EXPLORING IMMIGRANT FAMILIES’ PERSPECTIVES AS
THEY ACCESS AND UTILIZE HEALTHCARE SERVICES

by

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Abstract

Many health care professionals may be unaware of the range and nature of issues that immigrant families who have a child with a disability or chronic health condition (CHC) must address. Anyone may face challenges accessing and utilizing healthcare services or supports. However, barriers facing immigrant families may be varied and multifaceted and be compounded by concurrent challenges of establishing a life in their new home. In addition the perceptions of disability among immigrant groups can have a profound influence on how these families care for their child who has complex care needs. The aim of this qualitative study was to explore what barriers exist for immigrant families as they attempt to access and utilize healthcare services or supports to manage their child’s complex healthcare needs. Data gathered in this study through indepth interviews with 10 caregiving parents of 13 children with complex chronic health conditions, builds upon the limited knowledge and literature that exists about immigrant families’ access and use of the healthcare system for their child with a disability or CHC. The analysis identified key concepts that characterize the experiences of these families. Selected interview vignettes demonstrated the following processes: a desire for a better life and healthcare; experiences with accessing services and the families’ desire for autonomy and independence. With further reflection and interpretation of the data two specific concepts emerged: creating a future and personhood. These concepts served to provide a deeper understanding of immigrant families’ lives. It is hoped this information will further inform professionals’ practice as they collaborate with the families to meet the children’s needs, plan care and strive to achieve good health outcomes for the children while also promoting wellbeing within the family unit.
Preface

Ethical approval was obtained for the purposes of this study from the University of British Columbia Behavioural Research Ethics Board. The certificate number of the Ethics Certificate obtained was CW11-0246/H11-01612.
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Chapter 1 Introduction

Medical, technological and social advances have improved the lives of children with disability or chronic health conditions (CHC). Children born prematurely or with numerous health concerns, previously would not have survived infancy, and are now living well into adulthood. Consequently their care is being transferred into the community and their care needs met by their family with their homes becoming places of care (Dyck, Kantos, Angus & McKeever, 2005; Yantzi, Rosenberg & McKeever, 2006). These children have disabilities or CHC resulting in special needs that “require significant additional educational, medical/health and social/environmental support – beyond that required by children in general – to enhance or improve their health, development, learning, quality of life, participation and community inclusion” (Ministries for Health Services, Education & Children and Family Development, 2009). In British Columbia, there are many supports and services available to assist families who have children with a disability or CHC. However, these supports and services are grounded in mainstream Canadian western values which may or may not align to immigrant families’ values and beliefs (Daudji, Eby, Foo, Ladak, Sinclair, Landry, Moody and Gibson, 2011). These factors could influence perceptions of disability, healthcare decisions, service access and utilization. Healthcare providers may be faced with multifaceted situations as they work with different immigrant families. As Wang, Rosenberg and Lo (2008) discovered in their study “language, culture and ethnicity are intertwined in a complex way to influence the choice of healthcare providers and health management strategies in the host society” (p.1419). Therefore, it is important for healthcare providers to gain a
better understanding about what influences immigrant families’ decisions as they seek to access care and manage their child’s health complex health condition.

**Background**

**Immigration in the Canadian Context**

Canada is a country built on immigration with a reputation for supporting pro-immigration policies and, through the application of specific selection criteria tries to admit healthy immigrants (Beiser, 2005). In fact, due to the selection process and medical examination immigrants can be healthier than their Canadian born counterparts. Refugees are also admitted into Canada, though this group can potentially be in poor health due to the hardship they have suffered prior to their resettlement (Beiser, 2005). However, once these immigrant and refugee populations have arrived in Canada inadequacies in immigration and resettlement policies can place their health at risk as they try to access and use health care services. It then falls to the provinces to try to identify and meet their healthcare needs in an effort to restore or keep the new Canadians healthy (Beiser, 2005). Many immigrants are selected to live in Canada based on numerous factors such as education, job skills and their age. These attributes are seen to predict individuals’ capacities to contribute to Canadian society subsequent to migration. Such attributes make it more likely that families will have access to employment and such associated benefits as the opportunity to settle in neighborhoods that have safe, affordable housing, access to recreational facilities, and access to primary healthcare services. While immigrants elect to apply to settle in Canada refugees may have come to Canada involuntarily; and face separation from other family members, loss of possessions, wealth and status. Many refugees may bring with them traumatic histories
which can have a significant impact on their physical and mental health, in fact many refugees are in poor health on arrival. And this population may be particularly at risk of poor health outcomes. And, like many of their immigrant counterparts are unfamiliar with the Canadian healthcare system and struggle to navigate the complex system and do not to seek care and treatment especially if they feel it will negatively impact their refugee claim (McKeary and Newbold, 2010). However, it may be argued that immigrants and refugees are not the only vulnerable populations living in Canadian societies and struggling to access adequate healthcare. Lynam and colleagues (2011) discovered through their research in Vancouver’s inner city, that families with multiple forms of disadvantage may lack the knowledge or skills to navigate the healthcare system in order to “follow up on an referral, enact recommended treatment and /or clearly present their concerns about their child to healthcare providers in order to initiate treatment” (p. 42).

Canada’s immigration program is based on the Immigration and Refugee Protection Act (IRPA) and its regulations (Citizenship & Immigration Canada, 2011). The Immigration Act has historically been framed as a strategy for ensuring that Canada’s economic and cultural development will flourish. As the policy has been revised over the years it has sought to ensure that immigrants are not a burden on the Canadian society rather it is an expectation that foreign nationals (other than refugees) have the ability to make an economic contribution through employment or their own

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¹ When I undertook this study, refugee claimants were eligible for particular health care services. However, in 2013, the Canadian government restricted their access to healthcare coverage which poses ethical challenges for clinicians and considerable financial and emotional burden on families. At the present time (January 2014) this decision is being challenged I court as unconstitutional but there has been no ruling. In my study I have included both immigrant and refugee families with children with complex health care conditions.
supports. There are three main categories which allow entry into Canada: reuniting families, contribution to the economic development of the country and protecting refugees. A fourth category used in exceptional circumstances when residency is required for humanitarian and compassionate grounds not covered under the legislation.

In 2011, 248,748 people entered Canada as immigrants. Of this number 52,868 were children under fifteen years of age. The majority of immigrants come from Asia and the Pacific: with the second largest group arriving from Africa and the Middle East. This means that many immigrants have to orientate themselves to a new language, as well as different day to day traditions and social systems such as health and education. Most immigrants settled in Ontario (40%) with Quebec (20.8%) and British Columbia (BC) (14%) being the second and third desirable places to settle, in addition 11.8% of immigrants were unable to speak French or English (Citizenship & Immigration Canada, 2011). Under the IRPA the family class allows Canadians to sponsor their close foreign national relatives so they can enter Canada. This group can include spouses, dependent children, parents and grandparents.

**Disability in Canadian and International Contexts**

The United Nations Convention on the Rights of Persons’ with Disabilities defines people with disabilities as “those who have long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (as cited by Statistics Canada, 2006). In 2006, Canada’s last national survey of people with disabilities discovered 202,350 (3.7%) of children between ages birth to 14 years old had an identified disability. According to Disability in Canada Profile (2006) “the most
common chronic conditions that result in disability are asthma or severe allergies, autism, cerebral palsy and heart conditions or heart disease” (pg. 9). For children under 5 years of age Statistics Canada categorizes disability into 4 categories which include: hearing, vision, developmental delay and chronic health conditions (Statistics Canada, 2006). In 2012/13 (fiscal year), 4,826 children with a disability or CHC attended BC’s tertiary care centre for child development and rehabilitation and 1,779 children around BC received outreach services from this centre (Provincial Health Services Authority factsheet, 2013).

