Exploring Immigrants' Perceptions of Genetic Counselling

by

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ABSTRACT

There has been a steady increase in immigration to Manitoba. Several studies have shown that immigrants face barriers when accessing health care services, such as cultural differences, language fluency, lack of social supports, and difficulties in understanding health care providers. Unfamiliarity with Westernized health care systems limits their knowledge of the services available and can affect their health care seeking decisions. Currently, there is limited information on immigrants' use of genetic counselling services, as well as the ways in which genetic counsellors can best provide care. Previous genetic counselling research explored similar topics specific ethnic populations rather than the broad immigrant population. This exploratory study of immigrants' perceptions and experience of genetic counselling services is necessary to understand how genetic counsellors can provide immigrants with culturally sensitive care that they can appropriately utilize.

Semi-structured interviews were conducted with new immigrants referred to the Program of Genetics & Metabolism in Winnipeg, Manitoba. Interviews investigated immigrants' thoughts and opinions about genetic disease, testing, and counselling services. Convenience sampling was used to select participants. Eight participants were interviewed by telephone. Interviews were conducted until saturation of themes. Member checking was completed with a subset of respondents.

Genetic counselling was unknown to most participants before their referral, although there was a high interest in the service. Participants had varied levels of knowledge of genetic concepts, possibly resulting from experience, health literacy, and education levels. All participants reported

that they were satisfied with this service. Participants described language barriers and reflected on how appropriate communication is essential to building trust, some highlighting a preference for non-directive counselling. Support systems were lacking but necessary when starting a new life in Canada and managing a new or future diagnosis. This study describes the relevance of medical pluralism in the context of genetic counselling of newcomer populations. Further, the results provide vivid descriptions of living with a genetic condition, caring for a relative with a condition, perceptions of genetic conditions and reasons for pursuing genetic services.

Our findings support major themes as previously reported. They demonstrate a need to increase awareness about genetic counselling within the immigrant community and to provide more support systems that are appropriate for newcomers.

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TABLE OF CONTENTS

Table of Contents

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

CHAPTER ONE

1.0. Introduction

A review of the literature on immigrants experience with genetic counselling and genetic testing services revealed a gap in research of the immigrant population and the Canadian health care system. Research in this area arises from American institutions with few from Europe, the Middle East, Asia and Africa evaluating visible minority populations, rather than the overall immigrant or newcomer experience, and within the prenatal or cancer context. Continued research in this area in the last 20+ years tends to report similar disparities for ethnic minority groups with respect to access to health care and experience of genetic counselling and/or testing (genetic services). Canadian literature about genetic counselling and genetic testing is lacking and mainly summarizing the immigrant experience in primary health care rather than in subspecialties such as genetic counselling. Additionally, the Canadian and American immigrant experiences may differ significantly because of immigration policies and related acculturation strategies. Thus, representation of the Canadian experience is essential. In selecting our recent pan-ethnic immigrant group, we hoped to gain a better understanding of the processes relevant to immigration, such as barriers to systems and challenges prevalent within early relocation. The research fills a gap in the literature about immigrant specific perceptions, experiences and outcomes with accessing and utilizing genetic counselling services, and with genetic testing, specifically within the public health care system in Canada.

1.1. Rationale

This study is timely, given the recent genetic counselling literature that suggests a trending change in genetic counselling cultural competency training and approaches through the

emergence of the concept of cultural humility. This exploratory study evaluating the experience of this population in a medium sized public Canadian genetic counselling setting is warranted in order to find the link between the immigrant and ethnic specific experiences and contribute to the existing body of literature from the Canadian perspective. Through these initiatives, we will better understand how we can provide immigrants with culturally sensitive genetic counselling services that they can appropriately utilize. The research may have impacts on professional teaching and training in the future.

1.2. Research Aim

The research aim is to explore and describe immigrants' perceptions and experience of genetic counselling in Manitoba.

CHAPTER TWO

2.0. Background

2.1. Increasing immigration in Canada

The Canadian population has long been recognized for its diverse multicultural composition, which over time has added to and shaped its ethno cultural make-up through each new influx of immigrants and their descendants (Statistics Canada, 2017b; Survey, 2011). Four years following Confederation in 1867, the Canadian population was composed of 3.7 million people (Statistics Canada, 2017b). The results of the first Canadian census held in this year show that 16.1% of the Canadian population was foreign-born and that the main countries of birth for these people were the British Isles (84%), the United States (11%) and Germany (4%)(Statistics Canada, 2017b). This percentage will continue to rise due to Canada's increasing number of deaths, relatively low fertility rate and sustained immigration (Statistics Canada, 2017). On the 2016 census done over an interval peroid, Statistics Canada reported a *recent* immigrant population of 1,212,075 who permanently settled in Canada between 2011 to 2016 (Statistics Canada, 2017a). At this time, there was a reported 21.9% of the population who declared that "they were or had ever been a landed immigrant or permanent resident in Canada,"(Statistics Canada, 2017a) meaning that more than one in five Canadians are foreign-born (Statistics Canada, 2017a). The Canadian immigrant population continues to grow; Statistics Canada's population projections estimate that by 2036 the Canadian foreign-born population range from 24.5% to 30.0% (Statistics Canada, 2017a). Accounting for immigrants and their children, Statistics Canada estimates that by 2036, nearly one in two Canadians may fit this description (Statistics Canada, 2017b).

Although more than half of all immigrants and recent immigrants live in the major Canadian cities of Toronto, Vancouver and Montréal, there are increasingly more newcomers settling in the Prairie and Atlantic provinces (Statistics Canada, 2017a). In fact, the Prairie provinces saw a rise in new immigrants during the 15 year time period from 2001 to 2016 (Statistics Canada, 2017a). Specifically to Manitoba, the percentage of new immigrants rose from 1.8% to 5.2% over this time period (Statistics Canada, 2017a). The Manitoba new immigrant population comprising a total of 63,210 individuals during this time (2011-2016) (based on the population in private households – 25% sample data) (Statistics Canada, 2016).

As of 2016, most recent immigrants were born in Asia (including the Middle East) and thus Asia was the top continent of origin for recent immigrants with 61.8% of newcomers to Canada from 2011 to 2016. This value was increased over that seen in the 2006 Census (58.3%) and the 2011 National Household Survey (56.9%)(Statistics Canada, 2017a). Seven out of the top ten countries for the birth of recent Canadian immigrants were Asian and included the Philippines, India, China, Iran, Pakistan, Syria and South Korea (Statistics Canada, 2017a). Most Manitoba newcomers arrive from Asian countries (Table 1).

Table 1: Immigrant and new immigrant population by selected places of birth in private households of Manitoba – 25% sample data.

Place of birth***	Immigrants* by selected place of birth		
	Total	**Male**	**Female**
Americas	31,980	15,285	16,700
Europe	56,705	27,815	28,890
Africa	17,975	9,495	8,485
Asia	120,230	58,215	62,015
Oceania and other	575	290	280
Place of birth***	**Recent immigrants* by selected place of birth**		
	Total	**Male**	**Female**
Americas	4,130	1,840	2,290
Europe	5,155	2,650	2,505
Africa	7,860	4,120	3,735
Asia	45,915	22,395	23,520
Oceania	150	80	70

As adapted from the Census Profile, 2016 Census (Statistics Canada, 2016).
*Immigrants: "'Immigrant' refers to a person who is, or who has ever been, a landed immigrant or permanent resident. Such a person has been granted the right to live in Canada permanently by immigration authorities. Immigrants who have obtained Canadian citizenship by naturalization are included in this group. In the 2016 Census of Population, 'Immigrant' includes immigrants who landed in Canada on or prior to May 10, 2016".(Statistics Canada, 2016)
**Recent immigrants: "'Recent immigrant' refers to an immigrant who first obtained his or her landed immigrant or permanent resident status between January 1, 2011 and May 10, 2016".(Statistics Canada, 2016)
***Place of birth: "'Place of birth' refers to the name of the geographic location where the person was born. The geographic location is specified according to the geographic boundaries current at the time of data collection, not the geographic boundaries at the time of birth. In the 2016 Census of Population, the geographic location refers to a country if the person was born outside Canada."(Statistics Canada, 2016).

2.2. Who are the newcomers to Canada: refugee and immigrant classes

The Canadian Government defines the term "immigrant" as "persons residing in Canada who were born outside of Canada, excluding temporary foreign workers, Canadian citizens born

outside Canada and those with student or working visas (Statistics Canada, 2010). The "foreign-born population" or the "immigrant population" is defined in the 2016 Census as "persons who are, or who have been, landed immigrants or permanent residents in Canada…persons [who] have been granted the right to live in Canada permanently by immigration authorities…[including] immigrants who have obtained Canadian citizenship by naturalization (Statistics Canada, 2017a). The 2016 Census of Population includes immigrants who landed in Canada on or before May 10, 2016 under this term (Statistics Canada, 2016). This definition does, however, exclude non-permanent residents such as individuals with work or study permits and those who are refugee claimants (Statistics Canada, 2017a). Similarly, the definition classifies people who are Canadian citizens by birth but born outside of Canada as part of the Canadian born and non-immigrant group (Statistics Canada, 2017a). There are four admission categories of immigrants as defined by Statistics Canada (2016):

1. Economic immigrant. The economic immigrant is a category that includes individuals selected for their potential to contribute to the Canadian economy.
2. Immigrant sponsored by family. A family class immigrant is an individual who is sponsored by a Canadian citizen or an individual who holds Canadian permanent residency, and were granted permanent resident status due to their familial relationship to the sponsor.
3. Other immigrant. Other immigrants are those who have been given permanent resident status under a program different from the ones above.
4. Refugee Refugees are individuals who have evacuated their home country as a result of a fear of persecution and are unable to return home (Government of Canada, 2017). A refugee, however, has difference from immigrants in that an immigrant is an

> individual who has chosen to come to Canada and settle permanently - immigrants are not forced to flee such as refugees (Government of Canada, 2017). Refugees to Canada fall under two classes: convention refugee abroad class and country of asylum class (Government of Canada, 2017). The convention refugee abroad class of refugees consists of individuals who are outside of their home country and who cannot return for fear of persecution based on race, religion, political view, nationality, or particular social group (e.g. gender or sexual orientation) (Government of Canada, 2017). A convention refugee is sponsored by either the Government of Canada (and is known as a government-assisted refugee), an organization or a group of people (and is known as a privately sponsored refugee), or a mixture of both (known as a blended visa office-referred refugee), or is self-supported (Government of Canada, 2017). The country of asylum class of refugees is outside of his or her home country and is severely affected by armed conflicts or civil war, or is a person who is being refused basic human rights (Government of Canada, 2017). Such persons can be privately sponsored, or they may have the means to self-support after arriving in Canada (Government of Canada, 2017).

In 2016, about 6 in 10 recent immigrants were accepted into the country under the economic category if accounting for all of the principal applicants, their spouses and their dependants, approximately 3 in 10 recent immigrants where admitted as family class, and approximately 1 in 10 recent immigrants was accepted as a refugee (Statistics Canada, 2017a). During the period of January 1 to May 10, 2016, refugees composed 24.1% of the immigrant population admitted as a result of Syrian refugees landing during this time (Statistics Canada, 2017a).

2.3. The Canadian Health Care System

The Canadian health care system is publically funded and provides medically necessary services based on need rather than ability to pay (Government of Canada, 2018). This system has its roots in the Saskatchewan universal provincial health care plan introduced in 1947 (Government of Canada, 2018). Saskatchewan later brought about a universal provincial medical insurance plan and within 6 years, all provinces and territories had universal physician services insurance plans (Government of Canada, 2018). In 1984, the Canada Health Act was passed (Government of Canada, 2018). This legislation defined the portability, accessibility, universality, comprehensiveness and public administration of the Canadian health care system (Government of Canada, 2018). This act holds the same principles today.

New Canadian immigrants and refugees may not be able to access these publically funded benefits as equally as Canadian-born residents. In some Canadian provinces and territories there is a mandatory minimum waiting period whereby newcomers are not covered by the publically funded healthcare system (Health Canada, 2018). At the time of this study, there were no waiting periods to access the publically funded health system for the Manitoba Canadian newcomers as defined by the Residency and Registration Regulation and the Canada Health Act (Health Canada, 2018). As such, newcomers seeking medically necessary health services such as genetic counselling would not face economic barriers that differ from the Canadian born population with respect to this coverage.

Newcomers who relocate to Canada have access to the Settlement Program, a program which assists immigrants and refugees in areas of known difficulty associated with the relocation

experience (Government of Canada, 2019). Such areas include needs assessment and referrals along with information and orientation, language training, employment services and various community connections (Government of Canada, 2019). Additionally newcomers have access to support services that include transportation, child care and translation or interpretation services (Government of Canada, 2019). The Resettlement Assistance Program offers immediate support for essentials services and income for refugees (Government of Canada, 2019).

2.4. The Winnipeg Regional Health Authority and the Program of Genetics and Metabolism

The Winnipeg Regional Health Authority (WRHA) is a medium sized centre located in Manitoba's capital city of Winnipeg. The WRHA provides health care to more than 700,000 people living in the city of Winnipeg, surrounding areas and Northern Manitoba (Winnipeg Regional Health Authority, n.d.-a). Additionally, the WRHA provides support and specialty referrals for approximately 500,000 Manitobans living outside the province as well as those who live in north western Ontario and Nunavut who have a need for specialty services available in the city (Winnipeg Regional Health Authority, n.d.-a). The Program of Genetics and Metabolism provides genetic services to over 5,000 patients annually in both out-patient and hospital consultations (Winnipeg Regional Health Authority, n.d.-b). The clinicians work within four subspecialties: medical genetics (general genetics of children, adults and families), prenatal genetic screening and diagnosis, metabolics and hereditary cancer (Winnipeg Regional Health Authority, n.d.-b).

2.5. Immigrants face many barriers to accessing primary healthcare in Canada, which can dictate health care service utilization

It is widely documented that immigrants, refugees and asylum seekers face barriers to accessing primary care, which can influence choice of health care service (Asanin & Wilson, 2008; Blais & Maïga, 1999; Carrasco, Gillespie, & Goodluck, 2009; Edge & Newbold, 2013; Hadgkiss & Renzaho, 2014; Khanlou, Mustafa, Vazquez, Haque, & Yoshida, 2015; Leduc & Proulx, 2004; Woodgate et al., 2017) . Overall, newcomers to these countries (primarily Canada and the U.S.) tended to comment on similar themes on what has caused them distress when accessing primary care. Canadian newcomers shared barriers in access to primary care, including unmet expectations of health care (such as longer than expected wait times and referral process, the appointment feeling rushed impersonal or incomprehensive and lacking in depth), economic challenges, geographic limitations, socio-cultural difference, language barriers, a lack of culturally appropriate social supports and mistrust of patients in physicians (Asanin & Wilson, 2008; Chen, Li, Talwar, Xu, & Zhao, 2016; Woodgate et al., 2017). These individuals face the additional challenges associated with being new to a country, which can mean starting a "life from nothing", and facing "disadvantaged social positions" with respect to their race/ethnicity and gender; as well as their socioeconomic status (Woodgate et al., 2017). A concept articulated by participants of a recent Manitoba based study was that it was "difficult to communicate and understand a Westernized concept of health, health care systems, and health care approaches." (Woodgate et al., 2017) Overall, the most common barriers to access for immigrants in Canada tend to include language barriers, long wait times, barriers to information/lack of information about access or navigation of services, and cultural differences (Kalich, Heinemann, & Ghahari, 2016). These barriers can have impacts on how newcomer populations choose, utilize and experience services (Klassen et al., 2012; Leduc & Proulx, 2004). Leduc *et. al.* (2004) indicate

that immigrant families select services with high technical quality, close proximity, practical service hours and short waiting times (Leduc & Proulx, 2004). Immigrants may define the technical quality of their selected professionals as competent with respect to the medical specialization, or by their perception of the professionals ability to be caring (Leduc & Proulx, 2004). Furthermore, newcomers would consider the language of the service and the ethnic origin of the healthcare provider as important; the ethnic origin is likely important for those with language barriers as they try to mitigate issues to being understood (Leduc & Proulx, 2004). Ethnic minorities and newcomers may experience these and other limitations (Adedokun et al., 2015; Awwad, Veach, Bartels, & LeRoy, 2008; Belahcen, Taloubi, Chala, Thimou Izgua, & Mdaghri Alaoui, 2014; A. G. Buseh, Stevens, Millon-underwood, Kelber, & Townsend, 2017; Cheng et al., 2018; Gesser-edelsburg & Shahbari, 2017; Greeson, Veach, & LeRoy, 2001; Hann et al., 2017; Joseph et al., 2017; Joseph & Guerra, 2015; Jun, Thongpriwan, Choi, Sook Choi, & Anderson, 2018; I. Mittman, Crombleholme, Green, & Golbus, 1998; Ricker et al., 2006; Shen, 2018; Sussner et al., 2009; Sussner, Jandorf, Thompson, & Valdimarsdottir, 2013; Wal et al., 2015) with genetic counselling services upon arrival to North America, and around the world.

2.6. Acculturation: impact on immigration and study design

As a result of immigration, many regions around the world have become "culturally plural": people of multiple cultural backgrounds live in one mixed and diverse society (Berry, 1997). This often results in the meeting of people from multiple cultural groups; power differences arise when groups unequal in power come together (Berry, 1997). This tends to result in the acquisition of the names "minority" or "ethnic group" (Berry, 1997). Psychologists have asked, when two groups coexist in this manner what happens to the individuals who have developed in

one cultural context and are expected to act under their existing cultural influences (John W Berry, 1997). The term “acculturation” seeks to define the cultural changes and outcomes that occur from these diverse group encounters (John W Berry, 1997). The formal definition arises from Redfield, Linton and Herskovits who describe that “acculturation comprehends those phenomena which result when groups of individuals having difference cultures come into continuous first-hand contact with subsequent changes in the original culture patterns of either or both groups”. “Acculturation” is generally used to understand cultural changes within group encounters, whereas the terms “psychological acculturation” and “adaption” are more specific to the psychological changes and resulting outcomes that occur at the individual level (Berry, 1997).

The process of acculturation can occur via four separate strategies: assimilation, separation, integration and marginalisation, and may result out of choice or out of pressure from the dominant group (Berry, 1997). From the perspective of the non-dominant group, “assimilation” describes the process whereby the individuals of the non-dominant group do not wish to maintain their cultural identity and thus, seek continuous exposure to other cultures (John W Berry, 1997). If the individuals value retaining their culture and avoid new cultures, the process is described as “separation” (John W Berry, 1997). “Integration” is the process in which the cultural identity of individuals is retained to some degree yet there is an interest in participating in the larger social group (John W Berry, 1997). The process of “marginalization” occurs if is there is little to no interest or possibility to maintain culture (which may be a result of forced culture loss in some cases), and, in turn, there is little interest from the non-dominant group to blend with others (which can be a result of exclusion or discrimination) (John W Berry, 1997). Acculturation

strategies are directly influenced by the national immigration policies in the country of settlement: for example policies of multiculturalism support integrationist strategies of acculturation (Berry, 1997). As of 1971, the Canadian government has supported a policy of multiculturalism (Berry, 1991). Although this may apply to new Canadian immigrants and refugees, the authors of this thesis project acknowledge that this does not speak to the horrific Canadian history of marginalization and genocide of Indigenous populations. With respect to the strategy of *integration* in Canada, ethnic groups cooperate within a broader social system (Berry, 1991). This can lead to some level of structural assimilation but little cultural and behavioural assimilation (J.W. Berry, 1991). Although Canadian policy may describe itself as multicultural, there is still a need to acknowledge that Canadian immigration strategies are social, political, economic and demographic in nature (Guo, 2013). In spite of varied motivations for Canadian immigration, Canadian immigration prioritize a knowledge-based economy, favouring newcomers with education and skills, and resulting in a bias towards economic immigrants over family class immigrants and refugees (Guo, 2013).

The process and outcome of acculturation involve six changes as defined by Berry (1992):

- physical changes, including the new location, housing population, etc.
- biological changes that include nutrition and disease
- political changes that impact the non-dominant group and may involve a loss of autonomy
- economic changes may mean individuals look for different forms of employment
- cultural changes including language, religion, education
- social networks are altered

Individuals undergoing the process of psychological acculturation experience both behavioural shifts and acculturative stress (Berry, 1992). Behavioural shifts include changes in values, attitudes, abilities and motives; whereas acculturative stresses are social, psychological and physical consequences or problems (Berry, J, 1992). The extent to which an individual experiences these factors is dependent on individual characteristics (such as age, gender, education, pre-acculturation, status, migration, motivation, expectations, cultural distance in language, religion and others, as well as personality) and other moderating phenomena (such as length of time, acculturation strategies including attitudes and behaviours, coping, social support and societal attitudes like prejudice and discrimination) (Berry, J, 1992; John W Berry, 1997). While an individual adapts to these experiences, they may experience short-term changes that are sometimes negative, however, it is reported that generally after a period of time individuals experience some long-term positive adaptation to the new cultural situation (John W Berry, 1997; Beiser, M. et al., 1988 as cited in Berry, 1997).

Taken together, acculturation is an important factor to consider in conducting our research within the context of previous literature. First, acculturation for Canadian newcomers may look significantly different from for newcomers to other regions of the world. For example, the United States have historically and continue to employ "assimilation" acculturation strategies (Schwartz & Unger, 2010). This is important within the context of our qualitative research in that the results of this study may not be transferable/generalizable to the American context that has been the home to much of the previous genetic counselling research on this topic, and vice versa. This provides further evidence and supports the need our research. Second, although acculturation and immigration practices within Canada may be more multicultural than those of the countries

previously studied Canadian immigration biases towards highly educated and well-trained individuals, which may have a significant impact on the perceptions of and experiences with genetic counselling for Canadian newcomers. Again, this result would set our research apart from previous studies whose study populations may not be enriched for highly educated and trained individuals. Last, the process of psychological acculturation is associated with our project's inclusion criteria in an attempt to distinguish our sample population. In consideration of the process of psychological acculturation and its course that occurs over time, we have selected a population of recently immigrated newcomers in an attempt to capture the largest number of acculturative stressors associated with the genetic counselling service, which may be expected to be present earlier on in the migration process.

2.7. The Genetic Counselling Profession

Genetic Counselling is a health care profession defined by its professional body the National Society of Genetic Counseling (NSGC), as the "process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease."(Resta et al., 2006) Furthermore, the profession is qualified as providing services in three core areas:

1) Interpretation of family and medical histories for the assessment of disease occurrence or reoccurrence

2) Education about inheritance patterns, testing, management, prevention, resource identification and research, and

3) Counselling designed to promote the informed choices of patients and their adaptation to a risk or a condition (Resta et al., 2006).

The profession of genetic counselling was born out of the U.S. during a time of both feminist health and civil rights movements, and significant advancement in genetic technology (Stern & Richter, 2009). Specifically, prenatal diagnosis incidentally aligned with the decriminalization of abortion and trends in biomedical ethics supporting the growing role for patient autonomy (Stern & Richter, 2009). The first genetic counselling class was established at a New York institution, Sarah Lawrence College in 1969 (Stern & Richter, 2009). Since this time genetic counselling has grown rapidly and continues to expand, with estimates of nearly 7000 genetic counsellors providing care to patients world-wide (Abacan et al., 2018). Many countries modeled their creation of the profession on the U.S. scope of practice and training; as such there are many similarities between the approach to practice of genetic counselling across continents (Abacan et al., 2018). However, differences in healthcare systems, country specific regulatory systems and availability of university level training have led to differences in training and practice of this profession (Abacan et al., 2018).

As of 2018, there were over 4000 genetic counsellors, with approximately 350 genetic counsellors practicing in Canada and the remainder in the U.S. (Abacan et al., 2018). In the U.S., genetic counsellors mainly work in interdisciplinary teams without direct supervision by a physician, and can work in clinical and non-clinical roles (Abacan et al., 2018). The smaller Canadian population too works in both clinical and non-clinical roles (Abacan et al., 2018). The profession of genetic counselling is growing internationally in other Westernized and non-Western countries (Abacan et al., 2018). In Europe, genetic counselling is established or developing in at least 11 countries (Abacan et al., 2018). In the Middle East, there are approximately 100 genetic counsellors, practicing mainly in Israel and Saudi Arabia (Abacan et

al., 2018). In Asia, genetic counselling is just beginning to develop, meaning that genetic counselling services are mainly provided by physicians rather than independent professionals; although there are a few exceptions such as India, Japan, Malaysia, Philippines, Singapore, South Korea and Taiwan (Abacan et al., 2018). In Africa, medical genetic services are widely available, yet formal genetic counselling services are limited to South Africa (Abacan et al., 2018).

2.8. Culturally Competent Genetic Counselling

Cultural competence in health care provision has been defined by many (Lewis, 2010). Lewis (2010) defines the following components of cultural competency:

- *Knowledge* - describes having information about culture and cultural effects on the patient experience of health care such as prejudice/stereotypic, specific ethnic history and present challenges, group attitudes, beliefs and expectations of health care, customs and practices that can affect medical decision-making.
- *Skills* - refers to working with culturally different patients, having the ability to elicit an explanatory model of health, helping patients to navigate the differences between their understanding of illness and appropriate treatments as compared to the biomedical model, obtaining new information about ethnic/racial groups, demonstrating culturally appropriate empathy and mitigating countertransference.
- *Awareness* – relates to acknowledging internal bias towards individuals of different ethnic, racial, sexual, religious or other backgrounds difference from the self, moving past fears of appearing racist and/or sexist, acknowledging one's own resistance to

achieve cultural competences and understanding the culture as it is within one's own life context.

The provision of culturally competent genetic counselling continues to be a long-standing practice-based competency for genetic counsellors. The Canadian Association of Genetic Counsellors Practice Based Competencies acknowledged the need for competencies in section 1.4 "Awareness of Diversity", commenting on the counsellor's ability to:

1) "Recognize, acknowledge and respect differences relevant to client interactions, including but not limited to cultural, spiritual, physical, cognitive, political and sexual orientation",

2) "Communicate and practise in a culturally sensitive manner" and

3) "Reflect on and address their own biases and cultural differences when interacting with clients" (Canadian Association of Genetic Counsellors, 2012).

This mirrors a similar description of cultural competency in genetic counselling as described by the American genetic counselling program accreditation board, where the genetic counsellor is to: "Apply genetic counseling skills in a culturally responsive and respectful manner to all clients" (Accreditation Council for Genetic Counseling, 2015). This is further elaborated as the need to

1) "Describe how aspects of culture including language, ethnicity, life-style, socioeconomic status, disability, sexuality, age and gender affect the genetic counselling encounter",

2) "Assess and respond to client cultural beliefs relevant to the genetic counselling encounter",

3) "Utilized multicultural genetic counselling resources to plan and tailor genetic counselling agendas, and assess and counsel clients", and lastly

4) “Identify how the genetic counselor’s personal cultural characteristics and biases may impact encounters and use this knowledge to maintain effective client-focused services” (Accreditation Council for Genetic Counseling, 2015).

Kessler (1997) describes two forms of genetic counselling, the teaching model and the counselling model (Kessler, 1997). Employing the teaching model embodies assumptions such as, the patient has come to the appointment in search of information, and assumes that the provision of balanced information, will alone be enough for a patient to make their health related decision (Kessler, 1997). The counselling model is in opposition, as it embodies goals such as understanding the patient, fostering competence, control of and reduction of psychological distress (Kessler, 1997). Furthermore, it is based on the idea that patients come to the genetic counselling appointment for complex reasons (Kessler, 1997). These two fundamental models are essentially in competition in that they balance between information giving and providing support (Kessler, 1997). Neither model explicitly addresses the issue of culture, Lewis (2002) suggests that employing the counselling model is the most appropriate way to support multicultural genetic counselling, since it promotes discussion about important nuances such as the cultural aspects of the patient-counsellor relationship. In 2007, McCarthy Veach *et al.* described the implementation of a genetic counsellor derived “normative model” called the “Reciprocal Engagement Model”. This model employs many aspects of both of the above two historic models. The reciprocal engagement model suggests that a counsellors biomedical knowledge is “essential but not sufficient” to appropriately communicate information (Veach, Bartels, & LeRoy, 2007). Also, that communication is most effective when there is a strong patient-provider relationship where the provider considers the psychosocial factors involved

(Veach et al., 2007). Unlike the teaching or counselling models, the reciprocal engagement model involves aspects of patients cultural identify, values and perspectives (Veach et al., 2007). Recent literature suggests that genetic counsellors primarily practice under the framework of the teaching model and that there is a need to shift towards a more psychotherapeutic approach (Biesecker, 2016; Meiser, Irle, Lobb, & Barlow-stewart, 2008). Within the context of multicultural or cross-cultural genetic counselling, Joseph *et. al.* (2017) suggests that any new model employed to help meet the needs of diverse patients should include validated principles and strategies that are effective in communicating with individuals of limited health literacy.

2.8.1. An introduction to cultural humility in the context of genetic counselling: a shift from the cultural competency framework

As recently as last year, McGinnis *et. al.* (2018) proposed the need for further research exploring alternative approaches to cultural competency within the genetic counselling setting. In this publication, they made the connection to an existing concept called cultural humility, suggesting a place for this within future genetic counselling training (Mcginniss, Tahmassi, & Ramos, 2018). The concept of cultural humility was introduced by Tervalon *et. al.* (1998) in an effort to meet the needs of medical educators in the United States. Foronda *et. al.* (2016) define cultural humility "in a multicultural world where power imbalances exist", as "a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals". Moreover, they state that the "results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning" (Foronda, Baptiste, Reinholdt, & Ousman, 2016). Tervalon *et. al.* (1998) highlight that cultural competence has the connotation of acquiring mastery over a hypothetical finite body of

knowledge regarding culture (Tervalon & Murray-Garcia, 1998). Whereas, cultural humility does not have a measurable endpoint, and is more of a lifelong commitment to self-reflection, self-critique and learning (Tervalon & Murray-Garcia, 1998). Using patient-focused interviewing, cultural humility seeks to employ less authoritative questioning, thus bringing the patient-provider power imbalances into check and indicating that the provider values both biomedical and non-biomedical perspectives relevant to their patients (Tervalon & Murray-Garcia, 1998). The patient is given permission to speak about their own experience, an approach that may foster discussion about culture in as much detail as each individual patient may feel necessary (Tervalon & Murray-Garcia, 1998). As such, there is less of a need to have complete mastery over relevant cultural information (Tervalon & Murray-Garcia, 1998). Moreover, cultural humility incorporates the idea of patient uniqueness in that the patient is the expert in understanding the intersection of many demographic factors that creates their distinctive identity, race, ethnicity, religion, class, etc. (Lewis, 2002; Ridley, 1995; Tervalon & Murray-Garcia, 1998). This approach helps to illuminate the intragroup variability within cultural groups and allows for a better appreciation of individual experiences, which may be overlooked by traditional approaches to understanding culture (Lewis, 2002). Furthermore, the provider meets the patient with openness to work collaboratively to understand this identity of the patient and how these different aspects affect the patient-provider relationship (Hook, Davis, Owen, Worthington, & Utsey, 2013).

These values echo three of the central tenants and corresponding goals of the most current described model of genetic counselling – the reciprocal engagement model (Veach et al., 2007):

- Tenet 1: “genetic information is key” includes two process goals; “the genetic counsellor knows what genetic information is relevant to impart to a given patient, and the genetic counsellor presents the genetic information in a way that the patient can understand”.
- Tenet 2: “relationship is integral to genetic counselling” includes the goal that genetic counsellors “should strive to understand patient values, culture, and perspectives”.
- Tenet 3: “patient autonomy must be supported’: describes that the individuals’ “socio-cultural and family contexts (beliefs, practices) are valued and respected as important aspects of autonomous decision-making”. This tenet includes the goal of “the genetic counsellors understands the patient’s familial and cultural context and works within this context to engage in decision-making with the patient”.

Although this model resonates an openness to culturally appropriate care that asks the counsellors to be reflective, self-aware, ethical, objective and open to feedback (Veach et al., 2007). its goals are mainly in-line with the philosophy of cultural competency as it alludes to having an understanding of the patient rather than an openness to learning from the patient (Tervalon & Murray-Garcia, 1998). Moreover, employing cultural humility asks providers not to assume competence when working with patients based on prior experiences with particular groups (Hook et al., 2013). Taken together, it can be gleaned that the Reciprocal Engagement Model values the patient as an individual, but the framework of cultural humility takes a step beyond.

Cultural humility is an emerging area of research with potential for expansion in genetic counselling practice and training. Further, cultural humility highlights both 1) a shift away from

mastery over a body of knowledge to a more self-reflective practice, where 2) the patient is the expert who provides the necessary information including unique information about identity, and 3) the provider commits to a stance of lifelong learning.

2.9. What is culture?

Culture has been described by many and has been distilled down to "a group of people's total way of life: the way they act and think, organize themselves, related and communicative, make or build things, express feelings and emotions, and respond to the world" (Kroeber and Kluckhohn, 1952 as cited in Oosterwal, 2009). During the 1970's Dutch psychologist Geert Hofstede developed the Hofstede model of cultural dimensions, a paradigm for comparing cultures (Hofstede, 2011). Originally, Hofstede used survey data concerning individuals, values and thoughts collected from over 50 countries, all of whom worked for the global company IBM (Hofstede, 2011). The theory was developed through a statistical method of factor analysis in the context of the corporate world, and evaluated data at the country level (Hofstede, 2011). Following several iterations, the now widely known theory of culture comprises six dimensions aimed at understanding inter-country differences:

1. Power distances are the level to which individuals of less powerful positions within structures such as organizations and institutions, tolerate an unequal power distribution (Hofstede, 2011). Higher Power Distance Index scores, indicating higher tolerance, are typically seen for Eastern Europe, Latin countries, Asia and Africa as compared to Germanic and English-speaking Western countries (Hofstede, 2011; Hofstede, Hofstede, & Minkov, 2010).

2. Uncertainty avoidance is defined as a society's acceptance for ambiguity, or in other words, the cultures level of comfort with unstructured situation (Hofstede, 2011). For cultures that prefer more structured situations, people may avoid unstructured scenarios by abiding to strict behavioural codes, laws or rules, disapproval of deviant actions and a prevailing belief in one "absolute Truth", that "there can only be one Truth and we have it" (Hofstede, 2011). Uncertainty Avoidance Index scores are higher, indicating less tolerance with uncertainty, in Latin countries, Eastern and Central Europe, in Japan and German speaking countries, but are lower in English speaking countries and Nordic countries as well as countries that are culturally Chinese (Hofstede, 2011; Hofstede et al., 2010).
3. Individualism versus Collectivism relates to the level with which people in a society are integrated within groups (Hofstede, 2011). For individualistic societies, ties between people are loose and people look after themselves and their immediate family (Hofstede, 2011). For collectivist societies, people are well integrated into strong cohesive groups that may include extended family members and relatives; these groups bring unquestioning loyalty (Hofstede, 2011). Individualism is typically found in Western countries while collectivism is common in the developing nations and in the East (Hofstede, 2011; Hofstede et al., 2010).
4. Masculinity versus Femininity describes the division of emotional roles between the sexes on a societal level (Hofstede, 2011). The so called "assertive pole" and "caring pole" are known as masculine and feminine respectively (Hofstede, 2011). At the level of the country, women and men in feminine countries share the same modest and caring values; whereas in masculine countries there is a gap between the values of men and

women (Hofstede, 2011). Masculinity is most prevalent in Japan, some Latin countries such as Italy and Mexico, and German speaking countries, and is somewhat prevalent in English speaking Western countries as compared to the more feminine countries such as the Nordic countries, the Netherlands, and Latin and Asian countries such as France, Spain, Portugal, Chile, Korea and Thailand (Hofstede, 2011; Hofstede et al., 2010).

5. Long Term versus Short Term Orientation acts to describe where a society chooses to focus its effort, the past, present or future (Hofstede, 2011). This dimension is based in the Confucian Work of Dynamism which describes the "pole" of long-term orientation as perseverance, thrift, ordering relationships on status levels, and having a sense of shame (Hofstede, 2011). The short term orientation "pole" is associated with reciprocation of social obligations, a respect for traditions, saving 'face' as well as personal attributes such as steadiness and stability (Hofstede, 2011). Long-term oriented societies include East Asian, Eastern and Central European countries, whereas short-term oriented countries include North American, USA and Canada, Australian, Latin America, and African and Muslim countries (Hofstede, 2011; Hofstede et al., 2010).
6. Indulgences versus Restraint – societies of indulgence are those that support relatively free gratification of simple human desires, as opposed to societies of restraint that tend to control gratification and needs (Hofstede, 2011). Countries of indulgence are typically those in North and South America, Western Europe and a limited number of sub-Saharan African countries (Hofstede, 2011; Hofstede et al., 2010). Those of restraint are typically Asia, Eastern Europe and Muslims countries (Hofstede, 2011; Hofstede et al., 2010).

Altogether, Hofstede defines culture as "the collective programming of the human mind", and is thus what "distinguishes the members of one human group from those of another" (Hofstede,

1981). This model was chosen for its description of multiple samples across continents thus representing international cultures, which was necessary for the discussion of our results. Although the Hofstede framework is widely accepted, the model is not with out limitations. Others have highlighted numerous pitfalls of the model, which include but are not limited to: questioning if it is appropriate to differentiate cultures by 'nations', by which Hofestede assumes a nation as a single entity and appreciates the national culture of such entity, (e.g. the national culture is of "Great Britain" which happens to be comprised of England, Scotland and Wales) (Eringa, Caudron, Rieck, Xie, & Gerhardt, 2015; Mcsweeney, 2002). Further it has been argued that attributing the survey results of respondents from a single company (IBM employees) to the scoring of the entire nation would be an inappropriate representation of cultural dimensions of the entire population (Eringa et al., 2015; Mcsweeney, 2002).

2.10. Conceptualizing disease causation through established health/illness models and explanatory models

Cultural is widely recognized as a phenomenon that impacts the way in which different populations understand health and wellness and make sense of the root cause of disease. Understandings of disease causation vary drastically across different cultures and populations (Tamm, 1993). Researchers have developed theoretical frameworks to characterize and better understand how populations view illness. Many of these frameworks are based in prehistoric and primitive cultures or ancient philosophical works (Tamm, 1993).Further, explanatory models seek to describe both the etiology of the condition and also the treatments (Kleinman, 1980). Understanding how an individual sees the cause of disease is an important part of appreciating views about disabilities, disorders and pain and suffering (Oosterwal, 2009). Grasping the perspective of disease causation also provides insight into cultural views, of those affected with

disease, about appropriate disease prevention and treatment (Oosterwal, 2009). Health care providers should recognize that these models provide patients with comfort and may dictate coping (Oosterwal, 2009). Understanding these cultural perspectives on disease are essential to assessing and providing culturally appropriate and competent healthcare including genetic counselling (Greeson et al., 2001; Vaughn, Jacquez, & Baker, 2009). Although, not exhaustive, the following three models are widely discussed and understood in the context of genetic counselling and may accommodate the views of the participants in this study.

2.10.1. Biomedical Model

Most of the Western world, including Canada, tends to interpret the cause of disease, illness or disability within the framework of the biomedical model (Oosterwal, 2009). The biomedical model is firmly rooted in traditional Greek medicine and philosophy (Tamm, 1993). Philosophers of this time tended to see the world as dualistic, that there was a difference between spirit and matter or mind and body (Tamm, 1993). Greek medicine was influenced by numerous schools of thought at the time, including the natural science, and was a conglomerate of medicine, religion and philosophy (Tamm, 1993). It was not until the time of Hippocrates (460-379 BC) that science and religion began to separate, and the understanding of diseases were objective and a result of natural forces (Tamm, 1993). Today, the biomedical model acts to say that disabilities and disorders have biophysical, chemical and mechanical causes, which can be studied and controlled (Oosterwal, 2009). This paradigm suggests that there is an observable cause-and-effect relationship between natural phenomena, that can be tested and quantified (Oosterwal, 2009).

When medicine is distilled down to the dualistic nature of the biomedical model, it acts to exclude psychological, social and ecological factors (Seldin, 1977 as cited in Tamm, 1993; Tamm 1993). Thus understanding disease may be more complex and require an appreciation for interdisciplinary models that incorporate these extraneous factors (Tamm, 1993). In 1977 George L. Engle proposed such an interdisciplinary model, the biopscyhosocial model, to help explain the shortcomings he observed in the biomedical model. He described that the [bio]medical model is an appropriate framework for understanding and treating disease, but, that it does not have relevance to behavioural and psychological problems (Engle, 1977). Using the field of psychiatry as an example, he proposed that the biomedical model would reduce the field to behavioural disorders with underlying brain dysfunction (Engle, 1977). Engle (1977) suggested that the biopsychosocial model not only provides an understanding of "determinates of disease" and "rational treatments and patterns of health care", it also accounts for the patient's "social context'. This model offers a less reductionist and more inclusive approach to biomedicine. The biopsychosocial model opposed the dualistic view held by the biomedical model, of a separated body and mind, whereby the physician would focus on the disease and not the person (Borrell-Carrió, Suchman, & Epstein, 2004; Engle, 1977). Further the model accounts for the criticized reductionist medical thought that anything unexplained at a molecular level should be ignored (Borrell-Carrió et al., 2004; Engle, 1977).

In the ear of genomic medicine, diagnosis, treatment and prevention of many physical and mental disorders have become increasingly attributable to a genetic component (Roland & Williams, 2005). However, the idea of a genetic "risk" has made the distinction between chronic illness and wellness blurry at best, and providers are faced with the new challenge of future

disease risk, accessible through genetic testing (Roland & Williams, 2005). Roland and Williams (2005) propose that there is a need to utilize components of the biopsychosocial model in genomic medicine, especially when considering complex conditions characterized by their gene-environmental interactions (Roland & Williams, 2005). Overall, the model retains the biological causation of disease but incorporates psychological (beliefs, behaviour) and social (socioeconimc status, culture, religion) factors as well (Babalola, Noel, & White, 2017; Engle, 1977; Taukeni, 2019).The biopsychosocial model further suggests a need to treat the individual as a whole, evaluating behaviour, beliefs and coping strategies rather than changes to the physical state of the body alone (Taukeni, 2019).

2.10.2. Magico-Religious Model

Quite possibly the most widely spread model for understanding disease and illness is the magico-religious model (Uhlmann et al., 2009). This model suggests that people are surrounded by and depend on supernatural forces (Oosterwal, 2009). Disease and disability is thought to arise through sinning against God, disobeying social or religious taboos and other actions generally discouraged within a respective society (Oosterwal, 2009). As a result of the interaction with the supernatural world, disease and disability may also be caused by spells, curses, hexes and evil spirits (Oosterwal, 2009). The natural causes assumed in the biomedical model are thus mystical rather than organic (Oosterwal, 2009). It is logical then that treatments and coping are centred around the mystical, such as appealing to God through actions such as fasting, prayer, sacrifices and repentance (Oosterwal, 2009). As a result of understanding the cause of disease or disability to be from hexes, punishment, etc., there can be a negative view held of the affected individual

(Oosterwal, 2009). This can bring a great deal of shame to relatives, leading to isolation away from family and the public eye (Oosterwal, 2009). Although vastly different than the biomedical model, the magico-religious model may coexist with other models, and any one individual may be balancing more than one framework (Oosterwal, 2009).

2.10.3. Holistic Model

This paradigm suggests, individuals perceive themselves as being in harmony with their surroundings and nature, and with their spiritual world (Oosterwal, 2009; Tamm, 1993). If there is harmony, there is health; disease occurs when there is a loss of balance with the self and nature, self and others, or self and the spiritual realm (Tamm, 1993). Thus treatments for disease and disability may be those that aim to restore harmony and balance (Oosterwal, 2009). Hippocrates was influenced by the holistic concept of yin and yang, a practice common to Chinese and other Eastern and Southeast Asian cultures whereby there is a balance between two opposing forces (Oosterwal, 2009). This concept was taken on within the Arab peninsula, to Portugal and Spain, later to Mexico and across South America, and eventually to the Philippines (Oosterwal, 2009).

CHAPTER THREE

3.0. Review of Relevant Literature

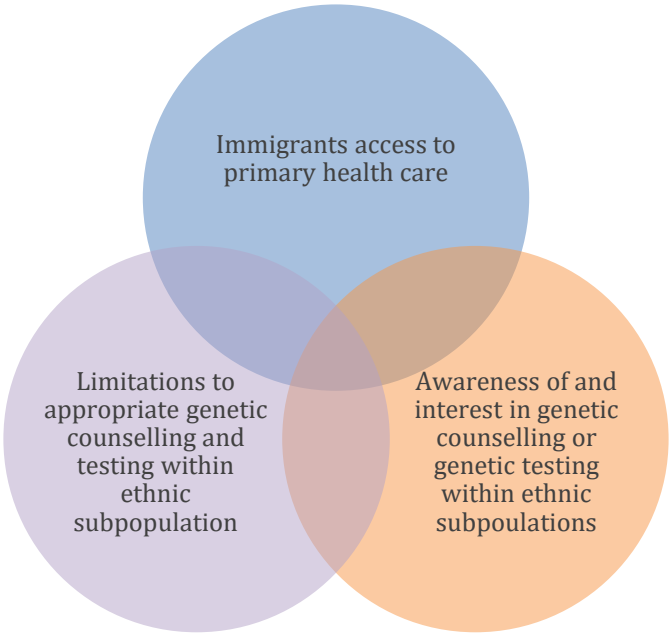


Figure 1: Literature review Venn diagram of overlapping areas of prior research. Literature was reviewed from all three subsections as depicted above. This research contributes to all three domains including immigrants' access to primary health care, knowledge and experiences with genetic testing within ethnic subpopulations, and outcomes of genetic counselling for ethnic subpopulations.

3.1. Introduction

To date, most literature regarding minority populations and genetic counselling and/or genetic testing have been selected for by ethnicity with or without a specific genetic indication. Although there is a large body of information regarding recent immigrants' access to primary health, the same is not true with respect to immigrants and genetic counselling and/or testing. To the best of the researchers' knowledge, there is currently little to no relevant genetic counselling research

that has selected a sample by recent immigration status. Additionally, there is a lack of Canadian specific research on this topic.

3.2. Minority populations' use of genetic counselling and testing has been historically limited but appears to be expanding with time.

Historical literature has indicated that most patients seeking genetic counselling had been upper and middle class Caucasians, and that those of minority cultures would rarely frequent such a service (RG & Whipperman, 1987 as cited in Greeson, Veach, & LeRoy, 2001). Recent literature suggests that there are still inequities in the utilization of genetic counselling and testing in ethnic subpopulations (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; Cheng et al., 2018; McCarthy et al., 2016; Muller et al., 2018; Sharkia et al., 2015). Such discrepancies are mirrored by recent literature exploring interest in participation in genetic and genomic research (A. G. Buseh et al., 2017). Armstrong *et. al.*, (2005) have suggested that this lower utilization is a racial difference that is not explained by socioeconomic factors, risk for carrying a mutation, risk perception, attitudes about testing or primary care provider discussion about testing. Yet others suggest underutilization of genetic counselling services is attributable, at least in part to income level, accessibility of service (physical location, transportation, and language barrier), attitude towards genetic counselling and religiosity (Sharkia et al., 2015). Moreover, this discrepancy might also be explained by awareness of genetic counselling services, something that can be quite low in certain populations (Adedokun et al., 2015; A. G. Buseh et al., 2017; Greeson et al., 2001; Joseph & Guerra, 2015; Sussner et al., 2013). Although there has historically been lower rates of utilization (RG & Whipperman, 1987 as cited in Greeson, Veach, & LeRoy, 2001), for example, low uptake of amniocentesis at an American centre that serves an ethnically diverse community (I. Mittman et al., 1998), it has been suggested that diverse populations do have an interest in genetic services, or at least agree to counselling and testing when offered (Komenaka et al.,

2016; Ricker et al., 2006). There has been longstanding acknowledgement for the need for a tailored service delivery to meet the unique needs ethnic minority populations (I S Mittman, 1998) and continued research with diverse populations, which is important and necessary during a time of genomic expansion to prevent disparities within these groups from continuing to widen (Cheng et al., 2018).

