally competent healthcare providers build better rapport with patients who have LEP (Flores, 2000; Mariño et al., 2017). Our results show that genetic counsellors expect themselves to be culturally competent, which aligns with expectations of medical interpreters from previous studies (Krieger et al., 2018). Part of a genetic counsellor's role is to practice cultural competency and humility (Accreditation Council for Genetic Counseling, 2015). This may help genetic counsellors build rapport with patients by providing culturally safe and appropriate care.

5.5 Similarities and Differences between Parties – Evaluating Participant Duos

The second aim of our study was to evaluate similarities and differences in perceptions between genetic counsellors and patients. The results of our study show that there were more similarities than differences between the two parties. In general, both participant groups 1) preferred verbatim interpretations, 2) felt that cultural and linguistic bonds were important for rapport building and 3) had difficulties with telephone appointments.

As mentioned in Section 4.3.1, one patient stated that they preferred that the medical interpreter take on the role of a cultural broker. This expectation went against what the other patient and genetic counsellor participants stated. However, this was the only difference of perception that opposed the majority. Although, given the small patient participant sample size, it is difficult to draw such generalizations. Both views are likely to be represented in a larger sample, and may be influenced by participant specific characteristics such as acculturation and familiarity with western medicine. Generally, most differences identified in this study were neutral; one participant group spoke to a specific experience or perception while the other did not. For example, genetic counsellors discussed expectations of themselves and their role, while patients did not describe their expectations of the genetic counsellor.

Our study contained two duos (a patient and genetic counsellor who attended the same appointment), allowing for the opportunity to corroborate the participant's experience of the genetic counselling session and added rigor to the study. Both duos described aspects of the appointment similarly. In one case, participant #2 (genetic counsellor) and #5 (patient) both spoke highly of the interpreter and described the bond that was formed between the patient and the interpreter. In another, participant #3 (patient) and #4 (genetic counsellor) both described the patient's previous experience with genetics and how the appointment was centred around how to have testing completed rather than information giving.

5.6 Summary of Recommendations

The final aim of our study was to obtain feedback and recommendations from the participant groups to optimize care provided to patients with LEP. Our results show that both participant groups had an overall positive experience with the appointment and working with medical interpreters. Genetic counsellors described strategies they have used when working with interpreters. Additionally, participants provided suggestions and recommendations that can aid working with medical interpreters and patients with LEP. The recommendations are divided into three categories: 1) prior to the appointment, 2) during the appointment, and 3) general recommendations and described in the following sections. A point-form summary of the recommendations is included below. The order of recommendations is chronological – from the time an appointment is booked to after the appointment is completed. However, a strong emphasis is placed on the first recommendation as it is considered the most important when working with patients with LEP.

1. When considering the need for an interpreter for an appointment, involve the patient and ask for their input.
2. If possible, in-person appointments are preferable to telephone appointments. Videoconferencing may be considered as an alternative if there are accessibility issues.
3. When multiple dialects of a language exist, try to request an interpreter with the same dialect as the patient.
4. Dedicate 5-10 minutes before the appointment for a pre-brief with the medical interpreter and health care provider to review expectations and goals of the

appointment. This may be included in the original appointment period or added as additional time.

5. Ask the patient about their level of English proficiency and explain the role of the interpreter to the patient during contracting.
6. Use short sentences, give information in small chunks, and avoid analogies.
7. Whenever possible, locate resources in the patient’s preferred language from trusted sources to send to the patient.
8. Facilitate a workshop for genetic counsellors to learn more about the profession of medical interpretation including role and expectations. This workshop would ideally be hosted by your local interpretation services.

5.6.1 Prior to the Appointment

The results of our study showed that patients want to be involved in the process of requesting an interpreter for an appointment and that linguistic similarities are important for rapport building. Based on these results, we suggest that all healthcare providers, including genetic counsellors, speak with patients about whether they would like an interpreter to be present during an appointment prior to referring them for a service. This is especially important when the patient has not previously used an interpreter. By involving the patient in this decision-making process, we can ensure that we are meeting the needs and preferences of our patients while respecting their autonomy (Schwei et al., 2017). It also allows the opportunity to explain why it may be helpful for one to be present. Even when the patient can speak and understand conversational English, it may be useful to have an interpreter present when complex medical concepts are being discussed. Additionally, we recommend requesting an interpreter that speaks the same dialect as the patient whenever possible. This can help build positive connections between the medical interpreter and the patient that goes beyond the cultural bonds (Hadziabdic & Hjelm, 2014). To illustrate, some languages, such as French, are spoken in different countries and have different dialects. Dialectical differences can make it difficult for individuals from different countries to understand each other, despite speaking the same language (Hadziabdic & Hjelm, 2014). Similarly, dialectical differences can determine what country or region an individual is from. This affects the cultural bonds that are formed between the patient and interpreter and is often preferred by the patient (Hadziabdic & Hjelm, 2014).