While the statistics Canada definition and data provides insight into the prevalence of disability among children, there are other definitions for disability. For example the International Classification of Functioning, Disability and Health defines disability as “an umbrella term for impairments, activity limitation and participation restrictions. Disability is the interaction between individuals with a health condition and personal and environmental factors” (World Health Organization (WHO), 2003). And it is further suggested that “disability is extremely diverse” (WHO, 2003). However, how disability is accepted or understood by a person’s family or ethnic enclave will affect how a person with a disability is perceived by their family and the larger community (Daudji et al, 2011). The implications of this are expanded upon by Groce (2005) who has observed that when an immigrant family maintains an ethnic heritage different from the mainstream society, acknowledgement needs to be given to these differing views and beliefs if health care professionals are to offer appropriate services and supports.

Within families, children are reliant on others to meet their health care requirements. Ultimately it falls on the parents or other guardians to identify, understand and meet the children’s healthcare needs. However, are the parents at a disadvantage to
address their child’s complex issues if the parents do not understand their child’s disability or CHC in the context of the mainstream society? Consequently as professionals we need to consider if this creates a barrier to children receiving appropriate services or supports and lead to poor pediatric health outcomes. When examining the adequacy of healthcare in all countries, the WHO (2003) confirms that people with disabilities tend to have decreased access to healthcare services leading to unmet healthcare needs compared to people without disabilities. The WHO has identified several barriers to accessing services that include lack of appropriate services for people with disabilities; transportation; inaccessible healthcare buildings and facilities; inadequate skills and knowledge of healthcare professionals that results in many people reporting being treated badly or being denied care. Within the Canadian context, these identified barriers may exist for many people with disabilities however there are other barriers which affect all members of society regardless of ethnicity, disability or health concern. These barriers include reduced healthcare funding, a lack of healthcare professionals and inability to fund closer to home initiatives, to name a few (Peter, 2004).

**Understanding the Canadian Healthcare System**

The Canadian healthcare system operates under provisions of the Canada Health Act which ensures most residents\(^2\) will have access to healthcare services (Romanow, 2002). However as with many systems inequities exist that result in many people struggling to meet their health care needs. The healthcare system within BC is no exception: it can be complex, hard to navigate and difficult to access or utilize the many services designed to help people maintain or improve their health (Gagnon, 2002). When immigrant families have children with complex health needs a detrimental effect on

\(^2\) Including citizens, landed immigrants and as previously noted in some circumstances refugee claimants.
health outcomes can exist not only for the child but also the parents as they struggle to make sense of a new health culture and overcome barriers to services. As Gagnon (2002) explains “difficulties navigating the system are not unique to newcomers but are compounded by language and cultural barriers and the newcomer’s expectations, which are usually based on experiences with the system in the country of origin” (p.9).

My experience from speaking with immigrant families during clinic appointments is that they have come to Canada in search of a better life for their families. When children with a disability or chronic health condition are members of these families, the parents have expressed a belief that their new home will possess a cure for their child’s life-long health concerns. As a clinician practicing within a pediatric clinic, I have witnessed firsthand what impact the difficulties navigating the Canadian healthcare system can have on these families as they attempt to access and utilize services. These observations have prompted me to undertake this research in order to generate understanding that may be used to inform other clinicians practice as they provide services and support to immigrant families who have children with disabilities or CHC.

Theoretical Perspectives in Addressing Barriers to Healthcare Access

According to Raphael (2006) social determinants of health are “specific mechanisms by which members of different socio-economic groups come to experience varying degrees of health and illness” (p.116). Raphael’s more recent work (2010) highlights several social determinants that are experienced by parents and indirectly influence their children’s health. These determinants include: parental education; employment and working conditions; unemployment and employment security; social safety net and social exclusion. Subsequently these determinants may result in a family
encountering: food insecurity, poor quality housing and lack of responsive healthcare services, all of which will have a direct and negative effect on a child’s health. In order to achieve a socioeconomic status which will have a positive impact on a person’s health and wellbeing, people need to be able to improve or access influencing factors such as education and employment opportunities. As Bolaria and Bolaria (2002) explain “children in low income families are less likely to have access to health services, particularly services that are not socially funded such as dental care and eye care” (pg. 294). Therefore an inability to sufficiently acquire a certain socioeconomic status could contribute to poor health outcomes. An idea supported by Anderson (2000) who suggests “it is not only healthcare reform and delivery of healthcare services that are at issue, but also the socioeconomic conditions that have an impact on health” (p. 221). According to Galorneau and Morissette (2004) “verbal communication challenges and discrimination impact barriers to well-paying jobs, education and welfare in Canada.” They also explain “gender, ethnicity and race influence how immigrant women access employment markets.” Further demonstrating that “gender interacts with socioeconomic status and social and cultural identity to influence access to health and social services” (Galorneau & Morissette, 2004). Several researchers have identified reasons that affect an immigrant’s ability to improve or access many social economic factors which will allow them to achieve an acceptable SES (Stewart, Neufield, Harrison, Spitzer, Hughes and Makwarimba, 2006). The Affiliation of Multicultural Societies and Service Agencies of BC (AMSSA) list the following reasons in their Newcomer Bulletin (2010): socio-cultural barriers, information barriers and economic barriers. Unfortunately, many non-European, university-educated immigrants face the reality; they are not guaranteed a
well-paying professional position. Instead many are forced to take low paying jobs further hindering their ability to improve their socioeconomic status and social determinants of health. In the context of my study’s interviews I hope to explore illness management in the perspective of the participants’ life circumstances.

Throughout my study I drew on a postcolonial feminist perspective to reveal what Khan, McDonald, Baumbusch, Reimer Kirkham, Tan and Anderson (2007) describe as “the complex matrix in which health and illness meanings are embedded” (p.229). A postcolonial feminist perspective allowed me to reflect on what issues face immigrant groups that maybe viewed as marginalised within the larger dominant western society. I was forced to question how issues such as language, class, racial/ethnic and gender differences could create imbalances in relationships between individuals from immigrant groups and macro systems such as healthcare organisations or even healthcare providers who may view themselves as different and superior to the immigrant group (Anderson, 2000; Varcoe, 2004). According to the World Health Organization (1986), “if differences remain even with universal access to services, then factors other than service must play a role and this has been clearly outlined in the Ottawa Charter” (as cited in Gagnon, 2002).

Limited Canadian data is available to enable theoretical analysis of cultural or historical variations in attitudes towards immigrant families of a child with a disability or CHC. The rise of the disability rights movement in the 1970’s brought about a dramatic paradigm shift in how western society viewed those with disabilities and CHC in respect to health needs, services and their value within society (WHO, 2011). However, my experience suggests that community differences in attitudes towards disability exist and
can have significant implications for people with complex care needs and those involved in their care. It is proposed by WHO and Disabled Rights groups that people with disabilities are entitled to equal opportunities and social integration. However not all countries can fulfil this proposition, some countries are better able to address these issues than others (Daudji et al, 2011). In addition not all citizens are willing to accept people with disabilities or CHC and still alienate those who are different from mainstream society. When the child is fully dependent on others to meet their needs this segregation from mainstream society can affect their primary care giver, who is usually the mother (Green, 2003; Hexem, Bosk & Feudtner, 2011). The caregiver role can be time consuming and stressful because it requires specific knowledge and skills in order to meet the child’s healthcare needs and to navigate the healthcare system. It also means much of this caregiving work takes place in the home with minimal support from outside agencies; further isolating the mother and potentially affecting her social well-being and mental health (Hexem et al, 2011). Groce (2005) further points out that within today’s North American society in order for some families to meet their financial obligations, “these women are often also expected to take a job outside the household. The multiple strain on mothers in these households has yet to be closely examined, but is significant and needs further investigation” (pg. 11).