3.3. Seeking genetic counselling is influenced by awareness of genetic counselling in the general population and in targeted groups, but little is known about awareness in immigrant populations

The state of genetic counselling on a global scale is varied in its practice, training, certification and the overall recognition and acceptance of genetic counselling as a professional and independent health care field (Abacan et al., 2018). In low and middle income countries, the provision of genetic counselling is typically the physicians as there is little to no recognition of the profession of genetic counselling (Zhong et al., 2018). Further, uptake and understanding of genetic services is affected by social determinants such as education and socioeconomic status (Abacan et al., 2018).

3.3.1. Awareness in general populations

There is a growing body of literature that suggests there are gaps in awareness of genetic counselling/testing within the general population and within ethnic minorities (Hann et al., 2017; LePoire, Basu, Walker, & Bowen, 2018). There are two recent publications focusing on population wide awareness, both evaluating perceptions in a mainly Caucasian population (Maio, Carrion, Yaremco, & Austin, 2013; Riesgraf, Veach, MacFarlane, & LeRoy, 2015). In an effort to gain a clearer picture of the Canadian public's perspective, Maio *et. al.* conducted a

quantitative study assessing the awareness of and perceptions of genetic counselling's purpose at a population level (Maio et al., 2013). About 1/3rd of these Canadian participants (31%) had heard of genetic counselling (Maio et al., 2013). A majority of individuals seem to have an understanding about the purpose of genetic counselling, with most people (87%) indicating that genetic counselling provides genetic testing for people with "family histories of genetic conditions" (Maio et al., 2013). Most individuals (87%) identified that genetic counsellors would provide "information and support to couples planning pregnancies that may be at an increased risk for genetic conditions" and 86% of respondents said that genetic counselling could provide information and support to "pregnant women whose babies may be at risk for a genetic condition" (Maio et al., 2013). However, there were also a sizeable number of participants who had a poor understanding of the roles of a genetic counselling. Approximately half of the respondents (46%) thought that the purpose of genetic counselling was to "advise people about whether or not to have children", to educate people about ancestry (51%) and most participants (75%) thought the purpose of genetic counselling was to "prevent genetic diseases or abnormalities" (Maio et al., 2013). Population wide perceptions and attitudes towards genetic counselling and genetic testing were further explored in the context of a rural American area (Riesgraf et al., 2015). Participants responded to anonymous questionnaires evaluating level of familiarity, perceptions and attitudes about genetic counselling, and hypothetical willingness to use genetic counselling for the residents of rural communities (Riesgraf et al., 2015). Most individuals from this rural population were unfamiliar with genetic counselling (Riesgraf et al., 2015). Nearly half (47%) of respondents reported that they had heard of the term "genetic counselling", and of these individuals, about half (48.4%) had heard of this from media (Riesgraf et al., 2015). Individuals had a representative perception of the scope of genetic counselling

services, agreeing that genetic counselling was not only useful to pregnant women (Riesgraf et al., 2015). These responded had more accurate perceptions of the profession than did those in the Maio *et. al.* (2013) population, however, this could be attributed to the provision of a definition of genetic counselling to participants which was not done with the other sample (Riesgraf et al., 2015). Much like Maio *et. al.* (2013), there was a large minority of individuals who agreed with the statement "the goal of genetic counselling is to keep genetic problems out of society" (Riesgraf et al., 2015).. Some people may feel that genetic counsellors have a eugenics-based agenda or that genetic counsellors do not accept individuals with genetic conditions (Riesgraf et al., 2015). Or that there was at least an extrapolation of the provided genetic counselling definition to this end (Riesgraf et al., 2015). It is possible however, that individuals may not think genetic counselling is eugenic in nature, rather that it acts to provide treatments, because nearly half of responded agreed with the statement "genetic counselling can help cure a genetic problem" (Riesgraf et al., 2015).

3.3.2. Awareness in ethnic specific populations

Awareness of genetic counselling/testing services is also quite low in ethnic populations both in North America and abroad (Adedokun et al., 2015; Awwad et al., 2008; Belahcen et al., 2014; A. G. Buseh et al., 2017; Greeson et al., 2001; Hann et al., 2017; Joseph & Guerra, 2015; Sussner et al., 2013), such that they may only seek this service if referred by other health care providers (Cragun et al., 2015; Greeson et al., 2001). Although some studies have been conducted outside of North America on both majority and minority non-Western populations (Adedokun et al., 2015; Belahcen et al., 2014) the majority of literature stems from America and is primarily investigating Hispanic, Asian and African American populations within the cancer and prenatal

settings. Awareness of genetic counselling services for BRCA testing in at-risk Latinas (both immigrant and American born) groups appears to be low or moderate (Joseph & Guerra, 2015b; Sussner et al., 2013). Although about half of participants reported little to no awareness about genetic counselling for inherited disease and for breast and ovarian cancer, knowledge about the benefits to undergo BRCA genetic counselling were quite high and attitudes and belief about genetic counselling for BRCA were mainly positive (Sussner et al., 2013). Belahcen *et. al.* (2014) highlighted limited awareness of Down Syndrome prior to the birth of an affected child in a study conducted with 50 Muslim Moroccan mothers of children with Down Syndrome (Belahcen et al., 2014). Furthermore, this study found that 2/3rd of respondents did not know what prenatal screening was (Belahcen et al., 2014). Despite these gaps in information, mothers had a positive attitude about prenatal screening for Down Syndrome; most felt that screening would be useful, and that they would undergo this screening in a future pregnancy (Belahcen et al., 2014).

Minority groups' awareness of genetic counselling/testing may also be a result of inadequacies of provider referrals to genetic services (Muller et al., 2018). In a recent study evaluating referral rates following abnormal tumour testing for colorectal cancers in African American, Hispanic and non-Hispanic white patients, referrals of African American and Hispanic patients were found to be lower than the non-Hispanic white population (Muller et al., 2018). There was, however, no population differences in those seen by a genetics provider if a referral was actually made (Muller et al., 2018). Health care provider recommendation and referral can be important in terms of awareness and accessing service (Hann et al., 2017; Muller et al., 2018). Overall,

inadequate referrals to specialist services in general are commonly reported among Canadian immigrant groups (Carrasco et al., 2009; Higginbottom, Hadziabdic, Yohani, & Paton, 2014). There exists a large gap in genetic counselling delivery and thus an associated gap in positive outcomes for potential patients, in that those who are unaware of genetic counselling services are unlikely to access it (Maio et al., 2013). This provides evidence of the need to increase awareness not only at the population level but also within minority populations. The idea of raising awareness and educating through community outreach or online education has been proposed by some (A. G. Buseh et al., 2017; Chen et al., 2016).

3.4. Ethnic specific populations' knowledge of general genetics

Although awareness of genetic counselling services may be low, knowledge of general genetics, inheritance and risk are moderate (Adedokun et al., 2015; Hann et al., 2017; Sharkia et al., 2015). In a study evaluating the perceptions of genetic testing in deaf communities in Nigeria, about half of respondents indicated knowledge about the heritability of hearing loss (50.0%) (Adedokun et al., 2015). Research investigating the utilization of prenatal genetic counselling services among Arab women in Israel found that most pregnant women enrolled in the study had good knowledge levels about genetic genetics and the risk factors associated with genetic diseases, as well as folic acid usage in pregnancy (Sharkia et al., 2015). However, a study asking 101 African American women about their health beliefs regarding genetic testing and counselling for sickle cell disease found that only half of respondents understood recessive inheritance, and that perceived susceptibility to having an affected child was associated with having this understanding of recessive inheritance (Gustafson, Gettig, Watt-Morse, & Krishnamurti, 2007).

Surveys investigating American Black African immigrants'/refugees' knowledge and perceptions of participating in genetic research revealed a correlation between genetics knowledge and participants' perceptions of the disadvantages of genetics research (A. Buseh, Kelber, Millon-Underwood, Stevens, & Townsend, 2014). Higher genetics knowledge was associated with decreased perceived disadvantages of genetics research (A. Buseh et al., 2014). Not unlike other groups selected by ethnicity, participants had a number of misconceptions about genetic concepts even though in this case half of the group was college educated (A. Buseh et al., 2014). In further studies of Black African immigrants in America, individuals argued for the need for more awareness about genetics and genomics with respect to improving health for African communities (A. G. Buseh et al., 2017). Some samples selected by ethnicity may have little or no awareness of genetic counselling (Awwad et al., 2008), while others may have higher knowledge levels with respect to genetics and genetic counselling (Sharkia et al., 2015), which may be in part a result of recruiting individuals who had or had not received genetic counselling.

3.5. Ethnic specific populations interest in genetic counselling and/or testing

Willingness or interest to undergo genetic testing and/or counselling for immigrants and ethnic subpopulations in Westernized countries appears to be high, but may vary depending on its purpose and knowledge of the genetic indication (Cheng et al., 2018; Greeson et al., 2001; Komenaka et al., 2016; Singer, Antonucci, & Hoewyk, 2004; Thompson et al., 2002). Some immigrants appear to accept and are willing to undergo genetic testing, seeing little negatives or reasons not to, even when they are unconvinced about the inherited nature of their condition (Cheng et al., 2018). Attitudes about genetic testing among ethnic minorities, including African

American, Hispanic and Asian population has also been found to be positive, with respect to cancer susceptibility (Hann et al., 2017). Interest in genetic testing and/or counselling may be influenced by perceived barriers to genetic testing, such as anticipated emotional distress, stigma, confidentiality concerns and family-related guilt and/or shame (Sussner et al., 2009; Thompson et al., 2002). In fact, Thompson *et al.* (2002) found that African America women who declined BRCA genetic counselling were more likely to be concerned about negative emotional reactions about genetic testing than those who underwent counselling, irrespective of decision to pursue testing afterwards (Thompson et al., 2002). Those who accepted genetic counselling, irrespective of genetic testing choice, were found to have more intrusive thoughts about breast cancer, suggesting that perceived and actual stress can have differing impacts on interest in genetic counselling (Thompson et al., 2002). In one study evaluating the impacts of acculturation and breast cancer-specific distress, results indicated that foreign-born African American women anticipated negative emotional reactions about genetic testing more than US-born African American women (Sussner et al., 2009). Interest in genetic testing in non-Western countries is also starting to grow. In a sample of 150 deaf individuals in Nigeria, there was a significant interest in genetic testing (57%) with a lower interest in prenatal testing for deafness (Adedokun et al., 2015). The majority of respondents indicated that they perceived genetic testing as "doing more good than harm" (79.3%) (Adedokun et al., 2015). It is also important to bear in mind that although the testing may be acceptable, the relevance of the results may be limited given the context and an individuals cultural or religious norms (Greeson et al., 2001; Singer et al., 2004). Furthermore, interest in genetic testing does not always correlate to high uptake of the process. For example, Gustafson *et. al.* (2007) found that African American women may feel that sickle cell disease is severe, that there are benefits to the screening of sickle cell trait and that there are

minimal barriers to attaining this screening, yet they feel there is a lower level of personal risk to have a child with such a condition (Gustafson et al., 2007). This perception of low susceptibility may act to explain the low uptake of genetic counselling and testing in some groups (Gustafson et al., 2007).

3.6. The health belief model as a framework for visualizing health seeking behaviour in the context of genetic counselling with newcomer populations

There are a number of health system models that explain health-related behavioural intentions, in an effort to understand, predict and modify behaviour. The Health Belief Model (HBM) was one of the first and most widely used behavioural science theories applied to health behaviour. The HBM arose largely during a time when the U.S. Public Health Service sought to explain the public's use of available preventable health services during the 1950's (Rosenstock, 1974). Today, the HBM provides a conceptual framework for an individual's propensity for engaging or not engaging in a health related behaviour. At its most basic level, the HBM can be described by three categories: individual perceptions, modifying factors and action (Rosenstock, 1974). Individual perceptions include both the perceived susceptibility or one's subjective feelings about contracting a condition, and perceptions of severity where an individual has evaluated the medical and social consequences of the disease (Janz & Becker, 1984; Rosenstock, 1974). Individual perceptions are also subject to the effects of the perceived benefits weighted against the effects of the perceived barriers to taking action, which in turn can also include perceptions of self-efficacy (Janz & Becker, 1984; Rosenstock, 1974; Strecher, McEvoy, Becker, & Rosenstock, 1986). Modifying factors include demographics, sociopsychologic and structural variables (Rosenstock, 1974). Cues or triggers to taking action might include internal or external events (Rosenstock, 1974). Models such as this have been useful in explaining uptake of genetic

services; one example includes, acceptance and uptake of genetic counselling and genetic testing for sickle cell disease in African American women (Gustafson et al., 2007). The model also fits well as a framework in other recent studies to explain decision-making and outcomes in pre-natal genetic counselling for Palestinians and Palestinian Americans (Awwad et al., 2008), and factors involved in underutilization of genetic counselling services in Israeli Arab women (Sharkia et al., 2015). A modified version of the HBM is depicted in Figure 2 (Janz & Becker, 1984; Rosenstock, 1974; Strecher et al., 1986).

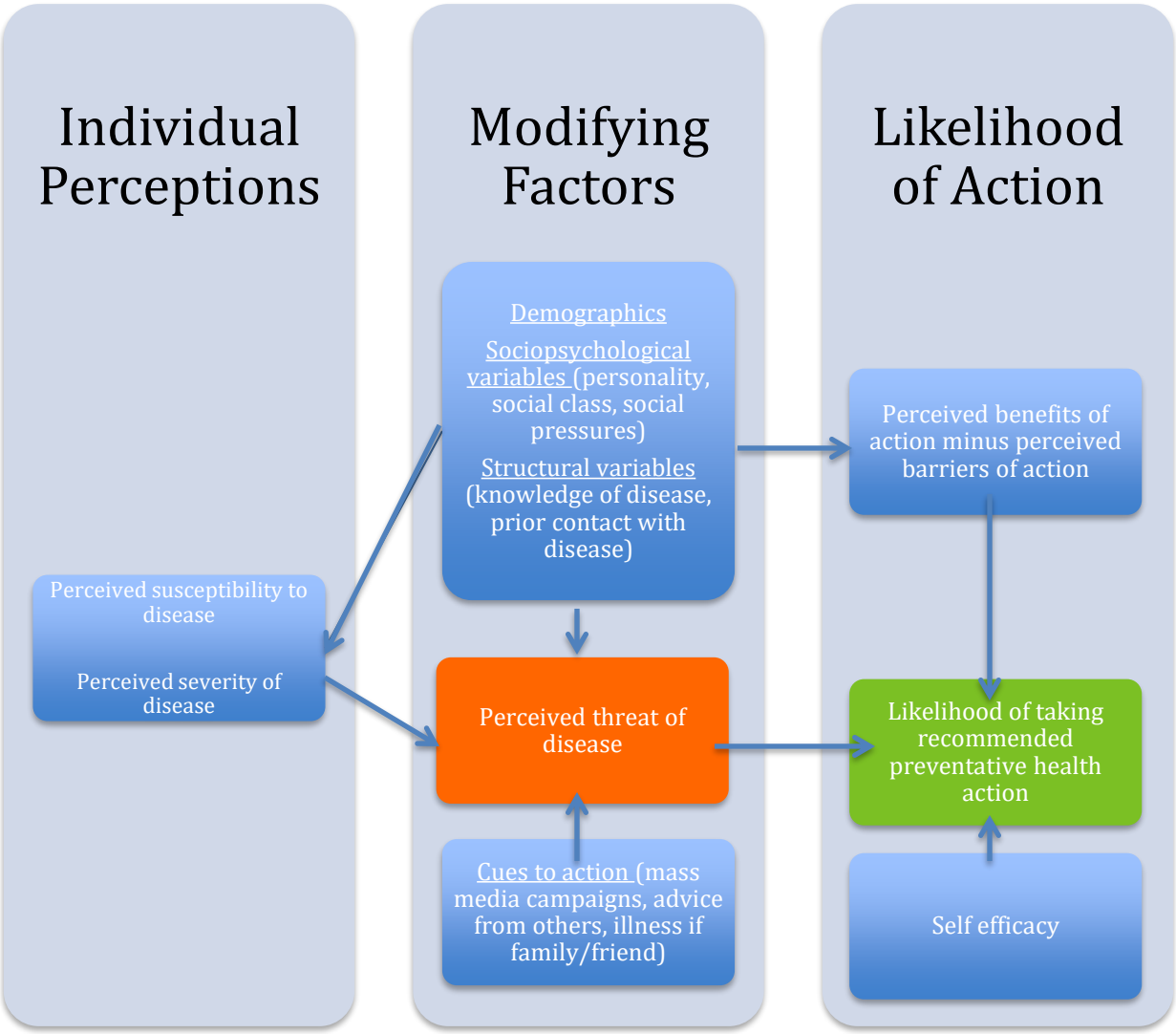


Figure 2: Health beliefs model*

*modified model based on models and comments of Janz & Becker, 1984; Rosenstock, 1974; Strecher, V.J., DeVellis, B.M., Becker, M.H., & Rosenstock, 1986

3.7. Limitations to effective genetic counselling and genetic testing, and the associated outcomes for immigrant and/or diverse ethnic subpopulations

A growing body of literature has evaluated patient experiences and outcomes with respect to genetic counselling and genetic testing. Some of the research evaluates the experience of immigrants in Western and non-Western countries and other research assess the outcomes for groups selected by ethnic subpopulation within a home country. This growing body of research has evaluated many aspects of the counselling and testing process including interest in testing, desired information, counselling and communication style and importance of counsellor to have cultural specific knowledge relevant to the testing (Adedokun et al., 2015; Joseph & Guerra, 2015; Wal et al., 2015).

3.7.1. Communication

Genetic counsellors recognize the challenges associated with communicating with patients through literacy level, language and cultural difference (Joseph & Guerra, 2015). Recent studies reveal that gaps in the communication process exist between providers and patients from ethnic specific subpopulations that have impacts on decision-making and outcomes for participants (Cheng et al., 2018; Gesser-edelsburg & Shahbari, 2017; Joseph & Guerra, 2015; Jun et al., 2018; Wal et al., 2015). These include communication style, ability to balance informational and emotional needs of patients, while providing clear and detailed information without confusing or overwhelming patients; additionally, it involves attending to language barriers, cultural differences and religious influences, and building trust with patients (Greeson et al., 2001;

Joseph et al., 2017; Joseph & Guerra, 2015; Ricker et al., 2006; Sussner et al., 2009; Wal et al., 2015).

A central tenet of genetic counselling is its non-directive approach to decision making (Accreditation Council for Genetic Counseling, 2015). That is, the counsellor empowers the patient to make their own autonomous decisions independent of the values of the counsellor (Oduncu, 2002). This style of counselling allows for the patients to make choices in line with their personal goals and philosophy on life, taking into account their ethical and religious affiliations (Oduncu, 2002). Although widely adopted and seen as important by professionals in the field, non-directive counselling may be perceived by some ethnic groups as lacking empathy and insensitive, or irrelevant in non-Western contexts (Gesser-edelsburg & Shahbari, 2017; Raz & Atar, 2003). Some may prefer a directive approach, given that the non-directive style may cause individuals to feel at a loss, when a clear direction about testing is not provided (Jun et al., 2018; I. Mittman et al., 1998). Interpretations of the non-directive counselling may thus be a result of an individual's cultural perceptions, expectations and values (Raz & Atar, 2003). Patients may look for these more directed answers by engaging with family, community members or traditional medicine practitioners (I. Mittman et al., 1998). Some feel that non-directive counselling is a Western ideal that is unattainable for ethic and religious minorities (Raz & Atar, 2003), which may be a sentiment shared by similar newcomer populations living within Westernized countries.

3.7.2. Information needs

Recent findings suggest an information barrier for patients of diverse ethnic backgrounds, bringing into question the relevance and utility of all information provided in a genetic counselling session, with some suggesting that the genetic counselling session may be less about information-seeking and more about emotional management (Cheng et al., 2018; Joseph & Guerra, 2015; Sussner et al., 2009; Thompson et al., 2002). In one such study, most participants appeared to lack understanding of education provided about genes and genetics, in that the counsellors attempted to simplify the message, but ultimately provided more information about genes and genetics than patients understood (Joseph & Guerra, 2015). This information overload, seemed to represent a misconception about the needs of the patient (Joseph & Guerra, 2015). Most of the Latina immigrant participants of this study did not seem to need or desire this information to understand the concept of risk (Joseph & Guerra, 2015b). Most were concerned about the purpose of the test and the impacts on family members (Joseph & Guerra, 2015). Further research has indicated that individuals may still make decisions based on imperfect understanding and erroneous information (Jun et al., 2018). A recent study of Korean-American immigrants decision-making in the prenatal context, found that the majority of participants reported not completely understanding the information discussed with their provider and that they experienced difficulties communicating (Jun et al., 2018).

3.7.3. Language barriers

Other limitations were simply a result of a language barrier. Although medical interpretation may be available, the language barrier may persist as a result of inconsistencies in medical interpretation, both in technologies and individuals used to provide this service (Joseph &

Guerra, 2015). This is a limitation that may be mitigated by genetic counsellors using a number of techniques or by increasing bilingual counsellors - an initiative not possible with the current genetic counselling workforce (Joseph & Guerra, 2015; Ilana Suez Mittman & Downs, 2008; National Society of Genetic Counselors, 2018a; Ricker et al., 2006; Sharkia et al., 2015). Other research has demonstrated that patients frequently misunderstand the information provided by genetic counsellors, even when trying to answer or clarify questions (Cheng et al., 2018). For example, patients wanted direct answers, which might be difficult for genetic counsellors to provide when they attempt to explain complicated nuances, uncertain information or information that changes with scientific discovery (Cheng et al., 2018). However, others have highlighted that participants require accurate and detailed information (Wal et al., 2015). A study of 12 pregnant Muslim women who were 1st or 2nd generation immigrants in the Netherlands, suggest that respondents wished for accurate and detailed information both about the protocol of the testing and the possible anomalies that the testing would illuminate (Wal et al., 2015). This discrepancy in information needs of patients of ethnic minority might represent the context and indication of the counselling.

3.7.4. Cultural differences

Genetics involves some of the most intimate and private topics, opening discussion about family structure, ethnicity, race and personal identity and thus demands that those who work within this field, approach such topics with cultural knowledge, empathy and openness (A. G. Buseh et al., 2017; Jennings, 2003). It is widely known that the cultural background of patients can impact patient care in genetic counselling (Oosterwal, 2009). Research regarding discrepancies between the cultural backgrounds of patient and counsellor show that there may be difficulties in

connecting between different worldviews in the genetic counselling setting, and that traditional genetic counselling might be limited for immigrant populations (Cheng et al., 2018; Greeson et al., 2001). Differences in patient and provider cultural backgrounds may allow for misconceptions to go unnoticed by the counsellor (Cheng et al., 2018). Understandings about the cause of inherited diseases, can be quite different for Western providers and non-Western immigrant, with disease causation having roots in spiritual, behavioural and environmental causes depending on the cultural group (A. G. Buseh et al., 2017; Cheng et al., 2018; Greeson et al., 2001). Individual's cultural beliefs can have important influences on actions taken to prevent or treat illnesses (A. G. Buseh et al., 2017). Culture, race and/or ethnicity can also have implications for patients' knowledge and sharing of their family health history (Chen et al., 2016; Orom, Coté, González, Underwood, & Schwartz, 2008). Furthermore, holding such non-Western cultural beliefs has been shown to influence participation in genetics and genomics research (A. G. Buseh et al., 2017). For example, there were prevailing views among low-income Chinese-American immigrants in a study that described participants understanding of the cause of cancer as environmental or behavioural despite having a working knowledge that diseases could run in families (Cheng et al., 2018). This study found that the new information given by genetic counsellors about inheritance was not incorporated into the patients' existing belief system (Cheng et al., 2018). This phenomenon was attributed to short-comings of the current model of genetic counselling where a large part of the session is focused on education of genetics and not on understanding patient expectations or bias (Cheng et al., 2018). Strong culturally specific views about the cause of disease can have impacts on reproductive choices and may limit the utility of genetic testing (Greeson et al., 2001). Studies suggest genetic counsellors should be familiar with patients ethno cultural worldviews, and that patients prefer if their counsellor has

practical knowledge of their faith relevant to the context of the screening test of interest (Raz & Atar, 2003; Wal et al., 2015). Moroccan Muslim 1st and 2nd generation immigrants wanted to be respected and treated as a person with an Islamic background, an issue that was especially relevant when they indicated a preference for their counsellor to bring up moral issues to allow for a values-based discussion about informed choice and testing in the prenatal context (Wal et al., 2015). Other research suggests that genetic counsellors should refer patients to culturally relevant supports, such a consulting a "Fikh" (and Islamic jurisprudence committee) to ask about the acceptability of termination in their situation (Greeson et al., 2001). Previous studies have shown a probable positive impact of culturally tailored genetic counselling, yet indicate that further research investigating its impact is needed (Sussner et al., 2009).

3.7.5. Trust

Genetic counsellors should foster trust, rapport and good communication within the patient-provider relationship (Veach et al., 2007). Building a trusting relationship with providers of different cultural backgrounds may be difficult (Browner, Preloran, Casado, Bass, & Walker, 2003). Medical mistrust between immigrants and health care providers, including genetic providers and the greater medical system, has been widely documented in North America (Browner et al., 2003; Chen et al., 2016; Dastjerdi, 2012; Greeson et al., 2001; Reitmanova & Gustafson, 2009; Suther & Kiros, 2009). Further, studies have shown that immigrants may withhold information from providers out of fear or mistrust (Chen et al., 2016; Greeson et al., 2001). Overall, immigrant patients may have low trust in their genetic service providers, with the exception of one study known to the researcher, that has indicated low medical mistrust in a

sample of at-risk Latina American women in New York City in the context of cancer genetic counselling (Sussner et al., 2013).

3.8. Summary

There is a long history of research indicating that the provision of genetic health care for ethnic specific groups and/or immigrant populations is less than ideal. Taken together it is evident that there are numerous barriers to appropriate access to genetic counselling services shared among immigrants and ethnic specific groups, although some limitations are more specific to newcomer populations. We ask the questions, why after many years of researching ethnic subpopulations experiences with genetic counselling service, do we continue to see similar trends? Where have we gone wrong? Are we asking the right questions, or rather is it an issue with training and implementation? With these important questions in mind, we aim to contribute to the substantial body of literature studying ethnic specific groups experiences with genetic services and the considerably smaller amount of research directed at immigrants use of the service. Moreover, we seek to elicit critical areas of future research and provoke discussion about emerging topics in this field.

CHAPTER FOUR

4.0 Methods

4.1. Study Design

This study followed an exploratory generic qualitative methods design (Kahlke & Hon, 2014; Merriam & Tisdell, 2016). Generic, basic or interpretive qualitative approaches are those who are not bounded strictly enough to be deemed methodologies in the traditional sense, e.g. phenomenology, grounded theory, narrative analysis or ethnographic study (Kahlke & Hon, 2014; Merriam & Tisdell, 2016). Originally constructed for the needs of nurses in research seeking to explore human health and illness experiences, this methodology is applicable to many disciplines such as health science and education that are linked closely to their practice settings (Kahlke & Hon, 2014; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). The generic qualitative approach seeks to understand how individuals make sense of their lives and experiences; generic qualitative approaches do this through investigation of 1) how an individual understands their experience, 2) how they construct their world, and 3) what meaning the individual then assigns to the experience in question (Merriam & Tisdell, 2016).

The participants, recruitment, interviews and data analysis are described in separate sections below. The overall study design is displayed in Figure 3.

The study was approved by the University of Manitoba's Bannatyne Campus Health Research Ethics Board (REB approval number HS21876; H2018:232) and the Health Sciences Centre Research Impact Committee (RIC #: RI2018:070).

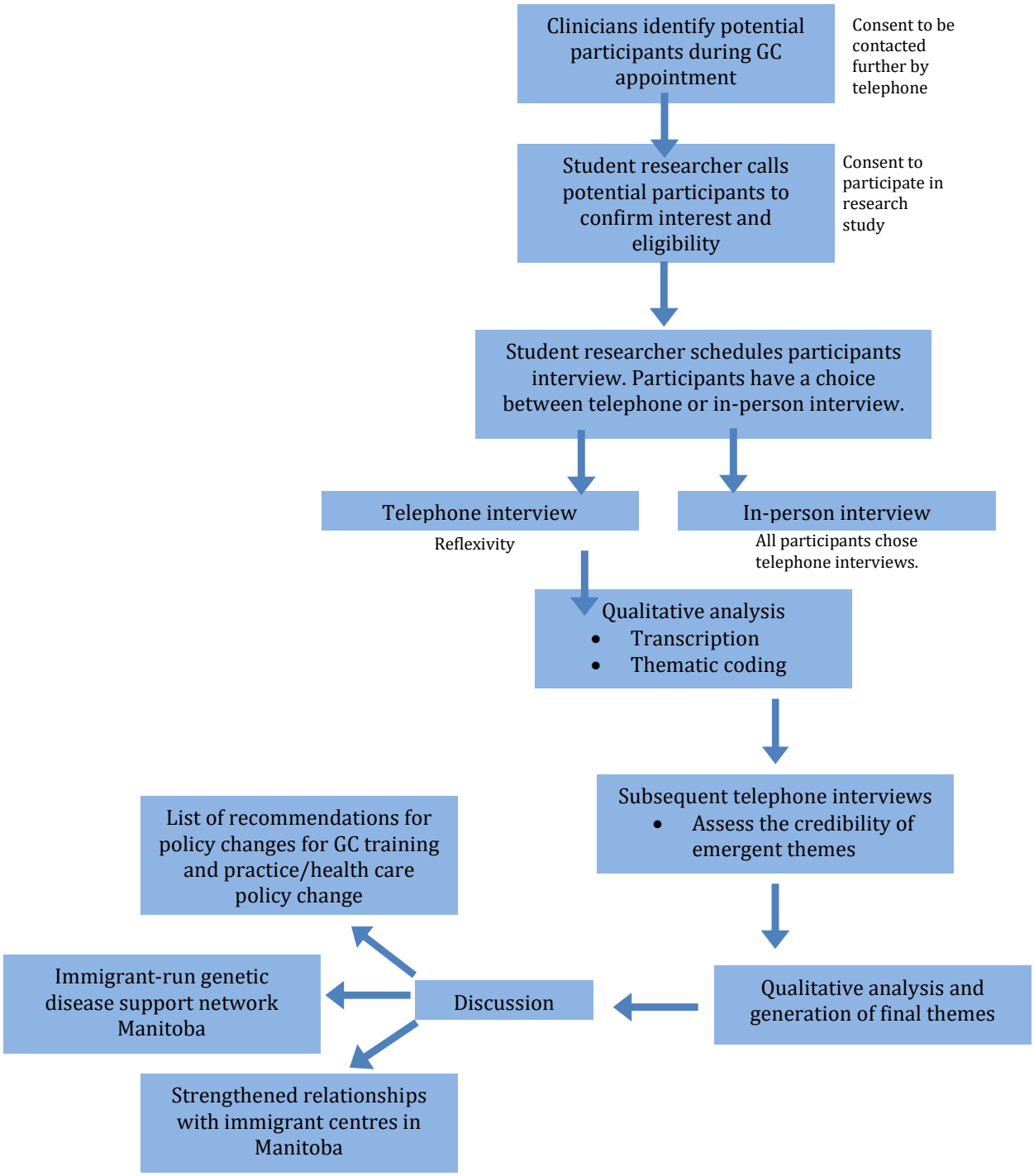


Figure 3: Overall study design/research plan flowchart

4.2. Interviews

4.2.1. Study participants

The participants of this study were recent immigrants to Canada from any country of origin (not born in Canada, currently lives in Canada, and resided in Canada for 5 years (Asanin & Wilson, 2008; Greeson et al., 2001; Leduc & Proulx, 2004; Woodgate et al., 2017) or less). They were 18 years or older (at the time of the genetics appointment), who were referred for a genetic counselling appointment (with a genetic counsellor or geneticist) for any indication. Individuals who were living in Canada for a period of time, who subsequently left Canada and then returned later, were considered recent immigrants to Canada if their total time living in Canada was 5 years or less. Individuals were recruited to the study by the clinician regardless of the context of the appointment. This means that some individuals may have been recruited following a short appointment, where "genetic counselling" in its formal definition did not take place. It was assumed that this interaction might be insightful in the context of policy changes given that individuals from this population may have these encounters with the Program of Genetics & Metabolism in the future. Participants were invited to participate in the study based on the following inclusion and exclusion criteria (Table 2).

Table 2: Participant eligibility including inclusionary and exclusionary criteria

To participate in this study, you must meet ALL of the following criteria:	You cannot participate in this study if you meet one or more of the follow:
✓ You are at least 18 years old ✓ You were born outside of Canada ✓ You currently live in Canada ✓ You have lived in Canada for 5 years or less ✓ At least one of the following situation applies to you: o You personally were referred for, and attended, an appointment in the Program of Genetics and Metabolism o You are the parent or guardian of someone who was referred for, and attended, an appointment in the Program of Genetics and Metabolism, AND you accompanied this person to their appointment o You are the spouse/partner of someone who was referred for, and attended, an appointment in the Program of Genetics and Metabolism, AND you accompanied this person to their appointment	X You are another relative of someone who had an appointment with the Program of Genetics & Metabolism who did not attend the genetic counselling appointment (i.e., you do not meet the criteria listed in the column on the left) X You are an individual who did not attend any appointment in the Program of Genetics and Metabolism X You are an individual who will not be able to be contacted in follow-up over the duration of the study (September 2017 – September 2019).

4.2.2. Recruitment

Recruitment took place at the Winnipeg Regional Health Authority (WRHA) Program of Genetics & Metabolism in Winnipeg, Manitoba, Canada. Prospective participants were patients referred to the Program of Genetics and Metabolism. Prospective participants were invited to participate in this study following their most recent genetic counselling appointment. Genetic counsellors and geneticists (henceforth called "clinicians") identified potential study participants during or following an appointment based on the eligibility criteria, as listed above (Table 2). The clinicians investigated if the patients were born in Canada. If not, the clinician further

evaluated participant eligibility. Following the appointment, clinicians briefly explained the study to the potential participant(s) and gained consent for the student researcher to contact them by telephone.

The student researcher contacted the potential participants by telephone (or by their preferred method of communication), to explain and discuss the study in detail, obtain verbal consent to confirm the appointment by using the participants kindred number (Medical Genetics chart number), and to obtain informed consent to participate in the study (although in practice, this appointment attendance verification process was ceased due to practical reasons). The student researcher obtained consent from the participants using the "Letter of Invitation and Informed Consent Form" (Appendix II). To avoid complications with English as a second language for participants, the student researcher followed the "Phone Script for Eligibility" (Appendix II) when obtaining informed consent from potential participants by telephone. If the participant had indicated the need for interpreter services, a telephone interpreter was arranged. After acquiring informed consent verbally, a telephone or in-person interview was scheduled with participants. The method of interviewing was left to the decision of the participant. For in-person interviews, participants were asked to bring their signed form to the meeting, or sign a new copy at the appointment. If the participant wanted to conduct the interview at the time of obtaining consent on the telephone, the participant was asked for their consent verbally over the phone, as long as they had time to read and review the Letter of Invitation and Informed Consent Form in advance of the phone call. Verbal consent also applied to an individual who had returned the Letter of Invitation and Informed Consent form by mail but whose form has not yet been received by the student research at the time of a scheduled telephone interview. Verbal consent at the start of the

telephone interview was sufficient as long as the participant had again, had time to read and review the "Letter of Invitation and Informed Consent for Participants to Participate in Research" in advance of the telephone interview date.

Consent was obtained from individuals with physical disabilities who are able to consent independently. Individuals with intellectual disabilities who are unable to consent independently were not a part of this study.

For all participants asked to give verbal at the time of the interview or at a phone call prior to the interview, a photocopy of the consent form, signed on behalf of the participants was mailed to them for their records.

Our aim was to recruit at least 10 participants. Recruitment was to be stopped at 30 individual participants, or until the point of data saturation, whichever occurred first (Hill, Clara E, Thopson, B. J., Williams, 1997; Hill et al., 2005; MacFarlane, Ian, McCarthy Veach, Patricia, LeRoy, Bonnie, 2014; Patton, 1990).

4.2.3. Compensation

Participants received a $15 gift card for a major box store as compensation for their time and to offset costs to travel to the interview. This compensation was provided to all individuals who consented to participate in research and who conducted the interview in full or in part. The compensation was mailed to participants.

4.2.4. Instruments

We used a semi-structured interview guide containing 7 open-ended questions and suggested prompts that invited participants to share their perspectives and describe their experiences with genetic counselling followed by demographic questions. The interview was designed to use original questions as well as themes from established empirical literature relating to genetic diseases and services (Adedokun et al., 2015). Immigrant Centre Manitoba Inc. and Manitoba Interfaith Immigration Council-Welcome Place, herein called "immigrant centres," were invited to participate in the validation of our interview guide and to ensure that all questions were asked in an appropriate manner so that they are neither too personally invasive nor culturally insensitive. The interview guide included questions to elucidate the participants' knowledge and experience of genetic counselling prior to and after their appointments, understanding of heritability of genetic disease, cultural perceptions of disability and disease, and opinions on whether genetic testing is helpful or harmful (which may include perceptions of the utility of carrier testing in parents, and genetic testing in children and/or prenatal diagnosis of the fetus, depending on the indication for referral). The interview guide also included questions about the participants' understanding of and the cultural appropriateness of the information received and the challenges encountered before, during, or after the appointment. Other issues that were addressed by the interviews related to how the participants felt the appointment would affect their management of genetic disease, and if the participants would have preferred to discuss different information that would have been more relevant and useful to them. In addition, the interviews included closed-ended questions about demographics. We assessed demographic variables that could impact acculturation, such as gender, country of origin, length of stay in Canada, mother tongue, age and marital status, ethnic background/religious belief, education

level, number of people in household, income level, and/or what social and financial supports are currently available, which may impact access to health care and/or the decision making process in genetic counselling (Asanin & Wilson, 2008; Awwad et al., 2008; Greeson et al., 2001; Woodgate et al., 2017). We inquired about these factors to better understand and explain how they pertain to our participant's experiences with genetic counselling services. We collected information about marital status, education level, number of people in household, income level and available social and financial supports, such that we could draw conclusions about the impacts that emotional and financial support systems have on cultural difference. These demographic variables were also collected so that we could speak about what supports are available or lacking for immigrants. Further, we asked participants for their reason for referral in order to discuss the data in the context of different medical indications. Moreover, these demographic questions were essential to analyse the transferability of our research findings (Trochim, 2000).

4.2.5. Pilot Study

The student researcher conducted a pilot interview session with a community member who was an employee of one of the immigrant centres and an immigrant to Canada of 1 year. The interview was conducted in the presence of two committee members. The interview was audio recorded for review by the student researcher. The pilot interview participant and the committee members gave feedback to the student researcher. Suggestions were minor and included changing the student researchers' phrasing in the way two demographic questions were asked, and encouraging the student researcher to use more probes and question participants further.

4.2.6. Data Collection and Interviewing

The student researcher conducted all interviews using a generic qualitative approach to understanding lived experiences (Kahlke & Hon, 2014; Woodgate et al., 2017). Individual interviews were conducted in-person or by telephone using an approved semi-structured interview guide. The interview guide can be reviewed in Appendix III.

The interviews were conducted in English, unless a telephone interpreter was requested or required (2 participants). In such a case, the student researcher scheduled a professionally trained and certified WRHA Language Access professional interpreter who performed their role in accordance with the WRHA Language Access Code of Ethics and Standards of Practice for Interpreters (Winnipeg Regional Health Authority, 2018) and the Personal Health Information Act. Interpreters were given a short information session about the research study and the qualitative interview style before the interview process. The same interpreter(s) were hired for the same language interpretation through the duration of our study. We collected information about the recruitment, screening and training required to be employed as an accredited WRHA Language Access Interpreter (Squires, 2009).

All telephone interviews were audio recorded and transcribed by the student researcher. The questions were asked in approximately the same order to allow for consistency of topics discussed and for comparison of participants' responses. The student researcher frequently asked probing questions or gave prompts to bring out the participant experience. The student researcher took notes during the interviews. Following the interview questions, participants were given the opportunity to provide suggestions about improvements to the genetic counselling services to

create a positive experience for them in using these services. The student research participated in reflexivity before, during and after conducting the interviews by taking notes about her expectations of the interview, knowledge of or biases that she may have about the participant, the interaction with the clinician who recruited the participant, feelings before/during/after the interview and events of the interview day. In addition, short notes about the style of the interview, affect of the participant, important points or interesting thoughts that the student researcher thought may be important were noted down.

4.3. Data Analysis

4.3.1 Transcription

The student researcher transcribed the audio-recorded interviews using verbatim transcription, into a password-protected Microsoft Word document (Mclellan-lemal, 2003). Any names or birthdays stated in the interviews were not included in the transcripts. The documents were later cleaned in an intelligent verbatim transcription method by removing repetitive wording, filler words (e.g. 'um', 'uh', 'you know', etc.) and minor grammatical issues that arose due to participants' conversational level of English (Aufegger, Bicknell, Soane, Ashrafian, & Darzi, 2019). Inaudible sections were excluded using a "…". This cleaning was done to help increase the clarity and meaning of the quotation. Reflexivity was used sparingly in jotting down important thoughts or observations about the interview setting, the affect of the participant, comments made or connections noticed. Both the student researcher and a study member reviewed the transcription by comparing the text with the audiotapes to ensure that there were no major discrepancies to the meaning of the participant responses.

4.3.1 Coding and Analysis

Following verification, the student researcher analyzed the text for themes using a generic qualitative method of analysis (as was determined by the data) (Greeson et al., 2001; Kahlke & Hon, 2014; Merriam & Tisdell, 2016; Woodgate et al., 2017) on the computer assisted qualitative data analysis software (CAQDAS) Dedoose ("Dedoose Version 8.1.8, web application for managing, analyzing, and presenting qualitative and mixed method research data," 2019). The student researcher generated thematic codes using an inductive iterative approach, partially with sensitizing concepts from theoretical and empirical literature (as discussed in chapter two and three), until code saturation was achieved (Figure 4) (Blumer, 1954; Bowen, 2006; Ford, Alford, Britton, McClary, & Gordon, 2007; Hill et al., 2005; Hsieh & Shannon, 2015; MacFarlane, Ian, McCarthy Veach, Patricia, LeRoy, Bonnie, 2014; Miles, Matthew B., Huberman, A. M., Saldana, 2020; Patton, 1990). First cycle coding was conducted with 3 thematic coding methods: concept coding, descriptive coding and emotion coding (Miles, Matthew B., Huberman, A. M., Saldana, 2020). This generated a preliminary codebook (Appendix V). Second cycle coding was conducted by collapsing and condensing codes and sub-codes into categories (emergent themes) (Appendix VI) (Miles, Matthew B., Huberman, A. M., Saldana, 2020). Categories were further condensed and distilled to formalized themes (Miles, Matthew B., Huberman, A. M., Saldana, 2020). Memoing was completed to note interesting ideas, cross-references to other data, or emerging categories or themes. This was an on-going process during coding, and was useful in the second round coding, categorization and description of the final themes. Reflexivity was applied in the form of memoing of inferences, personal reactions, and biases as the student researcher noticed them. Analyses of the results were

conducted using an inductive cross-case analysis, which included the researchers observations and reflexivity.

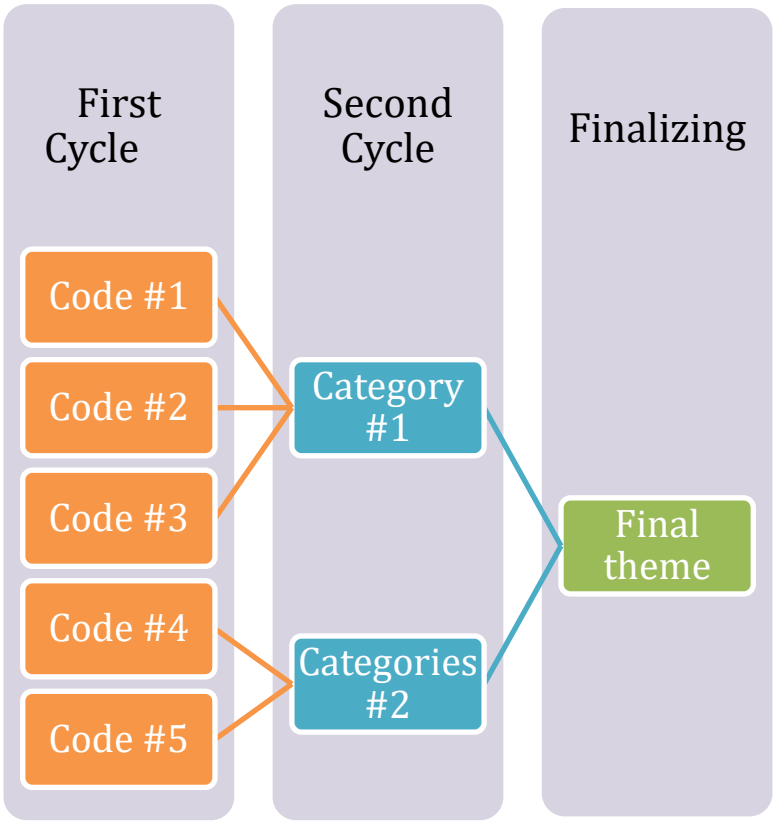


Figure 4: First to second cycle coding.*

*Initial coding is completed through selection of short passages of text (excepts), assigning terms or short phrases to describe the group of codes and respective sub-codes. The codes are continually reviewed for accuracy and renamed, merged, represented, or removed. Second cycle coding is completed by review of first cycle codes looking for patterns among codes and sub-codes. Categories are reviewed and condensed to become the final themes.

One advisory committee member was given the chance to examine the thematic codes for content validity. Due to the absence of objectivity in qualitative research, this process was necessary such that the student researcher could remain close to interpretation of the interviews,

and so that the advisory committee members could uncover potential biases of the student researcher.

Demographic information was analyzed using basic descriptive statistical methods such that it could be discussed further in relation to the experiential themes.

4.3.2 Reflexivity

Reflexivity was integrated at various times throughout the research process including the data collection and interviewing, the transcription, and the coding and analysis stages. The student researcher documented her thoughts and experiences in the form of field notes during the interviews, and memoing during the analysis of the data. A discussion of reflexivity is integrated throughout the Results and Discussion to highlight these observations.