The results of our study also highlight the importance of visual cues during appointments. All participants stated that they prefer in-person appointments to telephone appointments for this reason. We recommend that genetic counselling appointments requiring interpretation services are booked as in-person appointments whenever possible. There may be instances where a patient is unable to attend an in-person appointment or prefers virtual appointments. In these scenarios, videoconferencing appointments can serve as an acceptable alternative; the patient can attend the appointment virtually while still being able to see some visual cues (Brown et al., 2021; Uhlmann et al., 2021). There may also be instances where it is not possible to have an interpreter physically present during an in-person appointment, such as availability of the interpreter or the language not being spoken by an in-person interpreter. In these scenarios, it may be acceptable to have the interpreter join the appointment over the phone as patient outcomes are similar across different interpretation modalities (Pathak et al., 2021). This would allow for the genetic counsellor and the patient to still see each other and therefore pick up on visual cues.

Most genetic counsellors stated that they typically have enough time during the appointment when working with patients with LEP and medical interpreters. Although the amount of time appointments were booked for was enough to counsel the patient, genetic counsellors stated that they did not always have the ability to pre-brief with the medical interpreter prior to the patient being connected to the telephone appointment. One genetic counsellor described how in-person appointments can afford the opportunity to speak with the medical interpreter before the patient arrives to discuss goals and expectations. In contrast, the interpreter and patient may be connected to the telephone or videoconferencing appointment right when the appointment time begins. There may be less time spent on pre-briefing with the medical interpreter, and less time for the appointment in general, if there are any difficulties with connecting all the parties to the line. Clinic coordinators may consider booking an interpreter 5-10 minutes in advance of the appointment start time for virtual appointments. This can ensure that the genetic counsellor can pre-brief the interpreter prior to the patient connecting to the appointment.

5.6.2 During the Appointment

Genetic counsellors described different strategies they use when working with medical interpreters. These strategies included using short sentences, providing information in chunks, and avoiding analogies. It is easier for medical interpreters to follow and interpret what is being said when information is provided in short, 1-2 sentence statements. This strategy is often used by genetic counsellors and other healthcare professionals when working with interpreters as a way to not overwhelm the interpreter (Kamara et al., 2018; Lara-Otero et al., 2019; Schmitz et al., 2018). Providing information in this manner can potentially mitigate the risk of a miscommunication occurring as well. As one genetic counsellor mentioned, analogies may lose their intended meaning when interpreted into another language. Analogies are often used during appointments with English-speaking individuals as a way to illustrate a complex concept. However, other strategies for explaining these concepts should be considered when working with patients who have LEP as idioms, analogies, and slang may not be well understood (Skjeggestad et al., 2017).

Additionally, it is helpful for genetic counsellors to ask the patient about their level of English proficiency during contracting. Genetic counsellors described instances when a patient would understand and respond to some statements in English without any interpretation. Similarly, one patient was able to speak conversational English and understood most aspects of the appointment. Although it was helpful for the interpreter to be present during this appointment, it raises the question of whether an interpreter is necessary for the entire appointment when an individual has higher English proficiency. As previously mentioned, this patient began to doubt her English-speaking skills when she discovered an interpreter was requested. It is possible to create a plan of when and how an interpreter is utilized by asking about the patient's level of proficiency and their comfort level with responding in English. This may help empower patients during the appointment.

5.6.3 General Recommendations

One genetic counsellor stated that in a previous appointment, she had located and sent a patient genetic resources in their native language. Another genetic counsellor stated that it would be helpful to have resources available in different languages that can be given to patients. Genetic resources can include infographics, fact sheets, and other forms of media, like YouTube videos, that can help patients better understand their genetic health. Patients can be sent these resources before or after an appointment and can be used as a reference (Uhlmann et al., 2010). Many of these resources are developed by credible sources, such as genetics clinics, and have been translated into different languages. Providing resources to a patient can help increase their experience and knowledge of the topic, especially if it is sent prior to the genetic counselling appointment whenever possible. It may be beneficial to consider creating a working database of translated documents, videos, etc. in different languages that can be sent to patients with LEP. By having access to resources in a patient's native language, we can help ensure that we are providing equitable care to patients as this is often done for English-speaking patients.

Our final recommendation is to develop a workshop or seminar for genetic counsellors to learn more about medical interpreters. Two genetic counsellors stated that they wished to know more about the medical interpretation profession. One genetic counsellor explained that it would be helpful for her to know if they receive any psychosocial training, while the other was curious about their day-to-day schedule. Our study showed that genetic counsellors had general expectations of medical interpreters, such as providing verbatim interpretations and having knowledge of common medical terminology. By meeting with interpretation service coordinators, or the interpreters themselves, genetic counsellors can gain more insight into the role, expectations, and goals of medical interpreters. It can also help identify best practices when working with medical interpreters from their perspective. Overall, development of a workshop or seminar can help to create a stronger partnership between genetic counsellors and medical interpreters.