In addition, to managing the day to day demands of family life for families who need health care attempting to use the BC healthcare system can be complicated. This is especially true for immigrants who don’t speak English, and those who may have different worldviews about health, care, and disability. However, as Anderson (2000) explains by viewing issues through a postcolonial feminist lens means “we might come to
understand that the difficulty people face in accessing and utilizing healthcare may be due not to their “culture” but instead to historical processes that have produced systemic inequities and oppression” (as cited Anderson, 2007).

**Purpose of The Study**

The purpose of this study was to seek an in depth understanding of parents’ experiences as I explored immigrant families’ stories to understand their lived experiences, their beliefs about their child’s disability or chronic health conditions as well as their expectations and experiences of healthcare. I wanted to unearth and examine immigrant families’ perceptions about disability and the barriers that exist for them as they try to access services within the larger community as well as pediatric clinics at a tertiary provincial care centre that provides services to children from around the province. I was interested in discovering more about this phenomenon especially as I listened to other clinicians’ questions about immigrant families that resonate throughout the clinics: “Why does this family keep cancelling appointments?”; “Why are the parents not following through on our recommendations?”; “Why are they struggling to understand the diagnosis that I’ve explained a hundred times.” Hopefully this study will help other clinicians, administrators and educators gain a better understanding as to how immigrant families conceptualize and understand their child’s disability or chronic health condition, the challenges they face in managing their child’s condition and their goals for care.

**Significance of The Study**

As has been suggested in the preceding review, Canada has a significant proportion of immigrant families. Despite this there has been little western Canadian research focusing on immigrant families’ experiences about accessing and utilizing health
care services for their child with a complex health condition. Previous studies have investigated the experiences of ethnic minority groups accessing and utilizing healthcare services and supports in other countries that have different immigration laws and healthcare systems (Burgos, Schetzina, Dixon & Mendoza, 2005; Guendelman, Angulo, Wier & Oman, 2005; Javier, Wise & Mendoza, 2007; Javier, Huffman, Mendoza & Wise, 2009; Sheikh-Mohammed, Macintyre, Wood, Leask & , 2006; Wahoush, 2009; Weathers, Novak, Sastry & Norton, 2008; Yu, Huang & Kogan, 2008). Many studies have used secondary data from large national surveys. Few researchers have actually carried out qualitative studies using face to face interviews with immigrant families in order to solicit these families’ unique perspectives. More knowledge is needed to understand the specific experiences of immigrants living in BC. Nursing is ideally located in a variety of practice areas that allow nurses to hear these immigrant families’ stories and gain an understanding of the salient issues. Therefore it is hoped this qualitative study can be a starting point in providing some firsthand accounts, straight from the immigrant families’ themselves.

The Canadian population is predicted to increase over the next decade and immigration will continue to play a large role in the expansion. Therefore it is important to identify and understand what immigrant families’ worldviews are and how these and other issues maybe barriers to families attempting to access and utilize services for their child. How these children are cared for will have significant implications for their health throughout their lifetime.
Research Question

For the purpose of this study, I chose to refer to all participating families as “immigrant families” regardless of whether their original status on entry to Canada was immigrant or refugee. Consequently this study posed the question “What are immigrant families’ experiences of accessing and utilizing healthcare services within BC for their child with a disability or chronic health condition (CHC)?” The following secondary research questions were used to assist in exploring these families’ experiences:

1. What influences the decisions caregiving parents make in regards to their child’s health needs?

2. What were immigrant families’ experiences with accessing services at a tertiary care provincial centre situated in BC’s lower mainland and the subsequent services or care recommended by the diagnostic teams?

Summary

This chapter outlined the research topic and purpose of the project to be undertaken. I explained Canadian immigration policy and the Canadian healthcare system. In addition I explained what disability means here in Canada and introduced the reader to theoretical perspectives that can become barriers to Canadian citizens attempting to access care whether they do or do not have a disability or chronic health concern. The remainder of this thesis is organized into four additional chapters as follows: chapter two will describe the literature review undertaken to help inform my study. It will demonstrate the knowledge gap related to immigrant families and their perspectives on accessing and using Canadian healthcare services; chapter three will introduce the methodology and describe the research methods; chapter four will present
the analysis of the data and chapter five will discuss the analysis in relation to what is already known from the literature as well as how the families’ histories and experience inform their beliefs, values and decisions and what implications this information may have for practice, education and future research.
Chapter 2 Literature Review

A literature review was undertaken to discover what previous research had been completed. The intent was to position my study in what is known as well as identify gaps in knowledge that may be explored through my research study. The initial criterion for the literature review was qualitative studies of immigrant families who have a child with a disability or CHC. By reviewing literature using this qualitative methodology it was hoped a unique personal perspective could be gleaned from these specific family groups. However the search did not yield fruitful results so the criterion was broadened to include quantitative studies of immigrant families who have a child with a disability or a CHC. It was also hoped a Canadian perspective would be garnered but it became clear minimal Canadian research has occurred that would offer information about immigrant families who have children with complex healthcare needs so the search included worldwide studies.

Following Garrard’s (2007) suggestions a literature search was commenced using the following databases: “Pubmed,” “CINAHL” and “Sociology Abstract.” The search was initiated with the following keywords: immigrant; refugee; health utilization; healthcare access; children and disability. This process produced several articles that were relevant to the area of interest. Undertaking “skimming” (Garrard, 2007), each article was briefly read to provide a simple understanding of their contents. Additionally, the reference lists of pertinent articles were reviewed for potential articles.

A total of fifteen articles were selected because they referenced immigrant families who had children with a disability or a CHC. An additional four were later
reviewed and included because they described families’ lives caring for a child with a disability or CHC regardless of the families’ ethnicity.

**Critical Analysis of Literature Related to Families Who Access Healthcare**

**Parenting a Child with a Disability or Chronic Health Condition (CHC)**

Providing care to a child with a disability or CHC, regardless of ethnicity or residency status, can be long term, complex and difficult for professionally trained care providers and may be especially challenging for the child’s family members. Depending on the child’s health issues and age, a child may or may not be able to participate in meeting his or her own care needs which may result in the burden of care being placed on adult family members. Stevens and colleagues (2006) explored families’ perspectives of care for their child with cancer and receiving home based chemotherapy treatments. Families indicated a number of issues that for many could be barriers to accessing healthcare services when treatments are provided outside the family home. When families are expected to travel to a healthcare facility there are transportation costs associated with this and it validates one reason why families want home based therapies. In addition, parents who participated in Steven’s research indicated that taking time off work and making long trips to a healthcare facility were sources of frustration for both parents and children. Children who participated in the research expressed concern that their daily routines were being unduly disrupted. Adolescents found it stressful to miss school time and voiced frustration that upon arrival at hospital they still had to wait for services.

However, Stevens and colleagues (2006) also found that receiving healthcare services at home presented some challenges. Coordinating and monitoring the child’s
community based services often fell on the parents’ shoulders. This created a “burden of organization and communication” as well as a “burden of vigilance” because parents reported when different nurses were involved with their child’s care there was a risk of medication errors (Stevens et al, 2006).