4.3.2 Rigor

Member checking was conducted using a member check of synthesized analyzed data (Birt, Scott, Cavers, Campbell, & Walter, 2016; Griffee, 2005). Member checking was carried out through a short secondary interview to assess the credibility of the emergent themes, as initially determined. The approach to the member checking interviews followed the methods of Griffee (2005) with modifications to suit our sample population and work with the limitations of our research study. This method of member checking allowed for validation of results through seeking “disconfirming voices” as well as exploring whether the findings resonated with the participants’ experience; giving room for them to modify or add to their data, or agree or disagree with other participant experiences (Birt et al., 2016). The member checking was

conducted as individual secondary interviews on the telephone or through email by the participant request. The secondary interview was conducted using an approved interview guide that contained a description of the emergent themes in the style of short passages in lay-language. This interview guide was designed based on the responses from the initial interviews and was approved by the immigrant centres and the Health Research Ethics Board. Participants were given the opportunity to agree or disagree with the emerging theme and provide feedback. If conducted through email, participants were given the written interview guide and asked to respond to the summaries of each theme with whether they agreed or disagreed. If participants disagreed they were instructed to provide feedback. Participants were given as much time as needed to read the passages and return their feedback. This secondary interview was audio recorded but not transcribed; the student researcher also took detailed notes during the interview. The detailed notes from the telephone interviews and the responses gained from feedback provided by email were combined into short summaries as presented in section 5.3. of the results. These summaries denote the level of confirming evidence and describe most of the disconfirming evidence (although the disconfirming evidence could not be described in detail or by using verbatim quotations due to a lack of transcription of the secondary interview). These summaries were not used to modify the results of the primary interview, however the findings of the secondary interview were incorporated into the discussion.

The secondary interviews were conducted over the course of a two-week period following the completion of the data analysis which took place between four and eight months following each participants primary interview.

CHAPTER FIVE

5.0. Results

5.1.1. The Interviews

Primary interviews conducted in English were approximately 75 minutes in length and interviews conducted in another language with the service of an interpreter were approximately 170 minutes in length. Participants were not asked to stay in the interview longer than they wished. Thus one interview was conducted in two sessions, and another, answered the demographic questions through email following her primary interview. Secondary member checking interviews conducted by telephone were approximately 45 - 90 minutes in length. Six of the participants were reached during the two-week period during which the secondary interviews were held, and provided their feedback with respect to the emerging themes. One of these participant was unable to complete the entire interview and thus did not provide feedback on “experiences of adults living with a genetic condition”, a category that did not directly reflect the participants original interview.

5.1.2. The Participants

The Program of Genetics and Metabolism recruited a total of 15 participants. Convenience sampling was used in the process of contacting, determining eligibility and enrolling in the study. However, from this pool, a total of 8 participants were reached by telephone, were interested in participating, met the eligibility criteria and completed the primary interview. From those recruited, 1 individual did not meet eligibility criteria, 1 individual was lost to follow-up and the remaining 4 were not enrolled as data saturation had been reached.

Most participants were married females in their 30s. There was one male participant. Four participants were from Africa with one individual from Eritrea and three from Nigeria. One participant was from China, one from Russia and two born in Belize. The two individuals from Belize had family from and living in Canada. Two individuals required interpretation services; the other individuals were able to conduct the primary and/or secondary interview in English. Six participants disclosed immigrant status, one refugee status and one did not disclose although we assumed she arrived in Canada as an immigrant. Given that only one of our participants disclosed that they migrated to Canada as a refugee, little attention will be given to the refugee experience exclusively. The participant experiences are grouped together with the experiences of immigrants and newcomers as a whole. For clarity, the terms "immigrants" and "newcomers" will be used interchangeably to reflect our sample. Additionally, 3 participants asked specifically not to be quoted directly. Their comments are used collectively and presented in paraphrased content to protect the identity of the study participant. Another participant wished to not be identified by ethnicity and as such, "my home country" has been used to further anonymize the participant data. Participants quoted directly have been assigned a random number between 1-8. This participant indicator is not associated with the order of participant information as depicted in Table 3 and Table 5 again to protect the privacy of the research subjects.

Table 3: Participant demographic information*

Age	**30**	**30**	**33**	**37**	**30**	**35**	**28**	**37**
Gender	Female	Female	Female	Female	Female	Female	Male	Female
Country of origin	Nigeria	Eritrea	China	Nigeria	Nigeria	Belize	Belize	Russia
Length of time in Canada	3 years	2 years, 2 months	4 years, 6 months	3 years	3 years	2 years	1 year, 8 months	2 years
Immigration status	Working class immigrant (currently permanent resident)	Refugee (family sponsored) (currently permanent resident)	Permanent resident	Provincial nominee (currently permanent resident)	Working class immigrant	Canadian citizen	Canadian citizen	Permanent resident
Mother tongue	Igbo	Tigrinya	Cantonese	English	English	Low German	(“Pleubdeutsch”) [Low German]**	Russian
Marital status	Married	Married	Married	Married	Married	Single	Single	Married
Ethnicity	Igbo	Tigrinya	Chinese-Cantonese	Yoruba	Yoruba	Russian Mennonite	Mennonite	-
Religious background	Christian	Orthodox	None	Christian	Christian	Christian Mennonite	Mennonite	Jewish
Education level	Masters Degree (Human Resource Management)	Grade 9 equivalent	High school equivalent	Masters Degree	Bachelors of Science (Non-genetic), Accounting Degree	High school equivalent	Grade 6 equivalent	Masters Degree
Number of people in household	3	5	5	3	2	1	-	5

Employment status	Human Resource Assistant – currently on maternity leave	Office cleaning – currently stay at home mom	Sewing machine operator – currently employed	Pharmacist	Employed – Government employee	Unemployed – College Student (Massage Therapy)	Employed – steel factory worker	-
Total annual income level (self-reported total income from all sources before deductions)	$30,000 $100,000 from spouse $24,000 child tax benefit = $130,000	When working $12,000 $18,600 from spouse + child tax benefit =$30,600	$16,800 (net) + income from spouse + $4800 child tax benefit = $21,600+	$95,000	$53,000	$12,288 social assistance + $2000 student grant + $3096 part-time massage =17,384	$24,000	-
Social supports	Free children's play group, church	None	None	Husband, friends, family, church, (day care would be helpful)	Church, volunteering	Friends, church, uncles/aunts	Community career services, church, family, friends	Family
Financial support	Child tax benefit, income property	Child tax benefit, benefits from work	Child tax benefit	None	Work health benefits	Social assistance, student grant	Employment insurance through work	Rent assistance, child benefits

*information is as reported by participants
**participant reported his mother tongue as "Pleubdeutsch" which we assumed to be Low German

Table 4: Participant demographics summary

Demographic characteristic	Number	Percentage
Female		
Home country/place of origin:		
Africa	4 (8)	50%
Asia	1 (8)	12.5%
Europe	1 (8)	12.5%
Central America	2 (8)	25%
Length of time in Canada:		
	0 (8)	0%
> 1 year	1 (8)	12.5%
≥ 1 < 2 years	3 (8)	37.5%
≥ 2 < 3 years	3 (8)	37.5%
≥ 3 < 4 years	1 (8)	12.5%
≥ 4 ≤ 5 years		
Immigration status:		
Immigrant	5 (8)	62.5%
Refugee	1 (8)	12.5%
Canadian citizen	2 (8)	25%
English as a mother tongue	2 (8)	25%
Married	6 (8)	75%
Religious background:		
Christian	3 (8)	37.5%
Orthodox Christian	1 (8)	12.5%
Mennonite/Mennonite	2 (8)	25%
Jewish	1 (8)	12.5%
None	1 (8)	12.5%
Education level:		
Did not complete high school	2 (8)	25%
High school	2 (8)	25%
Post secondary degree	1 (8)	12.5%
Graduate level degree	3 (8)	37.5%
Number of people in household:		
1	1 (7)	14.3%
2	1 (7)	14.3%
3	2 (7)	28.6%
4		
5	3 (7)	42.9%
Employment:		
Employed	4 (7)	57.1%
Unemployed	2 (7)	28.6%
Maternity leave	1 (7)	14.3%

Table 5: Participants reason for referral*

Participant identifier:	Participants description:
Anonymous Participant #5	**Referral from the endocrinologist (who had concerns that the signs and symptoms may suggest a genetic condition).**
Participant #6	**Risk for trisomy 21 (a positive screen on maternal serum screening).**
Anonymous Participant #7	**A specialist referred to Genetics (an ophthalmologist made a referral to Genetics).**
Participant #4	**Alpha-thalassemia trait (positive screening result and a referral from a gynaecologist for further discussion and possible genetic testing).**
Interpretation, Anonymous Participant #1	**Seen in hospital when daughter was sick (possible in-patient consult for a complex presentation).**
Participant #2	**To determine the probability of Down syndrome in my baby (a positive screen on maternal serum screening).**
Interpretation, Participant #3	**Pediatrician thinks my son might have something genetic (son appears to have an intellectual disability as a result of a microdeletion – participant was most recently referred by gynaecologist because of a current pregnancy).**
Participant #8	**(Genetic cancer diagnosis in sister)****

*self reported

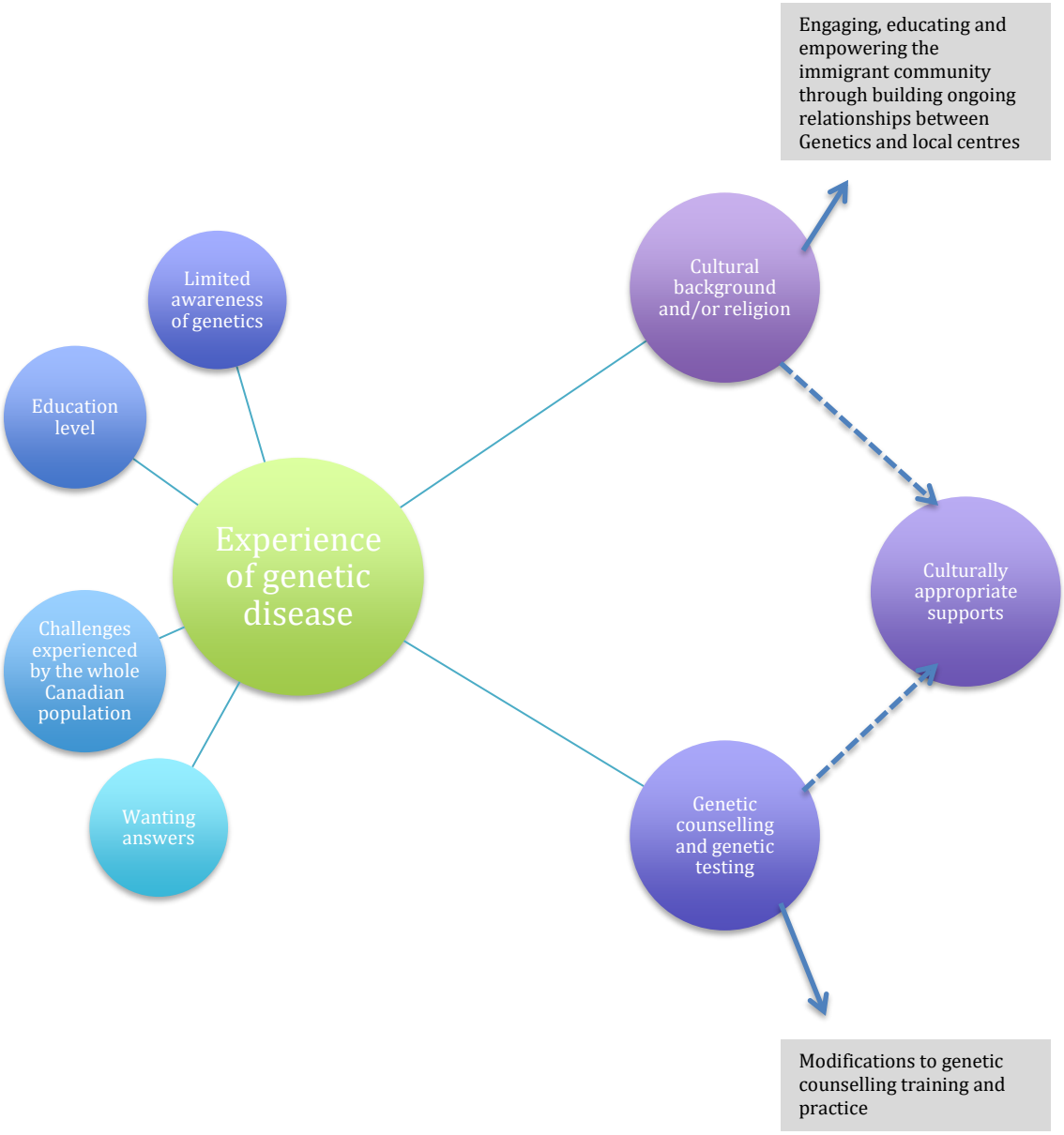
****The student researcher has added comments in brackets to elaborate on what was described within the interview and what she understands the referral to be for those who did not explicitly answer this question

5.2. The Emergent Themes

Table 6: Six emergent themes generated from the second cycle coding and meta-analysis

	Theme
1	*Communication is deeper than language*
2	*Health literacy, awareness of genetic counselling and education*
3	*Support systems are important but difficult to cultivate*
4	*The art of science and religion*
5	Living with a genetic diagnosis as an immigrant has its challenges
6	*Why I wanted genetic counselling/testing*

Figure 5: Overall mind map of emergent themes and their interconnected relationships



5.2.2. Theme 1 Communication is deeper than language

All participants were satisfied with the genetic counselling service that they received overall. Most participants made comments throughout their interviews that reflected a level of satisfaction about some or multiple parts of the genetic counselling service. When asked about improving the service or their experience, some participants made direct statements about their appreciation for the genetic counselling:

> "…I know, I think you, you guys are doing a very good job." (PARTICIPANT #2)
>
> "Like I said, everything was on point that day." (PARTICIPANT #4)
>
> "I don't even feel like for one second that there's something else that could be done better, I mean, I'm on my own, I did not pay for a service and someone thought it wise to, to do these extras for me." (PARTICIPANT #6)

One Participant stated that it would be difficult to comment on what could be improved given that they had only been to see their clinician one time so far. (ANONYMOUS PARTICIPANT #5) Satisfaction or dissatisfaction with the genetic counselling appointment related to five domains:

1. The non-directive style of the counselling
2. The thoroughness or depth of the appointment
3. The information desired/received
4. Communication/language barriers
5. Building trust

Three participants enjoyed the way in which the clinician provided the genetic counselling. These individuals felt supported and understood by the clinicians.

More than the style of the counselling, these individuals highlighedt a major tenant of genetic counselling, the non-directive approach to counselling:

> "…It was all good…the conversation, and all that…it was not one sided… it was not just the counsellor doing the talking...it was 'we' as a couple as well…gathering our own thoughts in the process and having our own questions and I'm sure they would respond in the process….it was like an engaging discussion, I mean put it that way… it was not just her doing the talking, you also have something to say, questions, I'm sure they do their best to answer them..." (PARTICIPANT #4)

> "She explained herself and she let me take my decisions without comparing." (PARTICIPANT #2)

> "I felt like… she gave the facts, which is you know the, the thing, not having people in authority, whatever authority that is, push their thoughts on you, right? I feel like I didn't even know her stand on it, which is great. Here are the facts, do with them what you want, you know? …I mean, if she was the doctor, she would have given me the abortion right there. …I feel like this woman would have made me commit to the termination and I would have regretted that very much later. But the genetic counsellor was very different, she gave me the, the options you know, she let me make my decisions and, either way, I didn't know whether she wanted for me to not do it, her opinion wasn't out there, you know? I think that's…how it should be if I understand the counselling thing correctly, look at the facts… well you choose one, and whatever you choose I support you in it, that's how I felt with her…whatever her personal convictions about it was, I didn't know, and she supported whatever choice you know out of the choices that she gave me, that I took. …I preferred it to the lady that I met when I wanted to not go through with the pregnancy…that I was being pushed, to go ahead and not keep the baby. But…that's the kind of experience I want to have with people, the one I had with the counsellor." (PARTICIPANT #6)

Half of the participants talked about their appreciation for the thoroughness of the genetic counselling encounter, making mention to the time spent and the depth of the conversation. The thoroughness helped participants to understand the material more, and that this due care and attention left them feeling support and respect from their genetic counsellors. Some individuals contrasted this thoroughness to their expectations from prior experience in their home country:

> "…because she was able to like ask different questions, able to draw some diagrams, family tree …and all those things so…she went in depth…it helped me to understand more…" (PARTICIPANT #4)

> "I didn't pay for this, it was just support, it's just someone looking out for you…someone sat down and thought, she needs to know…where I come from, if the doctors thought that you had that predisposition to that, they'll just share the result and not bother themselves, especially if it costs, you know?" (PARTICIPANT #6)

> "…we was really happy to talk with cancer counsellor in Canada because she talked with us so long time so we need it. She answered on all our questions and she was prepared! …I was a little surprised when she opened her folder and in her

> folder was my family tree. Really!? My family tree. My mom, my pop, my grandma, my grandpa, all of them was there and genetic counsellor know all about my genetic problems in my family tree…" (PARTICIPANT #8)

> "…in comparison with Canada, [in my home country] you have just a 5 minutes. Every 5 minutes: 'next, next, next, next patient, next'. Because it just for…referral to any test. I think it's not enough, 5 minutes, to explain your question for example, and sometimes, when you have…a lot of problems in the family, you sometimes need more time…sometimes it could be a big problem and you need to explain your doctor all specific moments when you feel pain, how you feel pain… It's not enough, 5 minutes." (PARTICIPANT #8)

For some, this is a feeling that they share about all health care providers in Canada as compared to their home country:

> "I feel myself really comfortable, no any hesitation of something else, no…but you know, it's um my feeling about all doctors in Canada. When I came to…any doctor in Canada…they pay attention to all your problems and they listen to you. Maybe I am lucky. …every doctor of mine just every time pay a lot of attention to my problems and ask me, listen me." (PARTICIPANT #8)

Still one of these individual commented on feeling rushed in a part of the appointment:

> "Well basically you know because it was a rushed thing…all she told me about was you know about the risks of miscarriage…" (PARTICIPANT #6)

All participants suggested that they were satisfied with the informational content of the genetic counselling appointment. Important information as recounted by individuals encompassed a wide array of topics from, what to expect from a procedural perspective and available testing options to descriptions of genetic disease. This information helped to answer many questions and in some cases helped people to feel relieved. Information helped increase understanding and was useful in building trust. Participants often described their clinicians as knowledgeable, which was a positive part of their experience.

> "…she was quite knowledgeable about what she was talking about, and she was able to explain properly the test, what it was going to be doing, what to expect, and, she was honest about the result…" (PARTICIPANT #2)

> "So what happens when I went for the appointment is I asked a question and they answer me, they give me the answer…upfront they gave me all those different information, it's just I [asked] the question and they gave me the answer." (INTERPRETATION, PARTICIPANT #3)

Although the information provided was relevant and helpful to the participants, in some cases individuals were still left with questions unanswered or were confused about the discussion:

> "…what happens is the doctor explains to me that my son issue is because he miss some DNA. But what cause him to miss this DNA I don't understand." (INTERPRETATION, PARTICIPANT #3)

> "…even now the genetic doctor told me that my sons developmental delay is caused by genetic. Okay, I accept that fact, but I don't know what makes him that he has this kind of genetic delay, I still don't understand." (INTERPRETATION, PARTICIPANT #3)

In one case, a participant describes her expectation not being met when she explained that she hoped to learn more about the risk to pass a genetic condition on to her children, or for other family members to pass it on to theirs, but that this information was not discussed in the appointment. (ANONYMOUS PARTICIPANT #5) Other areas of dissatisfaction included lack of knowledge of the plan for the appointment. One individual talked about her lack of understanding of the next steps of the appointment:

> "And then the genetic counsellor came to speak to me when the doctor was now already there to take the sample, so she spoke to me with both the doctor and the ultrasound technician already present, but I did not know, I thought that after speaking to her I'll be put to sleep." (PARTICIPANT #6)

In contrast, another participant described that her clinician followed the plan and this acted to build trust with her. When asked if she could trust her provider, she responded: "Yes! …I guess she did what she said she was going to do, that's why…." (PARTICIPANT #2)

Interestingly, regardless of other comments made in the interview, many participants still reported that all of their questions had been answered or that they did not feel a question was

unanswered: “Yah, she was able to answer everything to my satisfaction.” (PARTICIPANT #4) If participants felt unsatisfied about the information received, consistently it was relating to when a diagnosis or information about treatments/management was unable to be provided.

Participants were divided in their opinion of the comprehensibility of the genetic counselling session. For some participants the key to understanding the appointment was the use of language and the explanation of information. Complex terminology was seen as inhibiting understanding. Although rarely, the conclusion was drawn that the jargon used was appropriate for the patient’s educational background but would not have been appropriate for others:

> “She used the simple words to uh explain me, hmm, situation, to explain me about genetic cancer, about my family, she ask me about specific but with the common words. It was amazing.” (PARTICIPANT #8)
>
> “….she did her very best, there was no medical grammar.” (PARTICIPANT #2)
>
> “…I know that if I wasn’t a pharmacist and she was referring to the code, the genetic coding and all that, I would definitely be lost.” (PARTICIPANT #2)
>
> “…there’s um so many technical terms, they talk about uterus, the fallopian tube the eggs and then something about the husbands side, so I’m a little bit confused about, they tried to explain to me what it caused the genetic problem.” (INTERPRETATION, PARTICIPANT #3)

It does not appear that participants are aware of the fact that genetic counsellors tailor their conversation to knowledge level, but they do comment that genetic counsellors should try to do so. For participants with limited abilities to communicate in English, the consensus was that language did not prove to be a barrier to accessing care. The reason for this was that a professional interpreter was consistently available during an appointment or where necessary (such as in translation of documents). Interestingly, one individual who required interpretation services to communicate verbally disclosed a situation where they were not able to contact their

provider in follow-up to ask additional questions. While this participant explicitly stated an issue with contacting, the other participant requiring interpretation services implied this as an issue. Thus representing a gap in the provision of care to individuals requiring interpretation services:

> "…first of all I have limited English, I don't think people would understand what I want. Another thing I don't even how to connect to the genetic counsellor." (INTERPRETATION, PARTICIPANT #3)

Most participants talked about trusting their genetic counsellor/geneticist or described having trust in Canadian health care professionals or Canadian medicine. When asked directly about trust, individuals described their clinician as knowledgeable, honest, and allowing the patient to be heard:

> "Yah. I guess she did what she said she was going to do, that's why, also." (PARTICIPANT #2)

A few participants talked more generally or alluded to a broader trust in the Canadian health care system, or health care providers in general. Some participants had a high level of trust in the Canadian medical professional, speaking quite highly about their perception. Some had almost a blind trust in the recommendations or options presented by their provider. Some individuals described situations in their home country that had, in the past, acted to compromise their access to medical care or health, which contributed to this ability to build trust. Participants also described a less advanced health care system in their home country that they were less likely to trust. This is further described in "Theme 5 Living with a genetic diagnosis as an immigrant has its challenges".

Interestingly, one participant was very frank about her opinion of trust, and the seriousness of trusting another person. For her, trust was not associated with information and accuracy:

> "Trust? I don't know about trust. For me as a person I only trust God. I don't know about trust in humans. I'm just being sincere with you. I don't know about trust." (PARTICIPANT #4)

Although trust had been built in most appointments, there were still barriers to effective communication. It was clear that participants do not always say everything they mean. One participant disclosed, satisfaction with the non-directive style of the genetic counselling appointment, but later disclosed her frustration with the providers need to review all of the available options. Additionally, this participant stated that she would not have shown this frustration to her genetic counsellor, as she was too conscientious to do so. However, this was also influenced by the timing of the conversation in both the setting of the conversation and how far along the participant was in the decision-making process:

> "I didn't want to know about whatever there are options for you, I did not want to know that at that time, what I really wanted was for the procedure to be done, I think I would have actually…opened up to the counsellor or been receptive, but of course she would not have known that I wasn't receptive to her because I think I am just the most polite person in the world. I probably would have been more receptive to the things she said to me if it was said say thirty minutes before the procedure and not when the doctor is right there – at that point, what I wanted was to have the procedure done…any other thing was just delaying the process. I think if it [genetic counselling] was earlier or even later, I think if I had the thing [amniocentesis] done, and then they came to speak to me later, I may have been more… open to it…I had already made up my mind that I wanted to have the test." (PARTICIPANT #6)

Although this well-spoken individual, was the only participant to disclose that she was not completely open with her genetic counsellor it is cause for concern that other patients are not able to fully built trust, and may not disclose their true thoughts and feelings or questions.

Participants suggest that one cannot truly speak for another person, even if you have a good sense of their experience. Many individuals contrasted their thoughts and opinions to others in their home countries giving that caveat:

> "So I will say most people, because there might be a few that actually know about these [thalassemia and other genetic blood disorders], that I don't know, that's why I'm using the word most, most people." (PARTICIPANT #4)

> "…like I said it's up to the individual….people are different, right? …People are very different." (PARTICIPANT #2)

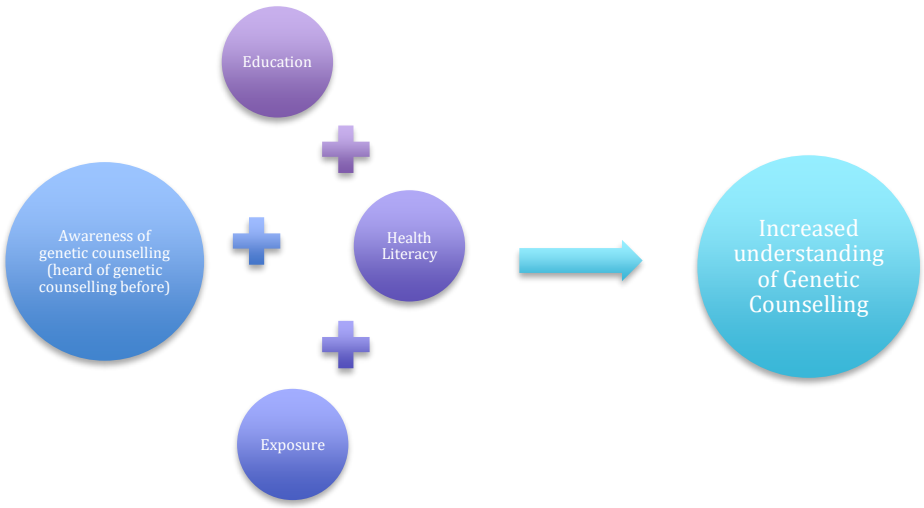
Although individuals of the immigrant communities share similar views such that key informants provide rich insight into a subgroup of the immigrant community, individuals stressed the individuality of others, in their thoughts, opinions, experience, and their communication styles.

5.2.3. Theme 2 Health literacy, awareness of genetic counselling and education

Most of the participants had not heard of a formal genetic counselling service before their first referral to Genetics in Canada. Most learned about this genetic counselling service through a physician referral, and some from a conversation with a family member:

> " I'm not familiar, I don't know anything about genetic counselling and so this is the first time I experience." (INTERPRETATION, PARTICIPANT #3

Figure 6: Education, exposure and health literacy. Most participants had not heard of genetic counselling before their appointment and thus had low awareness of the service. Individuals' previous exposures to genetic conditions and health care systems, along with their education acted as a proxy for increased health literacy. Altogether, awareness and higher apparent health literacy contributed to a better understanding of genetic counselling.



Although most were unaware of genetic counselling, there were varied levels of knowledge about genetics and whether or not physicians were providing a service similar to genetic counselling in their home country.

> "…nobody ever said, my genetic counsellor spoke to me about it. You know, it was, my doctor told me my child was at risk for trisomy 21...maybe it's a thing in Canada but not other places, I don't know" (PARTICIPANT #6)

Although one participant had learned about Genetic Counselling when she attended an appointment with her friend in Canada before her own referral, even still she was surprised to know that the service was not necessarily provided by a physician:

> "I don't know what I was expecting. I've actually been there before with a friend. I mean my friend told me about it, but I thought she was talking to a physician, I didn't know about a genetic counsellor. So when she told me she was a counsellor and not a physician, I'm like 'oh, okay'…I thought she was a physician, I didn't know there was a department called genetic counselling." (PARTICIPANT #2)

Overall awareness of genetic counselling was correlated to a participants exposure to medicine in their home country (Figure 6). Individuals described different experiences but with similar underlying themes about medical care - care being relatively self-directed and less advanced than in Canada, further suggesting limited access to appropriate medical care for many. Individuals talked about their reasons for not knowing about genetic counselling, describing intrinsic and extrinsic factors that would prevent them from knowing about the service. For most, they described that the genetic counselling service does not exist in their home country or a country that they lived in before moving to Canada. For example, few individuals described that they had seen multiple doctors over time to seek help about their or their child's health condition. However none of the physicians in their home countries had made a referral to a genetics provider. One individual elaborated about the nature of the self-directed diagnostic odyssey. The participant described that as a child they had been taken to see the doctor many times in her home country, but it was only after a neighbour had mentioned that the symptoms sounded like a particular condition, did the participant and her mother return to the doctor to ask for the specific testing for that condition. Sure enough, that was a diagnosis [although the genetic condition itself was not identified in the home country]. (ANONYMOUS PARTICIPANT #5) In addition, to acting as your own doctor, this individual stressed the inability to trust all doctors, as they had received conflicting information from physicians in their home country as to whether or not the condition was genetic in nature. (ANONYMOUS PARTICIPANT #5) Additional challenges with medical care in home countries included an assumption that genetic conditions have no

management available, which for some was not the case. Some participants described the health care system in their home country as a less advanced or developed than the Canadian medical system, mentioning that physicians were not as highly educated. Even for other participants who had received some form of genetic counselling from a physician back home, the experience looked different to the experience had in Canada. For one person who had genetic testing in their home country, the genetic result was mailed to them and was not discussed with them further:

> "…I call the doctor, and in the next day I go to genetic test, I paid money and they took my blood, and I think I wait 1 month and they send me the result by mail." (PARTICIPANT #8)

For others, the difference was the cost of genetic testing or the medical service in general:

> "You know it was interesting the day we did this test [in Canada], I thought it was going to be three hundred – five hundred dollars for the test, because I had read online that it was five hundred dollars, but then it's free. But in [Africa]…nothing is free…" (PARTICIPANT #6)

One individual described the culture of the population as different from Canada, suggesting that people in their home countries were not as interested in the *cause* of disease as much as they were in the management. For this participant, the Canadian population seemed to care more about the cause or origin of a medical problem. However, that individual was unaware of any physician in their home country who would be studying about the causes of diseases. (ANONYMOUS PARTICIPANT #7) Some individuals recognized that a similar such service was, or likely was being provided by physicians in special hospitals. Some of these individuals had contact with genetics providers or researchers in their home country:

> "…there's some sort of place at the special physician hospital, you know that there's a department of Genetics but the potential referral, I have no idea." (PARTICIPANT #2)

> "Just only special people. In a specific cancer hospital, because not every doctor knows about genetic cancer, and just only specific doctor know about it…." (PARTICIPANT #8)

> "Yah, I think in [my home country], there should be some genetic doctors however I wasn't referred by anyone of them, to go to see anyone of them." (INTERPRETATION, PARTICIPANT #3)

Some participants talked about the fact that their lack of awareness was due to never needing to seek out such a service (Figure 6). For some, they were not in a committed relationship; so learning about the risks of passing on a genetic condition felt unnecessary. For others, unless they were sick, they would not seek medical attention.

> "…I didn't have a committed relationship that would lead to marriage that I would be needing genetic counselling or whatever so, I didn't need it at that point." (PARTICIPANT #4)

One participant elaborated that back home, people would especially be unlikely to book an appointment, as appointments were for more major events like a surgery, and that check-ups could be done by walk-in clinics. For one participant that was already seeking medical attention in their home country, they were never referred to see a genetics provider, even though retrospectively they had assumed the service existed:

> "…it's only about 3 years old that we found out that he's [my son] slow in picking up speech and by that time we moved to Canada….I thought they must have genetic doctor in [my home country]…but for me, no doctor refer my son to go see genetic doctors." (INTERPRETATION, PARTICIPANT #3)

One individual acknowledged that even if someone were to seek genetic counselling back home that it would not be available to someone who was currently healthy:

> "…it's difficult to compare with something the same in Moscow because in Moscow nobody could answer my questions, nobody could counsel you, about cancer if you health[y]. Just after you have cancer, somebody could tell you about how to treat about surgery, about your future…" (PARTICIPANT #8)

The participant mentioned that in order to receive information about her genetic risks, she needed to attend the appointment with her sister who had already had a diagnosis of cancer:

> "Just only doctor. Not counsellor. Just only doctor…you can't call to say 'I want to know more genetic problem, could you speak with me?' – 'no'. No. That's why I came with my sister. It was just a one chance to ask him, but he did not told about me, he told about me in a group, like about me like about family of my sister." (PARTICIPANT #8)

Understanding of genetics, genetic disease and inheritance also varied among participants. Prior awareness of genetics, genetic disease and inheritance before a referral correlated most to an individual's prior exposure to genetic conditions and familiarity with health care systems; which thus acted as a proxy for overall advanced health literacy (Figure 6). Higher education levels correlated with advanced health literacy in general, but this was not a relationship that the results alone could establish because of the sample size. However, individuals with a higher level of education had a better understanding of what the genetic counselling appointment might entail, what procedures and processes may be expected and/or a better understanding of genetic concepts after their appointment:

> "I had never met anyone with Down syndrome. I don't even recall maybe being in a bus and seeing someone with Down – they are very rare, but, to help me with this experience I went online and I saw that there are many, it's just for some reason I have not come across them…" (PARTICIPANT #6)

Some participants had a sense of what a genetic condition was, since they were aware that it might run in a family, and that it was something that could affect a family member, and a pregnancy. Those who had knowledge about genetic conditions had previous exposures within their family or community. For one participant it was a sister with an inherited cancer, for another a son with developmental delay who had seen Genetics in Canada once before, another who came from a community with a high incidence of inter-family marriages where multiple

people had similar medical concerns, and someone who came from a culture that valued the genotypes of individuals before marriage:

> "…I actually don't know about this thalassemia thing. But I'm actually more aware of the sickle cell anemia stuff." (PARTICIPANT #4)

Taken together, previous awareness coupled with *exposure* and potentially *education, which* act as proxies for health literacy in this study, can influence an individual's knowledge of genetics and consequently perceptions of and understanding of genetic counselling.

Participants' knowledge of genetics and inheritance was not without some misinformation. A combination of education and exposure to genetic conditions lead to understanding or misunderstanding of genetic information. Lack of exposure influenced perceptions about the need for genetic testing:

> "Maybe there's a culture for over-testing people because there wasn't any, there wasn't anything in my background that would, you know suggest that, I would have a child with Down syndrome." (PARTICIPANT #6)

This specific view about "over-testing" was also related to differences in cultural perceptions of genetic conditions and testing:

> "…you probably wouldn't even know until you have the child at hand, and then two weeks later you are noticing the features and people are telling you, [to] take it to heart, you are a strong woman, whatever, and if you stay the next month they'll be like you know what, stop being a bother, relax, other people have children like that, it's not only you." (PARTICIPANT #6)

Although education was helpful in understanding more complex information about DNA and inheritance, alone it was not enough for a participant to be aware of genetic counselling. Several participants made mention about individuals having various levels of knowledge about genetics,

and one participant talked directly about the relationship of education and a patients understanding of the material covered within the genetic counselling appointment:

> "…every individual from every race, I don't know what their education here is like, for example, my country, if you're not in a science, if you're not science based from high school, you would not really understand genetic coding. Right? So…if somebody is here and the person is like maybe high school graduate, not a college graduate or something, I think they'd be lost like 'what's going on', you know?" (PARTICIPANT #2)

Education in turn played a role in a person's ability to incorporate a biomedical understanding of disease – something that was balanced against a persons cultural views and understanding of illness. On a personal level, learning about the cause of a genetic illness was generally quite important. For some, the concept of preparedness and planning was quite evident. Some individuals preferred to do their own reading before entering the genetic counselling appointment whereas others did not do this:

> "I started making my own research on this and I had some questions marked down in my head…once I get in the counselling room I would have some questions to ask, not just going there, going in as a novice, you understand?" (PARTICIPANT #4)

Some individuals took these preparations quite seriously, often relying on online resources:

> "…I read a lot a lot of information about the surgery, about how to live after surgery [mastectomy], because of the climate to which will be after surgery…that's why I got a lot of information." (PARTICIPANT #8)

> "…but you know I've read so much about Down syndrome I could write a book..." (PARTICIPANT #6)

Whether or not individuals' lack of preparation was due to a choice, the nature of the type of appointment (prenatal vs. adult general and symptomatic), a result of different experiences with health care systems in a home country, or a by-product of inadequate health literacy was unclear from the results.

On a broader level, educating about and increasing awareness of genetic conditions and the existence of genetic counselling services within the immigrant community were ideas amendable to a number of individuals. Some individuals might do this to help make the lives of their loved ones easier, so that they could help to answer questions or give information to family or friends. Additionally, some felt they could make people aware of the risk to have a child affected with a genetic condition. Some suggested providing education would help reduce the fear and stigma of curses or hexes for those who do not know about science.

> "…let them know that yes, there is genetic counselling available…they need to know, they need in depth knowledge about this thing [thalassemia/genetic conditions], let them know okay there is help available for them….if you want to know more." (PARTICIPANT #4)

> "I think the first thing you might want to look at is…information, at least some individuals they might think that it's something spiritual for example, I know that back home when a child is born, for example whether it is autism or with cerebral palsy or something like that or something informational challenge, there is definitely no conversation, they don't even think of genetics… they think something supernatural has happened to them, and feel like they are in a bad luck or something, they don't understand that it's genetics…I think the first thing to do, it's true, let them know that it is nothing spiritual." (PARTICIPANT #2)

To one of the individuals, sharing and disseminating this information to others within the immigrant community was extremely important:

> "…I let the counsellor know, I think it would be better for people to be more educated so that they're more aware of this because most people back home, what we know is like once we just check the blood group and all that and the two parties are compatible, that's it. They actually don't know there's anything like maybe thalassemia and all those things. Most persons are actually not aware, so actually just stuff like educate more people….maybe you should get more like, different kind of platforms." (PARTICIPANT #4)

This participant gave several actionable ideas for how genetic counsellors might go about this process of knowledge dissemination within the immigrant community.

5.2.4. Theme 3: Support systems are important but difficult to cultivate

Support systems were seen as critical parts to the every day struggle in the new life as an immigrant. One participant reflected on the everyday challenges she faced with the birth of her first son while living in Canada:

> "…when I think back to when I had my son… the first few months… even though I was very happy – I think what I remember now is feeling so hungry. I couldn't even like eat… if you drop him then he's going to cry…why don't you just carry him and stay hungry… so he doesn't cry." (PARTICIPANT #6)

When faced with the concern of a genetic disease or disability, newcomers reflected just how stressful life could be:

> "…I'm thinking it's [Down syndrome] a death sentence. I mean, it's not the best thing but as long as you know there are no health complications… well it's easy to talk now because my child is clear, you know… but um… it [positive maternal serum screen] was literally a cof- a nail on my coffin then…Well because we are immigrants right. My husband works as a nurse. He works out of town. We have no family here, right." (PARTICIPANT #6)

For those with children affected with genetic illness, or those who received a positive maternal serum screen, the lack of support systems were painful reminders of being more alone than ever before:

> "...keep people educated so they are more aware and prepared for what the future holds, so you don't bring an innocent child to this world to suffer.…I mean couples with the challenges that come with marriage… relationship is hard work as well…having a sick child based on you know this thalassemia thing and, and all that, you know? Could add a lot of stress to it, emotional stress, financial stress, you will have a lot of things, marital stress, you know…" (PARTICIPANT #4)

The support system served unanimously as the emotional bond for all participants, and could be extended to the physical support and reprieve of a partner providing childcare (Figure 7). For adults with a genetic concern or disability themselves, support networks could also contribute physical support to help make living life with a genetic condition a bit easier. (ANONYMOUS PARTICIPANT #7) For those with a spouse, the support network added the stability of additional financial income.

The support system was not only critical during the period of starting a new life and being unfamiliar with one's home in Canada, but also during the added stress of managing a new diagnosis, or a future diagnosis. For some participants, support systems contributed to a person's decision-making process to pursue testing (Figure 7):

> "My husband he's much more worried than I do…when he first found out my sons situation, he couldn't have a good sleep the whole year. Even his hair turn grey. Even when I have done this test for my unborn child, for the amino test, he was so worried that he told me not to go for the test but…I still went for it anyway… I discussed with him about those tests…it may have a chance to cause miscarriage, and then he says don't go for the test, don't go for- because of the high risk. He doesn't want I have to suffer the miscarriage, and he love his wife and he love his family very much, and he doesn't want any one of us, suffer anything." (INTERPRETATION, PARTICIPANT #3)

> "If you live long, you think just only yourself, but if you have children, you need to keep yourself in the health, that's why when I thought that something could happen with me, and when I understood that I have a lot of chance to be – to live with genetic problem, [I talked] with my husband how to resolve this problem and the first step was to go to genetic test…." (PARTICIPANT #8)

In addition to these more tangible outcomes, support networks were also means to share information and educate others to make their lives easier and to prevent the suffering perceived by the participant (Figure 7). Only a few participants recognized sharing information within the support system.

Figure 7: Types of support available with the support network. Support systems including spouses, family, friends, community, church, services and financial supports provided individuals with relief during the difficult time of relocating to a new country and managing the stress of a new or future diagnosis. These support systems provide different types of assistance as described by the participants and include support that the newcomer would provide to their support network. The main types received or given are broadly characterized above.

The support system is important but a somewhat lacking element for the emotional and financial care of the participants. It was not uncommon for an individual to describe the available supports systems as *none* or *no one*: "No, there's nobody." (INTERPRETATION, PARTICIPANT #3)

> "…it's something that as an immigrant you have to deal with, there's no quick fix to it because no one immigrates with their whole family, you know, so… what can anybody do for me, I don't know…"(PARTICIPANT #6)

Even if a participant said they had no support, all participants discusses what they felt to be their limited supports. Although support networks were clearly defined differently by each individual based on their needs and life situation, there was an overall trend in that the network was hierarchical to some degree, with the closest relatives on the inside, moving outwards to

unrelated individuals such as friends, then community members and church groups and lastly to community services (Figure 8).

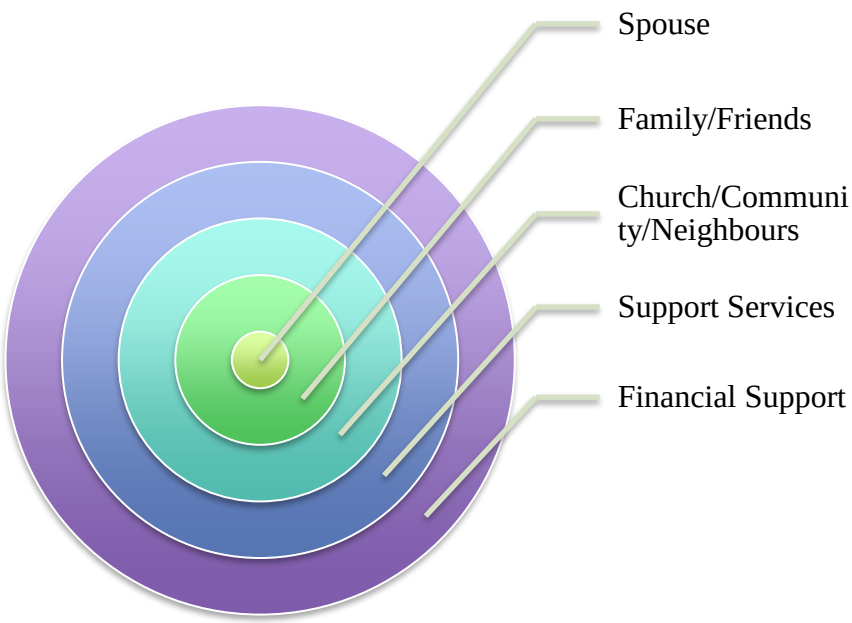


Figure 8: Hierarchical representation of participants views about support systems. Some individuals appear to define friends, neighbours and their immediate community about the same level as closeness. Some may see family and friends around the same closeness, whereas some may group friends into community, since they are not long-standing friends such as those from their home country. All participants who had a spouse treated the spouse as the closest person in their support network. Most alluded to or discussed support services as least close and/or desirable in their networks.

Most described their closest personal support networks as primarily composed of a spouse; second only to family members or friends. Although the description of the support network was dependent on the personal nature of what networks existed for the individual (i.e. if a spouse did not exist, a family member was the closest support). Important in some cases, the spouse may be the only appropriate individual to rely on when the nature of the concern involved a pregnancy or a child.

> "Two people are involved… It's a baby involved so I don't think I should be talking to any other person other than my husband." (PARTICIPANT #2)

Although the spouse could act as the main support person, one participant acknowledged that the spouse could actually need more support than herself:

> "My husband, he is more concerned about my son than myself and he would like to talk about, but he's very worried about it so that's why I try not to bother him about this you know, issue." (INTERPRETATION, PARTICIPANT #3)

Spouses were not only individuals who provided emotional support; they also provided financial support. In times where a participant was not working as a result of taking care of the children/family and or caring for a child with special needs, the spouse was acting as the primary breadwinner. However, it should be noted that individuals and families had other means to support themselves financially.

For those who did have a spouse, the spouse could not always be present, and thus could not represent an entire support network in and of itself. Other close individuals such as immediate or extended family members and friends were desired, and again were necessary for those who did not have a spouse. Some individuals were fortunate to have relatives nearby that they could be with physically, although this may have been grandparents, aunts/uncles and cousins over immediate family. Some participants did not have relatives of any kind near them and connected with family through long-distance communications or visits home.

> "…it's not like your sister lives in… Ontario… your sister lives in [Africa], you know. So, it's simply deal with no support at all…" (PARTICIPANT #6)

> "…you know there's nobody actually in [my home country] that can help me out, but only when I feel really depressed and I will call my sister in [my home country] and just you know talk to [her], express how I feel and [she] make me feel a little bit better after I talk with someone." (INTERPRETATION, PARTICIPANT #3)

> "…you know your mom is not texting and you say wait, she's six hours..forward in [Africa], you couldn't even call her then..." (PARTICIPANT #6)

Still others had strong ties to their families, and were able to visit them and provide them with support:

> "I fly to Moscow on a 2 and a half months and I lived with the family of my sister and I took care to her children, I helped her to cook because he had a problem- she had a problem with eating… and after chemical treat [chemotherapy]…she felt really bad. I just help, because it's family." (PARTICIPANT #8)

The views about friends were not as well discussed as views about family. Although among those who did describe a relationship with friends, individuals differed on their views. One individual mentioned friends and family as important parts of their support network. Another highlighted that friends in Canada were not long-standing like their friends back home, thus distancing friends, placing them closer to the level of community members within the support hierarchy (Figure 8):

> "What I didn't have was… a support system, which nobody can provide to you unless someone can magically make two or three of my family members appear here. …and then, or until I put down roots here, build my own network of people that are like-minded…because I do have friends, but my friends are single people, what they want to do on a Tuesday evening is watch something on Netflix and cook their lunch for the next day, they don't want to look after your child because you are feeling low because you went to have the amniocentesis, right?" (PARTICIPANT #6)

Community support was seen as the next accessible and acceptable option (Figure 8). This included support from community groups, which a few participants described as a religious group or church:

> "…we research a lot of information about Winnipeg. About Jewish community. About networking in Canada, and when we came to Canada, we known a lot of people who live in Winnipeg….we communicated before we came. We were prepared." (PARTICIPANT #8)

This also included more of a formal community service, which may or may not have been acquired at a cost to the participant. Altogether, community groups such as churches were described more favourably than community services but were not as favourable as family support (Figure 8):

> "Who would I turn to? We do go to a church here, we belong to a church, but… it's mostly people that have their own things too. You know it's different when it's someone you meet in a gathering…than it is if it were to be your cousin, or your mom…we don't have that luxury… I don't think that I would truly feel comfortable, you know… sending him [my son] to someone..." (PARTICIPANT #6)

Individuals described services that they had used in the past or were currently using as helpful (Figure 9). Some of these services included childcare, in home care to provide respite to a mother with multiple children, one of which required extra care. While another discussed the services provided to help a child with developmental delay in early development, this included services such as Speech and Language Pathology and government funded programming accessible until the age of 5 years. For later milestones, the same participant described in-school support programs (educational assistants) and technologies such as a customized iPad to provide special education and development. For this participant, the relevant in-school support programs suffered what appeared to be funding cuts and thus there was less available personnel time and they were slower to give the child a suitable iPad. Her child was not able to continue developing and she was quite distraught about this.