5.7 Limitations of the Study

5.7.1 Recruitment Strategy

Due to reasons outlined in Section 3.2.1, there were no medical interpreters recruited for this study. Our initial aim was to have medical interpreters, genetic counsellors, and patients with LEP to understand the genetic counselling session from all three perspectives. This would have provided a holistic understanding of the genetic counselling session. Without the perspective of medical interpreters, this study cannot speak to the expectations and experiences of medical interpreters attending genetic counselling appointments. Though WRHA Language Access Interpretive Services teams leads were engaged prior to the study, the third-party interpretation service providers that provided interpretation for most appointments occurring during our recruitment period were not engaged. Unfortunately, by the time this was recognized during the recruitment period, there were time limitations for study completion. As such, the principal investigator was unable to apply for an amendment to the previously received ethics approval to include this group of interpreters. Future recruitment efforts for this participant group should involve engaging with all interpretation services.

Initially, we aimed to recruit trios of genetic counsellors, medical interpreters, and patients. Due to the aforementioned reasons, this aim was modified to recruit duos of genetic counsellors and patient. The purpose of this recruitment strategy was to evaluate any similarities and differences from the patients' and genetic counsellors' perspectives of the shared appointment. In order to reach data saturation for the participant groups, individual participants were recruited, and less emphasis was placed on recruiting duos.

Finally, all recruitment occurred at a single clinic location (Winnipeg, MB). This was an intentional decision and part of our study design. However, the results of this study may be biased by the rules, procedures, and training for working with medical interpreters that are provided by this specific clinic. For this reason, it is not possible to extrapolate these results to other clinics across Canada.

5.7.2 Patient Recruitment

Although contact with possible patient participants was initially successful, only three patients consented to participate in the interview. Five patients who provided a consent to contact form to the principal investigator were not interviewed. Two patients stated that they had already “received treatment” for their indication and were no longer interested in the study when contacted. The principal investigator explained that the study was not a clinical trial but rather an invitation to be interviewed about their experience with genetic counselling. Both patients declined to participate in the study. It is not uncommon for individuals with LEP to decline participation in research. It has been found that patients with LEP have a lower enrolment rate in clinical trial research (Glickman et al., 2011; Hughson et al., 2016). Factors such as mistrust of researchers, complex consenting procedures, and linguistic barriers contribute to the low participation rate in research studies (Glickman et al., 2011).

The remaining three possible patient participants were lost to follow up. Each patient was contacted three times by telephone and a voicemail was left when the call was not answered. Two patients were unable to be contacted and did not follow up with the principal investigator. One patient expressed interest in participating in the individual interview and requested to be sent the consent to participate form. The principal investigator attempted to follow-up with this patient three times after the initial conversation but did not hear back from them.

5.7.3 Interpreters Used During the Interview

An interpreter speaking the patient's preferred language was present at two of the three patient interviews. The interpreter during the interview was not the same interpreter that was present during the genetic counselling appointment. It is possible that the patient did not feel comfortable sharing their honest thoughts and feelings about their experience with medical interpreters in the presence of another interpreter. One reason for this could be avoiding offense to the interpreter; if the patient had a bad experience, they may be more hesitant to share that with another interpreter present. It is also possible that the participants were less likely to be candid in the presence of a stranger (in this case, both the principal investigator and the interpreter) (Achbari, 2016; Ho, 2008).

Trust also plays a role during these interviews. Due to budgetary constraints, audio recordings of interviews with patient participants requiring interpretation did not have the non-English language content translated. As such, the principal investigator was forced to trust that the interpreter was providing verbatim interpretations or capturing the essence of the patient's responses and cannot speak to the accuracy of the interpretation. Additionally, budgetary constraints prevented the principal investigator from completing member checking with patient participants to confirm the credibility of the results.

5.8 Future Directions

Our exploratory study unveiled invaluable insight into the perceptions and experiences of genetic counsellors and patient with LEP. However, there is still more work to be done in this area to gain further understanding. As mentioned in Section 5.7, a major limitation to our study was the lack of medical interpreters. Previous research exploring medical interpreters' experiences of genetic counselling sessions has been completed in the United States. These studies have provided insight to the goals and expectations of the medical interpreters, as well as a unique perspective on the genetic counsellor-patient relationship (Krieger et al., 2018; Rosenbaum et al., 2020). Studies into the perspectives of medical interpreters who have attended genetic counselling sessions in Canada should be considered to obtain a more holistic perspective of these sessions.

Another limitation in our study was the small sample size of the patient participant group. In order to provide true patient-centred care, further research must be done to explore the patient perspective. To our knowledge this is the first study that recruited patients with LEP to explore their experience with genetic counselling in Canada. As shown in our study, patients with LEP are not a monolith. Everyone has their own culture, beliefs, and lived experiences which shape their perspectives. Further studies focusing on recruitment of patients with LEP are needed to better understand their perspectives and expectations of genetic counselling, as well as medical interpretation in general. Additionally, translation of non-English interview content and member checking should strongly be considered when pursuing future research involving patients with LEP to ensure credibility of the results.