For many families with children who have a disability or chronic health condition the burden of care tends to rest on the mother (Daudji et al, 2011). Mothers have a key role in their child’s life, regardless of whether their child has a disability or CHC. When the child does have a disability or CHC, caring for this child is no easy task and can result in mothers struggling to provide the basic care for their child with special needs. This observation led to Yantzi, Rosenberg and McKeever (2006) undertaking a study that explored the challenges faced when mothering a child with a disability or CHC. The mothers enrolled in the study had children with a range of complex conditions that included cerebral palsy, muscular dystrophy, brain tumor and Downs Syndrome. All the children required 24 hour care, 7 days a week to meet both basic care needs (dressing, bathing, toileting and feeding) as well as more complex needs such as breathing and mobility. Several children required technological assistance to meet their needs for mobility, feeding and breathing.

The mothers in Yantzi and colleagues’ (2006) study discussed the planning and preparation required to undertake an activity with their child outside the home, this could include attending medical appointments or therapy sessions. They found “leaving the house with the child requires a lot of physical work, expenditure of energy and planning” (pg. 49). When a child was in a wheelchair, the family needed the ability to transport the child in a suitable vehicle as well as the ability to manoeuvre the wheelchair through
often inaccessible areas. The mothers discussed not always having the energy to perform their care giving duties and undertaking the extra effort to leave the home caused some mothers to cancel appointments. Readjusting feeding schedules or medication times to accommodate travel schedules maybe difficult to organise. It could cause additional stress to the mothers who were aware their child was at risk of vomiting if they undertake a car journey too soon after their gastrostomy tube feed. This study also found the lack of trained care givers to provide respite services to these children so the families could have a break in caregiving or go out to work. The knowledge and training needed to care for these children with complex care needs was a barrier to the families being able to solicit assistance from extended family or friends.

Many skills required to meet the needs of a child with a disability or CHC are considered nursing tasks. Yantzi and colleagues (2006) discovered from this study that when an agency is hired to provide support, current home and community care policy states that only nurses can perform these skills. Within British Columbia an agency can choose as directed by the College of Registered Nurses to delegate nursing tasks to care aides as long as a nurse is available to “be responsible and accountable for overall assessment, determination of client status, care planning, intervention and care evaluation” (CRNBC, 2002, pg. 6). If nurses or care aides are not available to provide this care then it is a potential barrier to the families receiving respite/support services. Thus, these researchers suggest that all children with a disability or CHC, not only immigrant children, may require a high level of caregiving which places significant demand on time, knowledge, skills and so forth. Professionals need to understand what these children’s families face so service providers can attempt to respond in a supportive
manner to the families’ identified challenges. These studies underscore that health care for such children needs to attend to, or be concerned with the ongoing care of such children.

**Immigrant Families’ Access to and Utilization of Services**

A number of global studies used secondary datasets from national surveys to explore immigrant families’ access and utilization of healthcare services. Regardless of country and health insurance plan, immigrant families were found to have reduced access and utilization to services and supports for their children (Burgos et al, 2005; Guendelman et al, 2005; Javier et al, 2007; Javier et al, 2009; Sheikh-Mohammed et al, 2006; Wahoush, 2009; Weathers et al, 2008; Yu et al, 2008). In the United States Guendelman et al (2001) discovered that half of foreign born children were uninsured for medical services compared to 20% American born children. Here in Canada, Crockett (2005) explains “permanent residents can claim health coverage, although a three month waiting period is applied in BC, Ontario, Quebec and New Brunswick. Refugee claimants are eligible for emergency and essential health care services through the Interim Federal Health Program” (p.278). This suggests that immigrant families will generally have access to needed health services.

Burgos and colleagues (2005) controlled for health insurance and socioeconomic status in their US study that explored whether first generational Mexican American children have poorer healthcare access and utilization than non-Hispanic white children. Data from the National Health and Nutrition Examination survey confirmed that there were more inequities than previously discovered for access of healthcare services amongst Mexican American families. These families also showed the lowest levels of
utilization of healthcare services, use of prescription medications and screening services for hearing and vision. Conversely, the data suggested that first generation Mexican American children may actually have decreased healthcare needs that required contact with the healthcare system because there were lower levels of treatments reported for conditions such as ear infections, cold, flu or pneumonia. However, as time goes by and Mexican American children become more acculturated their healthcare outcomes worsen overtime. It is perhaps because of their immersion in integrated social settings such as schools and neighbourhood groupings that children are observed to acculturate quicker and in all aspects of their life than some older family members. This acculturation is due to children’s exposure to the host’s culture, belief and values through school attendance need to learn English and peer pressure (Sotnik & Jezewski, 2005). As Santana-Martin & Santana (2005) suggest “knowing a client’s level of acculturation is important” (pg. 170). The children in this study had typical health care challenges, therefore questions that need to be asked include: What if complex developmental and physical disabilities existed for these children?” What effect would this have on the families’ access to care? And, does universal access to care remedy the access challenges immigrant families face? This study aims to explore these issues for immigrant families in Canada.

Interestingly Burgos and colleagues (2005) who studied Mexican American families living in the United States, learned that newer immigrants may perceive health differently, “leading to different reporting patterns” (pg. 328). These researchers suggest further investigation is required because it is unclear if “perception of poor health is an indicator of undetected disease burden or a difference in the cultural view of illness” (Burgos et al, 2005, pg.328). In addition, when the families’ use of English increased,
something that may occur with acculturation, it was noted families reported an increased use of healthcare services and decreased barriers to care (Burgos et al, 2005). However, Burgos and colleagues state the following factors may also have an effect on how Mexican families access and use services especially if healthcare professionals “lack Spanish language proficiency, lack of knowledge of Hispanic culture and lack of Hispanic staff members” (pg. 329). Thus implying some kind of racialization in access or use of services whether from the families’ perspective or healthcare providers.

According to Flores (2000) “knowledge of the family’s cultural and religious beliefs, as well as traditional medical practices should be elicited” because “an immigrant family will bring their language, cultural normative values, health beliefs and an understanding of folk illnesses to each interaction with a Canadian health care provider” (as cited by Crockett, 2005, p. 278).

Other researchers also call upon the need for further study to review the impact of other cultural, social and organizational factors unavailable in the secondary datasets used in the US studies (Guendelman et al, 2001). Data from The California Health Interview Survey were used by Guendelman and associates (2001) to explore “the joint effect of healthcare insurance coverage and immigrant status on a wide spectrum of healthcare access and utilization.” These researchers recommended increasing language and culturally competent staff in medical facilities in order to reduce barriers to access services. They also advocated policy makers work towards addressing the inequality amongst minority children as their families attempt to meet their healthcare needs.

Burgos and colleagues (2005) as well as Guendelman and associates (2001) discovered immigrant families are more likely to perceive discrimination while receiving care, a
view shared by others who suggest that immigrant families’ fear an adverse effect on their residency status within the host country if they receive healthcare services or supports (Hagan, Rodriguez, Capps & Kabin, 2003). The families do not want to be seen as creating a burden on the host country’s resources. However, in the US when amendments to public health care services are made it can mean some immigrant families are no longer eligible for help (Hagan et al, 2003). In time such structural changes may create an added burden on healthcare services because low income immigrant families may be forced “to develop alternate healthcare strategies” resulting in “working more, relying more on family and friends, seeking services elsewhere or doing with less” (Hagan et al, 2003, pg. 458). As these authors conclude such strategies illustrate the ways social and material disadvantage operate to place immigrants’ health and the health of others at risk especially if family and friends are ill prepared to meet the health needs of those with a disability or CHC (Hagan et al, 2003).