Some participants also considered the genetic counselling service as a place to look for support when asked. (ANONYMOUS PARTICIPANT #5) Some felt supported by the genetic

counselling service emotionally. Although this finding was not universal, one participant discussed that they were not offered emotional support by the clinician who provided their service, more that they were given information about the prognosis of the genetic illness:

> "No, the doctors didn't you know try to comfort me for my emotional…I feel that I was the one who caused this [developmental delay in child]." (INTERPRETATION, PARTICIPANT #3)

> "…when I went to those counselling they just tell me that the boy if this kind of DNA deficiency have the developmental problems…the risk is higher than the girls, but they never try to console me about how I feel about it." (INTERPRETATION, PARTICIPANT #3)

This participant stated that they were not referred to community supports by their clinician and as such made several requests of the Genetics department. This participant's suggestions can be summarized as:

1. Genetic counsellors/geneticists might have the ability to reach out to teachers and school staff to educate them about what behaviours might be expected for a child with developmental delay, thus helping to set expectations and take the blame away from the child.
2. Genetic counsellors/geneticists might consider providing parents with guidelines describing what learning ability might be possible and anticipated milestones that are age appropriate for a child with developmental delays.
3. Genetic counsellors/geneticists may facilitate or provide help for a parent to teach their child with developmental delay how to take care of themselves.

Although most participants accepted the idea of a community support service as being beneficial in their lives, one participant discussed an opposing cultural norm with respect to community support services (Figure 9):

> "I don't want to be a burden in that way…a charity case, that's not just how I want to be and I stay thinking of other people that might want to migrate, you know there's a lot of burden that's placed on you being an immigrant, you don't want to take so much so that you don't take it away from other people …I'm [African] so, maybe if I take so much…it's kind of like 'oh, they don't contribute they only take', you know and it doesn't matter that I work and still pay taxes like other people, it's something that maybe someone that was born here would never even think of right? But I do have to think of…"
>
> [Interviewer: That comes into play when you're thinking about using support services?]
>
> "Yes! Especially support services, things that are not absolutely necessary, I mean if you have to have a child then you really have to have a child right, and you have to go into the hospital, but as far as now asking someone, come take care of this child for me, that's your primary role right? If you can't do that…it doesn't speak so well to the person that you are…" (PARTICIPANT #6)

She felt as though she might be "conditioned" not to rely on the support of such services:

> "… I don't want to – if people need it more, fine, they can have it. I don't want to be the person that says 'oh come look after my child while I do this or do that'…I think it's also from, where I'm from… maybe that's how we're conditioned and that's fine…" (PARTICIPANT #6)

For this participant there is a great difference between support networks and services. She highlighted that this lack of desired support represents a gap in the availability of *culturally* appropriate social support systems:

> "…you know support systems are not something… not something you build, it's a service, if, maybe at the end of the amniocentesis there were two women that are on the clock that were told to come look after myself or my child, that's not my support system, that's a service they are providing…" (PARTICIPANT #6)

Furthermore, this participant explains that there is also quite a different mentality about support between Canada and her home country in Africa suggesting that her home country is more "cohesive". The participant suggests that individuals back home would be willing and eager to help as a part of her support network:

> "…the people to ask would be there falling over themselves to do it…you wouldn't even have to ask. In [Africa], child care… it's it takes a village…literally the village raises your kid….but here it's very individualistic and when you try to ask it's like you're taking away from people, and of course I don't have my own people here, I don't know how to say it, my own people, my family, related by blood, people that I've known for a long time, you know…" (PARTICIPANT #6)

The lack of support that an individual is willing and comfortable to access, lead to quite dramatic planning and outcomes:

> "I mean, one of my biggest stress at this point is, what if I go into labour and it's at night… so my grand plan for that is – because I don't know who will keep my son for the night – my grand plan is, even if I go into labour at night, I'm not going to go to the hospital until it's morning and my son goes to daycare." (PARTICIPANT #6)

Although other participants did not explicitly vocalize this concern, another participant did help to corroborate these cultural differences, highlighting that there may not be services culturally relevant to newcomers. This additional participant described the culture back home as more *cooperative* than the Canadian way. (INTERPRETATION, ANONYMOUS PARTICIPANT #1) She also talked about the idea of a busy life, describing that back home people usually go to church on Sundays and this is a meeting place, but in Canada, they would go to church if there were time. This participant described that even if there were family members nearby in Canada, because of the Canadian ways, they too might be far too busy to provide support. The participant described that the culture of working was much different in Canada from back home, because in Canada it seemed that working was necessary for survival whereas back home it tended to be more seasonal and allowed for people to have more free time. (INTERPRETATION, ANONYMOUS PARTICIPANT #1)

Financial supports were an important variable in the support network for the participants. Although most individuals did not speak directly about financial resources, the one participant who did elaborate spoke about their ability or their spouse's ability to provide an income. In turn, the discussion about the participant or their spouse working brought up the idea that there would be less support available to the partnership and family as a result:

> "My husband – but you know realistically, if we have to keep a roof over our head, he has to go to work, and you have to deal with it, you know." (PARTICIPANT #6)

When asked about their financial resources, all participants listed a variety of different means of obtaining additional income (Figure 10). The most commonly mentioned financial support other than monies acquired directly from employment were benefits provided by employers and the child tax benefit received from the Canadian Government. Still one participant included 'none' as a response to "what financial supports might you access?" However, it is likely that this meant that no other financial supports were accessed outside of regular employment, since they provided an annual income (Table 3)

Figure 9: Self-reported social supports* used by the participants include a combination of programs and services for families, adults and children. These services may or may not be available to individuals at no or low cost. Still participants include 'none' as a response to what social supports might you access? *One or more participants mentioned the supports listed.

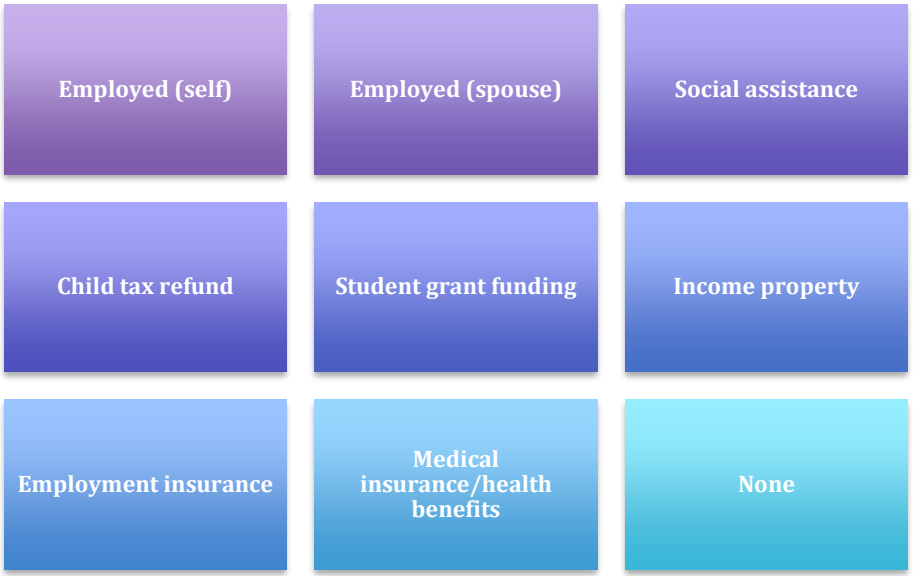


Figure 10: Self-reported financial supports* used by the participants include a combination of employment and government funding. Most individuals were employed or had a spouse who was employed. The most commonly mentioned financial support outside of employment were benefits provided by employers and the child tax benefit. One participant include 'none', which is likely meaning that no other financial supports were accessed outside of regular employment *One or more participants mentioned the supports listed.

5.2.5. Theme 4: The art of science and religion

Participants' perception, understanding or experience of genetic illness appeared to be a complex balance between exposure to and knowledge of science, and trust in a biomedical illness model versus an individual's personal belief in faith or cultural practice. All three illness/explanatory models were represented in by participants, some referring to biomedical, one describing holistic, and for most participants, magico-religious. These results demonstrate the varied psychological acculturation levels within our sample of newcomers and implicate acculturation as an influencer of illness models/explanatory models.

Although many participants stated some kind of religious affiliation, most participants did not fully disclose nor commit to one particular way of understanding disease. Most talked more openly about what people from their home countries might think. The participants' comments on traditional view of disease in their home countries', which was consistent with a magico-religious model of illness:

> "…there's a lot of um religious undertones to everything… [Down syndrome] could be your punishment for being a bad person, it could be your lesson for being a good person, it could be anything but it's about… you know, religion…" (PARTICIPANT #6)

Another describes views very different from her own – notably, this participant was the most highly educated of the participants in this study:

> "…they think something supernatural has happened to them, and feel like, they are in a bad luck or something, they don't understand that it's genetics." (PARTICIPANT #2)

When asked if newcomers from her home country would receive information about genetic illness well when explained by a genetic counsellor, the participant seemed to think it was no problem: "Yah! They will!" (PARTICIPANT #2)

On this spectrum of religion to science and science to religion (Figure 11), individuals fell anywhere along the wide gradient. Although some participants did have strong religious beliefs and others related more to a biomedical framework, individuals were able to acknowledge contrasting views and different ways of understanding the cause of genetic illness. Participants demonstrated the impacts of psychological acculturation as they worked with both cultural views from their home country and those held by the majority of North Americans. For example, a participant demonstrates how she held both religious and biomedical views, with her interest in biomedical testing and answers but her trust in God that things will work out:

> "…all these processes [medical procedures] is in Gods hands…for each test we pray for positive feedback like God's grace, you know things like that…it's going to be good news." (PARTICIPANT #4)

Again, whether or not faith played a role in the decision; personal beliefs were always carefully balanced when deciding to purse genetic counselling, genetic testing, and/or pregnancy termination:

> "…it's the question of your belief there, what is right, to choose children based off of their normalcy you know? …am I going to turn my back on this child because they are not going to be perfect and walk at nine months old…? …but don't forget, I was very open to having an abortion when I found out I was pregnant and I'm very okay to go through with it, but… having made up my mind to keep the child, there really was no question on now turning my back on the child based off of they not being normal…" (PARTICIPANT #6)

One participant further highlighted the impact of acculturation on illness models/explanatory models, acknowledging that differing levels of faith may be held by individuals, possibility explaining participants' ability to juggle contrasting perceptions.

Previous exposures including education, awareness of genetic illness or access to different types of medical care, were related to a high interest in understanding about the cause of genetic conditions. In particular, the ability for an individual to think about multiple causes of illness and an acceptance of the root cause of the illness. Although exposure increased interest in knowing and awareness about the cause of a genetic condition, awareness was also related to a participants' level of education.

Participants illness models/explanatory models arose from balancing both a biomedical and spiritual understanding of illness, thus individuals were not black or white on the topic of genetic causation, falling on a fluid continuum (Figure 11). For some, a lack of understanding of the biomedical model causes reliance onto previously understood causes of illness. Both holistic and magico-religious understandings of disease were mentioned. For example, one participant clearly highlights the nature of prior exposure in a home country impacting how they people in their home country would understand and thus manage a condition:

> "…you have to pray for things…when that's all you have, it works for you, because it's not like there are options." (PARTICIPANT #6)

Individuals had varied exposures to genetic illness, which affected their perceptions about outcomes, and coping ability. The coping strategy was highly impacted by psychological acculturation levels, as it was based on expectations about information desired, available resources (testing and diagnosis) and prior knowledge, or where they fell on the spectrum

(education, preparedness and planning, culture, religion). Individuals may fall on a continuum of perception and understanding about the cause of a genetic illness, which was unique to each individual much like their level of psychological acculturation (Figure 11). In terms of coping, participants also worked with multiple frameworks (biomedical and otherwise) to find answers and to cope:

> "Again, our faith protects us, and however stupid that sounds, it does work for people you know." (PARTICIPANT #6)

Those who were able to cope with a diagnosis or illness did so because they were either satisfied with the information or answers they received from the genetic counselling appointment, and/or because they had an ability to align their understanding of genetic illness into a preconceived framework. This was a phenomenon that was impacted by the life experience, culture and education of an individual.

Successful coping, however, was not always as fluid as incorporating new information into illness models/explanatory models. This participant highlighted this internal struggle to flex between multiple frameworks:

> "I am a Christian… and I know that sometimes things don't always go as you planned, I mean…why did God allow these things to happen? It's not something I have an answer to, but what I would tell you is that within myself…even though I was so worried…within the time I heard about this and the time that I got the all clear result, I think there was a part of me, I think it's that Christian part of me, the one that has faith you know, that knew that this couldn't be, and then there's this other rational part of me that understands that there's science and sometimes things don't go as you wanted…I don't know what I believe, as far as…this being an act of God or what…it's very difficult to know what you believe…I'm a Christian and sometimes the two don't mix let me tell you, Christianity and science" (PARTICIPANT #6)

For this participant, it was very difficult to accept the nature of the genetic condition without fully understanding the cause. This misaligned understanding led to inappropriate coping and self blame:,

> "Both my husband and myself we have the bloodwork in Canada to test my genetics…we both are normal… I was puzzled, why we both normal and we have a child with some DNA missing…I read some of the books from [my home country] and they said when the mother she was expecting the baby, if she have depression or something like that will cause the baby's developmental delay and so that's why sometimes I blame on myself…my mother pass away during that time, that cause…this genetic issue."(INTERPRETATION, PARTICIPANT #3)

Here the individual asks for clarification that is more specific about exactly how the DNA could be lost in an attempt to move closer to one side of the spectrum or the other:

> "…So even now the genetic doctor told me that my son's developmental delay is caused by genetic. Okay, I accept that fact, but I don't know what makes him that he has this kind of genetic delay, I still don't understand." (INTERPRETATION, PARTICIPANT #3)

This information is the missing link between understanding and self-forgiveness. Although the information was given, it was difficult to understand, process and incorporate it into the self-identity or current understanding of the cause of genetic disease. Whether there is a misunderstanding about cause of genetic illness due to lack of education, because concepts cannot be incorporated into a preconceived illness model/explanatory model or a combination of both, is not entirely clear. It is clear, however, that the individual experienced acculturative stress and that has impacted coping ability significantly.

For those with a strong level of faith, coping was stable whether there was an understanding of the root cause for the illness or not. Faith helped to overcome a level of uncertainty. A

participant further exemplified this idea - although they had confidence in western medicine, there was a strong conviction to understanding its limitations which together led to a balanced coping ability:

> "Turn to for help? God almighty. Because in such situations, what can human beings do…. the worst case scenario, even if blood transfusion gets at some point it's actually not making the decision better, in the end the child still dies….maybe it would help, you just talk to God…" (PARTICIPANT #4)

Again, this participant represents someone who is flexible and fluid along the continuum, describing both biomedical and magico-religious explanatory models.

Interestingly, one individual stressed the important difference between acceptance and complacency, speaking to the fact that one may have religious convictions, but that in no way would fate overrule free-will:

> "…doesn't mean the fact that I'm a Christian…based on my bible …God would definitely provide, all my, all my needs…it doesn't mean I shouldn't work with my hands…It doesn't mean that, I shouldn't work, because I have to work to bring something to the table… you still need to work…so, I wouldn't say because God put me in good health and sound health, I shouldn't take good care of myself…I shouldn't do my regular medical check-ups or something. The same doctors, God actually gave them the reasons as well to help human beings…" (PARTICIPANT #4)

For this participant, the balance of fate vs. free-will spilled into the idea of finding answers, becoming educated and having a degree of control about their health:

> "…it depends on level of faith though, people will just sit and say 'ok everyday I'm very sick', they don't want to go to the doctor, they just sit down…for me I think I'll just like maybe go talk just to be aware…because once you're aware then you can ask questions, 'ok what are the solutions' or 'where do we go from here', unlike when you just sit there…you don't know if there's something that could be used to actually make you feel better. So I would say being a Christian isn't easy like that…you still need to get yourself out there, be educated, be aware

> of things…Yah, to seek information…as a Christian, I won't say ok just fold my hands and not go to school." (PARTICIPANT #4)

Overall, acceptance about a genetic illness arises when an individual has sufficient knowledge about the condition to answer any questions that they may have, as well as the appropriate ability to cope. Coping ability was clearly an individualistic process, influenced by multiple factors not evaluated within this research. Aside from established variables that influence coping, in the context of these participants' experiences, there were three additional variables that affected coping ability. Individuals required sufficient answers and information to their questions. These may have been questions about a diagnosis, treatment or the mechanism that caused the disease. Coupled with whether an individual received appropriate answers, individuals coped better if A) an individual had a strong level of faith, and/or B) an individual could align the biomedical information they received about the cause of genetic illness with preconceived illness model/explanatory model. Again, the individual who was unable to understand the cause of disease tried to look for an answer by relying on what was known about disease in their home country. Additionally, this ability to align complex concepts with prior knowledge might also be simply the result of experience and education. One participant explains that those whose do not understand the biomedical explanation and thus, are not able to process those ideas, might rely on what they already know further solidifying this idea:

> "…if, scientific information is not, within their reach, they're going to think it's spiritual. If you couldn't have an explanation for, something.…that has happened. The other alternative is to say, probably something spiritual or mystical. That's the only other option they have to explain it to themselves. …the thing that genetic counselling might want to look at is, looking at what level of education they have, look at what they think is wrong, and because they are going through that, let them know that it's nothing spiritual, science can explain it.…and that's why it is there." (PARTICIPANT #2)

Taken together, acceptance about a genetic illness arises when an individual has sufficient knowledge about the condition to answer any questions that they may have, as well as the appropriate ability to cope.

Although all of the participants had some interest in genetic testing, the decision-making process surrounding pursuing genetic services as well as the resulting satisfaction with the service was influenced by where the individual fell on the spectrum between science and religion, the nature of their cultural experience and previous exposures. For example, this individual talked about what people back home might think of genetic service:

> "…it's simply a get on with it life, no one sits around you know doing counselling and, psychological things and all that because there are really pressing issues to survival like food, that's a problem right…there's nothing called counselling in [Africa] you know, genetic counselling…" (PARTICIPANT #6)

Although not directly stated to be a result of level of faith, this individual spoke about sickle cell anemia testing in their home country. The participant felt that although individuals in their home country have opportunities for this testing; some may still turn a blind eye:

> "…for some just out of ignorance they just do stuff and then the child comes to the world, without realizing they could have done the genotype or blood group test and all that, do you get what I mean?" (PARTICIPANT #4)

Here they describe the results of the conflict between fate and free-will, highlighting cultural differences and representing a result of varied levels of education within that population:

> "…back home maybe some people, it's not like you don't know these things [sickle cell anemia] happen or maybe based on being non challenged, and they don't think it's necessary and because some people back home have saying when you go and access and go for medical check-up and everything, they actually don't see the need for it, they have this very wonderful mentality thinking, if they go for medical check-up that could turn into something wrong with them, that there is something wrong with them medically so is that causing them to panic –

> because that's like the opposite, like medical check-ups are supposed to help you know what's happening, to make you aware of what's happening to your body, and before it's actually deteriorating to something, something that can not be repaired, do you get what I'm saying? (PARTICIPANT #4)

Although this participant seems to think that one cannot take a laissez faire attitude when it comes to her health, she talks about her experience with health care professionals during her pregnancy in a contrasting light, exposing value conflicts that individuals encounter when trying to make their decision to pursue further testing and/or genetic counselling:

> "…you go through procedures you have to, because if a persons like a midwife or they're non-faith, who have specialty, specialties in helping out with pregnant women, they push us and all that.." (PARTICIPANT #4)

Interest in understanding the causes of the genetic condition also falls along a spectrum. Multiple individuals stated that they thought the culture in Canada was focused more around finding a diagnosis, more so than it was in their home country. For some individuals, a culture of acceptance within their community caused a general disinterest in understanding the cause of a genetic illness unless it is married with treatments, management or implications for other family members. Although these participants stated a religious background, there really were no religious undertones to their comments about the nature of accepting a disease or disability. For some participants, appointments with Genetics gave them pause to consider the possibility that there is a culture of "over-testing" in Canada, one individual stating that they were "stressed unnecessarily at the time". This participant reflected about being offered invasive testing after she received her normal result from the amniocentesis:

> "I think it's…panic inducing, because I look back…at that time, and I'm thinking, maybe, I shouldn't have, you know, maybe the test shouldn't have even been done…but then again it, there's a case for it…because you're prepared if it will come to that…Maybe there's a culture for over-testing people because there wasn't anything in my background that would suggest that, I would have a child

> with Down syndrome…sometimes you know it just comes, and you see people that are twenty having people with Down syndrome… maybe there is a case for it." (PARTICIPANT #6)

Again, there was a culture-clash for some. The idea of counselling about a medical problem seemed foreign, since her culture did not believe in counselling, and her faith in God allowed for acceptance of what was to come:

> "The test itself is not taken in [Africa]. When I told one of my friends that I had done the test, was like 'what are you looking for that you would even do that kind of testing', I mean, 'why are you looking for a problem where there's not'…Just pray and believe that God will give you a healthy child…most of the things we do, is predicated on our faith…" (PARTICIPANT #6)

Although she debated the importance of prenatal testing, she also reflected an understanding of the biomedical model of illness. Her decision-making incorporated an appreciation for information sharing for the benefit of the greater population, a sentiment that is aligned with a collectivist ideology in a home country as opposed to an individualistic North American way:

> "… people are litigious this side of the world…I mean in my work I know, people can get very litigious about fifty dollars, imagine then something as serious as this [prenatal testing], so I suppose there's a kit for everything and for it to be the way it is, people must have done research…and offered recommendation, this is how we serve the society better..." (PARTICIPANT #6)

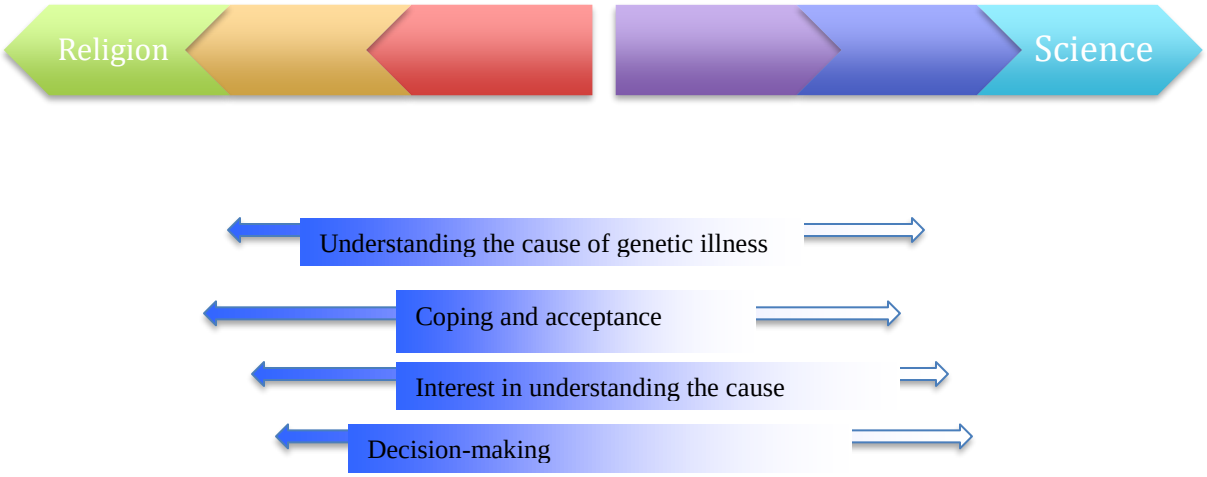


Figure 11: Individuals' balance between biomedical and alternative understandings of illness*

*(primarily magico-religious in this population but also including holistic) affects decision-making, coping and behaviours taken regarding genetic counselling.

Some individuals, who talked about experiences of genetic illness in their home countries, brought attention to the roles of organized religion and place for the church. Certainly in some of the participants home countries, the division between church and state was blurry at best, a stark contrast to what is known in North America. One individual commented on the business of religion back home and it's inundation into medicine:

> "… if your pastor has to pray for the baby…to cure the Down syndrome – which believe me people will do, they will also take money from you…religion is a big business in [Africa], so it wouldn't be prayers is twelve dollars, it would be, well you have to sew your seed, give your all to God, you know… …you're being scammed out of your money because… it's a medical condition…its not a headache that prayers can solve and this this is embedded in the genetics." (PARTICIPANT #6)

Another individual explained where the role of the church has an important overlap with medicine - in pre-martial genetic testing for sickle cell anemia:

> "…as a Christian I found a church… you're given a form at a certain stage whenever you guys start to court is they ask you both to go to a medical test like a test of your genotype or blood group, know if you're compatible medically." (PARTICIPANT #4)

> "…informing the pastor like this person want to get married to part of the process is keeping both parties informed, each, to actually go run a test and, I don't know, I think the results go back to the church or something, regarding genotype or maybe just bring a copy of the test or something to show that indeed you guys are compatible because you need to look into that as well, not just compatibility spiritually but also medically as well…" (PARTICIPANT #4)

The participant further brings life to the cultural norms surrounding marriage as alluded to above. She discussed a personally impactful story about sickle cell anemia:

> "…I have this family friend that the guy was AS [heterozygous] and the lady was actually SS [homozygous variant], they got married, even despite what the advice on the parents and everything…but actually can they actually love each other? They went ahead to get married and during childbirth when the wife was actually putting to bed their fourth child the wife passed on…sickle cell…the child didn't live up to 10 years, the child passed on as well." (PARTICIPANT #4)

She reflected how intertwined genetic testing was within her culture and the perception it has of great importance for a healthy marriage:

> "….I would say love is like down the list, when it comes to marriage to being committed in a relationship that you actually can bring children to this world, because at that point [raising a child with sickle cell], I don't know if love could actually sustain such stress and such challenging situations and all that, as I said it could result in splitting of the two parties at the end of the day." (PARTICIPANT #4)

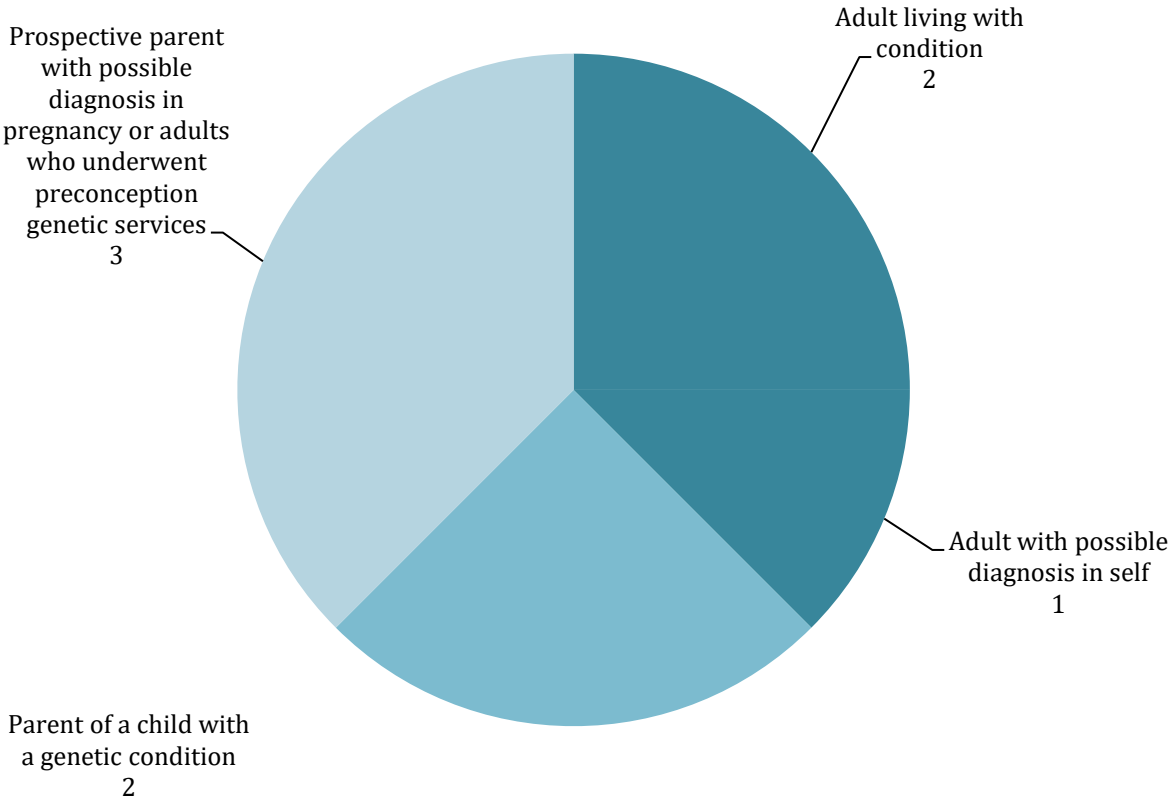


Figure 12: Number of participants per category of diagnosis group (total 8 participants).*

*The adult category includes those living with a genetic condition or an adult who was seen for pre-symptomatic testing for herself. The prospective parents category includes parents who are pregnant and have received a positive screening test in pregnancy and adults seen in the pre-conception context. One participant is discussed in both the parent category and the prospective parent category since she is a mother to an affected child and she is pregnant with a second child at risk.

Living with a genetic condition was always a challenge. Coupled with struggles unique to immigrants such as a lack of support systems, living with a genetic disease could be quite difficult.

Experiences of adults living or at risk of a genetic condition

Among those participants who were affected with a genetic condition (Figure 12) one described that they might have been physically limited in what activities they would be able to do, which may have made it more challenging to cope not having their desired lifestyle or typical lifestyle.

(ANONYMOUS PARTICIPANT #7). For this participant, acquiring and retaining employment became an unattainable goal because of a physical disability. (ANONYMOUS PARTICIPANT #7) For another participant who was given multiple diagnoses over their life, with the first diagnosis in childhood, receiving the second diagnosis was a big change and came as unexpected. (ANONYMOUS PARTICIPANT #5) Living with a genetic condition was adaptive, and was described by one participant as the only life they knew. Although receiving a diagnosis at a young age made it difficult to grasp the seriousness of the condition and the lifelong nature of the illness. (ANONYMOUS PARTICIPANT #5)

Disability affected many or all areas of the participant's lives. The genetic condition may have been associated with a life-limiting prognosis, but still finding peace and acceptance with the outcome was an important and on-going process. For the one participant who was tested pre-symptomatically for an inherited cancer predisposition, the perception of a possible diagnosis in themselves was accepted with little anxiety, an attitude reflective of previous expectations and prior experience of many other friends and family having a diagnosis of, and passing away from, cancer. Given this extensive family history and first hand experience with cancer, negative results were shocking and difficult to believe:

> "When I came to Canada, I wait my appointment…I remember it clearly it was October 5th…and then I got results from Moscow, and then I waited result [from Canada] because I told my family that it could not be a real result because all of you positive, how I could be negative! But uh then result in Canada was the same result. Yah." (PARTICIPANT #8)

> "…my sister positive, my mom positive…sister of my mom positive and all children of sister of my mom they're positive too… just me negative!...I was in shock in the first time…and I made the another genetic test in Moscow. And in Moscow genetic test result was negative too." (PARTICIPANT #8)

For this individual, supporting sick relatives was the biggest priority:

> "Ah I fly to Moscow on a 2 and a half months and I lived with the family of my sister and I took care to her children, I helped her to cook because he had a problem- she had a problem with uh eating…and uh after chemical treat she feel she felt really really bad. I just help, because it uh family. Yah. Yah, it is family. If I was in the same situation she made the same for me." (PARTICIPANT #8)

Supporting and educating family members were also priorities mirrored by one of the individuals affected with a genetic condition. (ANONYMOUS PARTICIPANT #5) This participant described that, they would want family members to have a diagnosis, so that they could help them avoid the discomfort they experienced, and so they could teach them about how to manage the signs and symptoms of the condition as soon as possible. (ANONYMOUS PARTICIPANT #5)

Experiences with a child affected with a genetic condition

For those individuals who were the parents of a child with a disability (Figure 12), there was consistently a great sense of responsibility and a discord of negative emotions. Parents felt sad and anxious about the developmental outcomes or the prognosis for their child, reflecting on the negative perceptions of disability:

> "…my husband he's much more worried than I do, he in regards to my son, and when he first found out my sons situation, he couldn't have a good sleep the whole year. And even his hair turn grey." (INTERPRETATION, PARTICIPANT #3)

> "…people still look at the people with genetic issues, developmental issues and have a kind of like a taboo thing to look at it." (INTERPRETATION, PARTICIPANT #3)

Participants reflected on their experiences as feeling helpless or turning to blame themselves. One participant exemplified this self-blame when reflecting on poor outcomes for their child:

> "…I feel very sad because it affects his future my sons future, the whole life and that's I'm the one who caused this problem and I feel guilty about it." (INTERPRETATION, PARTICIPANT #3)

Because of these strong negative experiences, parents wanted to do anything they could to improve the lives of their children. However, parents caring for a child with a disability found it difficult to balance the newly acquired and existing family responsibilities. For one participant, their child with complex needs had scheduled feedings requiring specific equipment and positioning as well as particular physiotherapies. This participant worked diligently to care for the child and the other children in the family, but the balance between many medical appointments, specialized therapies and taking care of the family proved to be a challenge. (INTERPRETATION, ANONYMOUS PARTICIPANT #1) Much like several participants, finding a spare moment to complete the interview itself was a struggle. One participant tried to push for further development and growth in their son, describing the parental responsibility to teach their child with a disability:

> "…I would like, somebody can teach me how to teach my son if for example you know he's behind compared to the other kids, how am I going to teach him…also if I don't want to waste my time …I know that he is supposed to developments up to 18 years old so I don't want to be up to 18 years old and I still haven't taught him anything, that's my burden…try my best before he reach 18 years old, I still give him as much opportunity to learn as possible." (INTERPRETATION, PARTICIPANT #3)

For this participant, there was a particular burden in carrying the weight of this responsibility and in having to educate others in an attempt to ask for help:

> "…I went to the school to explain to the teachers that because he could not communicate…he want to socialize with the other kids is just by his behaviours by pushing the kid to draw attention so they know that he want to play with them…. the teachers think that this kind of disturbing their classroom…it's so difficult for me to teach him how to socialize with other kids in a proper behaviour… I explained to the teacher but they still complain to me, and I don't

> think the teacher understand his behaviour cannot correct overnight." (INTERPRETATION, PARTICIPANT #3)

This participant clearly finding a correlation between developmental milestones and self-forgiveness:

> "…I found out my son has some improvement so I feel better, but before that I was really really sad." (INTERPRETATION, PARTICIPANT #3)

Still, the added demand of caring for a child with a disability was exhausting:

> "…sometimes I'm so tired and this almost like I want to give up to teach him." (INTERPRETATION, PARTICIPANT #3)

> "…you have to be very very patient, to train him to teach him and sometimes he, I have to control my temper because some times if I got impatient because so many times I teach him, he still don't get it. And then, however, when I think about because he has some developmental issues then I just sort of like calm myself down and I try again, control myself and then try again to teach him." (INTERPRETATION, PARTICIPANT #3)

<u>Experience of participants at risk to have an affected child</u>
(Including the experiences in of a pregnancy at risk for a genetic condition or carrier adults at risk for a future pregnancy to be affected with a genetic condition)

Perceptions were quite similar to the lived experiences for the parents of children with genetic conditions or disabilities (Figure 12). For the prospective parents of an affected child seen in the prenatal context, perceptions of a genetic condition or disability were also negative:

> "…really you don't often want to bring children to the world to suffer… worst case scenario they will be doing some suffering and the child, or the children may end up not living in the end of the day, they may end up dead… " (PARTICIPANT #4)

> "…regardless of what people say there's normal and there's other things… now as far as whether you want to say abnormal or whatever… will [they] meet their milestones or maybe meet them a few months later and flourish and go on to live their own life, not someone that you mother for the rest of your life right?" (PARTICIPANT #6)

Participants describe the intense weight of receiving the news of a possible disability in their future child and the loss of anticipated outcomes:

> "Was it necessary to be that bothered, cause I just can't sleep the entire time crying, you know…it's just, when you think the burden that will be placed on you, how much of yourself you have to give…" (PARTICIPANT #6)

One participant expressed that the view of parents of a child with a disability is quite different between a home country and Canada, with most Canadians having positive perceptions over Africans:

> "…if you had a genetic condition in [Africa]…this Down syndrome, I don't even for a fact know anybody that has Down syndrome so…they are people that, at the risk of being derogatory, they are called imbeciles in [Africa]…" (PARTICIPANT #6)

The participant truly felt that the Canadian population has a more positive view of disability, since the advanced testing available in Canada means having a child with a disability really becomes a choice:

> "….if you're like a parent raising a child with a disability, whatever disability it is kind of like a badge of honour right… I read the online forums about Down syndrome, they are celebrated. I don't think anyone in Canada would ever see a mom with Down syndrome- with a Down syndrome child and not think that mom to be a, a hero. Especially since they know that the mom must have somehow known before the child was born and you know still chose to do the right thing by the child…it's a lot of sacrifice to know that this is what I'm going to have to deal with and still take that on, I mean if that isn't love, right?" (PARTICIPANT #6)

Yet, one major difference surrounds the view of receiving financial support to help raise a child with a developmental disability:

> "…they told me well you know they pay them more right? I'm like, they pay people with Down syndrome genetics? They're like no, the people with all the sicknesses you know in their children… they pay them. That's why people are rushing to have their children diagnosed with these things, well I suppose maybe not Down syndrome but ADHD, all of these things that the spectrum is very wide you know. There must be a fraction that thinks that way…whereas if it was in [Africa] that you will receive any sort of compensation for raising a disabled

> child, you will be seen as a money grabber, nobody will be thinking about the sacrifices you make because how much could it be you know to watch your child not live out their life…" (PARTICIPANT #6)

Participants were typically able to reflect on the seriousness of the possible diagnosis with some context and realism for the most part:

> "I think it's imitating at its best…you know saying they are angels, and then at its worst you are mocking them because they are no angels you know, they are human beings with imitations…" (PARTICIPANT #6)

> "…of course people are going to have other different conditions, not just trisomy 21 right? If it was… the… 18…that when you have the child…it's a possibility that you are not living with the child you know? Do you even really want to put someone through that? And then there are other worse conditions, right?" (PARTICIPANT #6)

> "…imagine that you're the one going through such a thing, imagine the pain…imagine the having to be transfused by blood almost every now and then…just imagine the trauma, you just bring on your spirit there like almost every time I'm going through the crisis and all that, just imagine yourself, even on the child, on the victim…" (PARTICIPANT #4)

Although some perceptions about some parts of the condition itself were somewhat exaggerated and did not represent the most likely situation, possibly representing an area for future education:

> "…if I had a child like that that I'd probably have to be in the ER… once a week or two times in a month. That would literally just break me down because it will be only me and I have a one-year-old son…" (PARTICIPANT #6)

> "…most cases, where there was like consistent blood transfusion and all those things, actually not beneficial to the child and at some point, the child might, you know, not be able to like, live beyond a certain point and just pass on…" (PARTICIPANT #4)

These heightened negative perceptions were associated with the immigrants' busy lives. One participant discussed how the possible diagnosis caused them to worry about how they could manage the added burden of a child with a disability when they were alone:

> "and you know at that point I'm thinking it's a death sentence [positive maternal serum screen for Down syndrome]. I mean, it's not the best thing but as long as you know there are no health complications…but it was literally a cof- a nail on my coffin then…because we are immigrants…my husband works as a nurse. He works out of town. We have no family here…" (PARTICIPANT #6)

This possibility became all too real when the participant spent a night in the emergency room with her son:

> "And I had to take my son, you know still carry him and bare the news that I had received, and then that night I actually had to stay in the emergency room until 6 AM and that was when I began to think oh my goodness, imagine that I had a child with Down syndrome, you know at home, and this one [my son] is ill…I began to think, what if I had a child that is one month old and has Down syndrome too… where am I going to keep this one? Because my husband has to keep working for us to pay our mortgage, you know…" (PARTICIPANT #6)

Much like parents of children with a disability, this prospective parent felt a great sense of responsibility and discussed feeling much like they would be rejecting their child should they choose to terminate the pregnancy:

> "…where's my conscience as a mom if I [did] do this termination, because you know what, I like this child already, I love this child already, but now all of a sudden I don't love you because you have Down syndrome. Of course I love you, are you going to be more work? Yes. But do I love you? Yes." (PARTICIPANT #6)

When asked about a possible positive result or about waiting for results in general, participants were worried about the results, leading on that coping with the possible diagnosis was a struggle:

> "…I didn't want to imagine it. It would have been such like, exactly like a rollercoaster. A lot of things, like I mentioned, emotional stress, marital stress, a lot of things, a lot of questions going on in ones head…" (PARTICIPANT #4)

> "It was just that I was nervous because of the wait so…try not to think about it, go to work…just try not to think about it." (PARTICIPANT #2)

> "…I was just like asking myself so many questions, at the same time, we're waiting for the [genetic] counselling just like, ok fingers crossed it kind of helps calm my nerves it did, when I talked with someone." (PARTICIPANT #4)

For one of the parents of a child with a disability, previous experience and expectations made prenatal testing in the next pregnancy extremely anxiety provoking. Although a level of hope was not completely absent for all participants:

> "…maybe then there would be a choice in my mind, but being Down syndrome may be the best of it all right? …you could also be lucky and the person will not have any health problems at all and you're just dealing with a child forever, and there wasn't any choice in that for me." (PARTICIPANT #6)

Finding acceptance may not have actually been achieved since all of these respondents received negative testing in follow-up just a few days or weeks later:

> "I thank God when my spouse went for the test he didn't have anything…" (PARTICIPANT #4)

<u>Experiences of the medical system in a home country</u>

Participants also describe their experiences with medical systems and seeking support in their home countries as a world apart from what occurred for them in Canada. Participants talked about two main differences:

1) Availability of support and quality of care, or the level of medical technology, and reliability or trust
2) Financial limitations or other personal connections

One participant discusses the level of available support at a hospital in Israel as compared to Canada. In the hospital in Israel, the parents are required to provide all the support to the child 24 hours a day, and receive only occasional relief. This is in stark contrast to the readily available and intensive care of the nursing and support staff in the Canadian system.