From a genetic counselling perspective, our results show that there are some differences when working with patients with LEP compared to English-speaking individuals. However, there were many aspects of the genetic counselling session that remained the same. Currently, it is unknown if these changes between patient groups effects the quality of care that is received. To ensure equitable care, research directly comparing the genetic counsellors’ experience working with patients with LEP vs. English-speaking patients could help distinguish whether there are different outcomes.

Finally, we suggest a Canada-wide study that encompasses multiple modes of appointments. Since our study was completed at one site in Winnipeg, MB, we cannot be certain that other genetic counsellors or patients with LEP in different cities have had similar experiences. Similarly, our study was completed during the COVID-19 pandemic with most appointments occurring over the telephone. As our study showed, there is a preference for in-person appointments when using medical interpreters. Therefore, it is crucial to explore the experiences of genetic counsellors and patients with LEP across different modes of appointment.

CHAPTER 6: CONCLUSION

With the rising immigration rate in Canada, patients with LEP are accessing various areas of healthcare, including genetic counselling. Medical interpreters are often utilized during genetic counselling appointments to ensure that patients with LEP understand their genetic health. This exploratory, qualitative study describes the experiences and perspectives of genetic counsellors and patients with LEP attending a genetic counselling session that requires interpretation. The goal of this study was to understand these experiences from a Canadian context and provide patient perspectives that have not previously been studied.

This study highlights the expectations genetic counsellors and patients have for medical interpreters. Most participants preferred when medical interpreters provided verbatim interpretations and described how this style of interpretation built a positive, trusting relationship with the medical interpreter. Participants also preferred in-person appointments as visual cues were able to be seen and misunderstandings were more easily detected. Cultural and linguistic bonds between the patient and medical interpreter were shown to help build rapport between these parties from the participants' perspective. This study describes how the lived experience of the patient, including their English mastery and prior knowledge of genetics, affects their expectations of the appointment. Genetic counsellors described strategies when working with medical interpreters including using short statements and avoiding analogies. Finally, we provided recommendations and suggestions moving forward based on this study results including involving the patient prior to requesting a medical interpreter, booking an in-person appointment, pre-briefing with the medical interpreter before the appointment, and arranging a workshop for genetic counsellors to learn more about the medical interpretation profession.

The results of this study provide a foundation for future research into this field. Involving medical interpreters and more patients with LEP can ensure that equitable care is provided to patients seeking genetic counselling services.

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APPENDIX A. CONSENT TO CONTACT FORM

UNIVERSITY OF MANITOBA

Rady Faculty of Health Sciences
Max Rady College of Medicine
Biochemistry and Medical Genetics

336 – 745 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0J9
Telephone (204) 789-3593
Fax (204) 789-3900
bmgadmin@umanitoba.ca

RESEARCH PARTICIPANT CONSENT TO CONTACT FORM
Individual Interview

Title of the study: *Exploring the perspectives of genetic counsellors, medical interpreters, and patients with limited English proficiency in genetic counselling sessions.*

Principal Investigator: Narin Sheri, BSc, Genetic Counselling Student, Department of Biochemistry and Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba

Supervisor: Nicole Yang, MS, CGC, Adjunct Professor, Department of Biochemistry and Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba

Advisory Committee: Francis Amara, PhD; Tracey Bone, PhD; Ashleigh Hansen, MSc, CGC; Aman Mann, MS, CGC

You are being asked to participate in a research study involving an individual interview exploring the perspectives of patients, medical interpreters, and genetic counsellors involved in genetic counselling sessions. Please read all of the following information carefully and ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction. Taking part in this research study is completely your choice. You should not feel any pressure to participate. You can decide to stop taking part in this research study at any time for any reason.

PURPOSE OF STUDY

The purpose of this study is to explore your perspective of the genetic counselling appointment that included a genetic counsellor, medical interpreter, and patient with limited English proficiency. We plan to investigate general perceptions of the appointments, any challenges and successes in appointments using medical interpretation, patient decision making and empowerment, etc. We hope that this study will illustrate any differences or similarities between the participant groups, and to uncover ways that providers can improve the experience for an LEP patient.

CONSENT TO BE CONTACTED BY TELEPHONE

By filling out the form below, you are indicating that Narin Sheri, the student researcher, may contact you to discuss the research study described above. Filling out this form does not mean that you have consented to enrol in the study. You can consent to enrol in the study when Narin Sheri contacts you by telephone. Participation in this study is voluntary and participants may withdraw at any time.

If you agree to be contacted by telephone, the student researcher will ask for your verbal consent to document your full name and birthdate when she contacts you for the purposes of verifying your appointment. The research team will only verify your appointment using your name and birthdate after you have given verbal consent by telephone. The Genetics & Metabolism medical records are separate from your general hospital record, but they may include information from any medical visit. We cannot guarantee that the research team will see no other medical information. We guarantee that all your information will be kept confidential to the best of our ability (ie: we cannot guarantee that this information will not be subject to a court ordered subpoena).