In Australia, Sheikh-Mohammed and colleagues (2006) carried out a study to determine what barriers existed for newly arrived sub-Saharan refugees as they tried to access healthcare within the Australian healthcare system. Data was collected that suggested “not all refugee families are isolated in their new country; some families do form early connections with cultural, social and religious groups within their local community” (pg. 596). However, Sheikh-Mohammed and colleagues (2006) discovered if a family had negative experiences of healthcare in other countries it potentially had an adverse effect on how and if a family accessed care in their new home. Some participants in Sheikh-Mohammed’s study described issues which affected their ability to access health care services abroad “corruption and bribery – no money, no treatment; people
denied medical support by government, not enough medical facilities, healthcare workers wanted sexual favours from patients” (pg. 596). Other barriers were lack of language skills, poor access to health information, misunderstanding about infectious diseases, no transportation and unemployment. The researchers encourage more research that could explore issues of social isolation when these immigrant families are resettled away from ethnic enclaves. As well as exploring the social capital of areas where newly arrived immigrants are resettled. According to Sheikh-Mohammed and colleagues (2006) “such social capital includes access to public transport, health education and English language education programs” (pg. 596). These resources hopefully would improve access and utilization of healthcare services. I was curious to see if the families participating in my study brought stories from their homeland that negatively impacted their access to care or what social capital they garnered and the effects of such resources.

Wahoush (2009) studied health behaviours of immigrant mothers living in Eastern Canada and used Anderson’s Model of Health Behaviour to guide the study. This model is frequently used in health research with vulnerable populations to learn how broad concepts such as environment, population characteristics and health behaviour influences health access for these populations (Brown, Davidson, Yu, Wyn, Anderson, Becerra & Razack, 2004). Although Wahoush’s study focused on care for children during acute illnesses rather than a child with disability or CHC, it highlighted the limited research completed in Canada that looks at healthcare access for children and the response of the healthcare system to their needs (Hyman, 2001). Unlike the US studies that used secondary data from national surveys, Wahoush’s (2009) Canadian study employed a mixed method using face to face interviews to hear the mothers’ stories. The
mothers described having minimal or no information on what health services or potential resources were available to them, regardless of their health coverage. An example was the prevalent use of emergency departments for non-emergency medical care rather than attending less expensive models of care such as walk in clinics. The mothers did explain that having a regular health care provider was difficult for approximately 75 per cent of them due to either being new to the community or some care providers’ refusal to accept the fee offered by the health plans that covered these families. A few mothers perceived long waits in emergency departments or refusal of care providers to accept their child as a patient as confirmation of racism. Wahoush (2009) suggests additional training for health care professionals so they can attempt to address the concerns of these immigrant groups for example so complains about long wait times or difficulty accessing care is not seen as prejudice.

**Disability and Stigma**

Maloni, Despres, Habbous, Primmer, Slatten & Gibson (2010) carried out a study in Bangladesh with primary care givers of a child with a disability. Similar to western families, the care giver for a child with a disability or CHC in a Bangladesh family is frequently the mother so the researchers explored these women’s perceptions of disability and how these influence the care they pursue for their child. Maloni and associates (2010) highlighted several barriers facing these mothers as they tried to access and use services for their child: the mothers’ lack of education; their lack of literacy and language skills that meant an inability to fully understand health information and poor communication between the health care provider and the mother. This last barrier Maloni and associates (2010) discovered is not only a barrier to what services are accessed and
utilized but resulted in poor knowledge transfer between health care provider and mother. Consequently this affected the mothers’ ability to learn and carry out the appropriate skills required to meet their child’s complex care needs. In addition Maloni and associates’ (2010) study found that the older family members, for example grandparents, had a strong influence on a family member’s interpretation of health care needs. However, conflict could arise because the elder family members encouraged a more traditional care model while the young mothers favoured a more modern biomedical approach.

Daudji and colleagues (2011) completed a Canadian study as a follow up to the aforementioned research conducted in South Asia by Maloni and associates (2010). The intent was to explore the South Asian mothers’ perceptions once they had relocated to Canada and were exposed to “new values, influences and mediating factors” (Daudji et al, 2011, pg.513). The researchers employed a qualitative descriptive study design and used face to face interviews to gather their data. They wanted to explore the immigrant mothers’ perception of disability and how these ideas influenced the mothers’ access and utilization of rehabilitation services for their child in Ontario, Canada. A number of similarities emerged to the previous 2010 study: culture was found to play an important role in developing a person’s beliefs and perceptions about disability with family and ethnic enclaves continuing to have a strong impact on the mothers’ perceptions and behaviours. In this study mothers were still blamed for their child’s disability however their suffering and the degree of social isolation that resulted tended to be less within Canada compared to that felt within their home countries. In addition there remained the belief that God’s will existed however rather than believing they were being punished or
tested by having a child with a disability, the immigrant mothers in Canada described their child as “a gift from God.” Throughout this follow up study there was a recurrent theme that both biomedical and traditional discourses of disability influenced the mothers’ understanding about their children’s disability and were individual to each family’s situation. This resulted in the realisation that Healthcare providers cannot approach care for immigrant families with generic, generalised cultural ideas (Daudji et al, 2011).

A study carried out by Bywater, Ali, Fazil, Wallace and Singh (2003) in the United Kingdom focused on Bangladeshi families with a disabled child. The researchers set out to explore whether these families experienced shame and stigma related to having a child with a disability as well as what effect religious beliefs had on their lives and understanding about their child’s health issues. The researchers demonstrated that these factors had some effect on service utilization and the families’ expectations for their child’s future. Although the families may have felt “it was in God’s hands” they usually did not withhold or refuse to seek out the best care for their child. However, Bywater and colleagues (2003) did discover that “institutional and structural racism” (p. 508) either from within the family’s ethnic enclave or the host society did exist and significantly affected the families accessing and utilization of services.

Summary

This literature review reinforces the view that raising a child with a disability or CHC presents many unique and varying challenges. These issues will resonate differently depending on a family’s life circumstances and add another dimension to a complex care situation. As I undertook my research, I was intrigued to understand the
way the social organization of the family, their relationships to others in the community and their personal knowledge influences their approach to health service access. In addition I hoped to learn more about how gendered expectations and practices are enacted within these families and between families and care providers. Guided by this curiosity the journey began to gain a deeper understanding about what immigrant families face as they care for their child, their expectations of health services and experiences with the healthcare system.
Chapter 3 Methodology and Methods

For this study, I chose interpretive description: a qualitative research methodology developed by Thorne, Kirkham and MacDonald (1997). This methodology employs an inductive approach that allowed me to take an issue from my clinical practice and provided me with the tools to do more than just describe the phenomenon under study. As Thorne, Reimer Kirkham and O’Flynn-Magee (2004) explain, interpretive description “provides direction in the creation of an interpretive account that is generated on the basis of informed questioning, using techniques of reflective, critical examination, and which will ultimately guide and inform disciplinary thought in some manner” (p.3). By using interpretive description to examine a clinical phenomenon, I intended to identify themes and patterns amid individual families’ stories while also exploring the differences that exist between each family (Hunt, 2009). In keeping with the postcolonial feminist stance I sought to understand and describe the families’ experiences “in relation to historical, social and political forces that shape meanings of wellness, illness and personhood” (Wojnar & Swanson, 2007). Interpretive description challenged me to look beyond the initial explanation of the families experiences’ and their perceptions. Instead I was encouraged “to reconfigure what is found into a form that has potential to shift the angle of vision with which one customarily considers that phenomenon” (Thorne, 2008, pg.50).

As I undertook this research, interpretive description allowed me to draw on strategies used within the traditional qualitative methodologies (phenomenology, grounded theory and ethnography) without it being considered “method slurring” (Thorne, 2008). It also permitted me to enter the investigation with preconceived knowledge gained from experiential learning of my clinical practice and the literature.
review completed earlier. Thorne and colleagues (2004) describes this as “theoretical scaffolding” (pp.54) which encouraged me to “confirm or challenge my initial hunch that the problem is worth studying” and expected me to reflect on and account for the “theoretical baggage” I carried with me as I entered into my own study (Thorne et al, 2004).