(INTERPRETATION, ANONYMOUS PARTICIPANT #1) Another participant furthered the idea of appropriate supports with a comment about how surprised they were when all the necessary appointments and consultations were readily available to them in Canada:

> "Oh, we was happy. My husband told me, 'how could be?' we came to hospital and you just discuss your family doctor and then a Canada gave you all consultation which you need, all tests which you need and, we was happy." (PARTICIPANT #8)

A few participants discuss a kind of 'diagnostic odyssey', describing the limitations of the technologies and services available in their home country and commenting on or alluding to the medical technology:

> "But of course, you have to deal with, if the child has a health thing, you're dealing with a subpar medical um system and you're paying out of pocket too…" (PARTICIPANT #6)

> "…I don't even think that the technology for all these things are there." (PARTICIPANT #6)

> "…it's different ways in [my home country], because at first I found out it's because his speech slow and so I went to the to the, children's doctor, and they gave him some cognitive test and even he was 3 years old, he's more like a 2 years old…and they give him the CT scan…and they give him some medication in [my home country], that said it will…that will assist him with to develop…when he came to Canada and he went to see different professionals…the first thing they told me that his case cannot be cured by medication…they make the assessment and then those genetic counselling come into place, to tell me the reason." (INTERPRETATION, PARTICIPANT #3)

Others described health care providers/doctors providers as being less advanced or knowledgeable than those in other countries and/or Canada. (ANONYMOUS PARTICIPANTS #5 & #7) One participant described that the move to Canada was likely a factor in prolonging the diagnosis of their child. However, they contrasted this to the quick diagnosis received in Canada acknowledging that a referral to a genetics provider in their home country was never made:

> "…in [my home country], there should be some genetic doctors however I wasn't referred by anyone of them, to go to see anyone of them… [my son] only about 3 years old that we found out that he's slow in picking up speech and by that time we moved to Canada… in [my home country] he never mentioned anything about DNA…he did not refer my son to see the specialist..." (INTERPRETATION, PARTICIPANT #3)

Another participant discussed the less advanced medical system in their home country, describing it in the context of having to self-diagnose. (ANONYMOUS PARTICIPANT #5) This participant described having to know what symptoms to look for and to effectively bring your own differential diagnosis to your doctor, not something they worried about in Canada. Interestingly, this participant had many visits to different physicians during their childhood, never reaching a final diagnosis and only sometimes hearing that the condition may be genetic. Unfortunately, some participants thought that all genetic conditions are untreatable, since being told that that an illness was a genetic condition was synonymous with learning that 'there are no treatments available to help'. This participant was continuously told that there was no management available, which was not completely true in this case. When one of the overlapping conditions was eventually diagnosed in Canada, and appropriate treatments and management were initiated, this participant reflected very positively about this change. Even though this was not curative, the participant discussed that they never imagined that life could ever be better for them. (ANONYMOUS PARTICIPANT #5) Similarly, this participant described the prevailing perception of a more advanced health care system in neighbouring countries, pointing out that many people from their home country were likely to seek medical care elsewhere because of it. (ANONYMOUS PARTICIPANT #5)

Although not explicitly stated by all, most participants alluded to finding the Canadian health care system more reliable than in a home country as a result of the various concerns described:

> "…in comparison with Canada Moscow is a really really big country…everything's so quickly and you know that, sometimes we had a person mistake…sometimes your test could be with another name, and, sometimes in my first case…specific test we make double, one and then again, just to be sure that the first results was correct." (PARTICIPANT #8)

Some participants articulated this reliability as trust:

> "Yah because, when he been on that kind of medication for 6 months and I couldn't see any improvement and by the time when the Canadian doctor told me that it didn't help him anything, and I think about it's reasonable that it did not help him, and so I just stop it." (INTERPRETATION, PARTICIPANT #3)

Consistently, financial reasons put limitations on individuals' access to care:

> "…living here in [Africa] and you're having a healthy child, or an unhealthy child, if you come to the hospital and you don't have the money to pay, you're not going to get a bed, that's how bad it is." (PARTICIPANT #6)

> "…I am grateful to even be here in a place where I am able to go to the emergency room without thinking do I have money in the bank account… where I could go into labour at any moment and I'm not thinking will I have to pay six-thousand dollars – my sister paid almost ten-thousand dollars to have her baby in the U.S., you know?" (PARTICIPANT #6)

One participant described how these financial barriers limited *which quality* or level of treatments would be available:

> "And it depends of money…if you have money you could buy the best drugs and to get the best treatment…if you does not…you got uh just the usual, just the common, common treat. And uh sometimes you need to wait a long long time and sometimes it's too late. Treatment is too late." (PARTICIPANT #8)

Given these previous experiences in a home country, individuals have preconceptions about costs of services in the Canadian system, which, depending on the procedure, may not actually exist:

> "You know it was interesting the day we did this test, I thought it was going to be three hundred – five hundred dollars for the test, because I had read online that it was five hundred dollars, but then it's free. But in [Africa] …nothing is free, no, no Aspirin that you take is free so…" (PARTICIPANT #6)

> "You pay. Yep, 300 Canadian dollars you pay it on one genetic test not everyone could pay the same money you know. But in Canada, it's the opposite situation, really opposite…I cried because it was surprise for me because I thought that I need to pay something or do something for this." (PARTICIPANT #8)

> "...I don't even feel like for one second that there's something else that could be done better, I mean, I'm on my own, I did not pay for a service and someone thought it wise to do these extras for me…I think if I started saying that something else should be done then that would be really… that will be… what does it say about me as a person, I didn't pay for this, it was just support, it's just someone looking out for you…" (PARTICIPANT #6)

In addition to affording medical treatments, personal connections play a role in accessing care, although as this participant describes, sometimes the ability to access care or not can be out of ones control:

> "…how much money you have, then, who do you know, because you know sometimes you know you could have the money too, but the hospitals are on strike…" (PARTICIPANT #6)

> "Moscow is a really really strange country. When you have any contact, networking with any doctor…you are okay...my mom works in a medical government, that's why my sister got the best medical treatment..." (PARTICIPANT #8)

Overall participants expressed a great deal of respect for and trust in the Canadian health care system and may have even come to Canada in part for the positive perception of the medical system. "…I think that in Canada you have a lot of chance to control your health…"

(PARTICIPANT #8) This participant's reasons for moving to Canada summarize this overwhelming positive spirit well:

> "…we, would like to grow our children in a network where people think about people, but not about just only money… " (PARTICIPANT #8)

Other challenges experienced by newcomers

The experience of living with or caring for an individual with a genetic condition was universally difficult for participants. Some challenges, however, were more generalizable across participants and were shared among multiple individuals. The long wait times were most commonly discussed and acknowledged as a frustration and point of stress for half of participants. Wait times included time to receive an appointment and time to receive genetic testing results:

> "…what would have made this decision easier for me…I would have been happy to pay for that…if I could have got it [amniocentesis] earlier and had my mind be at rest earlier...I think the time between it… between the getting the call, getting the test and then getting the results, I do think that it was quite a length- a process…" (PARTICIPANT #6)

> "Everything got better after the appointment…all the challenges…the only challenge was the waiting time." (PARTICIPANT #2)

> "...the appointment with cancer counsellor she told us that they would- it will be one or two months, but the result it took three and a half." (PARTICIPANT #8)

Participants unfamiliar with the process of receiving prenatal genetic counselling, could become frantic between the time of learning about positive maternal serum screening and the time to see a genetic counsellor:

> "Well, it wasn't months, but it did feel the same, when you are thinking the worst…I was told that I was going to be called… in few hours…myself and my husband dressed up and went to the hospital, trying to see if we can see someone to speak to us about this…and I went to speak to my doctor to find out okay what percentage is my risk, you know, and all that. My doctor was not in, I went to the Women's Health Centre where I later would have the testing. I got bounced from

> office to office to office…nobody wanted to take ownership of it. Maybe because they hadn't received the thing from my doctor's office, right? And then I went home, thinking that, okay, fine, even if you are not giving me the right answer I'm going to just wait in the hallway and get the call, after all you're supposed to call me in, in a few hours…but then about five days passed and no one called me …I got the call from my doctor on a Monday and then I was invited to do the test… on the Friday…when you're irrational with fear it's just a long time…" (PARTICIPANT #6)

For one participant, the wait time was surrounding receiving primary care. This participant had to make many trips to the hospital to receive care for the complex needs of their daughter, who required special equipment and positioning to feed, and on a regular schedule. When wait times were longer than expected, or no beds were available to feed in a lying position, this participant was unable to feed their daughter on time. (INTERPRETATION, ANONYMOUS PARTICIPANT #1)

The concerns about wait times were mitigated by participant expectations. When a participant was familiar with short wait times or walk-in appointments from a home country, it was surprising to have to wait to been seen by a physician or a specialist as was the case for genetic counselling:

> "…it's not like there will be people on standby waiting to do amniocentesis everyday, but…I would have been happy to pay for that, you know?" (PARTICIPANT #6)

However, most were able to reflect on the need to remain patient:

> "…I was… taken care of…even though I'm saying maybe they should have called me earlier, a part of me realizes that it's probably not only me that received that call that day, you know? …a rational part of me knows that, they didn't just sit around and decide to let me stew in it [my positive maternal serum screen result] for however long, you know?" (PARTICIPANT #6)

One participant describes understanding the time consuming nature of genetic testing from her previous work experience:

> "…Genetics takes, it takes an amount of time, to do those kinds of things. I have a bit of a experience in in Genetics. …there was nothing she could have done, I knew it was going to take a long after this, I mean she said it was going to be like a month or so…" (PARTICIPANT #2)

Other less commonly mentioned issues included frustration with the process of scheduling an appointment with a genetic counsellor or how the session was held. For one participant, the *process* of which she received the genetic counselling was also less than desirable. She described that she received the genetic counselling while she was on the bed during her ultrasound. This was disorienting since she felt that she was already in the appointment for the amniocentesis and that this process did not allow her to go home to think about her testing options or learn about the process of genetic counselling:

> "I think I would have appreciated when the appointment was set someone speaking to me about whether or not – the risks, because up until the one second before I had the procedure done, I did not even realize that I was going to have this done without anesthesia I did not realize that I was going to be awake and…the thing was going to poke through my belly to my…to draw the amniotic fluid. …And then the genetic counsellor came to speak to me when the doctor was now already there to take the sample, so she spoke to me with both the doctor and the ultrasound technician already present, but I did not know, I thought that after speaking to her I'll be put to sleep…" (PARTICIPANT #6)

> "So, I think if… they, they sort of told you before you were at the appointment, this is what to expect, this is the choice you would make, go home and sleep on it, I think that would be the better use of the counselling,…what does it matter when my mind is already made up? Or even, maybe the counselling could even be, the doctor sends you to the counsellor, the counsellor tells you everything, and then you make the appointment through the counsellor, I think that would be a better thing." (PARTICIPANT #6)

> "…if the sequence was changed, you could actually even have people opt to not do the test and save the…is it the city or who, whoever funds it…maybe you can

> find that some percentage of people don't even go through with the testing." (PARTICIPANT #6)

This provides evidence that genetic counselling at the bedside can be disorienting and remove the perception of choice for the patient.

Less frequently, participants mentioned issues such as transportation, running out of essential prescriptions and concerns about the privacy and storage of genetic information and test results. Participants gave mixed reviews about concerns of transportation. For one participant who had previously been able to walk to appointments, a move to a far away neighbourhood posed a new challenge of transportation, in getting to appointments at the main hospital. (INTERPRETATION, ANONYMOUS PARTICIPANT #1) For others who lived outside of the city, or for an individual with a disability that limited driving ability, catching rides with friends and family seemed to solve the problem of transportation. (ANONYMOUS PARTICIPANT #7) For others, transportation was not an important concern. One participant had asked for a longer-term prescription for a medication for symptomatic management, since the constant need to refill the prescription could be quite taxing considering the participant needed lifelong management. (ANONYMOUS PARTICIPANT #5) The concern about storage of information and privacy was mentioned by one participant:

> "…privacy is a big issue… Very big issue across the world anyway. Not just Canada." (PARTICIPANT #2)

This participant was interested to know about privacy and the storage of information, contrasting previous experiences with a paper-based system in their home country:

> "…the level of technology it's not, it's not advanced…everything is still paper… you don't want anybody to know your name, don't write it down on the paper!...nobody's going to see your file…your medical information is intact

> because it's all in a file…it's all locked away….if you can't access the medical records room, nobody can see anything." (PARTICIPANT #2)
>
> "I think if I had a concern I'm just wondering, how the result end up. Are they going to be destroyed, how long my information will be on file…" (PARTICIPANT #2)

This highly educated participant considered the nature of genomic medicine with worry, cautiously raising the concern of the fate of her genetic information if found in the wrong hands:

> "…I'm just thinking what scientists can do with data, what scientists can do with that kind of data, with bioengineering now…can do a lot with anybody's genetic information….I don't know. Never mind, I've worked with pharmacologists who know too many things." (PARTICIPANT #2)

This was a concern that may not be obvious to many and was likely a direct result of this participants level of education. However, participant #2 felt that prevailing mysticism about advances in science and technology along with a general distrust of governmental organizations leads to serious concerns about genetic testing which can limit individuals from seeking genetic counselling altogether:

> "I'm just wondering how the genetic information is going to be destroyed or if it's ever going to be destroyed…a lot of people would be reluctant to come just because of that…there is no privacy anywhere in the world …and then you go to receive you blood! You gotta give your DNA to the government, you're screwed you know…some people from my country would never give your DNA even if that sample for genetic testing. They be like 'What! Oh my God!'…. there is a knowledge gap… Some of them will come and smile at what you say, and they know anyways, say "no I'm not doing it!". And some of them would look at you like 'what are you saying?' So you have various, various people with different knowledge." (PARTICIPANT #2)

5.2.7 Theme 6: Why I wanted genetic counselling/testing

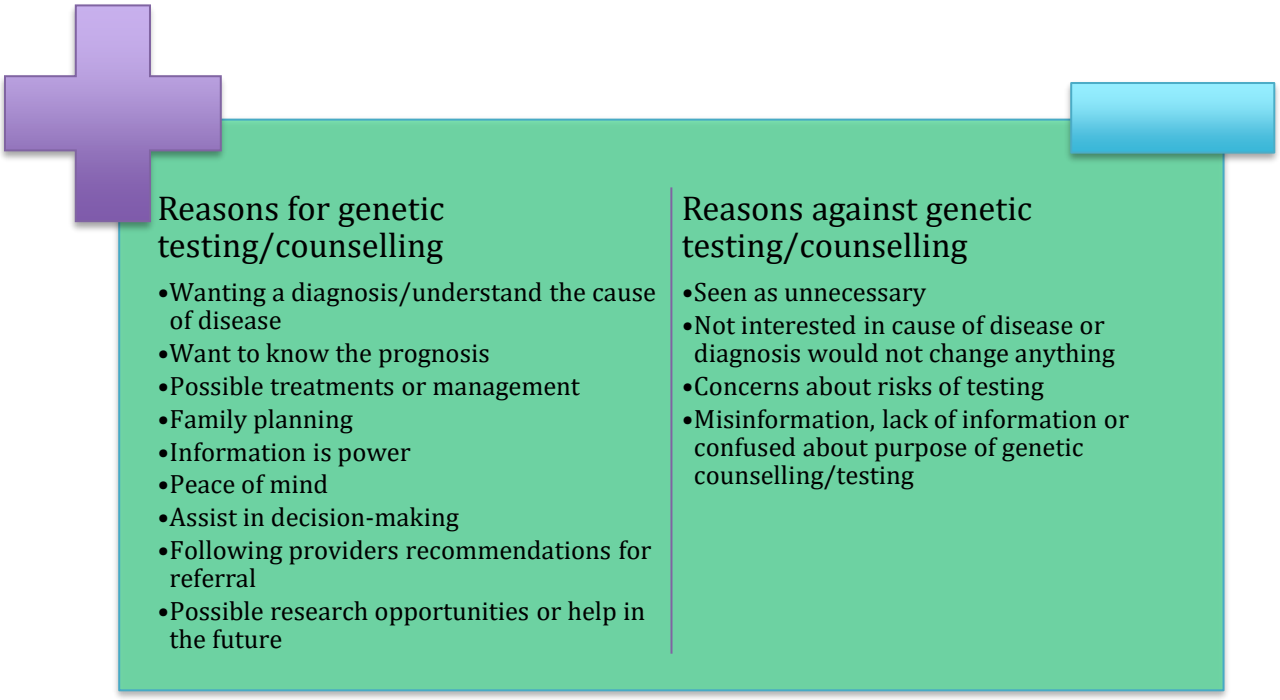


Figure 13: Participant's reasons for and against genetic testing and/or genetic counselling.

Individuals had different perceptions and thoughts about the genetic counselling service, the counselling experience and why they may want to have genetic testing. Although some individuals were skeptical about the need for genetic counselling or testing, all individuals wanted more information about the genetic condition, the risk to pass the condition on, prognosis, or a diagnosis, as most people felt that knowledge was power. The reason for wanting genetic testing was dependent on which individual was ill, i.e. the self/parent, child or pregnancy and their understanding of the purpose of and possible outcomes of genetic counselling and/or testing (Figure 13).

Adults living with or at risk for a genetic condition

Individuals wanted testing because understanding and information about the condition was seen as important. Finding a diagnosis was important mainly because of the possibility that there may be treatment or management options. For example, one of the individuals affected with a condition had been told in the past that their condition was genetic, and that nothing could be done to cure or manage the condition. (ANONYMOUS PARTICIPANT #5) For the participant seen for genetic testing in the pre-symptomatic context, preparing for the future was seen as important and could be achieved through screening and/or surgeries:

> "…I thought that everyone have 'necro-elements' in their body which could be cancer – everyone. But I never thought that it could be in a genetics situation, that if you have a genetical disease you will have a cancer and you need to prepare… right now my mom who had the genetic positive, she controls herself one time in the three months. She made uh she makes…ultrasound…" (PARTICIPANT #8)

For one participant affected with a genetic condition, there was an overwhelming need to look for preventative measures to stop the progression of the condition. The participant had in part come for genetic counselling to speak with someone who may have been able to provide this treatment, or who may investigate the condition further, which implied that the participant was hopeful that there would be research going on to help with the genetic condition. (ANONYMOUS PARTICIPANT #7)

A diagnosis was also seen as useful and important in answering questions about risks to future children or to family members. When one participant's questions about the risk to future children or the future children of siblings was not answered, the participant was unsatisfied and expressed that this was a question they would have wanted answered in their appointment. (ANONYMOUS PARTICIPANT #5)

For the one participant who was tested as an adult in the pre-symptomatic context, the reasons for testing were less about looking after oneself and more about supporting the family much like Anonymous Participant #5:

> "…genetic counsellor told me that if I will have that positive result of my test, or my daughters will have in their future the same test. But if I will have a negative, they will be okay in this genetic problem of my family." (PARTICIPANT #8)

> "…if you live long, you think just only yourself, but if you have children, you need to keep yourself in the health, that's why when I thought that something could happen with me, and when I understood that I have a lot of chance to be – to live with genetic problem…the first step was to go to genetic test…We know all about it, in our family, because my husband right now live long without his parents [who died from cancer]…(PARTICIPANT #8)

This participant personal experiences solidified this choice to have genetic testing, as she had already experienced a great deal of loss in her family from inherited cancers. She talked about educating other relatives and friends about the possibility of genetic testing, again trying to prevent the great loss, she had experienced, yet few people seemed to know about or have an interest in genetics testing in her home country:

> "When I asked my friends in Moscow… just me make genetic test. But I know that a lot of my friends have in their gen- genetical family situation: cancer…. a lot of my friends have mom or daddy or grandma or grandpa who died in a cancer, from cancer…That's why I think that they need to be sure that they have a negative genetic test. But when I ask them 'do you have, do you made any genetic testing, do you think about it', they every time told me 'no, I think I'm okay and I don't want to pay any money for this test'. You know?...It's so strange, it's so strange but it's true… It's money…it's time, not enough of information! But because I, from my sister got a cancer I did not know too that that cancer could be genetic." (PARTICIPANT #8)

The adult two individuals affected with genetic conditions in this study held contradictory views about genetic illness and their understanding of genetic testing. They spoke about their

conditions with a level of complacency, describing that they had to unconditionally accept the disease and the outcomes, thinking there was nothing that could be done to change the situation. At the same time, these participant sought treatment and management options. (ANONYMOUS PARTICIPANTS #5 & #7) As a result, understanding the cause of the condition was seen as less important, because providing a label for the condition was not seen as changing the outcomes or lifestyle for those affected with a genetic condition. When a diagnosis could provide information about a prognosis, there was some shock and surprise but individuals remained optimistic, again portraying an attitude of unconditional acceptance.

The adults affected with conditions demonstrated a lack of understanding about the purpose of genetic counselling and testing. Additionally, individuals had a lack of understanding of what a genetic diagnosis provides, yet they demonstrated a desire for information that could be provided by a diagnosis. A lack of knowledge or understanding was related to a strong reliance on the advice of the physician with respect to decisions to pursue genetic testing. One participant was confused about the nature of the genetic counselling and testing and pursued the appointment on the advice of a referring doctor coupled with a personal strong desire for preventative treatments. (ANONYMOUS PARTICIPANT #7) When asked about the decision to pursue testing for oneself, or if a family member were to pursue testing, this participant weighed the pros and cons of the testing. For this participant, the pro for genetic testing was that a physician recommended the testing, and if the testing would be helpful to physicians to find treatments. (ANONYMOUS PARTICIPANT #7) For this individual, it was more difficult to articulate the cons, but they were vaguely described as if they did not feel like doing the testing, or they felt the testing was not needed. (ANONYMOUS PARTICIPANT #7) Previous life experience in a home country also

left participants assuming that a genetic diagnosis was synonymous with no cure, resulting in the clinician discharging the patient, and not bothering to treat them.

Child affected with a genetic condition

Participants whose child was affected with a genetic condition not only wanted a diagnosis, but also desired to understand the *cause* of the disease:

> "Yah if they can explain to me what caused the child miss some DNA, then at least I be cautious in the future about having another child." (INTERPRETATION, PARTICIPANT #3)

Genetic testing provided information about the risks for the birth of another child affected with a genetic condition allowing participants to regain control in what felt like a helpless situation. For example, this participant had asked for a referral to speak with her genetics provider further about the risks of developmental delay in another child:

> "…this time when I see the genetic doctor because I'm pregnant, I arrange the appointment, not because the genetic doctor request me to see him, is I request to see the genetic doctor, because my first born has some issues so I want to see the risk of my second child…This time when I see the doctor I ask him is there any tests I need to do to confirm the baby is okay developmental, and then he told me that I have to go for amniocentesis…" (INTERPRETATION, PARTICIPANT #3)

As in the case of adults affected with genetic conditions, understanding the cause of disease was also thought to be helpful in acquiring appropriate treatments or management. Understanding the cause of disease was also important in planning for future pregnancies or providing information about risks for family members. Parents of children affected with a genetic condition and prospective parents demonstrated a parental responsibility to do everything in their power to protect their child, and provide the best outcomes for their child. However, the definition of this parental responsibility is in the eye of the beholder, andwais influenced by personal

beliefs/cultural views and experiences or exposures. In the case of parents of a child affected with a genetic condition, one participant's desire for a healthy child pushed her to pursue genetic testing to better understand the risk for a second child to be affected with a genetic condition:

> "It's kind of dilemma for me, I want to have a healthy baby and I don't want to have a baby with a genetic problem that will affect he or she the whole life…so that's why before four months I ask the doctors to have all kind of tests to see if the baby is healthy…you know I want to have the baby for sure, but at the same time I'm worried about the future of the baby if the baby also has a genetic problem. And that's what I'm caught in between, you know? Don't know what to do with it…I come to the test because I thought for the future child, it's not fair to the child…"(INTERPRETATION, PARTICIPANT #3)

However, this view of genetic testing was not held by her husband, who demonstrated his parental responsibility in a much different way:

> "…my husband and I discussed with him about those tests, it may have a chance to cause miscarriage, and then he says don't go for the test, don't go for- because of the high risk. And he doesn't want I have to suffer the miscarriage, and he love his wife and he love his family very much, and he doesn't want any one of us, suffer anything…he does not agree for abortion…even though the baby may have some genetic issues he still want the baby." (INTERPRETATION, PARTICIPANT #3)

Seeking genetic counselling and testing satisfied this responsibility at least in part. Knowing more about the cause of the condition was also seen to provide peace of mind to the parents, which represented a way for the parent to reduce self-blame and guilt about causing the illness, and allowed the parent to cope with the diagnosis. When a diagnosis was not identified or the parent did not completely understand the cause of the illness, Participant #3 became somewhat frantic and continued to pursue answers. They hoped for treatments and blamed themselves for causing the condition. For this reason, genetic counselling was desirable because of the possibility of gaining new information or guidance.

Participants at risk to have an affected child
(Including the experiences in a pregnancy at risk for a genetic condition or carrier adults at risk for a future pregnancy to be affected with a genetic condition)

The usefulness of genetic testing in the context of pregnancy varied among participants. Most wanted prenatal genetic testing and/or counselling to provide a diagnosis and/or prognosis and to help prepare for the future, once again revealing their sense of parental responsibility. This preparation included readying himself or herself for the birth of an affected child, or avoiding the birth of an affected child in the future:

> "…for me it's planning of a child…we should have a test for the parents, for the 'parents-to-be' that what's the chance of a genetic problem, that's important so they can you know, they be aware of it." (INTERPRETATION, PARTICIPANT #3)

> "Because I needed to be mentally prepared… for, you know longer hospital stays, possible surgeries in the first few days or weeks of life…It's very important to me that I don't walk into that blind… you prepared the best you can, because how do you prepare for that? So you prepare the best you can." (PARTICIPANT #6)

Parents who were currently pregnant did not want their baby to be affected with a genetic condition, and all chose to have some form of testing or screening in the pregnancy. However, because prenatal testing results were negative, the parents did not explicitly elaborate on their views about termination in most cases. The choice to pursue testing (and potentially parents' consideration of termination) was influenced by the burden of a new life in Canada. This left prospective parents wondering how they might manage this added stress. One participant explicitly talked about this challenge:

> "…if I had a child like that I'd probably have to be in the ER… once a week or two times in a month. That would literally just break me down because it will be only me and I have a one month- a one year old son…but I am a Christian, a child

> is a child but it's just amazing that I don't have to deal with that on top of all the stress that I have… being new to the country, having no family, the scope to which you are tested being new as parents and at every other thing… you couldn't capture it in words…" (PARTICIPANT #6)

One participant recognized the power of genetic testing in that it would not only be able to provide more information about risks in her pregnancy, but also offer information to her future children, and by going through the process she had gained the education needed to discuss the importance of genetic testing with friends and family:

> "…it's going to be helpful for me also in the future, it's going to be helpful for me right now maybe for my friends or family who actually intend to you know, to have children, for them to be aware if I actually have the chance to talk to them, to advise them … and also in the future for my own children, just so they are aware..." (PARTICIPANT #4)

Parents in the prenatal period agreed with Participant #3 who described decision-making about genetic testing in a pregnancy required recognizing the risks associated with invasive testing: "It was very important to me, if not I wouldn't have risked it." (PARTICIPANT #6) Although finding an answer was important for all participants, not all them were willing to take the risk, and opted for a less invasive test, settling for a less definitive answer. This choice was individualistic to each participant and based on his or her perceptions of the risk involved:

> "…I wasn't ready to deal with too much, to many risk…so I settled for the non-invasive…I've had about 3 miscarriages already, so I wasn't ready to be poked…. I spoke with my husband before on the phone, and we decided to go for the non-invasive…we wanted to reduce the chance of anything happening." (PARTICIPANT #2)

Some participants described that genetic counselling provided answers and reassurance, and the genetic testing provided them peace of mind:

> "…it helped me because previously I was, I had a lot of questions running through my head, okay what if…that was before the counselling even though I had made my research, after the counselling helped calm my nerves, drawing the family tree and all the conclusions that point at okay, the baby goes like to 99% chance baby wouldn't have it however for peace of mind we actually still have to go to do the test. So it's helpful to me in that way – helped calm my nerves…" (PARTICIPANT #4)

For this participant just having the knowledge about the future was powerful and gave her control over the situation, since it allowed for her to take action if needed.

Again, one participant disclosed that she felt the risk numbers were reasonably low, low enough to not warrant a referral or bother to having the genetic testing. Yet when she considered the available options, the non-invasive genetic testing was sufficient to provide reassurance, which was welcomed in this situation:

> "…like every other human being, you get a bit nervous, you're talking about a baby here….well of course the chances were quite very low so I didn't – I wasn't expecting the referral. But, I just decided to, I just decided to do it for the sake of peace of mind, because really, the chances were too low to do this thing in my opinion." (PARTICIPANT #2)

When questioned about why she would pursue the appointment given this opinion, the participant highlighted the importance of this reassurance:

> "Of course, the peace of mind can't be, cannot be explained in words, you know?" (PARTICIPANT #2)

One participant described a very different situation, suggesting that genetic testing was useful, but genetic counselling was less so, because she had already made up their mind to have the testing before arriving to the appointment:

> "Well, I wasn't ever not going to have the test, the only thing that I was rescinded on was that even if the child had the Down syndrome that I wasn't going to go

> ahead and terminate, I'm already eighteen weeks…I don't want to, you know?" (PARTICIPANT #6)

For her, the genetic counselling was seen as preventing her from receiving the testing that she wanted:

> "I think I would have preferred to be counselled prior to that day, but you know at the point that I was being counselled, my true thought was that the woman was delaying…the procedure, and I had waited so long and the doctor was standing by the side and that I'm having the counselling done you know I'm laying right there wearing the robe for them to take out the amniotic fluid and I thought, you're just delaying the thing, you're just delaying it, because nothing you say here could change the outcome you know, I'm at the point that I'm very impatient…" (PARTICIPANT #6)

Again, trust in Canadian health care providers was a major undertone to why an individual wished to have genetic testing; many alluding to trusting the Canadian system more so than the one in their home country. As described above, this trust was demonstrated by following the advice or guidance of physicians in the referral process to genetic counselling. In the context of genetics providers, trust was built through the thorough and honest communication style. Trust was also present as a result of perceiving the Canadian health care system as more advanced than one in a home country. One individual described not being able to trust medical results because of the lack of reliable testing back home, and that this lack of trust along with her personal experiences (described in "Theme 5, Living with a genetic diagnosis as an immigrant has its challenges"), prompted her to seek confirmatory testing in Canada:

> "Some times they have a lot of mistake and sometimes 'positive' means 'negative' and it it's difficult to be sure that the result in Moscow means that really result. That's why I made the same in Canada..." (PARTICIPANT #8)

Although not explicitly stated, even though participants held various cultural and religious beliefs and understood disease causation from a blend of biomedical, magico-religious and holistic models, all were open and interested in the testing available from the biomedical system. This further elaborates the idea that individuals balance their views, relying on different explanations of illness at different times and for different situations. To reiterate one of the participant's experiences of learning about the cause of disease, it can be appreciated that she had mixed feelings about the cause of the condition, but that she understood that the genetic testing provided her with information about the risk:

> "…I read some of the books from [my home country] and they said okay when the mother she was expecting the baby, if she have depression or something like that will cause the baby's developmental delay…in Canada all the doctors assure me, that is not the reason that cause the genetic problem..."(INTERPRETATION, PARTICIPANT #3)

> "So you know that this time when I see the genetic doctor because I'm pregnant…I ask him is there any tests I need to do to confirm the baby is okay developmental, and then he told me that I have to go for amniocentesis…" (INTERPRETATION, PARTICIPANT #3)

This balance worked well for most. Participant #3, however, struggled to align the cause of disease with their understanding of the genetic testing, which resulted in them turning to blame themselves:

> …I still blame on myself, every day, not just once in a while. It's my fault…because my depression, my mother pass away during that time, that cause, my sons, this genetic issue… (INTERPRETATION, PARTICIPANT #3)

5.3. Secondary Interview member checking: Results and Impressions

5.3.1. Theme 1: Communication is deeper than language

Most of the secondary interview participants agreed with the results and interpretation of this theme overall. One person commented further about the idea that individuals might not always say what they mean. This participant suggested that she might not say what she means because interview questions are too personal sometimes. This break in communication was not because of a lack of trust, rather, for her sometimes questions are just too personal to answer which may cause embarrassment. The participant suggested that this could happen in the appointment and the interview. However, for the most part, this participant described that she could openly express herself with the assistance of an interpreter. Another participant echoed this statement suggesting that she had no concerns with people in authority, and that she felt she could be herself.

5.3.2. Theme 2: Health literacy, awareness of genetic counselling and education

Most of the secondary interview participants agreed with the results and interpretation of this theme overall. One participant elaborated on the idea of genetic services in a home country. She suggested that there were genetic counselling services in her home country but that people do not think it is needed. Further, she described that people know about DNA but not about genetic counselling, and when in her home country, she had heard about genetics but she did not understand it. Reportedly, people in her home country are not recommended to see genetic counsellors unless they are at high risk in a pregnancy because of the age of the mother. Individuals might be told about genetic counselling but not referred. She thought that genetic counselling was only important for pregnant women (before and during a pregnancy). Overall,

she felt genetic counselling was becoming more popular in her home country but that people still think it is not a needed service. She felt that in Canada, there is a culture of wanting to know the *cause* of a condition and back home, people might not know that you could look for the cause. However, she suggests that this perception could be due to a lack of education and the high cost of the genetic counselling service.

5.3.3. Theme 3: Support systems are important but difficult to cultivate

Most of the secondary interview participants agreed with the results and interpretation of this theme overall. One participant felt that support systems were not difficult to find and using a support such as a community service would not make her feel like a burden. This individual highlighted that her lower support needs could be due to having relatives born in Canada (self described as having "roots" in Canada) and as a result of living with relatives in Canada. Additionally, she explained that she relies on faith and attends her church. Another participant agreed that there was not a lot of emotional support in Canada since there was no family nearby. In response to feeling like a burden in using community supports, this participant described that she would prefer family as support but would pay for services if needed. Another participant disagree somewhat with this theme in that she did feel supported by the medical system, but did not look for support from family. She described this as not wanting to bother family for long-term help and not wanting to rely on family because they do not have medical knowledge. In contrast, one participant said that the genetic counsellor did not feel like support to her, but she questioned whether there might have been more support had her genetic testing results been positive.

5.3.4. Theme 4: The art of science and religion

Most of the secondary interview participants agreed with the results and interpretation of this theme overall. One participant tried to bring light to the idea of medical pluralism by describing that genetics does not come from religion or faith, and that both genetics and faith each have their own place, in that they can coexist. Another participant clarified that she believes in the Western medical interpretations of illness and trusts Western medicine. She felt this might be related to her generation in her home country being told not to believe in God. She described that she does not use faith or religion to cope and that she preferred to see her doctor. Additionally, she described that she did not feel pressure from service providers to undergo testing that she did not want to pursue. This participant also disagreed with "over-testing" saying the more tests the better. However, another explicitly agreed, saying that there may be "over-testing" in Canada, but that she does think it helps with preparing people for what is to come in the future. This participant understood genetic illnesses as an act of God, but she thought that medicine was trying to help. She considered it is important to take advantage of faith *and* science and that they are not mutually exclusive, much like other participants.

5.3.5. Theme 5: Living with a genetic diagnosis as an immigrant has its challenges

Most of the secondary interview participants agreed with the results and interpretation of this theme overall. Although one participant suggested that, it was difficult to speak about their experience with genetic services, when their genetic testing result was negative, because they felt that they continued to live their life as if they were before testing. Another explained that she had no fears of organizations or about giving blood, and that she had trust in the privacy of the genetics clinic. With respect to the experience for adult patients, individuals agreed overall,

suggesting that having friends and family quickens the healing process, is motivation to heal and that they do not want their friends and family to suffer. With respect to experiences of caring for children affected with genetic conditions, participants highlighted the need for genetic counsellors to reiterate that parents should not blame themselves. Additionally, one participant echoed that she would take advantage of community services if she had a child in need, even at the risk of feeling like a burden on society. With respect to pregnancies or partnerships at risk for a pregnancy affected with a genetic condition, participants mostly agree. One participant suggested that the experience of testing depends on each person's choice and the situation they are in, thus is was hard to agree with all comments made in the results. Additionally, for one participant, with respect to severity of disease, Down syndrome was still seen as difficult to manage because it was a visible condition to her.

With respect to medical systems and experiences in a home country, one participant clarified that she did not expect things to be the same in Canada as back home, acknowledging that there are cultural differences. One participant elaborated on this idea, alluding to the medical system in Africa as corrupt. She explained that the system was not centred on the knowledge doctors have (i.e. their medical skill set). She called the system faulty, suggested that doctor's just want to make money and described that you cannot completely trust the medical system back home. To her, experiences in Canada were not dependent on money or faith, and she explained that one could expect to receive quality medical care regardless of religious background or social position. One participant described that her experience of medical services from her home country were much poorer, which affected how she viewed medical services in Canada. Additionally, there were no wait times for her in Canada since she reportedly took charge and

sought services, as she would have done in her home country. Still, some felt it difficult to respond since they did not run into many challenges with the service. One participant highlighted the importance of explaining to newcomers that many genetic tests are free and that genetics providers should educate newcomers because they might be confused or scared about the genetic counselling service.

5.3.6. Theme 6: Why I wanted genetic counselling/testing

Most of the secondary interview participants agreed with the results and interpretation of this theme overall, although some specific experiences were not shared universally, and one participant could not comment about adult experiences as there were time constraints on this interview. With respect to the experiences of prospective parents with a pregnancy at risk for a genetic condition, participants also highlighted the need to educate young adults about genetic services, not just expecting newcomer parents. Additionally, one participant described that sharing/educating the newcomer community about genetic services would not be helpful to her in better understanding her genetic condition.

5.3.7. Suggestions to improve service

1. Increasing awareness and education about genetic counselling services and genetic diseases.

Most agreed with this suggestion, although one participant stated that it would not be completely helpful for her, although it would be helpful to make others aware of the service. One other participant suggested that education should be specifically for those who actually had a need for genetic counselling and/or testing.

2. Assist in strengthening support networks, help to increase culturally relevant support systems and increase the provision of appropriate referrals being mindful that not all types of support are seen as acceptable.

Most agreed with this suggestion although a couple of participants talked about having enough support from multiple sources. One reiterated her roots in Canada (Grandparents born in Canada) as well as relatives and her church that offer support. Another participant gave somewhat conflicting messages, suggesting that a lack of support may exist for some people with different cultural backgrounds, but for her, she felt that there was no emotional support, but that there was enough medical support. Another suggested that genetic counsellors might provide emotional support by letting newcomers know that there are others going through something similar, they are not alone, and that things like this [genetic conditions/disability] do happen.

3. Reduce wait times.

All but one participant agreed with this suggestion. One elaborated on her awareness that the wait times are a result of the public health care system, a balance of time and money.

4.Include the patient in planning.

Overall patients strongly agreed with this suggestion. The original participant to make this suggestion further recommended that genetic counsellors could send a page about genetic counselling services to newcomer patients before the appointment to let them know about the appointment. One participant disagreed, she felt that the communication was clear and her questions were answered during the appointment.

5. Create centre specific protocols for patients who require interpretation services.

Although this was only explicitly applicable to one secondary interview participant, all agreed or could at least empathize with this need.

6. Consider immigrants in the discussion on the current topic of diversity and inclusion and NSGC 2019 initiative.

The sixth suggestion was not returned to participants in their secondary interviews.

5.3.8. Summary

Overall participants largely agreed with the results and analysis completed by the researcher. Additionally, most agreed with the interpretation of the participant-driven suggestions for improvement to service. Some participants emphasized slight nuances that would be important to consider. There were few areas where participants did not agree at all. However, participants did highlight that they did not share some experiences from the synthesized and analyzed data. As such, they could appreciate the ideas and comment on their perception of other newcomers' experiences. In some cases, the participants could not imagine a situation or the experience was not relevant to them, in these cases they tended described the experience as not applicable.

CHAPTER SIX

6.0. Discussion

Both historical and recent literature has highlighted barriers to service and outcomes and gaps in the provision of care for immigrants with respect to genetic counselling (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; Cheng et al., 2018; McCarthy et al., 2016; I. Mittman et al.; Muller et al., 2018; RG & Whipperman, 1987 as cited in Greeson, Veach, & LeRoy, 2001; Sharkia et al., 2015). There exists a substantial body of literature that has evaluated ethnic specific population's awareness, interest and outcomes with genetic services. Most literature suggests that there is generally low awareness about genetic counselling services within these communities (Adedokun et al., 2015; Awwad et al., 2008; Belahcen et al., 2014; A. G. Buseh et al., 2017; Greeson et al., 2001; Hann et al., 2017; Joseph & Guerra, 2015b; Sussner et al., 2013). Yet research indicates a moderate level of knowledge about genetics, inheritance and risk (Adedokun et al., 2015; Hann et al., 2017; Sharkia et al., 2015). Older research indicated that there was limited uptake of genetic services possibly due to access and appropriateness or relevance of the service (Greeson et al., 2001; I. Mittman et al., 1998; I S Mittman, 1998). Recent studies suggest that although there is a low awareness, diverse ethnic groups do have an interest or willingness to participate in genetic counselling and/or genetic testing (Cheng et al., 2018; Komenaka et al., 2016; Thompson et al., 2002). Current research has focused on understanding the impact of communication style and language, informational needs, cultural and religious differences and trust building with such underserved populations (Cheng et al., 2018; Gesser-edelsburg & Shahbari, 2017; Joseph & Guerra, 2015b; Jun et al., 2018; Ricker et al., 2006; Sussner et al., 2009; Wal et al., 2015). Thus, this research provides an update on over 20 years of findings and recommendations and endeavours to increase access and culturally

appropriate care for ethnic minority populations. It highlights that although some advances have been made, many concerns have remained the same with time.

6.0.1. Communication is deeper than language

Participants widely characterized successful counselling by five major domains previously highlighted in the literature as important for successful outcomes: counselling style, thoroughness or depth of the appointment, information desired/received, communication/language barriers, and trust building. In fact, successful communication predicted satisfaction with the genetic counselling service overall. Given that genetic counselling can be largely described as a communication process (Resta et al., 2006) it is no surprise that effective communication is closely connected to trust building and subsequent successful outcomes. Communication challenges have been reported as a significant limiting factor to immigrants and ethnic minorities across health care system access, and are among the most widely studied of the barriers (Salim Ahmed et al., 2016; Gesser-edelsburg & Shahbari, 2017; Hann et al., 2017; Joseph et al., 2017; Joseph & Guerra, 2015; Jun et al., 2018; Kalich et al., 2016; Leduc & Proulx, 2004; Raz & Atar, 2003; Sharkia et al., 2015).

With respect to genetic counselling, communication style is primarily defined by its non-directive approach (Accreditation Council for Genetic Counseling, 2015) and a balance of information giving versus emotional support (Kessler, 1997). The effectiveness of non-directive counselling in the provision of service to non-Western populations has been questioned and has been met with mixed opinion, given that the approach may be in direct contrast to paternalism, which is still widely integrated in the medical profession worldwide (World Health Organization,

2002). In an Israeli study within the Negev and Muslim-Bedouin populations regarding interpretations of directiveness within premarital and prenatal case vignettes, Raz & Atar found that Bedouin populations, which were more aligned with non-Western ideals (collectivism, tradition, patriarchy and family dependence) were more likely to interpret non-directive messages as directive (Raz & Atar, 2003). These results were consistent with more recent studies of Palestinian versus Palestinian-American interpretations of non-directive messages in the prenatal context, with native Palestinians more likely to view a non-directive message as directive (Awwad et al., 2008). Further studies in the prenatal context in Korean-American sample provide evidence that directive counselling is preferable (Jun et al., 2018), and that the non-directive message may be perceived as lacking emotion or to be insensitive in a Muslim Arab sample in Israel (Gesser-edelsburg & Shahbari, 2017). These results are directly in contrast to our findings, in that several individuals appreciated the style of the genetic counselling suggesting it made them feel supported and understood. Three individuals highlighted the non-directive style more specifically. Interestingly, these three participants were specifically seen for prenatal indications. The positive opinion about the non-directive approach was shared among three African participants, who were well educated, spoke English and had been in Canada for approximately 3 years. Thus, it is difficult to discern if this view might be due to their cultural perspective or because of their psychological acculturation level. As such it is possible that because of their education level and time spent in Canada, they anticipated and/or expected this sort of communication style. One of these individuals had lived in Britain for approximately 1 year prior to immigrating to Canada, possibly contributing to this psychological acculturation to a Westernized culture. Familiarity with Western society and the English language was found to contribute to utility of the non-directive approach in other research (Jun et al., 2018) and level of

acculturation has been associated with perception and appropriateness of non-directive genetic counselling (Awwad et al., 2008). The only issue mentioned in our study about the non-directive approach was the timing of the informed consent conversation, in that the participant felt it was getting in the way of the testing she had already decided to have. This participant later contrasts her experience with genetic counselling to that back home, further bringing light to socioeconomic differences that would make counselling unnecessary; this is discussed further in 6.0.5.2.

Taking the time to be with patients and to listen to their concerns was mentioned by about half of the participants as positive, and was perceived as respectful and supportive. Those who commented on the level of detail provided were pleased about the importance placed on patient understanding. Going through personal topics such as the family tree was comforting because it showed how much due care the clinician was taking, acting to build trust. This appreciation of time and attention is supported by literature that suggests Canadian immigrants may perceive and experience primary health care physicians as too busy, lacking empathy or interest in patient feelings and/or descriptions of their health (Carrasco et al., 2009). Newcomers may feel uncomfortable asking questions and may have poor access to specialized care through referrals and community supports (Carrasco et al., 2009). Furthermore in a study of primarily recent immigrants living in a medium sized city in Ontario, Canada, it was found that appointments with Canadian family physicians were often perceived as rushed and impersonal, incomprehensive and lacking depth as compared to the more holistic approaches provided by doctors in home countries (Asanin & Wilson, 2008). Participants also contrasted their experience to appointments in their home countries, which they described as less detailed and more rushed.

Jun *et. al.* (2018) found that Korean-American women were actually used to doctors in Korea who were very busy and as such found the counselling process in America time-consuming and troubling. Our conflicting results are surprising, yet they may simply be explained by the fact that our participants are comparing apples to oranges. For example, it is possible that participants in this study may compare the average genetic counselling appointment (approximately 45-60 minutes in length (National Society of Genetic Counselors, 2018b)), to a *primary care appointment* in their home country or other *primary care appointment* in Canada, both of which may be significantly shorter or less thorough. Taken together, it is possible that the participants expected a rushed appointment and were pleasantly surprised by the depth of the counselling session, but that this appreciation is likely dependent on the informational needs of the patient and possibly cultural expectations. It is also possible that the genetic counselling encounter was less biomedical and more biopsychosocial in nature. As such, the provision of genetic counselling under a biopsychosocial approach could mimic aspects of the holistic approach. Ideally, when clinicians are employing a reciprocal engagement model, they are providing information and supportive psychosocial counselling (Veach et al., 2007). The reciprocal engagement model is biopsychosocial in nature, because as described previously, it incorporates aspects of the teaching model (biomedical focused) and counselling model (psychosocial focused) (Veach et al., 2007). The model allows for an open discussion of psychological, social, cultural and spiritual concerns (Oosterwal, 2009; Tamm, 1993; Veach et al., 2007). It is important to note, that this study did not evaluate the model of practice the clinicians provided. Thus we can only speculate on this claim and assume that clinicians work within a spectrum of biomedical to biopsychosoical depending on which models of genetic counselling is employed for any given appointment.

Overall, individuals were usually satisfied with the information received. Participants were sometimes disappointed when information was not given in their appointment, or questions were left unanswered. Those who were not given a diagnosis or could not be provided with curative/preventative treatments were rightfully perturbed by this situation. Generally, our participants displayed a high level of trust in the Canadian Health Care system and the genetic providers at our centre. Thus, those who were not able to obtain a diagnosis of curative/preventative treatments likely felt let down by a system that they trusted for find an answer, and saw that they saw as advanced and reliable as compared to the medical system in their home country.

Immigrants' perceptions of the Canadian health care system as advanced and reliable are not overly surprising and may be known widely, although possibly only anecdotally. This perception is, however, in contrast to the well documented lack of trust in North American health care systems by multiple ethnic subgroups (Browner et al., 2003; A. G. Buseh et al., 2017; Chen et al., 2016; Dastjerdi, 2012; Greeson et al., 2001; Reitmanova & Gustafson, 2009; Suther & Kiros, 2009). For example, some American studies, have found a higher distrust in doctors by Black and Latino individuals as compared to non-Hispanic white people; a discouraging phenomenon attributed to historical wrong doings by the medical community (A. G. Buseh et al., 2017; Suther & Kiros, 2009). The perception held by our participants however is supported by a small amount of specific literature: for example low medical mistrust in Hispanic-American women in the context of BRCA genetic counselling has been previously reported (Sussner et al., 2013). The discrepancy seen between this study and recent literature may be due to a number of factors.

Firstly, participants' definition of trust may differ from previous literature. Newcomers in this study may simply be referring to trusting the more advanced technologies available to them in Canada, or the more advanced medical knowledge of health care providers as compared to their home countries, rather than the relationship with their genetics provider. Differences in definitions of trust might be true with respect to previous literature. Secondly, it is possible that immigrants in our study are highlighting a difference in trust of specialist care over primary care. Thirdly, historical wrong doings in ethnic populations may have limited impacts on immigrant newcomers' perceptions of health care. Fourthly, our participants represent persons already having chosen to seek genetic counselling services. Thus, there may be a selection bias towards those with attitudes that are more positive towards the system. These results however, might highlight a novel finding of higher trust in the Canadian Health Care system and the genetic providers at our centre within our pan-ethnic Canadian sample of newcomers as compared to previous American studies. It is possible that this result is due to a moderately high level of psychological acculturation within our sample. It is important to note that the studies that evaluate immigrants and trust tend to talk about trust in the general health care setting and/or primary care but do not evaluate specialist care and trust with these providers. Further, there is little literature evaluating newcomers' positive attitudes about health services. One study of older Korean-Americans found that satisfaction with healthcare was associated with having health insurance coverage, better English skills, greater trust of Western medicine and no experience of disrespect or discrimination within the healthcare setting (Jang, Kim, & Chiriboga, 2005). In a study of Iranian-Canadian health care providers views of Iranian immigrants barriers to health care, providers commented on the lack of trust in the Canadian health care system as complex and influenced by dissatisfaction with long wait times (Dastjerdi, 2012). Additionally, they

commented on a lack of access to lab reports and not having direct contact to specialists as they might have in Iran (Dastjerdi, 2012). Participants in our study were dissatisfied with the long wait times to see a genetic counsellor, yet this did not appear to impact trust with this service.

Trust is inherent to the genetic counselling relationship and attained through strategies such as contracting and eliciting a family history (Bennett, Hampel, Mandell, & Marks, 2003; Mcginniss et al., 2018; Veach et al., 2007). As mentioned above, trust building with participants in this study occurred during the family history taking when information was personal, as well as when providers were thorough and had long enough appointments to answer all questions. Additionally, trust building during the genetic counselling setting also occurred because of contracting where the provider set and followed their plan. Overall, the participants felt that their genetic providers were trustworthy because of their knowledge, honesty and ability to allow the patient to be heard. It is possible that these results highlight a changing opinion of a subset of newcomers to Canada, confirming what is already known anecdotally. Given these strong conflicting results, quantitative research evaluating immigrants trust in secondary health care services/specialist care such as genetic counselling, may be necessary to characterize the level of satisfaction expressed by the Canadian newcomers.

Individuals not only asked questions about the genetic testing and genetic illness, they also wanted to know more about procedures and processes. When they were not familiar with processes, they were dissatisfied. For example, the risks about passing on a condition to future children was not answered in one appointment, which may have simply been a result of the provider wanting to have the results of the genetic testing before providing the recurrence risk.