Participant Name(s): ____

Preferred method of contact: Telephone Videoconference (requires email)

Primary contact phone number: ____

Email Address: ____

What are the best date and time to contact you?

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Morning (8 am – 10 am)	Late morning (10 am – 12 pm)	Afternoon (12 pm – 2 pm)	Late afternoon (2 pm – 4 pm)	Evening (4 pm – 7 pm)

Please select a date/time that you would be available to complete a consent form and interview (90 minutes maximum)

If you are a patient participant, would you prefer to have an interpreter present when you are contacted?

Yes No

What is your preferred language?

I, the undersigned, have fully explained the relevant details of this research study to the potential participant named above and believe that the potential participant has understood and has knowingly given their verbal consent

Printed Name: ____Date ____________________
(day/month/year)

Signature: _____________________________ Role in the study: _________________________

APPENDIX B. CONSENT TO PARTICIPATE IN RESEARCH FORM

UNIVERSITY OF MANITOBA

Rady Faculty of Health Sciences
Max Rady College of Medicine
Biochemistry and Medical Genetics

336 – 745 Bannatyne Avenue
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Telephone (204) 789-3593
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RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
Individual Interview

Title of the study: *Exploring the perspectives of genetic counsellors, medical interpreters, and patients with limited English proficiency in genetic counselling sessions.*

Principal Investigator: Narin Sheri, BSc, Genetic Counselling Student, Department of Biochemistry and Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba

Supervisor: Nicole Yang, MS, CGC, Adjunct Professor, Department of Biochemistry and Medical Genetics, Rady Faculty of Health Sciences, University of Manitoba

Advisory Committee: Francis Amara, PhD; Tracey Bone, PhD; Ashleigh Hansen, MSc, CGC; Aman Mann, MS, CGC

You are being asked to participate in a research study involving an individual interview exploring the perspectives of patients, medical interpreters, and genetic counsellors involved in genetic counselling sessions. Please read all of the following information carefully and ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form. You should keep your copy for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

PURPOSE OF STUDY

The purpose of this study is to explore your perspective of the genetic counselling appointment that included a genetic counsellor, medical interpreter, and patient with limited English proficiency. We plan to investigate general perceptions of the appointments, any challenges and successes in appointments using medical interpretation, patient decision making and

empowerment, etc. We hope that this study will illustrate any differences or similarities between the participant groups, and to uncover ways that providers can improve the experience for an LEP patient. PARTICIPANT SELECTION
You are being invited to participate in this study because you were recently involved in a genetic counselling session that required interpretation services. You are eligible to participate in this study if you meet the following criteria for your participant group:

> **Genetic Counsellor: You are a board certified, or board eligible, genetic counsellor at the Program of Genetics & Metabolism at Health Sciences Centre (Winnipeg, MB), and only you counselled the patient with the use of a medical interpreter during the appointment. You may not participate if you are involved as an advisor or committee member for the project.**
>
> Patient: You are at least 18 years old, identify as having limited English proficiency, you or your child were referred to and attended a genetic counselling appointment at the Program of Genetics & Metabolism, your appointment involved the use of a medical interpreter, and the appointment was with a genetic counsellor. You may not participate if you accompanied someone that you are not the parent or guardian of to their genetic counselling appointment
>
> Medical Interpreter: You are at least 18 years of age, you are a WRHA Language Access Services interpreter, you are a certified medical interpreter (includes WRHA training), you attended and interpreted the genetic counselling appointment of interest, and you are bilingual in the mother-tongue of the patient. You may not participate if you have a personal relationship to the patient.

Taking part in this research study is completely your choice. You should not feel any pressure to participate. You can decide to stop taking part in this research study at any time for any reason.

PROCEDURES TO BE FOLLOWED
You will be asked to participate in a 60–90-minute audiotaped phone or video conference interview. During this interview, you will be asked questions regarding your experience of the genetic counselling appointment you attended. We plan to ask questions regarding your general perceptions of the appointment, any challenges and successes in appointments using medical interpretation, patient decision making and empowerment, etc. The interview will be audio recorded and the student researcher may take notes during the interview. The recording will be transcribed by the student researcher and/or research team for further analysis.

RISKS
Participation in this study presents no more than minimal risk. However, it is possible that taking part in the interview could cause distressing thoughts and feelings. You do not have to answer any questions that makes you feel uncomfortable or that you find too upsetting. Should you need any additional help or support, we will refer you to Klinic Crisis Line or help you find other counselling help.

SAFETY

Your confidentiality may be broken if you describe one of the following:

- You say something about harming yourself or others.
- You tell me about the abuse or neglect of a child.
- You report inappropriate or incompetent practice of a healthcare professional.

BENEFITS

There will be no direct benefit to you for your participation in the study. We hope that information obtained from this study will help us gain a better understanding experiences of a genetic counselling appointment that utilized interpretive services and help improve genetic counselling services for patients with limited English proficiency in the future.

ALTERNATIVES

An alternative is to not participate in this research study.