Methods

Sampling Strategy and Recruitment

A purposive, theoretical sampling strategy was used to recruit appropriate participants that meet the recruitment criteria (Thorne et al, 1997; Thorne et al, 2004; Thorne, 2008). I achieved a purposive sample by asking colleagues to review their caseloads and identify immigrant families who met my research criteria. Once identified the healthcare provider approached the family, showed them the study flyer, asked if they could be contacted by me to further explain the study and solicit their voluntary participation. This strategy took place because selected participants were required to have particular knowledge and experience of the phenomenon under study so they could give an insider’s perspective (Streubert-Speziale & Carpenter, 2003). I interviewed the parent or guardian who knew the most about the child’s health needs and required that perspective families be immigrants (i.e. parent or guardian not born in Canada), spoke English and resided in the lower mainland. I did not distinguish between class of immigrant (family, independent or refugee), instead I focused on the fact they all had a child, who was between the age of five years to 15 years old at time of diagnosis, with a disability or CHC that required the family to attempt access and utilization of healthcare services at least 12 months prior to participation in the study. The child may or may not
have been born in Canada however they were required to need assistance with activities of daily living, and / or nursing care and therapies. The children’s disability or CHC was a result of the following diagnosis: cerebral palsy; chromosomal abnormalities; syndromes or acquired brain injury from birth trauma, infection or accidental injury.

In order to achieve access to immigrant families who meet the required criteria I approached colleagues within a pediatric tertiary care centre. A letter (Appendix A) was sent to the Director of patient services requesting permission to approach the clinicians who would identify potential families that met the study’s criteria. The clinician’s then gave the families the flyer (Appendix B) to read as well as verbally reviewing this information in case the potential family had difficulty with written English. The flyer explained: the study’s purpose; eligibility criteria; benefits to participating and researcher’s contact information. Immigrant families wishing to participate in the research study were asked to contact the principal investigator. Some families requested the clinician give their name and contact information directly to the principle investigator so they could be contacted rather than the family making first contact. In addition if clinicians identified potential families and they were not attending the clinic then an initial contact letter (Appendix C) and flyer were mailed to the family. The letter encouraged the family to contact the researcher if they wanted any additional information or wished to participate in the study. I recruited eight families to elicit rich data. Throughout data analysis I was mindful of recurrent themes and the conceptualization of the participants’ perceptions which helped me decide if further recruitment was needed.
Description of the Participants

Eight immigrant families participated in this study. At time of interview the parents’ length of time in Canada varied from one year to 27 years. However all primary caregivers were born outside Canada and although the reasons for relocating varied there was a common theme that all the families desired a safe home and felt Canada had the best opportunities to meet their child’s disability or CHC. Most of the children with disability or CHC were born in Canada and diagnosed here too. One child was born elsewhere and diagnosed in his home country with autism. However on arrival to Canada his father discovered reassessment was needed in order to ensure the child met the North American definition of Autism. A reassessment was required to ensure eligibility for supports and funding available in British Columbia for children with autism.

The majority of primary caregivers for the child with disability or CHC were female: mothers, aunts or sisters. In one case it was the father due to the child’s mother being relocated to another country. During the interview, the father chose not to discuss any of these relocation details. However he did confirm that his nineteen year old daughter provided significant assistance to her younger brother when the father was not available.

Countries of origin for the participating families were: Burma, Egypt, Vietnam, Somalia, China, Palestine and Iraq. All the families spoke English as their second language and spoke their native language at home amongst family and friends. Therefore regardless of birth country the children’s first language was same as parents and English considered a second language.
All interviews were conducted in a location chosen by the participants. All but one of the 8 interviews were held in the participants’ homes; the one exception was a father’s choice to meet in a local café. The participants were allowed to decide who should be part of the interview. One father chose to have his older daughter present because he felt she would offer additional information which may be valuable to my research. For the other interviews: two included both parents actively participating, four were mothers only and the interview held in the café was with a father by himself.

**Data Collection and Analysis**

Data was collected using semi-structured, face to face interviews and audio taped to ensure the data was the participants’ actual responses. The primary caregiver was asked to share their perceptions about health, illness and disability. They were also asked to explain their experiences about accessing and using health care services for their child with a disability. I followed Lincoln and Guba (1985) suggestion that during the interview “it is important to keep an easy rhythm, and as much as possible, to keep the ‘talk turn’ with the respondent” because “the interviewer rarely learns anything when he or she is talking” (pg. 270). These taped interviews were transcribed verbatim so the written word then became the data for analysis. I carried out the transcription myself so the interview could be relived and it assisted me in capturing the essence of the participants’ lived experiences. Hearing their voices and own words again complimented any field notes written after the interviews. A set of trigger questions (Appendix E) were used to focus the interview on the research question and helped facilitate the participants’ reflection on their experiences.
Analysis of Demographic Data

Demographic data (Appendix F) was collected to provide a description of the participants. Factors that were collected included: family economic status; geographic and cultural background; age of parents and child; extended family members location; parents’ education and the child’s medical diagnosis. This information was sought in order to describe the study sample but also because these factors have been identified as influencing access to care and resources for illness management.

The interview location was at the participants’ discretion as was the time and date of interviews. Ideally a quiet setting with as little distraction was hoped so clear audiotaping could be achieved that would aid transcription (Polit & Beck, 2008). However, I was mindful that the many interviews needed to take place at the families’ homes therefore during the interviews the children were present as were other family members who the participants wanted to be included in the interview. When interruptions occurred the participant was given the option to stop the interview or continue. This strategy enabled the participant to exercise some power in a relationship that potentially I, the interviewer, could have dominated (Karnieli-Miller, Strier & Pessach, 2009). Field notes were kept that explain these situations and reviewed when analysing the data. These notes were written when I was alone, after the interview so the observations and reflections could be captured while still fresh in my mind. For example my first interview took place in a family home were the child with disability was present. I was fortunate to witness the interactions between the father and his son which helped me understand what services the family was requesting. When the son made a noise the father interpreted it as him wanting a snack. Instead of encouraging his son to choose
what he would like and help prepare it, the daughter was told to get a cookie and give it to the son. This reiterated the father’s comments that the only help they needed was someone to “look after” the son so the father could go to work. Whereas I was thinking the father would be requesting occupational therapy in order to help the son learn some independent living skills.

**Data Analysis Procedures and Processes**

After each interview, I transcribed the audiotape verbatim. I checked each transcript for accuracy by rereading them and listening to the tapes to get a general understanding of the initial data. This strategy also helped immerse me in the data again so I could re-familiarise myself with the participants’ responses. As a novice researcher I chose to follow Diekelman, Allen and Tanner (1989) seven stage process of data analysis. Originally developed for interpretive phenomenology their data analysis technique allowed me to be systematic and focused as I explored the data in depth and gained a deeper understanding about what immigrant families faced while attempting to access healthcare services. My investigation employed the following stages:

1. All the interviews were read to gain an overall understanding.
2. Interpretive summaries of each interview were prepared.
3. Examination of transcribed interviews.
4. Returning to the data to resolve any disagreement on interpretation.
5. Comparing and contrasting the interviews to each other to identify common themes.
6. Identifying emergence of relationships among themes.
7. Presentation of a draft of the themes, along with exemplars from the data, to the team (in my situation my thesis committee) and then incorporate their responses and suggestions into the final version.