However, it is clear that the patient had a lack of understanding of the genetic testing process and was unclear about what information is expected to come later. Lack of information or knowledge to access or navigate systems has been widely reported in quantitative and qualitative literature as a barrier for many Canadian immigrant populations in a number of different settings (Stewart et al., 2008), including primary health care access and navigation of the health care system (Kalich et al., 2016). This provides evidence that immigrant patients in the genetic counselling context may also find themselves confused about health care system access and should receive additional information and support with respect to appointments, procedures and follow-up steps. Educating patients of ethnic minorities about the process of genetic counselling has been suggested by multiple groups, although these suggestions stem from clinicians and researchers observations (Awwad et al., 2008; Cheng et al., 2018; Siani & Assaraf, 2017), rather than newcomers themselves as we have done with this study. Educating about procedures and processes in the genetic counselling setting could be achieved in many ways, one example could be through explaining the plan and aligning expectations during the contracting stage (Bennett et al., 2003; Veach et al., 2007).

No participant explicitly described dissatisfaction with too much detail in the appointment, although several individuals (adults with genetic conditions) talked about not needing to understand the *cause* of the condition so much as the diagnosis and management. One participant (parent of a child with a developmental delay, expecting another child) discussed that the cause would be very important to know what to do for the future pregnancy. These conflicting results might speak to the participant specific indication for testing and the information needs in this setting, although this is a complex topic; it is discussed further in 6.0.5.1.

Not all individuals agreed that the genetic counselling session was easy to follow and understand. Although a few commented on that absence of jargon and were happy with how this made things easy. One participant had the opposite opinion, describing concerns about complex terminology complicating their understanding about the cause of the condition. Participants agreed that complex terminology have no place in the genetic counselling session. It seemed that participants are not aware that their genetic providers tend to tailor their use of terminology to the understanding of the patient (Veach et al., 2007), a skill that seems to have been employed the majority but not all of the time for the research participants. These findings are consistent with recent literature of ethnic minorities, that suggests that genetic counsellors will make an attempt to simplify the complex message but may provide more information than is relevant or useful, or the message will be unknowingly filled with complicated terminology (Joseph et al., 2017; Joseph & Guerra, 2015).

It would appear as though the implementation and utility of interpretation services are good, although this sample size does not allow us to generalize this statement across our centre. It is widely reported that use of professional interpreters in the medical setting are associated with improved overall care of patients with limited English abilities (Karliner, Jacobs, Chen, & Mutha, 2007). They also seem to reduce communication errors while increasing comprehension (Karliner et al., 2007). However, some have argued that there is variable quality in medical interpretation within the genetic counselling setting (Browner et al., 2003; Cheng et al., 2018). Moreover, interpreters lack of familiarity with genetics terms may lead to misinterpretations (Cheng et al., 2018; Joseph & Guerra, 2015), an issue that the interpreters used for this study

made mention of. Cheng *et. al.* (2018) suggest the need for interpreter training within the genetics field. Although not explicitly described within our results, given the experience working with non-English speaking newcomers and interpreters closely during this study, we would strongly agree with this suggestion. Working with interpreters has also been criticized for it's strain on rapport building (Browner et al., 2003; Cheng et al., 2018). Our results did not reveal any of these concerns. In fact the two participants who requested interpretation services disclosed no concern with the service and had a large appreciation for their interpreters. Of course, these findings were reported through the use of the interpreter and thus the participant may not have been comfortable disclosing any concerns they had with this service. Interestingly, the researcher noticed a large issue with the system of requesting and booking an interpreter in the case of patient follow-up. This concern was arguably the largest issue noted within the theme of communication for this study. One participant with limited English ability made it clear that they would not have any way of contacting their genetics provider to ask follow-up questions, through contact with the researcher on this project, the participant disclosed an urgent need to connect with their provider. This unfortunate situation provides substantial evidence that:

A) Non-English speaking patients are potentially unaware or uncomfortable with current methods of connecting with providers in follow-up, possibly because they do not know how to connect with an interpreter

B) Health care providers and medical interpretation agencies should develop site-specific protocols and

C) Newcomers should be made explicitly aware of this process.

Lastly, communication within this study was influenced by two ideas: firstly, that people do not always say what they mean and secondly, that you cannot truly speak for others. These two concepts were largely drawn out of the researchers reflexivity about intra-interview communication challenges as noted during the interview, but were supported by several participant quotations as selected in the results.

The researcher reflects on multiple instances where participants said they were very happy with the genetic counselling service but later went on to describe issues. The researcher wonders if the participants are happy with the service overall, or if there are difficulties for some to verbalize their true concerns. Because of a lack of context or familiarity with genetics it can be difficult for patients to verbalize their thoughts and questions (Joseph & Guerra, 2015). The researcher proposes that this lack of context or familiarity also results in an inherent difficultly for the participants to verbalize their suggestions for improved service delivery, in other words, individuals do not know what they should expect so identifying issues can be difficult. This proposal is supported by one participant who mentioned that it would be hard to know what to suggest to improve the service having seen the counsellor only once. Additionally, it may be that the newcomers do not want to disrespect individuals of authority (i.e. the genetic counsellors/geneticist within the appointment and the researcher within the interview) out of a sort of social compliance common in a home country. This idea of social compliance is supported by a study of recent immigrants in Quebec that postulated that interviewer ethnicity/origin may have impacted the discussion of sensitive topics such as social exclusion and racial discrimination during interviews (Leduc & Proulx, 2004). This idea of not disrespecting the clinicians in the appointment was supported by our results with one

participant's comments, that they would not have disclosed their thoughts during their appointment out of conscientiousness for their genetic counsellor. Awareness of the social location and the patient-provider relationship should be considered when working with visible minority immigrant groups (also called "racialized" immigrants) (Carrasco et al., 2009). Furthermore, all of the participants in this study originated from countries of traditionally high power distances, indicating the possibility of our participants to have a higher tolerance for power imbalance (Hofstede, 2011; Hofstede et al., 2010).

When presented with the results in the secondary member checking interview, one participant disagreed with these ideas in part. The participant suggested that she might not say what she means as a result of embarrassment rather than a lack of trust. Another refuted the statement about speaking her mind to people in authority. Regardless, providers should be aware that it is possible that as a result of the power dynamics of the patient-provider relationship, patients may not speak about their concerns openly as Canadian physicians may expect (Fellin, King, Esses, Lindsay, & Klassen, 2013). Additionally, as an extension of this idea, it is possible that because of the social location of the researcher, there will be limits on the ability of the research to draw out all of the concerns of the participants.

Similarly, individuals usually (but not universally), explained themselves clearly during the interview. However, on more than one occasion, the researcher felt confused about the comments made by the participants, and as such asked several follow-up and clarifying questions to be sure she understood. The researcher wonders if this would be the case in a time-sensitive

appointment, and if clinicians would notice the nuances that could impede effective communication.

Participants often spoke about not wanting to speak for all immigrants as a whole, providing caveats to their responses to clarify that some but not all fellow newcomers may share their opinion. This is a similar phenomena to what has been previously reported in a population of Somali immigrants (Greeson et al., 2001). From the perspective of the researcher, it appears as though participants have highlighted an emerging point of discussion among the genetic counselling community: a need to transition from cultural competency to cultural humility, recognize the intragroup cultural variability and avoid stereotyping those within a cultural group (Lewis, 2002; Mcginniss et al., 2018). This is much the same as previous literature that suggests that cultural competency in healthcare cannot be accomplished by generalized cultural understandings of health for each of ethnic group (Daudji et al., 2011). Moreover, individuals should be viewed as having their own unique culture even if they identify with a particular ethnic group (Daudji et al., 2011). This shift toward cultural humility is described further in section 6.0.4.

Overall, there is significant overlap on the topic of communication between populations selected by immigration status and those by ethnic minority. Both bodies of literature suggesting that effective communication is needed to effectively access and utilize health services, including genetic counselling. The benefit of approaching the question of ethnic minorities' access to healthcare through our pan-ethnic sample of recent immigrants, however, is that we draw out increasingly more systemic barriers to effective communication. As such, these findings are

practical in suggesting improvements for services. Taken together, our findings suggest previously unexplored nuances in genetic counselling research, in particular, understanding immigrants' appreciation for non-directive counselling and the high level of trust in the genetic counselling service indicate areas for further investigation.

6.0.2. Health literacy, awareness of genetic counselling and education

There was uniformly low awareness of genetic services and moderate to high interest in genetic testing among our sample of newcomers. Most participants were unfamiliar with genetic counselling services before their referral, although one had heard about the service through a friend and another had talked to a physician in a home country about a genetic concern. Some participants had some knowledge of genetic services in their home country such as genotyping for marriage, and others had a vague idea that there may be some physicians providing this service. Although not unanimous, individuals tended to agree that immigrant communities should be made more aware of this service and education should be given about genetic conditions. Overall, low awareness of genetic counselling services within our sample of recent immigrants is mirrored by the body of research examining non-Western ethnic specific populations both in North America and abroad (Adedokun et al., 2015; Awwad et al., 2008; Belahcen et al., 2014; A. G. Buseh et al., 2017; Hann et al., 2017; Joseph & Guerra, 2015; Sussner et al., 2009). Interestingly, awareness among the non-immigrant Canadian population is also reasonably low (Maio et al., 2013). The results also suggest that there is a low awareness of genetic services within the less represented areas of pediatric and adult general genetic counselling subspecialties, although continued research in these areas is clearly needed. Furthermore, our findings highlight the importance of the physician referral for increasing

awareness of genetic counselling. These findings are supported by previous research that suggests physician referral correlates with intention to seek genetic counselling in ethnic minority populations (Barlow-Stewart et al., 2006; Cragun et al., 2015; Sussner et al., 2013). Additionally, Muller *et. al.* (2018) described a correlation between ethnicity and lower rates of referral to genetic services in a retrospective review of colorectal cancer patients who underwent tumour testing at 4 U.S. academic centres. They found that tumour testing occurred at an equivalent rate across ethnicities, but that there were several independent negative predictors of genetics referral, including medical centre, age, advanced tumour stage and African American ethnicity (Muller et al., 2018). Quantifying the number of recent immigrants currently unaware of genetic services may be challenging from a recruitment perspective, but more empiric studies regarding referral rates may be helpful in broadly characterizing awareness of genetic counselling/testing services in these communities and the limitations it poses on awareness in the Canadian context.

Awareness of genetic counselling is also related to previous experiences of genetic counselling in a home country. Although some participants had seen health care providers in a home country, the practice of genetic counselling appeared different from the practice found in North America. Individuals described difficulties in reaching a diagnosis, as well as in follow-up, often being told that a condition was "genetic" and then provided no further help. Others presented with genetic concerns but these were never further evaluated as such, and were only diagnosed in Canada later. One participant, who did receive genetic counselling of sorts, did so with a specialized physician who was providing cancer genetic counselling to her sister. This participant described that the difference with the genetic counselling in her home country was

that it is provided to those who are already sick, it costs money and the results are simply mailed to you without a provider's explanation. In the secondary interviews, one participant clarified her previous comments. Originally she had thought that there were no clinicians providing genetic counselling in her home country. She later commented that there were probably individuals providing such a service but that this service may not be needed or accessible to the people of her home country. It may be viewed as unneeded due to a cultural perception of the role of genetics as limited to the high-risk prenatal setting. Further, she describes that the service may be hard to access because of its high cost.

These results are not surprising when we consider the way in which genetic counselling is provided where there may exist no formal genetic services. Zhong *et. al.* (2018) offers a comprehensive systematic review of genetic testing and counselling in low and middle income countries, which include studies from South Asia (40 studies), Middle East and North Africa (38 studies), Latin America and Caribbean (34 stuidies), Africa (32 studies), East Asia (21 studies), Eastern Europe (18 studies) or a combination (9 studies). In this systematic review, they describe how genetic testing may be emerging within such countries, yet genetic counselling does not have such a global reach. As such, it has little recognition as a profession (Zhong et al., 2018). Physicians will typically fill this role (Zhong et al., 2018). Zhong *et. al.* (2018) report that medical genetics training is often inadequate and that clinicians report their medical genetics education as insufficient. This leaves physicians with limited knowledge about genetic conditions and limited abilities to counsel patients and provided information about genetic disease. (Zhong et al., 2018). Research suggests that genetic services are not widely available and that costs can put additional limitations on access (Zhong et al., 2018). Additionally, a

widely held thought is that genetic disorders can not be treated and as such, many patients do not pursue genetic testing (Zhong et al., 2018).

Coupled with low awareness of genetic counselling was a limited understanding of its purpose or relevance, represented by some misconceptions held by our participants. Some participants seen in the prenatal context talked about not knowing about genetic counselling before because there was no need for the testing. This might have been because the genetic testing was generally seen as unnecessary in their home country, or because the participant understood the role of genetic testing and counselling to be important only to couples intending to get pregnant. This represents both a cultural differences and lack of knowledge about the varied roles of genetic counsellors, which may both pose limitations on newcomers' awareness and perception of usefulness of genetic counselling services. Misconceptions about the purpose of genetic counselling have been explored at the population level in both the Canadian and American public (Maio et al., 2013; Riesgraf et al., 2015). Maio *et. al.* (2014) evaluated Canadian public perceptions of genetic counselling using 15 items including real goals and common misconceptions about genetic counselling. One false statement listed as a common misconception was "a purpose of genetic counselling is to provide information and support to all pregnant woman", a statement that about 60% of respondents agreed with (Maio et al., 2013). Although misconceptions about genetic testing and genetic counselling and its purpose have also been studied within ethnic minority populations (Cheng et al., 2018; Ford et al., 2007), the researcher is unaware of any studies that have evaluated newcomer perceptions of genetic counselling roles in particular. It is not overly surprising that there may be misconceptions within newcomer populations. Such misconceptions like 'genetic counselling is limited to the prenatal realm' are foreseeable, especially given that

genetic testing has its roots in high risk pregnancy counselling with the first genetic counsellors working in the prenatal setting, later transitioning into other areas such as inherited cancers (Stern & Richter, 2009; Stoll, Kubendran, & Cohen, 2018). Dispelling misconceptions goes hand-in-hand with increasing awareness of the genetic counselling service. Increasing awareness may improve the positive potential outcomes for patients (Maio et al., 2013).

An individual's understanding of genetic services (e.g. what the service was, what to expect, etc.) seemed to be higher in those with apparent increased health literacy. Higher health literacy in genetics appeared to correlate to higher education and increased exposure to genetic conditions and health care systems. In this study, higher education and increased exposures were thus called a proxy for health literacy. Higher health literacy was important for increased knowledge about general genetics principles and in conceptualizing the genetic counselling encounter. This theory is supported by research that suggests, for individuals in low to middle income countries, awareness and knowledge of genetic diseases and genetic services are related to their socioeconomic status and education levels (Zhong et al., 2018). Although, these findings must be interpreted in context, given that the sample included individuals who received service provision from both genetic counsellors and geneticists. It is possible that some participants have been seen in though out-patient appointments and/or hospital visits, thus genetic counselling in the formal sense, may not have been delivered to all. If this were the case, it would be understandable that an individual have a limited understanding of genetics post-appointment irrespective of education level.

Knowledge of genetic concepts were varied, with some generally understanding concepts such as inheritance, others understanding common conditions such as sickle cell disease, and some complex knowledge about genes and DNA. This is similar to what has been seen in the literature among ethnic minority and non-Western populations (Adedokun et al., 2015; Gustafson et al., 2007; Hann et al., 2017; Sharkia et al., 2015). Participants' genetics knowledge appeared to be related to their previous exposure to genetics from both lived experience of affected friends/family or from work experience in the case of one participant and/or higher levels of knowledge or experience with health care systems. Education does seem to have a correlation to increased knowledge but is difficult to evaluate given the small sample size of this study. One participant suggests that those with lower education from their home country may feel the cause of genetic disease to be supernatural.

Although lack of awareness of genetic counselling services/testing poses barriers to its use, increased awareness on its own does not guarantee increased access (Barlow-Stewart et al., 2006). Though we did not directly measure health literacy in this study, we did see a trend that suggested higher education and previous exposure increased understanding of genetic counselling. This was supported by literature within the American Somali immigrant community: a recent study found that the Somali community is less knowledgeable about genetics and genetic services as a result of perceived lower health literacy as reported by key informants (Cheung et al., 2019). Additionally, the community felt that those with higher education would understand genetic concepts (Cheung et al., 2019).

Health literacy is defined as “the ability to access and use health information to make appropriate health decisions and maintain basic health” (*Health Literacy in Canada: Initial Results from the International Adult Literacy and Skills Survey 2007*, 2007 as cited by Ng & Omariba, 2014)Nutbeam (2008) proposes a relevant model of health literacy, expanding on existing models of health literacy (Baker, 2006; Paasche-orlow & Wolf, 2007). Nutbeam (2008) suggests that although complex, health literacy has foundations in reading fluency, numeracy and existing knowledge, much like what we have seen in our results. He expands further to say that health literacy is an outcome of education and communication (Nutbeam, 2008). The model proposed by Paasche-Orlow & Wolf (2007) also describes several other contributory factors quite pertinent to the participants of our study. For example, individuals health literacy is also impacted by culture, language, social support, income, employment and occupation along with several personal characteristics such as verbal ability and memory (Paasche-orlow & Wolf, 2007). Moreover, the connection between health literacy and health outcomes is influenced by access and utilization of health care, variables specific to the patient such as navigation skills, self-efficacy and perceived barriers and system factors such as health care system complexity (Paasche-orlow & Wolf, 2007). Additionally, the patient-provider interaction also effect health outcomes (Paasche-orlow & Wolf, 2007). Thus, improved health literacy correlates to improved health outcomes (Nutbeam, 2008).

We could not go so far as to say increased health literacy improved outcomes in this study. However, participants with higher education and/or previous exposure did have a stronger and broader understanding of genetic counselling and tended to be more prepared for their appointment. This could have also been a side effect of those with higher health literacy having

an increased ability to better describe their experience in the research interview. Our preliminary findings are evidence of the need to specifically evaluate genetic health literacy among recent Canadian newcomers.

This concept of higher health literacy may again be another product of psychological acculturation. Education is consistently associated with a positive adaptation and lower stress (John W Berry, 1997). Education itself provides tools to the individual such as problem solving and can correlate to resources such as income, employment status and support networks (John W Berry, 1997). Education may also act as a "pre-acculturation" that makes newcomers more aware of the society they are moving into; for instance, the new values and norms and the new language (John W Berry, 1997). In this way, those with education and prior exposures may simply have a better idea of what to expect because of the inherent skills provided by a higher education and a prior knowledge of the new society, in this case, the new health system and the encounter with genetic services.

Health literacy, understanding and along with awareness of genetic counselling is only as useful as it is relevant to the patient. Our participants' action to seek genetic services is thus more complex than an awareness of the service. If there is no need to seek genetic counselling, awareness of the service is essentially irrelevant. The health belief model provides a framework for health related action. This model incorporates perceptions of disease susceptibility as well as perceived benefits of taking the action (Rosenstock, 1974). It also includes modifying factors such as self efficacy, demographics, "sociopsychological" variables and "structural variables", such as knowledge of disease, prior contact with disease, and perceived threat of disease

(Rosenstock, 1974). Lastly, the model includes cues to action, which in this scenario is clearly represented by awareness of genetic counselling. Taken together within the context of our research, this model provided a framework to suggest that awareness of genetic counselling among Canadian immigrants is likely to impact their health seeking behaviours, although likely specifically among those who feel a perceived susceptibility to genetic disease. Further research may provide a better understanding of newcomers' likelihood of seeking genetic services and an offer an explanation of individual perceptions and modifying factors specific to this population.

Some individuals prepared and planed before their appointment, while others did not. This appeared to be correlated with higher health literacy. This planning was helpful and important to some participants, as knowledge was seen as power. Those that did not prepare for their appointments might have not done so because they did not know how to prepare due to a lack of information about what to expect. Research has shown that those who know what to expect in their genetic counselling appointment have more positive outcomes (Albada, Van Dulmen, Lindhout, Bensing, & Ausems, 2012; Pieterse, Dulmen, Ausems, Beemer, & Bensing, 2005). Zhong *et. al.* (2018) describes that educated individuals in low to middle income countries seek out a wide array of materials to try to better understand their genetic condition; those with lower literacy are likely to ask less questions, however (Zhong et al., 2018). This is generally what we have found in our results as well. Albada *et. al.* (2011) found that a pre-visit tailored website better prepared patients with what to expect in the genetic counselling appointment (Albada et al., 2012). Individuals who viewed the pre-visit website had higher levels of accurate disease specific knowledge and lower information needs than those who did not view the pre-visit website, especially regarding procedural and emotional aspects of counselling (Albada et al.,

2012). Pieterse *et. al.* (2005) suggest that newly referred patients may benefit from receiving information about the counselling procedure before the appointment or cues about how to prepare. Preparedness and planning may be especially useful in a population of newcomers who are already unfamiliar with the Canadian healthcare system. This pre-appointment contact may open a way for genetic counsellors to connect with this community even before the first encounter. Taken together, it is possible that genetic counsellors will improve outcomes within this population by increasing awareness and sharing information about genetic diseases and genetic counselling before the genetic counselling encounter. Such conversations with immigrant communities may also reduce widespread misconceptions or stigma associated with genetic diseases. It could also address concerns about privacy and security of information that may limit individuals from seeking out this service (concerns about information security discussed in 6.0.5.3.).

Overall, our results show that there is limited awareness of genetic counselling services and moderate knowledge about general genetic concepts among new immigrants. Individuals with previous exposure to genetic conditions and health care systems as well as higher education tended to be better prepared for their genetic counselling appointment and knew what to expect, having a better understanding of the encounter overall. Increasing awareness of genetic counselling/testing services and improving understanding of what it entails may lead to improved outcomes for Canadian newcomers who may benefit from these services.

6.0.3. Support systems are important but difficult to cultivate

Resettling in a new country has been well described as a challenge. Newcomers may arrive in Canada after difficult migration experiences, which for some might include refugee camps and the violence of escaping persecution (Stewart et al., 2008; Woodgate et al., 2017). These families then have to build their lives from the ground up, essentially starting from nothing (Woodgate et al., 2017). Immigrants and refugee families then face difficulties in getting used to their new and their unusual surroundings (Jun et al., 2018; Woodgate et al., 2017). Newcomers may face challenges with language barriers and cultural difference, transportation and weather, employment, disrupted family dynamics, inadequate child care and a lack of social support (Stewart et al., 2008; Woodgate et al., 2017). A lack of social support is a widely documented difficulty in the settlement of immigrants (Reitmanova & Gustafson, 2009; Stewart et al., 2008; Woodgate et al., 2017) and has been associated with increasing challenges in accessing/utilizing health services (Reitmanova & Gustafson, 2009; Woodgate et al., 2017). Social support networks can ease the burden of the transition process (Stewart et al., 2008). However, when coupled with disability or its prospect, newcomers are faced with even more struggles (Fellin et al., 2013; Woodgate et al., 2017), which in turn may impact the perception of disability (Daudji et al., 2011). Many of our respondents agreed. The participants in this research discussed both a significant lack of emotional support. For one participant there was the feeling having missed being given referrals to needed support services. Many discussed relying on their limited support system consisting of only a spouse, as previously reported (Jun et al., 2018). The spouse however, may not be able to provide the necessary support because of existing commitments such as work, as seen before (Jun et al., 2018). Participants discussed how challenges living with, or supporting a family member with a genetic condition, might be worsened because of this

lack of support. Although not possible to measure over the course of this study, previous findings indicate that more support correlates with improved outcomes such as experiencing disability as a lesser burden, and having greater hopes for the future (Daudji et al., 2011).

Immigrants tended to break their support systems into emotional support and support services (Stewart et al., 2008). Emotional support was mainly described as any help given to the family from close relatives and friends, which is similar to previously described descriptions of social support (Greeson et al., 2001; Woodgate et al., 2017). Support services discussed were mainly paid or funded services accessed through the hospital or community. In the middle, participants placed friends made in Canada, gatherings and community meeting such as church. Overall, support may have included conversations with family, physical and emotional support for caring for a child with a disability or living with a disability, and decision-making about genetic counselling/testing to name a few. The description of support seemed to be dependent on participant's needs, life situation and reason for genetic counselling referral. Participants, however, differed on their views about the appropriateness of support systems, some describing any supports available as helpful, as previously seen (Stewart et al., 2008), and others favouring different parts of the support network to various degrees.

Our results suggest that most newcomers have inadequate emotional supports, primarily because of limited numbers of family members living in Canada. Emotional support also appeared to be restricted because participants felt the need not to burden the friends or family they did have in Canada since they felt people lead such busy lives in North America, or further, that friends in Canada may not be as long-standing. Although not verbalized by all of the participants

explicitly, some discussed a sort of comfort level with support services, which one participant expressed was related to a cultural difference between individuals. Varied comfort levels tended to cause the support system to fall into a kind of hierarchy of appropriateness or desirability. The relevance and appropriateness of the support networks as seen by our participants may be dictated by traditional cultural views held in their home countries. This result introduces the idea of culturally appropriate or relevant support, a concept acknowledged within immigrant specific literature as well as genetic counselling literature in ethnic minority populations (Greeson et al., 2001; Stewart et al., 2008). When speaking to participants later on in their secondary interviews, some recounted that there was a lack of emotional support. However, when asked about culturally appropriate supports, newcomers provided multiple caveats, suggesting that there may be a time and place for different types of support. Greeson *et. al.* (2001) conducted in-depth qualitative interviews with American Somali immigrants asking them about their perceptions of disability. One of the major findings of this study was a difference between support systems that were considered appropriate to Americans versus Somalis (Greeson et al., 2001). Somali immigrants felt more comfortable with informal supports which included emotional support from family, friends and neighbours (Greeson et al., 2001). The respondents found that although material supports were readily available, the social supports that were most desired were not (Greeson et al., 2001). Stewart *et. al.* (2008) found differences in the definition of social supports between Chinese and Somali immigrants. Chinese newcomers tended to classify their support network as formal support from the Canadian government or more informal support of relatives and friends (Stewart et al., 2008). Whereas the Somali newcomers descussed financial, psychological and moral supports, generally describing more emotional supports than Chinese immigrants (Stewart et al., 2008). Some of the newcomers felt mixed about the types of support

available in Canada, commenting on the limited informal support available and the need to use more formal supports (Stewart et al., 2008). Some faced or perceived discrimination when seeking formal supports and as such relied on families and ethno-cultural communities (Stewart et al., 2008). Most turned first to peers then to professionals and other culturally specific organizations (Stewart et al., 2008), much like some of our respondents.

Support needs can differ with time. During the early part of relocation, support needs are more essential, such as food, housing, and navigating the systems of a new country, but also may include information and emotional support from both formal and informal sources (Stewart et al., 2008). Over time, newcomers begin to settle and seek support for long-term challenges such as language challenges, cultural understanding and employment (Stewart et al., 2008). Overall, our results are not surprising, considering our participants immigrated from largely collectivist cultures, where people are born into strong groups composed of extended relatives and their unconditional support (Hofstede, 2011). The researcher did, however, notice some nuances. Although personal situations such as socioeconomic status and reason for genetic counselling referral differed, it was clear not all individuals of the same cultural background shared the same views about appropriateness of support networks. Arguably, an individual's comfort level with support networks may be influenced by the individual's process of psychological acculturation. As time passes newcomers adapt to a new culture (Redfield, Linton, & M., 1936 as cited in Berry, 1997), it is plausible that process of psychological acculturation dictates individual perceptions of appropriateness of support networks that needs to be considered. Acculturation can occur at the group level where there are changes in the culture of groups which can result in changes to social relationships and culture including language, religion and value systems (John

W Berry, 1997). Acculturation can also occur at the individual level (which is specifically termed psychological acculturation) where the acculturation process is affected by personal demographic and social characteristics such: as age, gender, education, expectations, cultural distance (between self and new environment) and personality (John W Berry, 1997). Thus, at the individual level it may be difficult to characterize culturally appropriate support networks. In fact, this provides evidence of the importance of looking at the person on an individual level, bearing in mind the impossibility to understand the individual on their cultural background alone (Hook et al., 2013). This is again speaking to the need for further evaluation and implementation of the principles of cultural humility in the genetic counselling setting.

The families in this study presented with varied levels of financial support, ranging from low income to high income, with additional sources beyond primary employment such as work, tax benefits and in one case an income property. Taken together with Canada's social health care system whereby access to health care is offered freely and universally, financial limitations did not appear to pose constraints on our sample of newcomers. Although not explicitly described as a limiting factor by our participants, one area that may have been impacted by financial constraints is the choice between publicly funded and private-pay prenatal testing options. Currently, Canadian genetic counsellors can offer three forms of diagnostic testing in pregnancy, two of which are invasive options (amniocentesis and choric villus sampling), and one of which is non-invasive (Non-Invasive Prenatal Testing). One participant described opting for the Non-Invasive Prenatal Testing (NIPT) because of wanting to avoid the risks associated with more invasive methods such as amniocentesis. This invites the timely discussion about publicly funded NIPT services in Canada. Currently, the indications for funded NIPT are often limited and

variable across jurisdictions (Birko et al., 2019). A recent study of pregnant women and their partners at three Canadian hospitals in Alberta, British Columbia and Quebec found that the decision to use NIPT would be significantly affected if offered free of charge (Birko et al., 2019). This raises the question of whether minority populations and immigrant groups have similar concerns and if their prenatal decision-making is limited by financial constraints. This would be a timely project to endeavour in the Canadian setting.

What can be done to provide the most desirable and appropriate support to Canadian newcomers? It has been suggested that responsive health care providers should first acknowledge the unique situation of living away from social support networks (Reitmanova & Gustafson, 2008). Previous literature emphasizes the importance of bringing awareness to available supports and resources, and guidance in navigating the health care system (Fellin et al., 2013), to assist newcomers who may have no prior knowledge of what referrals they may expect. Specifically, Fellin *et. al.* (2013) suggests introducing third parties to assist in immigrant families' navigation of the health care system and to provide in home supports to newcomer families caring for children with disabilities. Research also highlight the importance of emotional supports from both formal and informal sources in the initial stages of resettling (Greeson et al., 2001; Stewart et al., 2008). Genetic counsellors are primed to offer both emotional support and referrals that are more appropriate to this community. To offer emotional support, genetic counsellors should consider their approach to provision of care. Utilizing a counselling model has been proposed as more supportive of multicultural counselling over a teaching model framework (Lewis, 2002). Others have also advised the shift towards genetic counselling models that incorporate communication strategies proven effective within populations with limited

health literacy from other aspects of medicine (Joseph et al., 2017). Further, research recommends that appropriate referrals be made through careful consideration of the ethnocultural competence of the support groups and the receptivity of the given patient (Greeson et al., 2001). Additionally, considering that "church" was a commonly sourced support network for many (but not all) of our participants, it may be important for genetic counsellors to inquire about the appropriateness of this as a support. Considering this information, the researcher tenuously proposes the introduction of peer groups (immigrants supporting immigrants) as a middle ground to offering culturally appropriate supports to newcomers outside of informal support of family and formal support services or specific gatherings such as church. Peer groups have previously been documented as successful and acceptable supports for immigrants (Daudji et al., 2011; Jun et al., 2018; Stewart et al., 2008). Although this may not address the reluctance of some to use formal supports, it may help to mitigate the significant lack of emotional support seen in our study. The researcher feels strongly that further questions need to be asked of the immigrant community in the design of such support groups, to bring the newcomer voice to this suggestion. Moreover, we might consider borrowing ideas proposed in the conversation about strengthening the relationship between genetic counsellors and the disability community. For example, genetic counsellors should continue to pursue conversations with communities, develop genuine relationships and collaborate among organizations and individuals (Bellomo, 2009 as cited in Madeo, Biesecker, Brasington, Erby, & Peters, 2011; Madeo, Biesecker, Brasington, Erby, & Peters, 2011). Through this effort, we may also illuminate additional avenues for improving support networks. Taken together, it is clear that genetic counsellors should evaluate their clinical practice, not shying away from psychosocial counselling and be highly attuned to the responsibility of informing individuals of available resources. In turn providing appropriate

referrals, which may include informal support such as religious groups. Genetic counsellors may need to familiarize themselves with the specific resources available in their region.

Overall, support systems are important to the recent immigrants in our study especially during the difficult time of starting a new life and when considering the possibility of living with a genetic condition. Participants characterize support networks into a hierarchical framework and may view some supports as more culturally appropriate than others. Most felt that there was little to no emotional support, yet a few did acknowledge the abundance of support services in reach. Given a significant lack of emotional support, and that not all support systems are seen as culturally appropriate, appropriate referrals may be missed. Increasing awareness about this lack of appropriate supports for immigrant patients is necessary to begin to understand how genetic counsellors can better position themselves to help.

6.0.4. The art of science and religion

The use of different illness and explanatory models of disease are well documented concepts among the biomedical, behavioural and social science fields (Kleinman, 1980; Tamm, 1993). Three main models of understanding illness, including the magico-religious, holistic and more Westernized biomedical model have been applied within the genetic counselling setting (Oosterwal, 2009). Explanatory models are slightly different from perceptions of disease causation in that they seek to describe more than just the etiology of the condition but also the treatments (Kleinman, 1980). Explanatory models affect a persons understanding about the cause of health and illness, including the associated behaviours a person may take when faced by disease, and what actions are appropriate to take to become well (Lewis, 2010). Individuals were mixed on their understanding of the cause of genetics disease and the ways in which they cope.

Although understanding of disease appeared to be important for successful coping, it did not seem to influence interest in genetic counselling and testing, as most individual wanted this information. Most of the individuals appeared to value and trust Western medicine, and a biomedical model; however, this interpretation was limited for some. Some individual utilized more magico-religious interpretations of disease, such as God brining the illness, others invoking a more holistic model by considering environmental factors such as stress or depression. Notably, most participants appeared to be able to incorporate their existing views with the idea of the biomedical causes as presented by their genetics providers. The idea of balancing competing models seen within our participants is not a novel concept. In fact, it appears to be an extension of a well-documented concept termed medical pluralism. Medical pluralism is widely understood concept originating from the medical anthropology field (Pelto & Pelto, 1997). To the best of the researchers' knowledge, it is a concept underrepresented in the context of genetics. Medical pluralism describes the use of more than one medical system both conventional and traditional in combination, which may be derived from divergent and incompatible explanatory models (Barker, 1992; Minas, Klimidis, & Tuncer, 2007; Pelto & Pelto, 1997; Wade, Chao, Kronenberg, Cushman, & Kalmuss, 2008). This idea of balancing different understandings of illness and appropriate treatments may be quite familiar to some immigrants as they come from cultures where medical pluralism already exists and thrives (Barker, 1992). The Indigenous medical system in Nigeria arose as a reflection of the environment, using locally sourced resources in the treatment of disease (Adefolaju, 2014). Early Christian missionaries introduced the idea of Western medicine to Africa, causing traditional approaches to fall out of favour and suffer a decline during British rule (Adefolaju, 2014; Mbiti, D., & Theol, 1976). These two practices coexist together today (Adefolaju, 2014). Therefore,

those who exhibit medical pluralism may wish to use any treatment thought to be able to cure illness, yet retain original understandings about cause of illness (Clark, 1983 as cited in Barker, 1992). Further, Pelto & Pelto (1997) suggest that regardless of cultural belief, people are likely prepared to use modern pharmaceuticals and other aspects of modern medical practice without losing the foundation of their traditional understandings of disease.

With respect to the provision of culturally appropriate health care, it is important for genetic counsellors to bear in mind the impacts of psychological acculturation on patients' explanatory models of disease. Ying & Miller (1992) found an association between acculturation levels and help seeking, and attitude about mental health concerns among Chinese Americans. For example, they suggest that English ability, younger age, married and lower socioeconomic status mediated more positive attitudes, with less acculturated individuals needing more education about the utility of mental health services (Ying & Miller, 1992). Further, Lin (2012) suggests that even among highly acculturated individuals such as second generation Chinese-Americans, patients may still hold culture-specific beliefs in combination alongside an appreciation of the biomedical model. Culture-specific beliefs may be influenced by patient personal history, the community they were raised in and the community in which they live (Lin, 2012). Thus, although acculturation may influence acceptance of new ideas of health, individuals may retain original ideas. Minas *et. al.* (2007) describe that causal beliefs about illness held by immigrants and modernizing communities are subject to transformation because of social influences within new cultural environments. They suggest that traditional beliefs do persist to some extent even within modernized and acculturated groups of Turkish immigrants in Australia (Minas et al., 2007). Under times of crisis however, individuals may rely on more early-learned cultural ideas even if

the individual has a high level of acculturation (Barker, 1992; Beyene, 1992). Taken together, these ideas explain why a number of the participants in our study appreciate and desire genetic counselling and testing, yet when asked about their coping strategies, discuss the comfort they find in religion. Additionally, these findings explain why the few participants who had unanswered questions, relied on prior understandings about the cause of illness. For example, one participant, whose daughter remained undiagnosed, turned to an explanation about disease as it was from God. Another, who described a trust in a biomedical/biopsychosocial medical system, could not completely understand the cause behind the biomedical concept of a micro-deletion (or "missing DNA"), which led her to assume that the cause of disease was a result of depression during pregnancy. When under the stress of a future pregnancy at risk for a genetic condition this participant coped by relying on previously held understanding about the cause of disease. When we spoke to this participant in her secondary interview, she elaborated on her coping strategy. She felt that her upbringing in her home country pushed her to not believe in God, as such, she felt the best way to cope was to speak her doctor.

Although acculturation level may influence perceptions of disease, causal beliefs about illness are dynamic (Minas et al., 2007) and acculturation alone can not act to predict an individuals understanding. This is supported by our findings of individuals falling on what appeared to be a fluid continuum of understanding of disease. Inter-ethnic group differences at the individual level can act to cause variation about disease causation (Minas et al., 2007). Minas *et. al.* (2007) suggest that demographic factors and the presence of illness also contribute to a persons understanding of disease. Again, this is also represented within our results with individuals of similar ethnic background holding moderately to significantly different views of disease

causation. For example, some individuals in the study stressed that there are differences in level of faith and practice of religion, which could contribute to different ideas of disease causation, treatment and coping. In a study of Somali-American immigrants, respondents stressed the importance of genetic counsellors to be aware that each patient is an individual and that they may have varied degrees of cultural and religious beliefs, again highlighting the idea of psychological acculturation at the individual level (Greeson et al., 2001). Therefore it is important for genetic counsellors not to generalize acculturation influences on disease causation and medical pluralism to the ethnic group or larger newcomer population.

It is also important to note that decision-making in the context of a medical pluralistic framework is not solely affected by cultural belief systems regarding cause of illness (Pelto & Pelto, 1997). One must consider the other variables impacting the patient, such as their economic, geographic and social positions, along with other facilitating factors (Pelto & Pelto, 1997). Considering these variables, along with other intracultural variations and macro level influences from economic and political structures, may provide a clearer understanding about health beliefs and actual behaviours (Pelto & Pelto, 1997).

As discussed above with respect to communication in the genetic counselling setting, it may be reductionist to view clinicians as providing care strictly under a biomedical model. In light of individuals' abilities to balance multiple illness/explanatory models of disease including incorporating a biomedical framework, it is important to recognize that genetic counsellors and/or geneticists may not provide care strictly under the biomedical framework. In fact, clinicians who employ a Reciprocal Engagement Model of care may actually be described better

as utilizing a biopsychosocial model over a strictly biomedical model because of the inclusion of psychosocial factors (Veach et al., 2007). As such, participants' medical pluralism may have been fostered because biomedical concepts were presented alongside social and psychological factors important to participants. This finding provides evidence that a biopsychosocial model may be effective for working with individuals of diverse ethnic backgrounds. Further evaluation of the Reciprocal Engagement Model (Veach et al., 2007) and a biopsychosocial framework in the care of diverse populations is needed.

The results from our study have direct relevance to cross-cultural genetic counselling; in particular, they provide further evidence for the need to shift towards cultural humility in care. Unlike cultural competency a principle philosophy in the genetic counselling field, cultural humility does not attempt to reach an endpoint, having acquired sufficient knowledge about an ethnic minority's culture (Tervalon & Murray-Garcia, 1998). Rather, it requires self-reflection, self-critique and reflective practice (Tervalon & Murray-Garcia, 1998). At its heart is patient-centred interviewing that is less authoritative and controlling, such that the patient may bring to light their experience of illness (Tervalon & Murray-Garcia, 1998). This allows for the patient to include as much detail about the impact of culture on the clinical encounter that they feel is needed (Tervalon & Murray-Garcia, 1998). Moreover, it encompasses the patient as an individual, acknowledging intersectionality in the patient identity (e.g. race ethnicity, religion, etc.) (Ridley, 1995; Tervalon & Murray-Garcia, 1998).

Health care providers must appreciate that patients in general may not volunteer their understanding of illness, and if they do, it may be a short explanation as a result of

embarrassment or fear of being criticized (Kleinman, 1980). Kleinman (1980) posit that understanding the patient's perception of illness is important for employing appropriate treatments. This can be elicited through a series of genuine and non-judgemental questions (Kleinman, 1980). Kleinmans (1980) questions include:

1) What do you call your problem? What name does it have?

2) What do you think has caused your problem?

3) Why do you think it started when it did?

4) What does your sickness do to you? How does it work?

5) How severe is it? Will it have a short or long course?

6) What do you fear most about your sickness?

7) What are the chief problems your sickness has causes for you?

8) What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?

Greeson *et. al.* (2001) suggest employing such a model to modify traditional risk/inheritance counselling for diverse patients in their example, Somali-American immigrants, who may have non-Western ideals about cause of genetic illness.

The interplay of medical pluralism and acculturation may have unique impacts on individuals' decision-making, understanding of disease, and acceptance and coping. It is difficult to predict individual responses based on group level assumptions, which is a central tenant of culturally competent care. Our findings suggest a need to appreciate patients on an individual level when considering the cultural and psychological acculturation influences on illness and explanatory

models of disease. Again, we suggest that cultural humility replace cultural competency as a philosophy in the field of genetic counselling.

6.0.5. Experiences of genetic conditions and interest in genetic counselling/testing

Although the participant experiences of disability and illness are important and unique on their own, within the context of this study, the experience of illness is integral to the reasoning for or against genetic counselling/testing. As such, the results from themes 5 and 6 will be discussed together to highlight the most relevant findings. When asked to recount the experience of living with a genetic condition or disease, or in caring for or supporting a family member with a genetic condition or disease, most individuals provided a rich description of their lived experience. Others, who had not experienced such a condition or disease, but were at risk of a condition in a current or future pregnancy, were asked about their perceptions. Living with or supporting a relative with a genetic condition was described as a challenge, along with the additional strain of immigration and lack of support systems. In the secondary interview, when asked about her experience, one participant highlighted the important point that it was difficult to speak about their experience with genetic testing when their results had been negative. Additionally, one participant explained that the experience of testing might look different for each individual because of his or her unique choices and situation. It was therefore difficult to agree with all comments made about experience of disease and genetic testing.

Genetic disease or disability was seen mainly in a negative light. Most describe intense negative emotions such as feelings of guilt and blame, shock, sadness etc., although emotional response varied in degrees of strength. Universally, participants describe a drastically different experience

of disease as it relates to a home country medical system. It is possible that these discrepancies contribute to differences in health seeking behaviour with respect to genetic counselling in a country such as Canada.

Interest in genetic counselling and testing and desire to take such health related actions could be conceptualized within the health belief model (HBM) framework (Figure 2). Under the HBM framework, variables that affect health related actions can be divided into three categories: individual perceptions, modifying factors and action (Rosenstock, 1974). The first tenant involved in an individual taking a health related action, are the individual perceptions, including perceptions of susceptibility and severity of disease (Becker, 1984; Rosenstock, 1974; Strecher, V.J., DeVellis, B.M., Becker, M.H., & Rosenstock, 1986). With respect to genetic counselling and testing, individual perceptions may include thoughts about illness and disability. Studies show that perceptions of disability or disease are associated with interest in genetic screening and testing (Wal et al., 2015). An individuals acceptance of the susceptibility to a disease, that is thought to be serious, is further modified by perceived benefit of actions to take and perceived barriers to taking this action (Becker, 1984; Rosenstock, 1974; Strecher, V.J., DeVellis, B.M., Becker, M.H., & Rosenstock, 1986). Perceived benefits and limitations among our participants appear to be related to participants lived experience and indication for genetic counselling appointment and testing (Table 7). Likelihood of taking action are further influenced by opinions of self-efficacy, or the belief about capability to perform the behaviour (Janz & Becker, 1984; Rosenstock, 1974; Strecher et al., 1986). Modifying factors include individualistic factors such as demographics, sociopsychologic and structural variables (Rosenstock, 1974). Although difficult to distil out in our small study sample, it does appear that interest in genetic testing may

be related to genetic indication as well as the particular motivations specific to the individual. This is supported by previous literature that has indicated, historical disparities (RG & Whipperman, 1987 as cited in Greeson, Veach, & LeRoy, 2001, Greeson et al., 2001; I. Mittman et al., 1998) and continued underutilization of genetic services for immigrant and diverse ethnic minority groups, with low uptake compared to White and higher income populations (Cheng et al., 2018; Joseph et al., 2017; Levy et al., 2011). Research indicates an increasing interest among diverse ethnic minorities and non-Western populations in genetic services (Cheng et al., 2018; Komenaka et al., 2016; Sharkia et al., 2015; Sussner et al., 2013). However, the utility of genetic counselling and/or testing could vary by population and by purpose/subspecialty. Thus, it is difficult to make wide generalizations about our small sample with respect to the literature, which is primarily focused on cancer and/or prenatal genetic services. Whether the high interest in genetic services seen in our sample can be explained by increased psychological acculturation among our group of newcomers, more education or prior knowledge/experience with genetic services remains unclear. Additionally, our recruitment method of approaching newcomers following the genetic counselling appointment may have resulted in a sample selection bias towards those with interest in genetic counselling and possibly genetic testing. Further, more specific research, investigating the interest of immigrant populations in genetic counselling and testing should be conducted by genetic indication specifically to draw out these important nuances and investigate other genetic subspecialties further.

6.0.5.1. Adults

Important perceived benefits of genetic counselling and testing for adults with or at risk for a genetic condition included the ability to provide risk information to family members and to

direct treatments, management or prevention of future disease. Systematic review of previous research within ethnic minority groups (Asian American, African American, White, Hispanic and Australian Chinese) support the positive perceptions of benefits of genetic counselling and testing for inherited cancers (Hann et al., 2017). This literature suggested perceived benefits from these populations were quite similar to our findings. They included decision-making about screening, receiving information for at risk family and children, helping plan for the future, reducing concern of cancer or uncertainty and to provide a sense of personal control (Hann et al., 2017). Other less commonly cited reasons for genetic testing included family/personal motives and information seeking (Hann et al., 2017), which was similar to our findings in that individuals wanted information but usually for disease management. The main reason for not wanting to pursue genetic counselling/testing reported by two of our participants was a lack of interest in finding a *cause*. These individuals talked about differences in interest in genetic testing for self and individuals back home. Understanding the *cause* of the condition was not seen as useful or of interest to individuals back home, which may have been a view shared by and limited to these participants. However, disinterested in a *cause* was further corroborated by another individual in the secondary interview. She described a feeling that there is a culture of wanting to know the cause of a condition in Canada, but back home people might not know they can look for a cause. She felt this could be a result of a lack of education, for example in rural individuals such as farmers. It is important to note that this individual came from a different home country on a different continent, thus generalizing this finding beyond the culture(s) of the other two adults. Taken together, it is possible that patients do not feel the need to understand the genetic mechanisms of disease to appreciate the diagnosis, prognosis and the action they should take with respect to recommended treatments and providing risk information to relatives. This finding

is similar to a previous study that suggests genetic counsellors may provide more information about genes and genetics than patients found understandable and useful in their decision-making (Joseph & Guerra, 2015b). In the context of genetic counselling and testing for hereditary breast and ovarian cancer, low-income Latina patients' main concerns were surrounding the reason for the testing and how it would benefit themselves and family members (Joseph & Guerra, 2015). A study of American public hospital patients of different ethnicities on Medicaid, Medicare or who were uninsured, revealed information mismatch between genetic counsellors and their patients in the context of cancer risk counselling (Joseph et al., 2017). Counsellors provided information about genetics, genes, mutations, risk assessment methodologies, and the method of genetic testing and the possible results/limitations of the testing (Joseph et al., 2017). In contrast, the patients in this study wanted to understand if their cancer was inherited, if the cancer would come back and if their family members were at risk of the cancer (Joseph et al., 2017). They also report that patients and providers shared a desire for information about taking action: patients wanted to know about cancer prevention and providers wanted to share information about screening and surgery (Joseph et al., 2017). This finding was very similar to our patients' strong desire for treatments and management. However, compared to our findings Joseph et. al., (2017) found that patient did have an interest in understanding the *cause* of their cancer. Nonetheless, it was important for patients to have less information provided in a conceptually and linguistically less complex manner (Joseph et al., 2017). Overall this study and our current research show similar findings, except that our participants lacked interest in understanding the *cause* of disease. Such discrepancies in information needs might suggest a lack of knowledge about the purpose of genetic testing in the genetics evaluation, as many of our participants' questions would be answered in understanding the *cause* of the condition. An alternative interpretation is

that the patients' lack of interest in the *cause* of a condition is due to the belief that the *cause* of disease is much like providing a label for the condition, participants implied that a diagnosis would just provide a name for their condition not a cure. This is a conclusion drawn by others who suggest that information mismatch can leave patients without a solid understanding of the value and purpose of genetic testing (Joseph et al., 2017). Further education and explanation about genetic diagnosis could be useful in helping to realign expectations and provide individuals with realistic outcomes of genetic testing.