PRIVACY AND CONFIDENTIALITY

All records containing identifying information, such as names, email addresses, telephone numbers, and home or work addresses will be kept strictly confidential during the study. All study related documents and materials (including interview transcripts and audiotapes) will be kept in a secure location accessible only to the Principal Investigator and supervisor, and any databases containing identifiers will be password protected using a password known only to the Principal Investigator and supervisor and stored on a secure hard drive. Transcripts, interview notes, and audiotapes will be labeled with a coded ID number, which will be assigned to you upon enrollment into the study. The audiotapes and typed notes will be kept for 7 years after the study ends as per the Masters in Genetic Counselling Program standards for thesis projects. Only the research staff and the Genetic Counselling Program will have access to these files. Additionally, HREB may require access to these files for quality assurance purposes (contact information for HREB below under "Whom to Contact". The collection and access to personal information will comply with provincial and federal privacy legislations.

We may wish to quote your words directly in reports and publications resulting from this. With regard to being quoted, please check either yes or no for each of the following statements:

Researchers may publish documents that contain my quotations under the conditions below:	
☐ Yes ☐ No	I agree to be quoted directly if my name is not published (anonymously). You will never be referred to by your real name or any other identifying information in any written or oral reports based on the interview.
☐ Yes ☐ No	I agree to be quoted directly if a made-up name (pseudonym) is used. If you are quoted or referred to in any written or oral reports of the study, you will be given an alternate name.

COMPENSATION

You will receive a $10 gift card to a big box store (such as Walmart, Superstore, etc.) for participation in the research study as a gesture of appreciation for your time.

COST
There will be no cost to you to participate in the study, other than the time it takes to conduct this interview.

VOLUNTARY PARTICIPATION AND WITHDRAWAL
Your decision to participate in this study is voluntary. You may refuse to participate or withdraw from the study at any time, within three months following the interview, by contacting the student researcher, Narin Sheri. If you withdraw from the study, all data you provided will be destroyed. Your decision not to participate or to withdraw from the study will not affect your medical care.

WHOM TO CONTACT
If you encounter any problems related to study participation or have questions about the study, you may contact the student researcher:

Narin Sheri
Email: [redacted]
Telephone: [redacted]

You may also contact the supervisor for this project:

Nicole Yang, MS, CGC
Email: [redacted]
Telephone: [redacted]

If you have questions about your rights as a research study subject, contact the University of Manitoba Research Ethics Board at [redacted]

<u>PARTICIPANT'S STATEMENT</u>

1. I have read this consent form and have discussed with Narin Sheri (student researcher) the procedures described above.
2. I have been given the opportunity to ask questions, which have been answered to my satisfaction.
3. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that my participation is voluntary.
6. I understand that I may refuse to participate in this study.
7. I understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so.
8. I am providing verbal consent to the researcher to sign on my behalf.

If I have any questions concerning my rights as a research subject in this study, I may contact the University of Manitoba Research Ethics Board at (204) 789-3389.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above.

I understand that as a participant in this study my identity and data relating to this research study will be kept confidential.

Participant printed name: __________________________ Date ___________________
(day/month/year)

Participant phone number: _____________________________

Participant signature: ____

APPENDIX C. SEMI-STRUCTURED INTERVIEW GUIDE FOR PATIENTS

INTERVIEW GUIDE FOR PATIENT

Hello, May I speak with (name of participant)? This is Narin Sheri from the University of Manitoba. I have an (language used) interpreter on the line with me, they will be helping with the translation.

wait for interpreter to translate between every 2-3 sentences

I am doing research exploring on "Exploring the perspective of genetic counsellor, medical interpreters, and patients with limited English proficiency. You had previously signed the "consent to contact" form and indicated to be contacted at this time. Is now still an okay time for you to do the interview?

I need to review the consent form with you before beginning. If you need any clarification, please do let me know.

(Some patients may opt to have the consent form emailed/mailed to them, but it will be in English; if they opted to have it sent to them, we will ask that they have it in front of them as we go through it with the interpreter.)

[Student researcher will read through "consent to participate in research form" with the interpreter translating every 2-3 sentences.]

If the patient requires more time to consider participating in the individual interview and to sign the consent form, they can take as much time as they need. We will offer to send the consent to participate in research form to the participant if they wish to review it on their own, however we will explain that the form will be in English, and a translated document cannot be provided.

[Student researcher will begin interview after receiving verbal consent from the patient participant.]

Thank you again for agreeing to participate in this interview. As I mentioned, we will be exploring your experiences of the genetic counselling appointment. There will be some questions will be related to your experience with the genetic counsellors and some questions will be about the interpretive services. If at any point you do not feel comfortable answering any of the questions, please let me know.

1. General impressions
   What were your general impressions of the genetic counselling appointment?
   Clarification questions

- Was it generally positive or negative?

Follow-up questions
- What made it a ____(descriptor) experience?
- Can you tell me why it went _____(descriptor)?
- Was there anything in particular that made you feel ____ (descriptor)?
- What were your general impressions of the GC? The interpreter?