At the same time I needed to ensure I used a postcolonial feminist lens to reflect on the data. As Racine (2011) explains “postcolonial feminist approaches unpack the cultural, historical, social, economic factors that intersect to shape different oppressive context that affect health and well-being” (pg. 18). I was also mindful that in interpretive description Thorne (2008) endorses “making accurate records and spending time to be immersed in those records, developing a sense of whole beyond the immediate impression of what it is that they contain” (p.143).

As I embarked on my journey of discovery, I read each interview again before starting to search for themes or recurring regularities. This allowed me some initial reflection about the information contained within the data and how it pertained to my research question. As Rubin and Rubin (2005) suggested this gave me the opportunity to get “a working idea of what important concepts, themes and events are present” (p. 206). My search followed an inductive analytic technique with the initial intend to treat each paragraph of information as “a data unit” (Rubin & Rubin, 2005) rather than line by line coding. I numbered each main paragraph within each interview and where possible assign a theme which allowed me to find specific topics easily (Holloway & Wheeler, 2010). I was cognizant that “themes often develop within categories of data but sometimes cut across them” (Polit & Beck, 2008, p.515). I was aware of the importance to analyse the data not only for what themes are present but how they are patterned. For
example does the theme only pertain to certain sub group of immigrant families? Or occur in certain contexts or at certain periods in the child or family’s life?

Since I was trying to answer a question that pertained to the lived experience of immigrant families as a starting point I was interested in such statements throughout the data set that commence with “I” or “we.” I highlighted such phrases early in the analysis process so I could return to them later if I discovered they were significant to my research question. Simultaneously, as I read the interviews, undertook highlighting and coding, I made note of events and topical markers which could potentially provide me with “hooks” that could “tie separate parts of a narrative together” (Rubin & Rubin, 2005, p.207).

Criteria of Quality

I was aware as I undertook this qualitative research that I needed to attend to a rigorous process if my end product was going to be viewed as truthfully capturing the essence of what I set out to investigate. From the outset, Thorne (2008) weaves the notion of credibility throughout her book. Credibility is enhanced the longer you are able to stay connected with your participants, build a rapport and establish meaningful relationships. However due to time constraints related to my work schedule and the participants’ schedules, I was not afforded the ability to undertake prolonged engagement with my participants. Instead I hoped that my interview questions & technique during the time I spent with the families would create an atmosphere where the interview participant felt comfortable to share a wealth of information. I did this by allowing the participants to speak freely, minimised my interruptions and keep my facial expressions and body language as neutral as possible so as not to show any preconceived judgement or biases.
The intent being to create data which would be considered “thick description” and from which would emerge salient themes and patterns. I elicited the advice of my thesis committee to provide investigator triangulation to validate that the themes identified were a correct representation of the phenomenon: this is an important part of the analysis process if I was to make decisions about what “constitutes truth” (Polit & Beck, 2008, p.315) and hopefully minimize bias. My committee’s review provided constructive feedback to ensure my exploration was on the right path. As a researcher using a qualitative methodology I wanted to make sure, as Thorne (2000) explains, to “recognise that the relevant reality as far as human experience is concerned is that which takes place in subjective experience, in social context and in historical time” (p.68). Therefore I was mindful “about uncovering knowledge about how people think and feel about the circumstances in which they find themselves” rather than “making judgements about whether these thoughts and feelings are valid” (Thorne, 2000, p. 68). Thus when a father told me how he felt on hearing doctors discussing what he calls “murdering my son,” it is not for me to dispute these comments. Rather I need to be mindful that this father may bring these feelings to future healthcare interactions and it could have a profound influence on the way he relates to healthcare professionals.

I maintained a reflexive journal throughout my research experience. This allowed me to gain some additional insights about these immigrant families or even immigrants in general. Journaling helped me remember that I too am an immigrant and have certain beliefs and values stemming from my life experiences. It gave me an outlet to keep these views in check as I interacted with the families during their interviews and analysed the data to construct credible knowledge. My journaling allowed me to think about my
parents’ comments related to immigrants “coming to England and expecting free healthcare while the rest of us have to wait for a long time or pay for things.” It also allowed me quiet reflection and contemplation about many sad stories I was hearing during my times with these families.

In presenting the analysis I include direct quotes from families. I have chosen not to edit these in order to illustrate the challenges some families faced in expressing their ideas in English. I discussed this issue with my committee because I realize that in not editing I may inadvertently be eroding these parents’ credibility as having expert knowledge of the caregiving experience. I did however want to illustrate not only parents’ challenges in communicating but also the ways this can influence how professionals or other members of the healthcare team may respond to them or view them. In presenting the excerpts in some situations I have included clarifying comments in parentheses and italics to assist the reader in their interpretation of the quotes.

**Ethical Considerations**

Approval of the study was obtained from the Research Ethics Board at the University of British Columbia (the researcher’s affiliation) and the ethics committee of Children and Women’s hospital (the tertiary centre’s affiliation). Recruitment was by clinicians who worked in the tertiary centre and by posting flyers. Once participants expressed an interest in participating they were provided with a consent form (Appendix C) to read during the recruitment phase. The information on the consent form explained the study procedures and was also presented verbally. Polit and Beck (2008) explain that “oral presentation provides opportunities for greater elaboration and for participant questioning” (p.177). This discussion allowed the prospective participant to make an
informed decision about their involvement. Simple language was used both written and verbally. Additionally I sought to avoid language that may have been viewed as coercive by potential participants. Prospective participants were given enough time to review the consent form and ask any questions before they signed. On agreement of their involvement the consent form was signed by the participant and me, with a copy retained by each of us. There were two instances where the principal participant requested another family member also participate in the interviews. At these occasions the consent form was reviewed in the presence of all parties however the principle participant was the one signing the consent form. The additional participants indicated that they did not feel the need to sign but did verbally acknowledge they understood the consent.

Confidentiality was maintained throughout the study. Each participant was assigned an identifier rather than using their real names. If a person’s name was mentioned during the interview, a pseudonym was used in the written transcript. I chose to use western names for this purpose. Also, as this study involved a small number of families and their personal migration stories and their child’s diagnosis could allow them to be identified, I have elected not to identify families from one another in the presentation of the analysis. But, in my own files I have attached an identifier to each family’s audiotaped interview, transcript and demographic data. When the study findings were initially written up, the families became known as “family #1,” “family #2,” etc. Once the analysis was completed and quotes are presented in the thesis I sought to further protect families’ confidentiality by removing these identifiers presenting quotes. Instead I refer to parent participant, family member participant. Similarly, the countries of origin were also amended to the region for example “Egypt” was referred to as the “Middle
East.” Audiotapes, transcripts, field observation notes and demographic data were stored in a locked filing cabinet and only accessed by myself and my thesis committee members.

**Limitations of the Study**

One of the limitations of this study was the fact the participants had to be fluent in English because financial constraints limited the ability to hire language interpreters. Therefore the primary limitation of this study is the inability to hear non-English speaking immigrant families’ perspectives regarding health, illness and disability as well as their experience in accessing and using healthcare services. It could be hypothesised that due to significant language barriers these families would be an even more marginalised group. This may be the case especially if the family and service provider do not share the same language which may affect the development of a trusting relationship and the person’s healthcare needs being adequately met (Gagnon, 2002). In addition this study relied on only data from participants’ interviews and my field notes, I did not interview or observe service providers at work with these families.

Although this process did provide rich and varied information, I was mindful during transcription that there was an effect on audio quality when some participants spoke with strong accents. On occasion I was unable to understand what a participant was trying to convey and I often wondered if the true essence of the participants’ words and meaning were lost as their shared their stories. During the interviews I did not want to focus on my difficulty understanding their words. I wanted to preserve the relationship and allow the participants to speak freely, for some participants, the more passionate they got about an issue the more difficult it became to understand their message. In a study
with a larger sample size, professional transcription services or ability to use additional data sources the credibility of findings may be strengthened.