Regardless of thoughts about the *cause*, there was a need to find acceptance and cope with the disease and with things beyond ones control. This overriding sense of acceptance may be related to a strong reliance on faith much like has been reported previously (Greeson et al., 2001; Jun et al., 2018).

6.0.5.2. Parents of children with a genetic condition

Parents of children with genetic conditions shared the feelings of helplessness, sadness and anxiety about the future for their child, as well as the responsibility to do everything in their power to improve the life of their child. This strong desire to care for their child seems to be shared quite widely among mothers of children with disabilities (McKeever & Miller, 2004). The two parents of children with genetic conditions had somewhat different situations but both found themselves quite busy in their new lives in Canada, and with the added stress of the affected child as previously reported (Woodgate et al., 2017). One parent was stuck in the diagnostic odyssey, having a child with an undiagnosed condition. The other was the parent to an older child with what was described as a known micro-deletion. This parent sought information about

risks in the next pregnancy. All the same, these parents had positive attitudes about genetic testing (Belahcen et al., 2014; Greeson et al., 2001) and sought genetic counselling appointments for a diagnosis and an explanation of what was happening to their child. The second parent also sought a diagnosis for the current pregnancy. Unlike adult participants affected with conditions, these parents looked for explanations, possibly to understand how to help their child, to plan for the future and, quite apparent in the case of the second parent, to reduce the self-blame associated with the genetic condition. In their secondary interview, one parent stressed the importance of reiterating that parents are not to blame for causing genetic conditions. There is little research supporting the views of immigrant parents on genetic testing in their children; most recent literature tends to focus on immigrants' perceptions of prenatal genetic testing. However, blaming mothers, including mothers placing blame themselves, for causing genetic condition has been seen across numerous ethnic populations (both ethnic subpopulations in Westernized countries and populations in low and middle income countries) (Awwad et al., 2008; Daudji et al., 2011; Shaw & Hurst, 2008; Zhong et al., 2018). Such blame has been related to various environmental exposures and/or wrong-doings of the mother (Shaw & Hurst, 2008), as was the experience of one of the participants of our study who contemplated that the idea of her depression causing developmental delay in her son. More commonly reported is that the cause of the condition arises from religious or spiritual beliefs about disease (Daudji et al., 2011; Shaw & Hurst, 2008). These beliefs have historically been in conflict with uptake and understanding of genetic explanations of disease within non-Western countries (Zhong et al., 2018). However, research on ethnic minority populations within Western countries has shown that religion may be compatible with genetic explanations of illness much like the parents in our study (Shaw & Hurst, 2008). For example, British Pakistani parents of children with disability may understand

how a genetic condition arose, but may attribute the reasons *why* a genetic condition happened on religious explanations (Shaw & Hurst, 2008). Further, religious explanations have been shown to reduce self-blame and feelings of responsibility (Shaw & Hurst, 2008), a difference that could be noted between the two parents in our study, with one parent stating no religious affiliation.

Genetic providers who work with newcomer parents may consider that individuals could have conflicting views about the cause of genetic conditions because of cultural beliefs, yet if discussed in the clinical setting, such cultural beliefs may be effectively integrated into a genetic understanding of the condition (Zhong et al., 2018). Similarly, genetic testing, such as prenatal testing may be quite acceptable to newcomers, but what to do with the results may depend on parents cultural beliefs (Greeson et al., 2001). Clinicians may reduce guilt by addressing misconceptions directly and by incorporating traditional cultural practices in an effort to increase understanding (Zhong et al., 2018). Our research suggests that it is important to help increase parents understanding of genetic conditions so they may incorporate these concepts into their existing perceptions, which may possibly act to reduce guilt and blame about causing the condition.

6.0.5.3. Prospective parents of a current or future pregnancy at risk of a genetic condition

Historically, research has indicated low utilization of prenatal testing by amniocentesis in ethnically diverse populations, such as seen in the Asian-Pacific and Latino new immigrant populations in San Francisco in the late 1980's (I. Mittman et al., 1998). The idea of testing, however, may be acceptable (Greeson et al., 2001) with increasing interest in some diverse

populations (S. Ahmed, Ahmed, Sharif, Sheridan, & Taylor, 2012; Belahcen et al., 2014). Previous research with immigrant parents raising a child with disabilities indicates that parents past experience with disability have an impact on their perceptions about the future for their children (Fellin et al., 2013). The prospective parents in our study shared the negative overall perception of genetic conditions and disability with each other, although some perceptions were somewhat exaggerated. Prospective parents discussed that a child requiring special attention could be quite a burden on an already very busy life with limited support systems as a newcomer (Daudji et al., 2011; Greeson et al., 2001; Woodgate et al., 2017). Some questioned how they might manage this possibility in their current situation, which, for some influenced their decision to pursue genetic testing. Genetic counsellors may consider addressing newcomer expectations more thoroughly when it comes to perceptions of the future for a child with disabilities. Although severity of the condition was a consideration for planning, it did not dictate choice to undergo testing or not in this sample. Most saw having more information as powerful, with genetic testing bringing peace of mind. As such, genetic testing was important for all of the prospective immigrant parents in this study (Belahcen et al., 2014; Greeson et al., 2001; Wal et al., 2015), who felt it was important to plan for the future of the child and make decisions about continuing the pregnancy and future pregnancies. The risk involved in prenatal testing did seem to dictate the choice of test. Notably, most participants did not discuss their opinions about termination in detail, as most had already received a negative result from the prenatal testing. As such, it is difficult to compare the utility of the genetic testing result to previous literature where the focus is on termination of pregnancy. Some participants, however, commented on the magnitude of their prenatal screening results (i.e. a risk number was seen as high or low). They perceived results as low and considered Canada to have a culture of "over-testing". Our result is

similar to historic literature that suggests that individuals who arrive from societies that have little prenatal monitoring may find Western obstetric care intrusive (I. Mittman et al., 1998). Additionally, Mittman *et. al.* (1998) found that risk perception was influenced by patients' personal experiences, as those who did not perceive the increased risk for a child affected with a chromosomal condition tended to know women who had healthy babies at older ages (I. Mittman et al., 1998). Taken together, genetic testing can be very important to immigrants planning or carrying a pregnancy because of the information provided by the results and the peace of mind afforded by knowing what to expect. This may be in contrast to what has been previously accepted about ethnically diverse populations interest in genetic testing, which may influence health care providers in delivering appropriate services (Lewis, 2002; Wang, 1998). For example, assuming cultural homogeneity in a population's values regarding pregnancy termination, may impact the equality of provision of genetic counselling services (Lewis, 2002; Wang, 1998).

Table 7: Participant described experiences with genetic conditions and the associated reasons for and interest in genetic counselling and/or genetic testing services.*

Participant Group	Experience of Genetic Conditions	Reasons for Wanting Genetic Counselling/Testing	Reasons for not Wanting Genetic Counselling/Testing
Adults with or at risk of a genetic condition	• Acknowledged physical limitations • Adaptive attitudes • Important to cope and find acceptance	• Desire to support and educate at risk relatives • Interest in understanding the condition • The more information the better • Hope for answers to direct treatments, therapies, prevention and research	• No interest in "cause" of condition, seen as just a label
Parents of children with a genetic condition	• Sad and anxious about future for child • Helplessness and self-blame • Parental responsibility - wanting to improve life of child • Become very busy with child	• Very important to understand the cause of the condition for peace of mind (e.g. reduce self-blame) • Interest to prevent or prepare for future affected pregnancy • Directing treatments • Responsibility to do everything possible to help child	• Genetic testing for future pregnancies not always acceptable because of risk of miscarriage
Prospective parents of a pregnancy at risk of a genetic condition	• Negative perceptions of disability • Burden in an already busy life • Some exaggerated descriptions of illness • Responsibility and love for the unborn child	• Planning for the future • Parental responsibility to look out for the future child • The more information the better • Peace of mind to prospective parents	• Genetic testing not always acceptable because of risk of miscarriage • Low risk numbers – possibly a culture of over testing • Key informants suggest some individuals (other than themselves) may not want genetic testing because of a lack of education about its purpose,

	privacy concerns or fears about providing DNA to the government.

* Also included in this table are participants' reasons for not wanting this service, although this is in the context of all individuals stating an intention to pursue testing in their genetic counselling appointment.

6.0.5.4. Differences in medical system between Canada and home countries – emerging challenges for newcomers

Overall individuals tended to comment on their home countries as offering them less support (e.g. no nursing support for a sick child in hospital) with a lower quality of general care. Counselling was provided differently; in one case, genetic counselling was provided but results were mailed to the patient with no further discussion. Some described the diagnosis odyssey they underwent given the lack of referrals to specialists and/or the lack of specialists working in Genetics. Participants described the medical care and the associated technology as less advanced than what was available to them in Canada, even talking about doctors as less knowledgeable than those in Canada. Individuals also discussed how their home countries had less reliable and less trust-worthy medical systems which added to their trust in Canadian health care providers. In the secondary interviews a participant suggested that the medical system in her home country in Africa was faulty and not focused on the knowledge that doctors have. She described that the system is there to make money and thus it cannot be trusted completely. Furthermore, negative experience in her home country acted to highlight the positives of the Canadian health care system, which to her included that the system was independent of money or religious affiliation. One participant however, was clear that she did not expect the medical system in Canada to be the same as her home country Our results are supported by previous studies of clinical genetic counselling in low- and middle-income countries (Zhong et al., 2018). Zhong *et.al.* (2018) describe that clinicians in such countries often bear the responsibility of providing genetic counselling, yet they lack knowledge about genetic disease; this creates a barrier to providing care to their patients. Because of inadequate knowledge, clinicians may be dismissive of patient follow-up questions (Zhong et al., 2018). Some of our participants view genetic disorders as

untreatable. This a perception shared by others, which is known to prevent individuals from undergo genetic testing (Zhong et al., 2018). Additionally, individuals described financial limitations that could seriously inhibit access to desired care (Leduc & Proulx, 2004; Zhong et al., 2018). Zhong *et. al.* (2018) describes financial and geographic barriers preventing low-income and rural patients from accessing genetic services. Newcomers may have preconceptions about the cost of genetic services, based on experiences in their home countries. In her secondary interview, one participant corroborated this interpretation in explaining that genetic services cost a lot in her home country. Thus, education about the freely available services should be advertised to immigrants.

Newcomers in our study highlighted several challenges faced when trying to access the genetic counselling services. The main point of contention was surrounding long wait times, in accessing the genetics specialist, obtaining testing and receiving results. This has been previously reported for Canadian newcomers experience with accessing *primary care* in the Canadian public health care system (Asanin & Wilson, 2008; Dean & Wilson, 2010; Woodgate et al., 2017) as well as in accessing specialist services (Reitmanova & Gustafson, 2009). The long wait times were disorienting in an already complicated process of receiving specialist care and added to the participants' stress. The wait times were also particularly upsetting to one participant who was unable to follow appropriate feedings for her ill daughter as a result, although these wait times were likely with respect to general hospital admissions not to a genetic counselling appointment. Previous research conducted in presumably the same Manitoba city as our study found a similar result (Woodgate et al., 2017). Woodgate *et. al.* (2017) found that immigrant and refugee families expected acceptable, affordable and accessible primary health care, but were

disappointed and distressed by long wait times encountered at health care service points along with high cost of medication and non-basic care. Although several participants demonstrated patience with this shortcoming of the public health care system, individuals may not have anticipated such long wait times given their prior experiences with medical services in a home country, where wait times may not have been as lengthy as a result of paying for service. This is similar to previous findings; for example, Ledux and Proulx (2004) found that recently immigrated families had different experiences with health care services in Canada as compared to their home countries. Their study participants delineated the differences as the free service offered in Canada, and the choice between "poor-quality public services with long waiting lists" and "high-quality, readily available private services" (Leduc & Proulx, 2004). Other less commonly reported concerns for our study participants were those of procedures related to scheduling an appointment and seeing the genetic counsellor, and privacy of information. One participant was unhappy with receiving counselling while undergoing her ultrasound as she was disoriented to the process of testing. It may be advisable to separate the ultrasound and genetic counselling appointments completely for newcomers to leave space and time for discussion about the process of genetic counselling and testing. The researcher is unaware of any specific literature evaluating immigrant women's preference with regard to the setting of receiving prenatal genetic counselling. However, it is logical to extend the idea that receiving prenatal genetic counselling during an ultrasound examination may add to the stress and confusion already experienced by newcomers in trying to navigate new and unfamiliar health care systems (Woodgate et al., 2017). Concerns about privacy were raised by one of the Nigerian female immigrant participants. She was concerned that others from her home country may avoid genetic counselling and/or testing because of a lack of education about the use and storage of

DNA/samples as previously reported (A. G. Buseh et al., 2017). Two participants, each with a different ethnic backgrounds, refuted this idea in their secondary interviews, one suggested that she had no fears about giving blood, and both describing that they had trust in the privacy of genetics clinics. This suggests that concerns about use and storage of samples may be an issue some minority groups or cultures over others. Buseh *et. al.* found similar concerns among African immigrants with respect to participation in genetics research. Cultural beliefs about keeping the body intact may impact the collection of human tissues, especially blood samples – blood, in the African context has been widely reported to have associations with strength, superstition, historical exploitation, witchcraft etc. (A. G. Buseh et al., 2017; De Vries et al., 2014). Additionally some may have concerns about genetic researchers 'playing God' and interfering with the "natural order of things" (A. Buseh et al., 2014). Furthermore, previous research implicates concerns of privacy of information and discrimination for African immigrants participating with respect to genetic testing (A. G. Buseh et al., 2017; A. Buseh et al., 2014). African immigrants may fear exploitation and feel uneasy because of a perception of the government having information about them (A. G. Buseh et al., 2017). Additionally, exploitation by Western researchers in home countries in Africa may cause African newcomers to bring fears of victimization with them to North America (A. G. Buseh et al., 2017).

6.1. National Society of Genetic Counselors: key points from the 2019-2021 Strategic Plan

This research is quite timely in the context of the larger professional body goals for the profession. In the fall of last year, the National Society of Genetic Counselors (NSGC) Board of Directors published their 2019-2021 Strategic Plan (National Society of Genetic Counselors, 2019). The plan outlines 4 main areas of focus, "Strategic Area of Focus 4: Diversity and

Inclusion", is of particular interest. It states that the "NSGC will promote a culture of inclusivity that supports visible and invisible diversity, and leverage that culture to expand the perspectives represented in our field, build community and foster equity in genetic services" (National Society of Genetic Counselors, 2019). This goal encompasses 2 objectives as listed in Table 8 below (National Society of Genetic Counselors, 2019).

Table 8: NSGC Strategic Goal 4: Diversity and Inclusion, Objectives 1 and 2 with respective action steps, as described directly from the Strategic Plan (National Society of Genetic Counselors, 2019).

	Objective	Action Steps
1	Establish an organizational structure to advance, monitor and revise our approach to inclusion, diversity and community building	• Develop an organizational inclusion and diversity statement by June 30, 2019 • Create ongoing opportunities for members to connect in a manner that bridges practice settings, geographic location and background through December 31, 2021 • Develop and implement a plan for an ongoing, structured NSGC community-building initiative by October 31, 2019 • Assess barriers to professional development of underrepresented groups within the genetic counseling profession and identify any opportunities for NSGC to reduce identified barriers by June 30, 2020
2	Identify, guide and develop resources and partnerships to facilitate member outreach to engage with diverse communities	• Advance education and provide opportunities for self-reflection around cultural competence and sources of conscious and unconscious bias through December 31, 2021 • Identify and engage with organizations with influence in targeted and underrepresented patient communities by March 31, 2020 • Create tools for members to engage with community organizations to reach potential patients by December 31, 2020 • Assess barriers to recruitment of underrepresented groups into the genetic counseling profession and identify any opportunities for NSGC to reduce identified barriers by June 30, 2020 • Develop mechanisms to highlight genetic counseling as a career within hard-to-reach communities by December 31, 2020

Our research is not only well positioned during a time of strategic growth within the professional body; it also contributes to these goals. The research adds to the body of literature describing the underrepresented patient experience. Additionally, it draws connections between these

experiences and the emergence of cultural humility as a philosophy within the context of genetic counselling, providing evidence for the need to shift away from cultural competence. Additionally, our research involves the engagement with underrepresented communities such as newcomer populations and the organizations created to serve these groups.

The NSGC initiative to increase diversity within the genetic counselling workforce, taken together with our findings, suggests that there is still room to improve the experience and outcomes for immigrants who receive genetic counselling. Increasing cultural diverse in the work force may provide this solution. The inclusion of a more diverse work force may help to illuminate issues that we are currently overlooking in clinical practice and research. This idea is supported by the notion that participants do not always say what they mean, either because of difficulties verbalizing the idea or out of respect for those with authority. Moreover, the research considers that the increased diversity in the genetic counselling workforce might help attend to the needs of more culturally appropriate social supports lacking for this population. In summary, a culturally diverse genetic counselling workforce may help clinicians and researchers in the field of genetics to illuminate areas of weakness and assist in mitigating these concerns.

6.2. Participant driven suggestions for improved service

Although no one suggestion was consistent throughout the participant interviews, several participants acted as key informants of specific topics. Explicit participant suggestions taken together with the gaps in service provision, and the challenges experienced by participants as established by the qualitative themes suggested six areas for improved provision of care. These six areas as defined by the researcher include:

1. Increasing awareness and education about genetic counselling services and genetic diseases.
2. Assist in strengthening support networks, help to increase culturally relevant support systems and increase the provision of appropriate referrals being mindful that not all types of support are seen as acceptable.
3. Reduce wait times.
4. Include the patient in planning.
5. Create centre specific protocols for patients who require interpretation services.
6. Consider immigrants in the discussion on the current topic of diversity and inclusion, and NSGC 2019 initiative.

Most newcomers felt that it was important to increase awareness about genetic counselling services and genetic diseases in the immigrant community to ensure that all individuals interested or in need of such a service will be aware of its existence. Educating newcomers empowers them to share and disseminate important information about genetic conditions and available services to others such as friends and family as they see fit, allowing them to help others. By increasing awareness and sharing information, genetic counsellors and immigrants might help to reduce stigma about the cause of genetic disease, inform newcomer populations about aspects of counselling available, and answer questions about genetic testing, privacy and security of information. Speaking to potential concerns might increase interest in this service.

Providers should not only be aware of the concern regarding the paucity of support systems and its impacts on coping and management, but they should also play a role in fostering support.

Health care providers need to consider the level of hierarchy placed on different types of support, and that not all kinds of support will be seen as equal based on cultural backgrounds. Genetic counsellors are poised to foster appropriate coping and as such need to consider ways to work with immigrant communities to develop support systems that are culturally appropriate, accessible and relevant to newcomers. Genetic counsellors may consider providing emotional support to newcomers by lettering them know that they are not alone. This could mean, telling newcomer patients that there are other newcomers going through a similar situation, while normalizing the occurrence of genetic conditions and/or disability. Genetic counsellors should be aware that some newcomers may have different living situations (than the majority of our participants, such as living near to extended relatives) and thus do not feel a lack of support in Canada. Genetic counsellors may consider continuing to build and strengthen their relationship with immigrant communities and the support systems they already use, such as churches. However, so as not to implement irrelevant programs, further research from within the immigrant community is needed to understand the appropriate solution and to facilitate the emergence of useful change.

Long wait times were a widely shared issue for the immigrants in this study. The sensitive nature of starting a new life and working with limited supports, coupled with expectations of a medical system from a home country, may heighten the experience of a wait time as considerably negative. Genetics providers might consider this experience when triaging newcomer patients in their clinics.

Genetic providers should be more clear when giving information and answering questions. This may include directly asking participants about their understanding and if the explanations make sense and are relevant to the patient. Clinicians should be mindful that patients may not feel comfortable asking questions or saying exactly what they mean, or may have difficulties conceptualizing what questions to ask. Patients may also feel the need to respect and follow the guidance of professionals. Clinicians should be transparent about the plan for the appointment and follow-up which helps to set realistic expectations and avoid confusion. Clinicians should include the patient in this plan. Most newcomers liked the ideas proposed by one participant, which included informal meetings with communities to educate and increase awareness. They also included the idea to send out simple informational pamphlets explaining genetic counselling, before individuals attend their appointments, to help increase understanding.

Clinicians should acknowledge the challenges of persons requiring interpretation services and the limitations within the system for these people to call their providers with questions. Clinicians should be aware of the processes in place their respective centres and understand if the patient will be able to arrange an interpreter themselves to call the provider. If not, clinicians should set a plan to contact them at a later time (with an interpreter) in the case that they may be trying to reach their provider. There are gaps in patients accessing this service to call providers after an appointment, which can leave people feeling stressed and isolated. Creating a centre specific protocol may be necessary.

6.3. Future directions and practice implications

The researcher suggests the need for quantitative studies investigating Canadian immigrants' trust in specialist health care providers, such as genetic counsellors, and their interest in genetic counselling and testing by specific genetic indication. Additionally, we suggest a further investigation of immigrants' appreciation for non-directive genetic counselling. Research involving immigrants outside of the genetic counselling encounter would be helpful in quantifying the overall knowledge, awareness and interest in genetic services in the broader immigrant community. Further, we suggest a need to evaluate genetic health literacy levels in the Canadian newcomer population. There is a need to conduct further research among males and fathers in this area, as our research and the research of others have primarily focused on women. Furthermore, we recommend engaging further with interpreters to investigate the level of genetic knowledge incorporated into training and how further education initiatives may be introduced for interpreters working in Genetics. There is also an opportunity to engage with and educate immigrant communities through outreach workshops and relationship building with immigrant centres. Education should include information about genetic counselling/testing as a freely available service. However, there is a need to further elucidate whether private-pay prenatal testing options pose financial barriers and influence decision-making for immigrant and minority populations in Canada. Moreover, quantitative research on the outcomes of recommendations made in previous literature on ethnic minorities and genetic counselling (over the last 20+ years), is needed to measure if there has been progress made in the field.

Additionally, there is an opportunity and responsibility to investigate the need for and shift towards cultural humility as a professional philosophy replacing cultural competency in genetic

counselling training and practice. This may also include an evaluation of current models of practice, and an evaluation of which models are being employed in practice with diverse populations. Moreover, an evaluation of the Reciprocal Engagement Model, to determine if there are variations and limitation, as a result of patient cultural considerations (Veach et al., 2007), is needed to validate the model further in non-Caucasian and lower socioeconomic populations. Ultimately, the Reciprocal Engagement Model may be improved by further adoption of goals built from a cultural humility framework. Moreover, the model may be strengthened by explicit and validated strategies and behaviours necessary to achieve cultural humility in the practice of genetic counselling.

6.4. Benefits of the methodology

The project design has strengths within the depth and openness of the research interviews. In undertaking an exploratory project to describe a previously poorly researched topic, our 75 – 170 minute open-ended semi-structured interviews invited participants to explore and describe their experiences deeply (Hill, Clara E, Thopson, B. J., Williams, 1997). Our research has been conducted from the perspective of the immigrant population, a point-of-view that demands further representation within the literature (Carrasco et al., 2009). Our approach allows for this population to describe the nature of their everyday *lived* experience with genetic counselling services (Miles, Matthew B., Huberman, A. M., Saldana, 2020). Internal validity was increased by having the same researcher conduct all primary and member checking interviews (MacFarlane, Ian, McCarthy Veach, Patricia, LeRoy, Bonnie, 2014). Furthermore, the same interpreters were used for all interviews, respective to each language. Dependability and confirmability was increased in this research study by detailed note taking before, during and

after the interviews as well as during the analysis and write-up (Korstjens & Moser, 2018). Additionally, memoing was employed throughout the interviewing and analysis which allowed for the researcher to remain close to the data (Hesse-Biber, 2017). The credibility of the results were increased by the process of member checking through the secondary interviews (Korstjens & Moser, 2018). This was completed with six participants, all of whom agreed with the findings as a whole with limited discrepancies or disconfirming evidence. Reflexivity was employed throughout the interview, analysis and writing process of this project which allowed for the researcher to be more aware of her biases and their impact in all aspects of the study, including her relationship with the participants in co-creating meaning (Hesse-Biber, 2017). This resulted in a thoughtful, introspective interpretation of the results. Descriptions of the student researcher and primary investigator are listed below. One of the benefits of the members of this research team was the personal experience and expertise of the primary investigator as an immigrant himself.

About the researchers:

The student researcher is a Canadian-born Caucasian female in her mid-twenties, from an upper middle-class family in a medium sized city in Canada. She is a Masters student who holds a Bachelors degree in Science. She is a Genetic Counselling student completing this thesis in partial fulfillment of her degree. Part of her course work taken during this degree included exploration of the models of illness, dimensions of culture, cultural competency and cultural humility among other subjects related to the topics of this document. She would consider herself to be aligned with Western ideals of culture, religion and medical practice, although she has no overly strong religious view. The student researcher is a native English-speaker with a low level

of conversational French abilities. The student researcher has a strong family network, and has never had to relocate outside of Canada.

The primary investigator is a Sierra Leonean-born Canadian male in his mid-fifties. He is originally from Sierra Leone, West Africa, from a wealthy family, who studied in the UK. He is a professor who holds a doctorate degree in Biomedical Science and Masters in Education. He considers himself to be aligned with Western ideas of culture.

About the interpreters:
Interpreters are hired and trained by a professional organization affiliated with the Winnipeg Regional Health Authority (the WRHA Language Access) and abide by a professional Code of Ethics and Standards of Practice for Interpreters (Winnipeg Regional Health Authority, 2018; Winnipeg Regional Health Authority Language Access, n.d.). *All WRHA Language Access interpreters undergo a language and skills testing via the Community Interpreter Language and Interpreting Skills Assessment Tool (CILISAT Test) as a part of their interviewing process* (CISOC, n.d.). *Additionally, all interpreters receive 72 hours of intensive skills-based training that includes an introduction into medical terminology* (Winnipeg Regional Health Authority Language Access, n.d.). *Interpreters are then assessed with a final evaluation that is both written and oral* (Winnipeg Regional Health Authority Language Access, n.d.).

6.5. Limitations

As with all qualitative studies, the transferability or generalizability of this study may be limited to Canadian immigrants at medium sized Canadian health care centres (McMillan, 2004).

However, transferability is in the eye of the reader and it can be increased with the provision of a 'thick description' of the research and research setting, which we have done (Korstjens & Moser, 2018). Sample size, recruitment and sampling posed limitations on our research. Although we recruited participants until thematic saturation of major themes was achieved, a number suggested to be between 8-15 participants (Hill, Clara E, Thopson, B. J., Williams, 1997; Patton, 2015), additional participants would have been ideal to explore subthemes more thoroughly. Recruitment through clinical visits was beneficial in increasing numbers of potential participants in a sample typically characterized by low participation in clinical research (Emami & Mazaheri, 2007). Our recruitment strategy added strength to our study design in that it allowed us to acquire a diverse sample population representative of Winnipeg, Canada newcomers. In selecting for recent immigrants, we were able speak with individuals at a time that we proposed reflected earlier stages of acculturation and higher levels of settlement challenges. However, our recruitment criteria did not eliminate the possibility that participants could have lived in other countries other than their home country before immigrating to Canada. In fact, two participants disclosed this. This factor may have impacted the experience of settling in Canada and the psychological acculturation process. Moreover, it is possible that we have described the experience of a sample with a higher psychological acculturation level and that this sample may not represent the acculturation level of the Canadian immigrant population at large. Additionally, regardless of psychological acculturation, it is also possible that this sample does not represent the experiences of Canadian newcomers. Together, this may limit the transferability of the description of this samples' experience. This recruitment method, however, provided us with participants from all genetics subspecialties offered within our centre (cancer, prenatal, pediatric, adult general). Notably, this sample was limited in its representation of males and of refugees.

Our recruiting strategy, however, allowed for the involvement of both genetic counsellors and geneticists as clinicians to our participants, which is likely more representative of the standard Canadian Genetics team (Canadian Association of Genetic Counsellors, 2016). Although, we do not assume that genetic counsellors and geneticists provide care in the same manner,. It is widely known that genetic counsellors focus on provision of psychosocial support in their practice (Canadian Association of Genetic Counsellors, 2012; Resta et al., 2006). Unfortunately, this recruitment method was likely susceptible to clinician bias in that they may be more likely to invite a patient who had not received bad news or who had an emotionally charged appointment. Therefore, our sample is likely skewed towards individuals with more neutral or positive experiences inherently. Additionally, it is possible that clinicians were more likely to invite a person who presented visually as a person of an ethnic minority. An additional limitation of the recruitment method was the process of calling to consent potential participants to research. Often potential participants did not answer phone calls, did not have voicemails, provided the incorrect contact information and were generally difficult to reach. This had a significant impact on final sample size. All interviews were conducted by telephone as requested by our participants. Although telephone interviews have been critiqued for the limitations they pose on rapport building, this form of interviewing may be preferable in sensitive situations were participants might be vulnerable or embarrassed (Hill et al., 2005). We found this was the case for our research. Additionally, our participants continually commented on their busy lives. The student researcher believes that allowing participants to select an interview by telephone may have actually improved recruitment.

A limitation inherent to our study design was a lack of evaluation of the clinicians' models of practice within the genetic counselling encounter. Because we were unable to characterize the model with which the clinician has provided care, we can only speculate that clinicians strived to provide care under a Reciprocal Engagement Model. It is possible, however, that clinicians provided care under different models such as a Teaching Model. This unknown variable thus impacts the interpretation of our findings associated with participant's appreciation for particular aspects of the communication as well as individuals ability to exhibit medical pluralism. To be cautious, the results of the study were interpreted to assume that clinicians provided care with a biomedical framework at least. Although, the researcher has acknowledged the biopsychosocial model further in the discussion.

Conducting a research study in the cross-language context has intrinsic limitations. Some of the limitations faced in this research include the interpreters' ability to provide a conceptual equivalence (Squires, 2009), especially for genetic terms. Fortunately, our generic qualitative approach was amendable to the use of interpreters (Squires, 2009). Further, we were able to use the same interpreters for the entirety of the research study, working together with them as research team members (Squires, 2009). Moreover, our interpreters were professionally trained and certified medical interpreters and their qualifications are briefly described above (Squires, 2009). Although working with interpreters was a limitation in our study, it was important for increasing inclusiveness and barrier reduction within this population, allowing for us to speak with a diverse representation of Canadian newcomers. An additional limitation to the cross-language context is the impact on accurate transcription. It is possible that sections of the

participant responses were transcribed incorrectly due to difficulties understanding participants who had accents and/or as a result of poor telephone connections.

This study was constrained by time and resources. These factors affected the length of time in which recruitment took place, impeding the number of participants recruited and interviewed. These factors also put limitations on our quality control measures such as Time and resource constraints also affected the secondary interview/member checking in that transcription of the audio-recordings was not completed. However, detailed note-taking was done to compensate. Member checking by synthesized analysed data has inherent methodological limitations. Some limitations include, the requirement of time to analyze data, lengthening the period between interviews increasing the potential for losing participants to follow-up (Birt et al., 2016). If several participants do not provide feedback, this can pose a limit to the trustworthiness of the finalized report (Birt et al., 2016). Additionally, participants may find it difficult to identify their original experience within higher levels of constructed meaning as found within the analyzed data (Birt et al., 2016).

Qualitative research methodologies typically involve analysis by interpreting data for meaningful themes and patterns (Patton, 2015) thus, requiring researchers to make generalizations about larger groups. Such methods may be at odds with frameworks like cultural humility, that ask clinicians to see the individual patients as having distinct cultural identities rather than making assumptions based on their affiliated cultural groups. It may be difficult to make wide evidence-based recommendations within and across groups, which incorporate the individual experiences of culture taking into account factors unique to individuals, such as psychological acculturation

level. These competing values may pose limitations when evaluating culturally humble models of genetic counselling practice and their effectiveness in diverse populations. Moreover, this perspective of the specific versus the general may have posed limitations on this research where the researcher attempted to incorporate both feedback unique to the individual and comments shared across groups.

6.6. Summary

This research provides an update on many years of prior recommendations within the area of increased access and culturally appropriate care for ethnic minority populations. Our research highlights that although some advances have been made, many concerns remain the same. There is low overall awareness of the genetic counselling services available but a high interest in genetic counselling and testing within this sample. Given the difficulties of a new life, participants highlighted the struggles of living with or caring for a relative with a genetic condition. As such, lack of support networks was identified as a concern for many individuals. Study participants had a high level of trust in the Canadian health care system as well as with their genetic counselling providers, which was in contrast to a lack of trust or reliance in the medical system of a home country. This trust appeared to be associated with well-received communication styles provided by clinicians, which may provide evidence for an appreciation for the non-directive style of counselling traditionally employed in this profession. Additionally, these participants exhibited medical pluralism in their understanding of disease, interest in genetic services and coping mechanism. These findings draw comparison between the primarily American research on this topic and the Canadian experience, as well as drawing a link to barriers to genetic counselling service access for immigrants. Further our results reveal several

novel findings that set this work apart from the previously conducted American research; for example increased trust and an appreciation for the non-directive approach to counselling. Interpretation of these novel findings must be taken with caution, due to the limitations posed on transferability in this study. It is impossible to discern whether our novel findings truly described the experience of the Canadian recent immigrant population or whether we have described the experience of a population with an increased acculturation level. Further, it is important to consider whether the findings from our population can be generalized to the larger Canadian newcomer population. Nevertheless, our results expand on previous research with newcomers, providing a rich description of the lived experiences with genetic counselling and testing. In selecting for participants based on recent immigration status, we have highlighted several immigrant specific barriers such as difficulties navigating systems and limited appropriate support networks, which do not tend to be the focus in other genetic counselling literature. Additionally, this research draws connections to current initiatives within the professional body strategic plans. This study provides evidence in support of the movement towards cultural humility as a philosophy to replace cultural competency in training and practicing of genetic counselling. Lastly, the project identifies multiple areas for future research and exploration, and includes a list of participant driven suggestions to improve service delivery for newcomers.

CHAPTER SEVEN

7.0. Conclusion

This study explores and describes the experiences of eight recent Canadian newcomers with genetic counselling services. Our results add the novel experiences of our population to the largely American body of research. In particular, within this Canadian setting, we have described effective communication and the components of building trust with newcomer patients. We provide evidence of a low participant awareness yet moderate to high interest in genetics services. Additionally, we describe the role of medical pluralism in understanding of disease and coping, and discuss barriers to the effective utilization and associated positive outcomes with genetic counselling and testing. Importantly, we provide participant driven suggestions for the improvement of genetic counselling service delivery for Canadian newcomers. Moreover, in light of evidence presented, we define a need for a movement towards cultural humility training and practice, and away from an approach rooted in cultural competency in genetic counselling to an increasingly diverse population.

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APPENDICES

APPENDIX I: BUDGET

Item	Rate	Quantity	Total
Professional Interpreter(s) Language Access Winnipeg Regional Health Authority	In person: $55/h days and $56/h evenings +0.05% GST (minimum of 2 hours in-person) Telephone: $55/h days and $56/h evenings +0.05% GST (minimum of 0.5 hours)	$117.6/interview* (2 hours)	$823.20
Transcription	Student Researcher	Maximum 30	$0
Qualitative Analysis Software	Dedoose	-	$135.00
Recording Equipment	UofM IT Service Rental		$0
Honorarium or Incentive	For up to 30 participants	$15 each	$450.00
Postage and office supplies	$0.85/stamp + envelopes	$1.50 each (max 60)	$90.00
Total			*$1498.20*

*The budget permits 14 hours of interpretation both in-person and over the phone.

APPENDIX II: CONSENT, RECRUITMENT AND DATA COLLECTION FORMS

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Introduction Cover Letter

Exploring Immigrants' Perceptions of Genetic Counselling

Supervisor/Principal Investigator: Dr. Francis Amara
Student Researcher/Investigator: Ashleigh Hansen, BSc, Genetic Counselling Trainee

You are being asked to participate in a research study being conducted by a master's student at the University of Manitoba as part of her thesis project. The student researcher's name is Ashleigh Hansen. She is also the investigator of the research project.

WELCOME TO THE RESEARCH STUDY

I am running a research project to look at experiences that recent immigrants in Manitoba have had with Genetic Counselling, through the Winnipeg Regional Health Authority Program of Genetics & Metabolism. You have been identified as someone who may be eligible for this research study because, during your genetic counselling appointment, you said that you were not born in Canada.

I will be inviting you for telephone or in-person interviews to ask you about your recent appointment with Genetics and your experience living with a genetic condition. The interview is not meant to quiz or test you and there are no right or wrong answers. The style of the interview is designed to allow you to tell me your personal experiences, as you experienced them. I will host the in-person interviews in a private office at either Welcome Place or Immigrant Centre.

Your choice to join the study is completely voluntary and it will not affect your current or future genetic counselling appointments with Genetics. The interviews will not become a part of your medical records. You can leave the study at any time.

Please find the Letter of Invitation and Informed Consent for Participants to Participate in Research form attached. Take some time to read through this form and decide if you would like to join the research study.

If you chose to participate, you can return your signed consent form directly to me at XX or through mail to the address above. Please keep a signed copy for yourself.

Kind regards,
Ashleigh Hansen, BSc
Genetic Counselling Program
University of Manitoba

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Consent to Contact by Telephone

Exploring Immigrants' Perceptions of Genetic Counselling

Supervisor/Principal Investigator: Dr. Francis Amara
Student Researcher/Investigator: Ashleigh Hansen, BSc, Genetic Counselling Trainee

INTRODUCTION

Ashleigh Hansen is a Master's student in the Genetic Counselling Program at University of Manitoba. She is conducting a research study that explores immigrants' perceptions of genetic counselling. The study is in partial fulfilment for requirements of her Masters of Science degree. Dr. Francis Amara supervises her research study. You are being invited to participate in this research study because you are an immigrant. 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 immigrants' perceptions of genetic counselling. We plan to investigate this by asking questions about immigrants' experiences with genetic counselling from their recent appointment and/or in their home country. With these data, we plan to generate recommendations for how genetic counsellors can best meet the needs of immigrants. Through the facilitation of our project, we hope to build relationships with local immigrant centres and to encourage the development of an immigrant-run genetic disease support network in Manitoba.

CONSENT TO BE CONTACTED BY TELEPHONE

By filling out the form below, you are indicating that Ashleigh Hansen, 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 Ashleigh 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 individual Genetics & Metabolism chart number (K#) when she contacts you for the purposes of verifying your appointment. The research team will only verify your appointment using this kindred number after you have given verbal consent by telephone. The Genetic & 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 DO guarantee that all of your information will be kept confidential.

Participant name(s):

_____

_____

Primary phone number:

_____

Additional phone number:

_____

What is the best time of day to contact

you?_____

Is English your first language? ☐yes ☐no

What is your preferred interview style? ☐telephone ☐face-to-face (at Welcome Place)

Will you require interpreter services? ☐yes ☐no

What is your preferred language?

_____

_____ _____

Date Participant's Signature

_____

Participant's Printed Name

_____ _____

Date Witness's Signature

_____

Witness's Printed Name

UNIVERSITY
OF MANITOBA

Letter of Invitation and Informed Consent for Participants to Participate in Research

Exploring Immigrants' Perceptions of Genetic Counselling

Supervisor/Principal Investigator: Dr. Francis Amara
Student Researcher/Investigator: Ashleigh Hansen, BSc, Genetic Counselling Trainee

INTRODUCTION
This is a research study exploring immigrants' perceptions of genetic counselling. The principal investigator is Dr. Francis Amara. The student researcher is Ashleigh Hansen, a Master's student in the Genetic Counselling Program at University of Manitoba.

Please read all of the following information carefully. Ask any questions that you have about this research study of the study staff. You may also chose to talk to your friends, family, or individuals you trust at the Manitoba Interfaith Immigration Council Inc. and/or Immigrant Centre if you have any concerns. 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. Please take a copy of the signed form or ask the student researcher to provide you with a copy of the signed form, You should keep a copy for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

Please sign this form in advance of the interview, keep a copy for yourself, and send a signed copy to the student researcher. You can email, mail or bring a signed form to your interview. Emails can be sent to XX.

PURPOSE OF STUDY
The purpose of this study is to explore immigrants' perceptions of genetic counselling. We plan to investigate immigrants' perceptions of genetic counselling from their recent appointment in Manitoba and in their home country. From our research, we hope to better understand how immigrants perceive and experience genetic counselling, and with these data we plan to generate recommendations for how genetic counsellors can best meet the needs of immigrants. Through the facilitation of our project, we hope to build relationships with local immigrant centres and to encourage the development of an immigrant-run genetic disease support network.

ELIGIBILITY
You are invited to participate in this study because you are an immigrant. Your eligibility to participate in this study is determined based on the table below. A maximum of 30 participants will be asked to participate in this study.

To participate in this study, you must meet ALL of the following criteria:	You cannot participate in this study if you meet one or more of the follow:
✓ At least 18 years old ✓ Born outside of Canada ✓ Currently lives in Canada ✓ Has lived in Canada for 5 years or less ✓ At least one of the following situation applies to you:	X Other relatives of someone who had an appointment with the Program of Genetics & Metabolism who did not attend the genetic counselling appointment (i.e., they do not meet the criteria listed in the column on the left)

o You personally were referred for, and attended, an appointment in the Program of Genetics and Metabolism o You are the parent or guardian of someone who was referred for, and attended, an appointment in the Program of Genetics and Metabolism, AND you accompanied this person to their appointment o You are the spouse/partner of someone who was referred for, and attended, an appointment in the Program of Genetics and Metabolism, AND you accompanied this person to their appointment	X Individuals who did not attend any appointment in the Program of Genetics and Metabolism X Individuals who will not be able to be contacted in follow-up over the duration of the study (September 2017 – September 2019).

PROCEDURES TO BE FOLLOWED

You will receive a phone call from the student researcher herself. During this phone call, she will explain the research study to you further. She will walk through this consent form and she will answer any questions you might have. If you are interested in participating in this study, she will ask for your consent to participate and she will schedule an interview with you.

If you agree to participate in this study, she will also ask for your verbal permission to confirm three pieces of information from your Genetics & Metabolism medical records: Your name, your unique Genetics chart number (this is called a Kindred number), and the date of your appointment. These three pieces of information will be collected to ensure that your appointment with the Genetics & Metabolism Program meets the criteria required for you to participate in the research study. They will not be published or used in the study in any other way without your explicit written permission. These Genetic & Metabolism Program medical records are separate from your hospital chart but may include information from any medical visit, thus, we cannot guarantee that no other medical information will be seen by the research team. We do guarantee that all of your information will be kept confidential.

You will be asked to participate in an individual 60-minute minimum audiotaped phone or in-person interview. The student researcher herself will interview you. During this interview, you will be asked questions regarding your thoughts, opinions and experience with genetic diseases, your views on genetic testing and to describe your recent experience with a genetic counsellor and/or geneticist. The student researcher may also take notes during the interview. You may refuse to answer any question and stop the interview at any time.

The interview will be audiotaped and transcribed by the student researcher, and studied by the student researcher and the research team. The aggregate data from this analysis will be summarized into a report. We will then contact participants by telephone for a second interview to validate our results. You will be invited to provided your feedback on the telephone or to attend a group interview (this interview could be 60- to 90-minutes). The student researcher will contact you to schedule your one-on-one telephone interview or your attendance at the group interview. Should you choose to attend the group interview, you and the other participants will be asked to keep all information disclosed within the discussion confidential. You will not be referred to by name during this group interview, but it is possible that other

group members may call you by name. It is important to know that, although we ask all participants of the group interview to keep information confidential, it is possible that some information may not be keep private or confidential by others in the group. Secondary interviews will also be audio recorded and transcribed by the student researcher. Should you be referred to by name by a group member, your name will be removed from the transcripts and you will remain anonymous on the transcript. An informal copy of the report will be made available for all participants who wish to see it. These results may be presented at conferences, in posters, and published as written transcripts in abstracts or peer reviewed journal articles.

RISKS

Participation in this study presents no more than minimal risk. Your participation or non-participation will not affect your current or future genetic counselling appointments with the Program of Genetics and Metabolism. The information discussed in the interviews will not become part of your medical history. However, it is possible that taking part in the interview could cause distressing thoughts and feelings. Should that occur, Ashleigh Hansen is available to provide additional support and help you seek counselling services should you feel this is needed. You may contact her XX. Some available free or low cost counselling supports in Winnipeg include: Klinic Community Health at XX and Family Dynamics at XX. These services are available in Winnipeg upon professional advice to access them; the research team does not advocate for these services. You can also speak with the Welcome Place (Manitoba Interfaith Immigration Council Inc.) at XX or Immigrant Centre at XX should you want additional support. In addition, because of the nature of this study, it is possible that some of the information you provide in the interview may be used in a written transcript and could identify you even with your name removed. Other people (for example, people in your community or family, language interpreter, or caregivers and healthcare professionals) may identify you. Individuals will also be asked to return for a secondary interview held in a group setting to provide feedback at the end of the study. This meeting will be with other participants and will reveal your identity to them. Should you not wish to participate in this group interview, your feedback can be collected over the telephone in an individual interview.

BENEFITS

There will be no direct benefit to you for your participation in the study. We hope that in the future, information obtained from this study will help us gain a better understanding of immigrants use of genetic counselling services in Manitoba. From this research, we hope to generate recommendations for how genetic counsellors can best meet the needs of immigrants, build relationships with local immigrant centres and possibly encourage the start of an immigrant-run genetic disease support network.

ALTERNATIVES

An alternative is to not participate in this research study. You may also choose how you would like to be quoted using the permission to quote section below.