2. Success/Positives

What were some of the successes/positive outcomes of the appointment?

Follow-up questions
- What was successful/positive?
- Did you feel that you got along well (built rapport) with the genetic counsellor? With the interpreter?

3. Challenges/Difficulties

What were some of the challenges/difficulties of the appointment?

Follow-up questions
- Were there moments in the session that were difficult to understand the genetic counsellor? The interpreter?
- Were there moments were you felt that you were not being understood by the genetic counsellor? The interpreter?
- *define cultural bump* Did you feel that there were any cultural bumps within the appointment?
  - Were these addressed?
  - How did you recognize it was occurring? Do you think the genetic counsellor or interpreter recognize it as well?

4. Informed Decision Making

Do you feel that you had enough information to make an informed decision about your genetic test?

Clarification questions
- Did you understand the: possible results, risks, benefits, utility, implications, and limitations of the test?

Follow-up questions
- Was there anything that did not make sense?
  - Was there anything you wish was explained more?

Do you know what the results could potentially mean for you and your family?

Follow-up question
- Would you feel comfortable explaining what you were told to your family?

5. Empowerment

Do you feel that you have enough information about the genetic condition in your family?

Do you feel that you are able to cope with the diagnosis/test results?
Follow-up question
- Did you feel that your feelings were tended to?
- Were you able to open up about how you were feeling with the genetic counsellor and interpreter?

Do you feel like you have control in this situation?
Follow-up question
- Did you feel that you were able to make the decision by yourself? I.e.: with no pressure from others

6. Experience with Medical Interpretation
Were there any concerns about the presence of a medical interpreter, or the medical interpretation?

Follow-up questions
- Did you know the interpreter? Had prior experiences with the interpreter or medical interpretation?
- Were there concerns about the interpreter being part of the same community? E.g. privacy, small community?
- Was it helpful having a medical interpreter present?

7. Perception of the Medical Interpreters Role
What are your perceptions of the role of medical interpretation within the genetic counselling appointment?

8. Time Constraints
Was there adequate time to address all of your questions/concerns?

Did the appointment feel rushed?

Did you feel that you had an opportunity to express your feelings?

9. Suggestions
Do you have any overall suggestions that the GC or interpreter could have done to improve your experience?

Is there anything you feel that the genetics department or medical interpretation services needs to understand about providing care to patients with LEP?

[Interview concludes]

Thank you for participating in this interview. We will email you a $10 virtual gift card to you as an appreciation of your time and willingness to participate in our study. Is the email you gave me earlier still the preferred email?

If you have any additional questions about this research study or how the information you provided will be used, please feel free to contact me by phone or email. I will send a copy of the consent form by mail to your address, and I can provide it via email as well, if you would like.

[Confirm email address]

The consent form has my contact number, as well as the contact information for my supervisor and the Research Ethics Board. Thank you again for your time.

NB: Follow-up questions will be asked as necessary/relevant to the participant's response. Not all of the follow-up questions will be asked.

Examples of wrap-up

- I want to be mindful of the time, and I do have a few more questions to ask.
- Thank you for your detailed answer – I do have to move on to the next question, but if there is time maybe we can come back to this question.
- Thank you for sharing that – I do want to get your perspective on a few more questions, is there one final point you would like to add before we move on?
- Those are all of the questions I have; do you have any questions for me about the interview or the study?
- Thank you for participating in this interview – I have no more questions.

Examples of affirmations

- Thank you for sharing that with me.
- It sounds like you were feeling ____, does that sound right?
- That sounds like it was a(n) ______ experience for you.

Examples of prompts/probes

- Why do you say that?
- Can you explain what you mean by _______?
- Can you give me an example?
- You mentioned ____, can you tell me more about that?
- What did that mean to you?
- How did that make you feel?/How do you feel about that?
- What do you mean by ____?

APPENDIX D. SEMI-STRUCTURED INTERVIEW GUIDE FOR GENETIC COUNSELLORS

INTERVIEW GUIDE FOR GENETIC COUNSELLOR

Hello, May I speak with (name of participant)? This is Narin Sheri from the University of Manitoba. I am doing research exploring on "Exploring the perspective of genetic counsellor, medical interpreters, and patients with limited English proficiency. You had previously signed the "consent to contact" form and indicated to be contacted at this time. Is now still an okay time for you to do the interview?

I need to review the consent form with you before beginning. If you need any clarification, please do let me know.

(Some genetic counsellors may opt to have the consent form emailed to them; some may have previously signed off on the consent form and sent it to the student researcher. If they opted to have it sent to them and did not fill out the consent form, we will ask that they have it in front of them as we go through it)

[Student will read the "consent to participate in research form" as necessary]

If the genetic counsellor requires more time to consider participating in the individual interview and to sign the consent form, they can take as much time as they need. We will offer to send the consent to participate in research form to the participant if they wish to review it on their own.

[Student researcher will begin interview after receiving verbal consent from the genetic counsellor participant.]