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. The collection and access of personal information will meet provincial and federal legislations. Transcripts, interview notes, and audiotapes will be labelled with a coded ID number, which will be assigned to you upon enrolment into the study. If you are quoted or referred to in any written or oral reports of the study, you will be given an alternate name. 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. All study related documents and materials (including

eligibility questionnaires, interview transcripts and audiotapes) will be kept in a locked filing cabinet or in a locked office in the Department of Biochemistry and Medical Genetics and the Program of Genetics and Metabolism. Digital material and documents containing participant consent and contact information will be stored in a password protected word/excel document on a password secured University of Manitoba computer in a locked office. Only study staff will have access to these files and only the principal investigator and student researcher will know you by name. Interpreters from the WRHA Language Access may be present in the interview if they are requested or required. The interpreters work under the WRHA Language Access Code of Ethics and Standards of Practice for Interpreters (version September 2018) and Personal Health Information Act. They would not have access to any research or personal health information beyond what was disclosed in the interview. All confidential participant information including interview audio-recordings and interview transcripts will be stored on and accessed by the research staff through the password protected program called Dedoose and the Dedoose cloud service. Written materials will be destroyed (by shredding) 10 years following the completion of the study in the fall of 2019. Digital materials (transcripts, demographic information and audio files) will be permanently deleted from the computer hard drive 10 years following competition of the study.

Some people or groups may need to check the study records to make sure that all the information is correct. All of these people have a professional responsibility to protect your privacy.
These people or groups are:

- The Health Research Ethics Board of the University of Manitoba is responsible for the protection of people in research and has reviewed this study for ethical acceptance
- Quality assurance staff of the University of Manitoba who ensure the study is being conducted properly

PERMISSION TO QUOTE:
We may wish to quote your words directly in reports and publications resulting from this research. With regards to being quoted, please check yes or no for **ONE** of the following statements:

Researchers may publish documents that contain quotations by me under the following conditions:	
☐ Yes ☐ No	I agree to be quoted directly (my name is used).
☐ Yes ☐ No	I agree to be quoted directly if my name is not published (I remain anonymous).
☐ Yes ☐ No	I agree to be quoted directly if a made-up name (pseudonym) is used.
☐	**I DO NOT agree to be quoted directly. The data from my interview may be used in a general way.**

SAFETY
Your confidentiality is important and will be kept private as indicated by your selection above. Your confidentiality may be broken if you describe one of the following:

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

If you tell the interviewer about a situation such as any of the ones above, the interviewer may need to a) discuss this with you further to address the situation and/or b) share this information with the research committee and address the appropriate agency that can provide help and/or c) report to child and family

services and/or the police. Confidentiality may also be broken if a research staff member is required to do so by law (for example, subpoenaed).

PAYMENT

You will receive a $15 gift card to a major box store or grocery store of your choice for participation in the research study as a gesture of appreciation for your time and money spent to travel to the interview. You will be provided this payment following your participation in the first interview. This will be mailed to you should your interview be by telephone. You will receive payment even if you withdrawal from the study following the first interview. You will not receive payment if you withdrawal before the first interview.

COST

There will be minimal cost to you to participate in the study. The costs include: the time it takes to conduct this interview and the expense for you to travel to and from the interview(s) should you select the in-person option. Winnipeg bus fare is $2.95 (adult) and $2.45 (senior) for one-way travel. You can ask for a free bus transfer when you get on the bus if you require one.

VOLUNTARY PARTICIPATION/WITHDRAWAL

Your decision to take part in this study is voluntary. Taking part in this research study is completely your choice. You may chose not to participate or to withdrawal from this study at any time. You should not feel any pressure to participate. Whether or not you choose to participate will not affect the service you receive from the WRHA Genetics & Metabolism Program. You can decide to stop taking part in this research study at any time for any reason by contacting the student researcher, Ashleigh Hansen. If you withdraw from the study (**within the 3 months following your first interview**), the data that you provided will be destroyed.

WHOM TO CONTACT

If you encounter any problems related to study participation or have questions about the study, you may contact the student researcher, Ashleigh Hansen at XX (email) or XX (phone). You may also contact the principal investigator for this project, Dr. Francis Amara, at XX.

If you have questions about your rights as a research study participant, contact the University of Manitoba Research Ethics Board at XX.

PARTICIPANT'S STATEMENT

1. I have read this consent form and have discussed with Ashleigh Hansen (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 my participation is voluntary. I also understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so. If I chose to discontinue participation in this study, I will contact Ashleigh Hansen to advise her of my choice.
4. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
5. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the principal investigator and student researcher and the agencies and organizations listed in the Confidentiality section of this document.
6. I understand that I will be provided with a copy of the consent form for my records or I will take a copy myself.
7. I agree to participate in the study.

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.

Please sign this form in advance of the interview, keep a copy for yourself and send a signed copy to the student researcher. You can email her at XX, you can mail to the above address or you can bring the signed form to your interview. If you need assistance taking a copy of the signed consent form, please bring the form to your interview where the student research can make a copy for you.

_____ _____

Date Participant's Signature

_____

Participant's Printed Name

_____ _____

Date Student Researcher Signature

_____

Student Researcher Printed Name

If applicable

I, the undersigned, attest that the information in the Letter of Invitation and Informed Consent Form was accurately explained to and apparently understood by the participant and the consent to participate in this study was freely given by the participant.

_____ _____

Date Witness Signature

_____ _____

Date Witness Printed Name

K# (Program of Genetics & Metabolism medical record number – used to confirm the appointment with genetics) (*please note that the student researcher will ask for your verbal permission when contacted by telephone)*: _____

Date of appointment: _____

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Letter of Invitation for Clinicians

Exploring Immigrants' Perceptions of Genetic Counselling

Supervisor/Principal Investigator: Dr. Francis Amara
Student Researcher/Investigator: Ashleigh Hansen BSc, Genetic Counselling Trainee

Dear Clinicians,

My name is Ashleigh Hansen. I am a second-year student in the University of Manitoba Masters of Genetic Counselling Program. I am conducting a thesis research study and I require your help to recruit potential participants. Your commitment should be no more than 2 minutes per clinic.

I am interested in studying immigrants' perceptions of genetic counselling. It is widely documented that immigrants face barriers to accessing health care services in North America and Canada, including differences in culture and language, lack of social supports, economic inaccessibility, unfamiliarity with Westernized systems, limited knowledge of services available, and difficulty understanding service providers. However, there is currently very limited data on the utilization of genetic counselling by immigrants. My study aims to fill in these gaps in the current literature. I endeavour to investigate immigrants' perceptions of genetic counselling by asking open-ended questions about immigrants experience of genetic counselling.

For my study, we will be conducting interviews with immigrant individuals who have received genetic counselling with the Program of Genetics and Metabolism about their experiences. Eligibility criteria include:

- Adult (age 18 or older)
- AND born outside of Canada
- AND has resided in Canada for 5 years or less (and currently resides in Canada)
- AND at least one of the following: 1) An individual who has personally had a genetics appointment, OR 2) An individual who accompanied a dependent to a genetics appointment and made medical decisions on that dependent's behalf (e.g., the parent or legal guardian of a minor who had a genetics appointment), OR 3) a spouse/partner who accompanied their spouse/partner to a genetics appointment. The spouse/partner is invited for an individual and separate interview.

We will use data from our study to generate recommendations for how genetics services can best meet the needs of immigrants in Manitoba. We also hope to expand on the relationship between the Department of Medical Genetics and Manitoba immigrants. For instance, our research may encourage the start of the first immigrant-run genetic disease support network in Manitoba.

Your assistance is vital for the recruitment of participants, and therefore the success, of my project. Your participation in my research requires little time, and minimal change to your practice. If you are interested in helping with my study and you encounter patients who meet the eligibility criteria, I ask that you please do the following:

1) Briefly inform them of the study and of their eligibility. If the individual who received genetics services was accompanied by a spouse who also meets eligibility criteria, they can both be recruited.
2) Ask the patient(s) if I may contact them by telephone. Have **each eligible participant** complete the "Consent to Contact by Telephone" form **before** they leave. **This form is required for me to contact them and to review informed consent to enroll in the study.** Return these completed forms to my mailbox in the residents' office. I will collect them on an on-going basis.
3) Provide **each eligible participant** with the following to take home: an "Introduction Letter", a "Letter of Invitation and Informed Consent for Participants to Participate in Research" (stapled together) and a prepaid return envelope if they are unable to use email (which I will provide).

Your participation in the study is essential to recruitment of this population. I thank you in advance for your interest and cooperation. Please do not hesitate to contact me with any questions or concerns regarding the study at XX.

Kind regards,

Kind regards,

Ashleigh Hansen, BSc
Genetic Counselling Trainee
Biochemistry & Medical Genetics, Genetic Counselling Program
University of Manitoba

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OF MANITOBA

Interpreters Letter and Consent Form

Exploring Immigrants' Perceptions of Genetic Counselling

Supervisor/Principal Investigator: Dr. Francis Amara
Student Researcher/Investigator: Ashleigh Hansen, BSc, Genetic Counselling Trainee

WELCOME TO THE RESEARCH STUDY

I am running a research project to explore the perceptions that recent immigrants to Manitoba have of Genetic Counselling, and their experiences with genetic counselling through the Winnipeg Regional Health Authority Program of Genetics & Metabolism (and their home country if applicable).

I will be interviewing immigrants by telephone or in-person to gain a better understanding of their perceptions of genetic counselling. I will do this by asking open-ended questions about their recent appointment with genetic counselling and any previous genetic counselling experience. The interview is not meant to quiz or test the participant and there are no right or wrong answers. The style of the interview is designed to allow the participant to tell me their personal experiences. The lived experience of the immigrant is very important. For this reason, the student researcher may ask clarifying questions about the context or use of language of the participant and/or probing questions to gain more information about the topic.

PROCEDURES TO BE FOLLOWED

I will be conducting a 60-minute minimum primary interview and a 60- to 90- minute secondary interview. The primary interview will be individual; the secondary interview could be in a group setting or in an individual setting. Each interview will be audiotaped and transcribed by the student researcher, and studied by the student researcher and research team. The aggregate data from this analysis will be summarized into a report. The results of this research study may be presented at conferences, in posters, and published as written transcripts in abstracts or peer reviewed journal articles.

I will also be conducting phone calls to invite and enrol participants in our research study and to schedule their interview times. These enrolment/scheduling phone calls will not be audiotaped.

You may be scheduled to work with me during a primary interview and/or a secondary interview and/or an enrolment phone call.

PRIVACY AND CONFIDENTIALITY

The privacy and confidentiality of the research participants is of the utmost importance. Interpreters will perform their role in accordance with the WRHA Language Access Code of Ethics and Standards of Practice for Interpreters (version September 2018) and the Personal Health Information Act.

Your privacy and confidentially is also important to us. All records containing your identifying information (the Interpreters Letter and Consent Form) will be kept strictly confidential during the study. You will remain anonymous in the transcripts of the audio recordings.

In order to discuss the limitations imposed on qualitative research supported by the work of interpreters, I am collecting general information about WRHA Language Access Interpreter Services including interpreter recruitment, screening and training. This information will be used to describe the interpretation service in a general way.

The results of this study may be presented at conferences, in posters, and published as written transcripts in abstracts or peer review journal articles. **Your name will not be used.**

If you have questions regarding this study please or the confidentiality of the research, ask the student researcher Ashleigh Hansen (XX or XX).

INTERPRETER'S STATEMENT

1. I have read this consent form and have discussed with Ashleigh Hansen (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 agree to abide by the WRHA Language Access Code of Ethics and Standards of Practice for Interpreters (version September 2018) and the Personal Health Information Act.
4. I agree to participate as an interpreter in the study.

_____ _____

Date Interpreter's Signature

_____

Interpreter's Printed Name

_____ _____

Date Student Researcher Signature

_____

Student Researcher Printed Name

If applicable (for phone interviews requiring interpreters):
I, the undersigned, attest that the information in the Interpreters Letter and Consent Form was accurately explained to and apparently understood by the interpreter and the consent to interpret this interview and collect and/or publish general interpreter recruitment, screening and training information for the purposes of this research study (as outlined above) was freely given by the interpreter to me the student researcher.

_____ _____

Date Witness Signature

_____ _____

Date Witness Name

Participant Unique Code Number: _____ (do not use a personal identifier)

Phone Script for Eligibility

Hello, my name is Ashleigh Hansen. I am a genetic counselling student at University of Manitoba. As part of my graduate school training, I am conducting a study about immigrant perceptions of genetic counseling.

Do you have time to talk about the study? This should take less than 30 minutes.

The aim of my study is to explore your perceptions of genetic counselling. During the study I will be asking you questions about your experience with genetic counseling from your recent appointment and in your home country. Any experiences you can share will be valuable.

The data will be used to help provide the best genetic counselling services to immigrants. Taking part in this study is completely voluntary and you can stop at any time. If you have any questions or concerns we can stop at any time, you can ask me your questions or you can talk to someone you trust before we continue. Let me know if you would like to stop or if you have a question.

Any questions so far?

Are you interested in learning about how you can participate in the study?

I. Determine eligibility

Firstly, would you be willing to answer a few questions to see if you are eligible to participate?
REVIEW THE CHECKLIST FROM THE CONSENT FORM FOR ELIGABILITY

II. Conduct informed consent process and discuss confidentiality

We can walk through the consent form now, or I can email you a copy of the informed consent after this conversation. Do you still have the copy that your clinician provided? Have you read the informed consent form? Would you like to follow along now as I go through it?

Explain that the informed consent can be emailed to them, that they can use the form that the clinician provided to them at their appointment or that they can fill out an informed consent form before the interview starts.

We ask that you read the consent form before the interview and if you are comfortable with it, sign it and email it back to me. If you are having trouble understanding this form or have further questions or concerns after we have gone through it together today, I encourage you to speak with someone you trust (friends, family, staff at local immigrant centres). If you are not able to use email, we ask that you bring the signed copy to the interview or that you mail this back using the prepaid envelope addressed to the University of Manitoba that your clinician provided. You will be asked if you understood all the information in the informed consent form, whether you have any questions, and if you voluntarily agree to participate in this study, before we begin the interview.

Participant Unique Code Number: _____ (do not use a personal identifier)

Walk through the remainder of the informed consent form:

III. Explain the procedures to be followed

a. You will be asked to participate in an individual 60-minute minimum audiotaped phone or in-person interview. I will be interviewing you. During this interview, I will ask you questions about your thoughts, opinions and experience with genetic diseases, your views on genetic testing and to tell me about your recent experience with a genetic counsellor and/or geneticist. I may also take notes during the interview. The interview will be audiotaped and transcribed by the student researcher, and studied by the student researcher and the research team. You can choose not to answer any question and stop the interview at any time.

b. The data from my analysis of all of the participant's interviews will be summarized into a report. I will then contact you and the other participants by telephone for a second interview to confirm our results. I will invite you to provide your feedback on the telephone or to attend a group interview (this interview could be 60- to 90-minutes). I will contact you to schedule your one-on-one telephone interview or to schedule you for the group interview.

c. Following final data analysis, an informal copy of the report will be available to you if you wish to see it.

IV. Explain the presence and purpose of recording equipment

a. I will be audiotaping our interviews so that I do not miss anything. Afterward, each interview will be transcribed (by me) so that I have written copies of my conversations with participants. I may also take notes while we are talking.

b. Neither the tape and notes, nor the transcripts, of the interview, will have your name on them. They will be labeled with a code that will be connected with your name on a separate sheet of paper that will be kept in a separate locked file from the interview information. Any potential identifying information that might come up as we talk (such as names, birthdays, or addresses) will be not be entered into the transcript during the transcription process, the coded ID number or a pseudonym will be used. The pages and files with your name and contact information will be destroyed 10 years after the study ends. I will not be sharing your individual answers or your personal information with anyone other than the researchers associated with this project. However, because of the nature of this study and its association with a particular group of individuals (immigrants), it is possible that some of the information you provide may identify you, even with your name removed. I will also conduct a group interview after the original individual interviews to ask for your help in validating the themes that have been found. These group interviews will reveal your identity to other participants. Should you wish to not participate in this group, you will have the choice to have your second interview conducted by telephone.

V. Explain the risks and benefits of this study

a. The risks to participation in this study are minimal; speaking about your experiences may cause distressing thoughts and feelings. If you chose to participate or not participate, it will have no

affect on your current or future genetic counselling appointments with the medical genetics program. If you would like to speak to counselling services for further support I can help you arrange this. You can also talk to our contacts at the local Immigrant Centres for support.

b. It is possible that some of the information you provide in the interviews may identify you even when your name is removed. This may be from the interviews we have one-on-one or from the follow-up group interview. If you do not want to participate in the group interview, your feedback can be collected over the telephone in an individual interview.
c. There will be no direct benefit to you for your participation in the study. We hope that in the future, information obtained from this study will help us gain a better understanding of immigrants' use of genetic counselling services in Manitoba.
d. An alternative is to not participate in the study. You can also choose how you would like to be quoted. I will go over that next.

VI. Privacy and confidentiality

a. 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. Transcripts, interview notes, and audiotapes will be labelled with a coded ID number, which will be assigned to you upon enrolment into the study.

b. A professional interpreter may be present during the interview. Interpreters are hired through the Winnipeg Regional Health Authority Language Access service. The interpreter would not have access to any research or personal health information beyond what you say in your interview.

c. Some people or groups may need to check the study records to make sure that all the information is correct. All of these people have a professional responsibility to protect your privacy.

These people or groups are:

- The Health Research Ethics Board of the University of Manitoba is responsible for the protection of people in research and has reviewed this study for ethical acceptance
- Quality assurance staff of the University of Manitoba who ensure the study is being conducted properly

d. If you agree to participate in this study, I will also ask for your verbal permission to confirm three pieces of information from your Genetics & Metabolism medical records: Your name, your unique Genetics chart number (this is called a Kindred number), and the date of your appointment. These three pieces of information are collected to ensure that your appointment with the Genetics & Metabolism Program meets the criteria required for you to participate in the research study. They will not be published or used in the study in any other way without your explicit written permission. These Genetic & Metabolism Program medical records are separate from your hospital chart but may include information from any medical visit, thus, we cannot guarantee that no other medical information will be seen by the research team. We do guarantee that all of your information will be kept confidential. I will use your verbal consent for the purposes of verifying this information for study eligibility only. Your consent to

participate in the research study requires that I receive your signed written consent form. Do you give verbal consent for me to do this?

e. We may wish to quote your words directly in reports and publications resulting from this. Are we able to quote you? How would you allow us to quote you? Please refer to page 4 of the consent form under permission to quote.

SAFETY

Your confidentiality is important and will be kept private in the way you indicate on your consent form. Your confidentiality may be broken if you describe one of the following:

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

VII. Cost and payment

There is no cost to you to participate in the study, other than the time it takes to conduct this interview and the expense for you to travel to and from the interview(s) if you chose the in-person option. You will receive a $15 gift card to a major box store or grocery store of your choice for participation in the research study as a gesture of appreciation for your time and money spent to travel to the interview.

VIII. Voluntary participation and withdrawal

You may withdrawal from this study at any time. This decision does not affect your medical care with WRHA Genetics & Metabolism now or at any point in the future. If you withdraw from the study (**within the 3 months following your first interview**), the data that you provided will be destroyed.

Please contact me (Ashleigh Hansen) to tell me that you would like to leave the study.

Any questions so far?

Are you interested in participating in the study?

When would be a convenient time to schedule the interview?
Date and time for interview: _____

Phone _____or in-person_____

You will receive a $15 gift card to a major box store or grocery store of your choice for participation in the research study as a gesture of appreciation for your time (and money spent to travel to the interview, if

in-person). We can provide gift cards to Walmart, Superstore, or another major box store of your choice. Which do you prefer? _____

VIIII. Contact and confirm

How can we best contact you?

Please sign this form in advance of the interview, keep a copy for yourself, and send a signed copy to me, the student researcher. You can email, mail or bring a signed form to your interview. Emails can be sent to XX. Do you have a way to copy this form yourself? If no, I can provide you with a copy at the interview.

Participant Unique Code Number: _____ (do not use a personal identifier)

Data Collection/Capture Sheet

(To be used with Master List)

Exploring Immigrants' Perceptions of Genetic Counselling:

Data to be collected on paper: Yes ☐ No ☐

Data to be entered directly into computer spread sheet Yes ☐ No ☐

Data Elements to be collected:

Demographic data and identifiers

Reason for referral: _____

Age: _____

Gender: _____

Country of origin: _____

Length of stay in Canada: _____

Immigration status: _____

Mother tongue (first language you spoke): _____

Marital status: _____

Ethnicity (Ethnic group): _____

Religious background: _____

Education level: _____

Employment status: _____

Income level: _____ (would you be willing to tell me something about your income, the total income you receive from all sources before deductions)

Number of people in household: _____

Social supports (family, friend, community groups, church, other services):

_____

_____

Financial supports (benefits, government assistance, investments, other):

_____

_____

Data elements verified from chart:

Reason for referral: _____

Date of appointment with WRHA Genetics & Metabolism Program:

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Previous appointments with WRHA Genetics & Metabolism Program:

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Interview notes:

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Participant Unique Code Number: _____ (do not use a personal identifier)

Interviewer reflexivity notes:

Expectations: _____

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Biases: _____

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_____

Before Interview -

Feelings:_____

_____
_____
_____
_____

After Interview -

Feelings:_____
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Other things that happened during day:

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Participant Unique Code Number: _____ (do not use a personal identifier)

Other things that happened before/during/after interview:

_____
_____
_____
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_____

Other:

_____
_____

Data collected by (printed name and signature): _____

Date Data collected: _____

Time of interview: _____

Research Participant Master List

(The master list will be locked in a separate cabinet from the Data Collection/ Capture Sheet)

Protocol Title: Exploring Immigrants' Perceptions of Genetic Counselling

	Name of Participant	Kindred Number (K#)	Method to contact (telephone/email/mailing address)	Unique participant code
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APPENDIX III: PRIMARY INTERVIEW GUIDE

As you know, I am interested in your experience with genetic counselling as you experienced it. Let's start with when you/your [relative] were first referred…

Prompts:

- *Why were you referred?*
- *Did you know about genetic counselling before your referral?*
- *Is there a situation that stands out for you that you might want to talk about?*
- *How did you feel about genetic counselling after your appointment compared to before your appointment.*
- *Why do you think someone would want to talk to a genetic counsellor?*
- *Was the information helpful?*
- *Did you have questions for your genetic counsellor? Were they answered?*
- *Did you feel understood? Could you trust your genetic counsellor?*
- *Does the genetic counsellor understand your needs?*

Tell me about any challenges that you experienced.

Prompts:

- *Were there any challenges before, during or after your genetic counselling appointment? (e.g. transportation, language barrier, long wait time for appointment)*
- *What was done to help?*

I am also interested to know about your experience of genetic counselling in your home country…Tell me about your experience before coming to Canada.

Prompts:

- *Where you ever referred to talk to a medical professional about a genetic disease in your home country?*
- *What was done for the genetic disease in your home country?*
- *Tell me about what has been different or the same in Canada as compared to your home country.*

I'd like to know more about your experience as a person affected with a genetic condition [or caregiver of a person affected with a genetic condition]...Tell me about your experience living with a genetic condition/caring for your [relative] with a genetic condition.

Prompts:

- *How does living with [caring for a relative with] a genetic disease affect your daily activities at home and in your community?*
- *Who do you turn to if you need help? Family, friends and/or community?*
- *Tell me about what has been different or the same in Canada as compared to your home country.*

Was genetic testing discussed about your appointment and if so, how do you feel about the genetic testing services discussed?

Prompts:

- *Is genetic testing important for you?*
- *How would you feel about [your relative] having genetic testing?*
- *How will/did you make your decision about genetic testing?*

How could genetic counselling be most helpful for you?

Prompts:

- *Is there anything that could be done to make it easier to live with a genetic condition?*
- *What would make it easier to get the help you need?*
- *What could be changed to improve your experience with genetic counselling services?*

Is there anything else you would like to discuss today?

Demographics

Reason for referral? (General, e.g. a child with disability or pre-natal testing)
Age
Gender
Place of origin?
Number of years in Canada?
Immigration status?
Mother tongue?
Married?
Religious belief/ethnic background or group?
Education level
Employment status
Income
Number of individuals living in household/family members?
Social supports
Financial supports

***Suggestions for improved service**

APPENDIX IV: SECONDARY INTERVIEW GUIDE

The Results:

Theme	Summary
Communication is deeper than language	Overall, all participants said that they were happy with the genetic counselling service they received. Most people talked about 5 different parts of the appointment: the style of the counselling (it felt like an open conversation and the counsellor did not push their own views and this made people feel supported and understood), the appointment was thorough (the counsellor covered a lot of information and took their time with the details), most of what people wanted to learn was discussed, (and the information was useful and/or important). Some people still felt rushed in their appointment, and some were not told all the information that they wanted, meaning they left the appointment with questions. Some people feel confused about the plan for the appointment and/or the follow-up. Usually participants understood the information, but sometimes if complicated terms were used, people did not understand. Language barriers were generally not a problem, except when people try to contact the genetic counsellors in follow-up. This might be because people do not know how to connect with an interpreter. Most people trust their genetic counsellor and the Canadian health care system in general. Some describe the genetic counsellor as knowledgeable, honest and allowed the patient to be heard. Some people said that there were no concerns with the appointment; if there was a reason to be unsatisfied it was usually when a diagnosis or treatments could not be given. Still, most people seem to say the experience was good overall. Some times people do not say exactly what they mean, or they do not share the whole story (in the appointment and maybe in the interview). Maybe this is because it is hard to remember everything that happened in the appointment or interview, or answer the interview questions because it puts people on the spot and it's hard to know what to say, or maybe because they do not feel that they can completely trust the genetic counsellor, or they do not want to disrespect a person in authority. Some people may be able to verbalize areas for improvement where as others may not.

Health literacy, awareness of genetic counselling and education.	Most people in the immigrant community had not heard of genetic counselling before their appointment. Most had no prior experience with genetic services in their home countries as they did not need the service and/or genetic testing/counselling or screening does not exist there. Some knew about genetics and what inherited diseases are, and some did not. Some had an idea that there may be doctors providing genetic counselling services in their home country and some did not know if there was or was not. Knowledge about genetic counselling or understanding about genetics was usually influenced by what previous experiences people had with health care systems in their home country. For example, some had visited doctors but were not referred to Genetics (even though it is possible that there is a genetics service in their home country). Some people knew about genetic testing in a home country, which might have looked a lot different than in Canada (costs, and the way the results were given). Some had knowledge about genetics from previous work experience. Some thought there was no need for genetic counselling or testing at the time because they understood that it was for answering questions about risks in a pregnancy or for future children. Some pointed out that the culture of Canada was more interested to know the cause of disease, which was not as important to people back home, something that may also have limited why people do not know about genetic counselling. People tended to know more about genetic conditions if there was a family/friend with a condition, they knew about the medical system in their home country, and/or their knowledge may have been related to having more education. Some individual would come to genetic counselling appointment having done reading before to be prepared and ask questions, some people did not do this. Many people think it is important to educate about genetic conditions and increase awareness of the existence of genetic counselling services within the immigrant community. Doing this would be important for helping friends and family, and reducing fear and stigma of genetic conditions and disability.
Support systems are important but difficult to cultivate	Support systems are very important to people, especially in starting a new life in Canada and with the possibility of having to manage a genetic condition or disability in a child, or the reality of living with a genetic condition in himself or herself or a child. When talking about support systems, many people said that there was no support for them. Most of the time people are referring to their being no family members in Canada. People described how they see their support system and who they would prefer to relying on with the closest relatives first, then friends, then community members and church groups and lastly community services where people are paid to help (which might have been helpful but was least preferred). The support system served as emotional support for all participants, and could also be more physical support from a partner, especially if providing childcare. For those with a spouse, the support network added the stability of financial income, although this could add strain because this would mean the other partner would have to look after the family on their own. Support systems were also helpful for people to make decisions (for example people talk to husbands about the genetic testing or screening options). For adults with a genetic condition/disability, support networks could also contribute physical support to help make living life with a genetic condition a bit easier. Some saw friends and family as important parts of their support network, and some said friends in Canada were not long-standing like their friends back home, so they did not rely on them as much. Some thought that even if there were family or friends in Canada, they would not bother them since

	people have very busy lives in Canada. Some saw the genetic counselling service as a way to get support emotionally and further support with the genetic condition. Genetic counsellors might educate schoolteachers about genetic conditions, provide parents with information about what to expect for their child with a genetic condition and how to help them. When talking about community supports one person talked about how they would not want to feel like a burden by using these supports (something they thought was a cultural difference). With these comments in mind, it is possible that there is a significant lack of supports that people are willing and comfortable to use.
The art of science and religion	People understand the cause of a genetic disease based on what they know and can makes sense of. People might know and trust Western medicine/science, and be comfortable with this practice. Others might rely on their religion/faith and culture to explain why a genetic condition has happened. If people do not understand the answers Western medicine gives, they might rely on what they already know or are used to, such as spiritual causes. Some people might explain the cause of genetic disease as a *combination* of these different factors, meaning that they might appreciate traditional and spiritual beliefs common in their home country and Western medicine *at the same time*. People might also think the cause of disease can be explained by Western medicine, but might find peace and comfort in their faith. However people understand the cause of disease, people were still okay with Western medicine since they showed interested in having genetic testing (although one person pointed out that non-faith health care providers might pressure people into procedures they were not interested in). Those who were able to cope or manage with a diagnosis seemed to do so because they were satisfied with the answers they received from the genetic counselling appointment, and the cause of disease made sense to them. If they did not understand the cause, it was harder to cope. Not understanding might have been because the information the genetic counsellor gave was from a Western medicine perspective and the participant thought the disease was caused by another reason. Some people can appreciate Western medicine but acknowledge that there are limits. They might turn to God for help in dealing with the situation and making peace, but of course, this is related to each person's own level of faith. Also, having faith does not mean that you are not doing everything you can to have a good outcome (faith does not mean being complacent). One person talks about how culture might affect someone's interest in genetic counselling. They say that back home there would be no need to stress about something you could not change (such as a child born with a disability), that you might pray for a good outcome, and that there were more important things to care about like food and survival. People back home may not be interested in the cause of genetic diseases as much as people in Canada, and participants might feel that there is a culture of "over-testing" in Canada.
Living with a genetic diagnosis	Living with a genetic condition or disability was described as being a challenge and appeared to be more challenging because there were limited support systems in Canada (such as family support).

as an immigrant has its challenges	Adults with genetic condition – adults with a genetic condition talked about how they might have been limited in what they were able to do physically, or that it affected their desired lifestyle in some way. Although the condition was seen in a negative way, it was still important to accept the condition and move on with life. People with a genetic condition wanted to educate their family members about the condition and the risks to have the condition. They wanted to be able to do everything they can to make the lives of family and friends (at risk for or with the condition) easier. Children with genetic condition – parents of children with a genetic condition or disability often felt sad about the future for their children, and they felt responsible for that future. Some parents even blamed themselves for causing the condition in their child, and some felt hopeless about the situation, hoping that the genetic counsellors could provide answers about the diagnosis and cause of disease. Having a child with a disability was difficult to balance with an already busy life. Parents talked about doing special things for their child like specialized feedings, physiotherapy, and repeatedly teaching or training behaviours and skills. Doing these extras can become very exhausting and frustrating for parents. Parents might turn to genetic counsellors to give information about what developmental milestones to expect in the future and how to teach a child with developmental delays. Pregnancy at risk for a genetic condition – expecting parents who received the news that there was a risk for a genetic condition in their pregnancy talked about genetic conditions and disability as a mostly negative thing. The genetic condition was seen as negative for a number of reasons including: heartbreak and suffering for the family and child, seen as not normal and/or a burden. Parents said that some genetic conditions are worse than others, and in some cases the baby might die very young which was upsetting. Some parents were concerned because they thought that the child would require a lot of extra medical visits which would be a challenge with other children in the home and a partner who has to work to pay the rent/mortgage. Some people thought that people in Canada had a more positive view of a child with a disability, since parents may use genetic testing and know their child has a disability before birth, thus *choosing* to keep the child. Parents talked about feeling love and responsibility for their unborn child already, which made waiting for the results of genetic testing very stressful; most people did not want to think about the possibility of a positive (affected) result. Some relied on their faith to cope with the possible diagnosis. But, coming to terms with this possible diagnosis might not have fully happened because parents received a negative (not affected) result fairly shortly after hearing the news. Experiences of the medical system in a home country – Participants talked about there being significantly less support for people in hospitals in a home country, suggesting parents hard to care for children all day and night. People were surprised when they were offered all necessary appointments and referrals in Canada, maybe because previously receiving all the referrals they wanted had been a challenge in a home country. For some people, getting a diagnosis in a home country took a long time or never happened. Some talked about how this was because the health care system has less advanced technology and/or health care providers or doctors are not as knowledgeable as those in Canada. Some people described having to act as your own doctor when dealing with the health care system in their home country, knowing what to look for and going to get that tested. Sometimes, when people were told their condition might be genetic, it meant that they did not receive any

	treatments or medications, even if there might be ways to help someone with such a condition. Overall it seemed as though most people felt they could trust and rely on the Canadian health care system more than the medical system in their home country. Many talked about having to pay for medical services in a home country and expecting they might have to do the same here. Those who have this expectation in Canada might not seek genetic counselling because of the concerns about cost (which likely do not exist). This might be something worth telling immigrant communities about. Other challenges - The most commonly discussed challenges included dissatisfaction with long wait times. Long wait times could be quite stressful, especially when most were not used to long wait times in a home country. Other less commonly mentioned issues included frustration with the process of scheduling an appointment with a genetic counsellor or how the session was held, concerns about the privacy and storage of genetic information and test results, transportation and running out of essential prescriptions. Some people were unhappy with the process of the genetic counselling, for example, one person describe that she received the genetic counselling while she was on the hospital bed during her ultrasound. This was disorienting since she felt that she was already there for the testing and did not understand the process. The participant talked about changing the process to allow for her to go home and think about the options the genetic counsellor gave her. In terms of concerns about privacy and the storage of information, one person mentioned that some people might avoid genetic counselling altogether because they would not want to give their blood/DNA. This might be due to general distrust of organizations (potentially governmental) or people might not understand the reason for doing the testing because of a lack of education or fears. Some people might come to genetic counselling and be agreeable about the process but never go for testing because of these fears.
Why I wanted genetic counselling/testing	Although some individuals were skepitcal about the need for genetic counselling or testing, consistently all individuals wanted more information about the condition, the risk to pass the condition on, prognosis, or a diagnosis, as most people felt that knowledge was power. Genetic testing in the context of adults living with or at risk for a genetic condition - In the event of an adult, individuals wanted an answer or diagnosis because understanding and information were seen as important. Finding a diagnosis appeared to be most important for the possibility that there may be treatment or management that could help control symptoms and prevent progression of disease. For one participant genetic testing in the pre-symptomatic context (before illness) was useful for preparing for the future and screening and surgeries were kind of like treatments for were for those already effected. The choice to have genetic testing might have also been influenced by experiences of genetic conditions in the family, such as many people affected with cancers. The individuals affected with genetic conditions in this study held contradictory views about genetic illness and their understanding of genetic testing. They often spoke about the condition with some level of complacency, describing that they had to unconditionally accept the disease and the outcomes, thinking there was nothing that could be done to change the situation. At the same time they looked for treatment and management options. This discrepancy may have been the result of cultural differences that promote this style of coping and acceptance. It may also be a response to being told there was nothing that could be done in their home country and hoping that the Canadian system

	may have more options. As a result, understanding the cause of the condition was seen as less important because ultimately, providing a label for the condition was not seen as changing the outcomes or lifestyle for those affected with a genetic condition. Some participants pursued the genetic testing because of the advice of a referring doctor. Some people might not know everything that a genetic diagnosis provides, which would answer many of the questions they had. Further education about what a genetic diagnosis provides might be helpful in increasing awareness about genetic testing. Genetic testing is the context of a child affected with a genetic condition - In the case of a child who is affected, these participants wanted a diagnosis, but more so, there was a desire to understand the *cause* of disease. Some wanted to know how to prevent a condition from happening again in another child, to better understand and provide treatments, to share risk information with family members or plan for another pregnancy. Parents seem to have what we are calling "parental responsibility", a desire to do everything in their power to help their child and future child. Knowing more about the cause of the condition was also seen to provide peace of mind to the parents, which likely represents a way for the parent to reduce self-blame and guilt about causing the illness, and may allow for the parent to cope with the diagnosis. When a diagnosis was not identified or the parent did not completely understand the cause of the illness, parents appeared to become somewhat frantic and continued to pursue answers, they hoped for treatments and may have blamed themselves for causing the condition. It would be helpful if genetic counsellors could be clearer about what could be done to help and what to expect in the future. Genetic testing in the context of a pregnancy at risk for a genetic condition - most expecting parents wanted a diagnosis and/or or what to anticipant in the future. People wanted to be prepared for the birth of an affected child and/or avoid the birth of an affected child in the future. All parents decided to have some kind of testing in the pregnancy to understand this risk. Parents talked about the burden of having this new life in Canada and having to look after a child with a condition or disability, and how this would be very challenging on top of everything else. Some participants describing that genetic counselling provided answers and reassurance, and the genetic testing provided peace of mind. For one person, it seemed that just having the knowledge about the future was powerful and gave her control over the situation, since it allowed for her to take action if needed. Some people felt that the risk numbers for testing in pregnancy were too low to bother, but people were still interested in having genetic testing for the peace of mind. Some people talked about having their mind made up about genetic testing before they arrived to their appointment, and they felt that the counselling was delaying them from the testing they wanted. Some people wanted testing because they felt they could trust the results of from the Canadian medical system more than those in a home country. Overall genetic testing was seen as useful because most people felt that knowledge was power, and many wanted to share the idea of genetic counselling and testing with family members and friends.
Suggestions to improve service	1. Increasing awareness and education about genetic counselling services and genetic diseases. - Educating newcomers empowers them to share important information about genetic conditions and available services to others such as

	friends and family as they see fit, allowing them to help others. By increasing awareness and sharing information, genetic counsellors and immigrants together might help to reduce stigma about the cause of genetic disease, inform newcomer populations about aspects of the counselling that is available to them (what to expect), and answer questions about genetic testing, privacy and security of information. Anticipating and speaking to potential concerns for this population might increase interest in this service. 2. Immigrants describe that there is very little support. Genetic counsellors should assist in strengthening support networks, help to increase culturally relevant support systems and increase the provision of appropriate referrals, while being mindful that not all types of support are seen as acceptable to all new comers. 3. Reduce wait times. - The sensitive nature of starting a new life and working with limited supports, coupled with expectations of a medical system from a home country, may heighten the experience of a wait time as considerably negative. 4. Include the patient in planning. - Be more clear when giving information and answering questions – directly asking participants about their understanding and if the explanations make sense and are relevant to the patient. Be mindful that patients may not feel comfortable asking questions or saying exactly what they mean, as it may be hard to conceptualize what questions to ask or what to say, or they may feel the need to respect and follow the guidance of professionals. Be transparent about the plan for the appointment and follow-up to help set realistic expectations and avoid confusion. 5. Create centre specific protocols for patients who require interpretation services. – Immigrants requiring interpretation services might not be able to re-contact providers to ask important follow-up questions as a result of not knowing about the interpretation services available and ways to connect.

APPENDIX V: FIRST CYCLE CODING

First cycle coding generated the preliminary codebook which included 11 root codes with corresponding 47, sub-codes as listed. These preliminary codes were utilized in the generation of the final themes upon a second cycle of coding.

ROOT CODE	SUB-CODE	SUB-SUB-CODE
Challenges	Access to appropriate care	
	Language barriers	
	Support	
	Transportation	
	Wait times	
	Other (e.g. information safety, prescriptions)	
	No challenges	
Education	Knowledge is important	
	Knowledge of genetic condition	Knowledge of treatments
	Sharing or educating others and the ways to disseminate information	
Feelings	Calm/relieved/happy	
	Worry/stress	
	Confusion	
	Empathy	
	Guilt/blame	
	Sadness	
	Shock/disbelief	
	Trust or distrust	
Knowledge/awareness	Medical knowledge and knowledge of healthcare systems	Knowledge of genetic counsellor/counselling/geneticist

	Preparedness and planning	Patients may do their own research before their appointment
Parental responsibility		
Perceptions, understanding and thoughts about genetic testing	Knowledge/understanding of genetic testing	
	Reasons for genetic testing or counselling and the decision making process	Avoid or prepare for the birth of an affected child
		Looking for treatments/management
		Reassurance
		Understanding recurrence risk
		Wanting an answer or diagnosis
	The importance of genetic testing	Other screening tests are important
Perceptions or experience of a genetic condition	Genetic counselling in home country	
	Knowledge or feelings about diagnosis, prognosis or outcome of testing	
Religious/spiritual or cultural beliefs about life	Acceptance	
	Beliefs and values about family/relationships	
	Holding religious views alongside biomedical views	
	Non-biomedical causes of condition	
	Questioning biomedical treatment	
Respecting and acknowledging the immigrant community	Engaging the community	
	Intra-interview challenges	
	People can not speak for others	

Satisfaction	Satisfaction with the information received	
	Satisfaction with the thoroughness of the appointment	
	Satisfaction with the style of counselling	
	Unsatisfied or still have questions or concerns	
Other		

APPENDIX VI: SECOND CYCLE CODING

Second cycle coding generated the secondary codebook which included 8 codes as listed. These codes were further combined to generate the final 6 codes and participant-driven suggestions

Theme	Description
Communication is deeper than language	What leads a participant to report that they have had a positive experience with genetic counselling. Genetic counselling may be in direct contrast to the wide spread paternalistic approach to medicine that is still active across the world today. When does a patient trust their provider and what parts of the communication process increase success (depth of appointment, style of counselling e.g. non-directiveness, increased understanding). Although many may verbalize that they have had a positive experience, many were still left with information that they did not understand, questions that were not answered, or concerns that were never addressed. Some people may be able to verbalize areas for improvement where as others may not. The ability to verbalize this lack of satisfaction and provide explicit feedback may depend on personal expectations, knowledge of the system and what could be possible. Vocalizing these concerns may also be influenced by the power dynamic between clinician, research participant and student researcher, and the respect that most individuals have for those in respected roles such as medicine. These appointment challenges may be mirrored by intra-interview challenges for some. Furthermore, individuals from the immigrant community stress that each individual is quite different, in their thoughts, opinions, experience, background, such that you can not really speak for another person even if you might have an idea of their experience. Although key informants may provide a rich insight into a subgroup of the immigrant community, in order to respect the immigrant community you must appreciate this fact.

"I thought she was talking to a physician, I didn't know about a genetic counsellor": Health literacy, awareness of genetic counselling and education.	There may be a low awareness of genetics and genetic counselling services in the immigrant community. Individuals may differ greatly on their overall knowledge of health systems, yet, consistently most individuals were not aware of genetic counselling services prior to the referral process. Most individuals had no prior experience with genetic services in their home countries as they did not require the service and/or genetic testing or screening does not exist there. Here we describe the experience of the service or experience of the genetic condition without this service as it were in the home country. *May connect this experience to "why I wanted genetic counselling".* In addition to the low awareness of genetic counselling, there is a wide array of knowledge levels or understanding of genetic concepts. Some may have had knowledge before their referral, knowledge may increases as a result of learning about these concepts in the appointment., and still some may not be familiar concepts following their appointment. The concept of genetics may relate to an individuals education level, general knowledge of health systems, medicine, treatments, or what to expect. Some individuals stress the importance of preparedness and planning. Some people feel that it is important to be prepared with what questions to ask in their appointment. Some chose to go in blind. Perhaps there is a connection between preparedness and the different experiences that a person has had with their genetic condition, or perhaps there is a connection with their cultural experience. Never-the-less, some feel that information is so crucial that they should be sharing it with others, and they postulate different ways to educate others and disseminate information. *May or may not keep reasons why I think others should have testing or should be informed in this section, or move to why i wanted genetic counselling.*
Support systems are important but difficult to cultivate	The support system is created by a collection of spouse, family, friends, neighbours and community members including churches and social services (school programs, work placement programs, home care AND GENETIC COUNSELLING). Personal networks, cultural background and genetic concern impact whom individuals invite into their support systems and how they go about doing this. Sometimes it is difficult to achieve a support system that is seen as culturally appropriate, and in some cases the only support system available is a spouse. For some, there is great stress within their daily lives, which the student researcher wonders, is a support network of one other really enough? What happens if the spouse is too stressed to support you? Who supports the spouse? What can genetic counselling do to provide support both from emotional support in the appointment, to providing education to others, and with the referral process (one example is providing age appropriate developmental milestones for a child with DD). More than

	the role of the genetic counsellor is the role of the community – what other supports need to be developed to fill these gaps and help this community to feel appropriately cared for?
The art of science and religion	The perception, understanding or experience of genetic illness is a complex balance between knowledge of and trust in a biomedical illness model, and an individuals level of faith. Individuals may be balancing both a biomedical and spiritual understanding of illness, which can lead to varying levels of *acceptance* and a wide array of emotional responses. The decision-making process to pursue genetic counselling/testing along with satisfaction with the service are influenced by this balancing act between science, culture and religion. Individuals have varied descriptions of their perceptions and experience of genetic illness, including the expression of many strong feelings from patients and their parents. The coping strategy seems to be based on expectations, available resources (testing, answers, explanations, understanding) and prior knowledge (education, preparedness and planning, culture, religion).
Living with a genetic diagnosis as an immigrant has its challenges	The descriptions of living with a genetic disease, caring for another with a genetic disease or the concern and perception of the genetic disease. Here we provide a rich description of the lived experience. *This may also describe the contrasting experience with the health care system in another country (may also be found in health literacy, education and awareness of genetic counselling).* Individuals have intense emotional responses both positive and negative, including feelings of guilt/blame, shock, happy, sad, etc. **This theme may be merged with "we aren't that different, you and I", because we could contrast with what Canadians experience**
We aren't that different, you and I	Other challenges may be faced by both immigrants and Canada-born Canadians. Some differences however may be so stark, and may heighten the negative experience of that challenge. One example is that immigrants have to build a new

	life from nothing, a challenge that spills over into many areas of their lives. A challenge that Canadians do not have to face. *For example, the experience of calling you GC to ask questions is very difficult if you don't know how to or you can't speak English. Interesting to talk about the way a Canadian may percieve or experience this challenge, but then talk about why this is so much more of an issue for an immigrant....e.g. conspiracy and corrupt governments may cause a loss of trust in professional systems. Could tie into feeling of trust.*
Why I wanted genetic counselling/testing	Individuals have different perceptions and thoughts about the genetic counselling service, the counselling experience, why they wanted ultimately wanted to have genetic testing. The reason for wanting genetic testing is influenced by the individual who is ill, in the case where it is a pregnancy, most people wanted testing for avoidance or preparations for the birth of an affected child, or to provide themselves with reassurance. In the case of a child who is affected, most wanted answers as to why their child was sick. In the event of an adult, individuals wanted to understand the diagnosis, and wanted to know more about treatment or management. In some cases there was also a concern about passing their condition on to children. Consistently, all individuals wanted an answer or diagnosis as most people felt that knowledge was power. Trust is a major undertone, since most people seem to trust the Canadian system a lot, and a lot more than the system of their home country. As a result of this intense trust, individual may have different experiences with decision making and the utility of non-directiveness. In some ways individuals look to their provider for direction, which can be helpful for some but not all. *This may include "knowledge is power" kind of statements. But education of others is "health literacy, education and awareness of genetic counselling".* *Also includes information about how well someone understands the idea of genetic testing.* *Includes reasons for referral.*
Suggestions to improve service	In most cases, suggestions to improve the service were not made. Although it does appear that there are significant challenges or areas for improvement. It is possible then that individuals may not be able to quantify their experience into a suggestion, they might not feel they know the system appropriately to make a recommendation, or there may be

	the feeling of respecting the health care professionals such that a suggestion would be inappropriate. This section includes any explicit or implicit suggestions made by participants, or gleaned from the data by the student researcher.