Thank you again for agreeing to participate in this interview. As I mentioned, we will be exploring your experiences of the genetic counselling appointment. There will be some questions will be related to your experience with the genetic counsellors and some questions will be about the interpretive services. If at any point you do not feel comfortable answering any of the questions, please let me know.

10. General impressions
    What were your general impressions of the genetic counselling appointment?
    Clarification questions
    - Would you describe it as a good experience or a bad experience?
    - Was it generally positive or negative?

    Follow-up questions
    - What made it a ____(descriptor) experience?
    - Can you tell me why it went _____(descriptor)?
    - Was there anything in particular that made you feel ____ (descriptor)?
    - What were your general impressions of the patient? The interpreter?

11. Success/Positives

    What were some of the successes/positive outcomes of the appointment?

    Follow-up questions

    - What was successful/positive?
    - Did you feel that you got along well (built rapport) with the patient? With the interpreter?

12. Challenges/Difficulties

    What were some of the challenges/difficulties of the appointment?

    Follow-up questions

    - Were there moments in the session that were difficult to understand the patient? The interpreter?
    - Were there moments where you felt that you were not being understood by the patient? The interpreter?
    - *define cultural bump* Did you feel that there were any cultural bumps within the appointment?
        - Were these addressed?
        - How did you recognize it was occurring? Do you think the patient or interpreter recognize it as well?
    - How might you recognize and/or address the cultural bump in the future?
        - Who do you feel is responsible for recognizing/addressing the cultural bump and correcting the misunderstanding?

13. Informed Decision Making

    Do you feel that the patient made an informed decision about the genetic test?

    Clarification questions

    - Did you feel that they understood the: possible results, risks, benefits, utility, implications, and limitations of the test?

    Follow-up questions

    - How were you able to gauge this understanding?
        - Verbal cues? Non-verbal cues?

14. Empowerment

    Do you think the patient felt empowered?

    Empowerment: "the ability to affect control and positive life changes within a personal context"

    How do you measure empowerment during your appointments?

    Follow-up question

    - Did you feel that this was the case during the appointment?

    Do you think the patient understood enough of the appointment to make a decision about their genetic health?

    Follow-up question

- Did you feel that they were able to make the decision by themself? I.e.: with no pressure from others

15. Experience with Medical Interpretation

    Were there any concerns about the presence of a medical interpreter, or the medical interpretation?

    Follow-up questions
    - Did you have any prior experiences with the interpreter or medical interpretation?
    - Was it helpful having a medical interpreter present?

    Do you feel that you were able to trust the interpretation provided by the medical interpreter? Why or why not?

16. Perception of the Medical Interpreters Role

    What are your perceptions of the role of medical interpretation within the genetic counselling appointment?

    Follow-up questions
    - Have you ever felt that they are not doing a verbatim translation?
    - What to you is good medical interpreting?

17. Time Constraints

    Was there adequate time to address all of the patient's questions/concerns?

    Were you conscious of the appointment time throughout the session?

    Was there enough time to address any psychosocial concerns?

    Were there other constraints (other than time) in the appointment?

18. Suggestions for improvement

    What do you think might be helpful for the patient/interpreter/yourself to improve the experience for other patients?

    Follow-up question
    - Are there are resources that you think would be useful?
        - Would you as a genetic counsellor want a resource for counselling patients with LEP?
        - Is there anything you want or would help facilitate these appointments?
        - What would this look like to you ideally?

    Is there anything you wish to know about medical interpreters or interpretation?

[Interview concludes]

Thank you for participating in this interview. We will email you a $10 virtual gift card to ________ as an appreciation of your time and willingness to participate in our study. Is there a preferred e-mail address you would be comfortable with providing?

If you have any additional questions about this research study or how the information you provided will be used, please feel free to contact me by phone or email. I will send a copy of the consent form by mail to your address, and I can provide it via email as well, if you would like. [Obtain email address]
The consent form has my contact number, as well as the contact information for my supervisor and the Research Ethics Board. Thank you again for your time.

NB: Follow-up questions will be asked as necessary/relevant to the participant's response. Not all of the follow-up questions will be asked.

Examples of wrap-up

- I want to be mindful of the time, and I do have a few more questions to ask.
- Thank you for your detailed answer – I do have to move on to the next question, but if there is time maybe we can come back to this question.
- Thank you for sharing that – I do want to get your perspective on a few more questions, is there one final point you would like to add before we move on?
- Those are all of the questions I have; do you have any questions for me about the interview or the study?
- Thank you for participating in this interview – I have no more questions.

Examples of affirmations

- Thank you for sharing that with me.
- It sounds like you were feeling ____, does that sound right?
- That sounds like it was a(n) ______ experience for you.

Examples of prompts/probes

- Why do you say that?
- Can you explain what you mean by _______?
- Can you give me an example?
- You mentioned ____, can you tell me more about that?
- What did that mean to you?
- How did that make you feel?/How do you feel about that?
- What do you mean by ____?