I was also intrigued by a statement one of my thesis committee members (Dr Gladys McPherson) made in her own master of nursing thesis project. She stated “the complexity of this study is influenced by the fact that this is my first research project. Experienced researchers have described the advanced skills required in conducting interviews and engaging in methods of qualitative research (cited in May, 1989; Thorne, 1991). These are skills I began to develop in the process of this research” (McPherson, 1999). It was reassuring to know I wasn’t alone in feeling my novice skills could be limiting the data I was collecting in order to answer my study’s questions. As I engaged in more interviews I felt more comfortable in trying to guide the interviewees’ responses to provide me the information I needed at the same time mindful not to influence their words.

**Summary**

I have described in this section my study’s research design and the qualitative research methodology, interpretive description, used to guide my data collection and ethical considerations. In the next chapter I will present the analysis of the study data.
Chapter 4 Presentation of Analysis

The families in this study shared a wealth of information which allowed me a glimpse into their past and present lives as they raise a child with disability or chronic health care condition (CHC). The participants explained that by providing information for this study, they felt they were giving back to the professionals who have helped them navigate the health care system or meet their child’s needs. The families spoke openly about challenges they have faced in either settling into their new home or while caring for their child(ren) with a disability or chronic health concern (CHC).

As I examined the transcripts I was struck by several themes and patterns that characterized the families’ experiences in managing their children’s’ health conditions and in accessing health care for their children. Although the families had different experiences in regards to how they came to Canada or what health issues their child faced, commonalities resonated in their stories. In the initial part of this chapter, I will describe the processes relating to the immigrant families’ lives here in Canada and the influences affecting decisions they need to make when caring for a child with a disability or CHC. I have chosen to categorize these processes as: desire for a better life and healthcare; families’ experiences with accessing services in the Canadian context and desire for autonomy and independency. The second part of this chapter will focus on two specific concepts chosen after further reflection and interpretation of the data. These concepts are creating a future and personhood. I will begin by describing why the families chose to live in Canada.
Desire for a Better Life and Healthcare

For the Children

All families, even those who had immigrated before they had a child with a disability or health concern, described Canada as a place they could have a better life for themselves and their children. Regardless of the families’ status (refugees or immigrants) the families had chosen Canada versus another country because there was a strong belief Canada would be a safe haven, enable an improved lifestyle and provide a high standard of healthcare compared to their countries of origin:

Father: We just come here we just try to build up for my kids.
This is my main dream in my head now because
I am very old, 57 years already, my father was 62 when he passed away so if I live to be my father’s age I only have a few years left.

Father: We knew from the beginning before we moved that the education and healthcare here is better for the kids.
Of course, so it was a matter of shall we move &, we had a very good & decent life back home. Yes so it’s a trade-off. Shall we stay & then the kids have whatever is available in (middle east) for education & healthcare medical care or should we move & it’s sort of a sacrifice for the kids. So that’s what we decided we would move.

Mother: So coming here to Canada was like thinking about the
future for them (referring to her children). It’s not for Jim & I, it’s for them (all their children). So we can secure their future.

Many of the families shared what life would be like in their home countries for someone with a disability or CHC. One mother explained what living in her home land would have meant her children with CHC having limited treatment options:

Mother: If I was still in East Africa and had children like Peter and Sue, first thing I can explain to you there is no g-tube feed. So they would have to struggle choking on everything they can eat. Or I would have to use puree and maybe it depends on certain families who can get out and get a generator. And they can have a blender and they can blend and they can feed through that. But medication would be another problem. I know a charity who collects certain medical equipment to send to East Africa because certain families who have either elderly or children with special needs on wheelchair transport the way they transport people is in a wheelbarrow. They put the children or people on a wheelbarrow to take them from point a to point b.

These views were contributing factors to why these families wished to live in Canada and access this country’s healthcare system.
Motivating Factors to Come to Canada

Care Options

Another mother described what she saw as untenable option for her child, in her home country. This mother explained care options for Jane were limited in Asia. She had explored what was available which caused emotional distress as she thought about her daughter having to live in an undesirable setting:

Mother: I have visited some of the service centre and they say you can leave Jane, like a group home something like that, leave Jane here but when I visit there I burst out cry. When I see the environment there I couldn’t take it, if I leave Jane over there. That’s why I decide not to take Jane with us to Asia.

As a consequence of this experience, this mother was prompted to explore the opportunities that might exist in Canada. For a family whose child requires facial reconstructive surgery living in Canada means there’s no cost to the family.

As the following account illustrates, other families experienced similar financial challenges in accessing care in their home country. One child’s parents explained that their country of origin only had a private medical system thus and if they had no health insurance coverage then all costs were incurred by the family:

Father: In ‘Middle East’ it’s a private medical system so money comes sometimes in opposition of what the profession should do. So you can get 3-4 different opinions on how they should deal with case. One of them (surgeon) could
be bias more that he wants bigger surgery than it would be for more money……

We will have to pay for it or my work will cover it if I have private health insurance. It will be the concerns that whether what this doctor says is the same or we have to see another doctor until we come up with something we like (and can afford), we would have to make our own mind in the end. What is good here (in Canada) is because everyone is liable & I think the government is very strict on every professional

Mother: Especially concerning everybody’s health.

Father: So we don’t have doubt that what the doctor would say is the best for him (son). Or if there’s a team of doctors like craniofacial clinic, their decision is the best for him. So this is the part that gives us peace of mind.

The accounts described the markedly different levels of care available for children in their parents’ countries of origin. This last example demonstrates an inequitable system whereby the family has to make health care decisions based on their ability to pay. I wonder what distress this places on parents as they may be forced to consider how their monetary resources are shared amongst family’s members. Could it mean a family with several members who require care are ranked according to their contribution to the family’s overall wealth? For example would a child with a disability who will not be able to have employment rank lower for example less money spent on them for
healthcare, than a child who’s going to be able to have a job and therefore bring money into the family or enable that child to become independent and leave the family home sooner. This could also affect how people with disabilities or CHC are viewed especially if others view them as a drain on the country’s limited health resources.

**Tolerance of Difference**

Many families spoke about the lack of support, in the countries of origin, for people with disabilities that extended beyond their physical care needs. For example, many families highlighted the fact that people from their countries of origin have limited exposure to people with disabilities or CHC. This reason may be due to people with disabilities being “routinely institutionalised” (Groce, 2005, pg. 4) or those with CHC dying due to a lack of medical interventions. Families indicated that people in their countries of origin didn’t understand their children’s health issues or disabilities and were less tolerant of those who are different. One family member explained:

Daughter: Not so many people know what is autistic, what’s Down syndrome. It because there’s not a lot handicapped people in the street, they will be more comfort to stay in their house, not going outside. It’s totally different.

Some families seemed to feel it was not just the fault of individual people. Their comments indicated that they felt governments should be responsible for informing citizens about disabilities and healthcare issues.

Mother: Yes it’s the government or the Asian people.

The government didn’t think or inform or educate their people that the city has a lot of different people.
They are equal even though they have a disability or they just have an illness. So in Asia most people don’t show any kind of affection (towards people who are different).

By contrast, many of the participants indicated that they expected Canada would offer a solution to the problems faced in the countries of origin. More than providing access to health care, the families also expressed hope that living in Canada would mean that their child would be integrated into community life and have opportunities to experience activities the same as any other child. Conditions that families observed could influence the achievement of these goals related to physical and social accessibility.

**Physical and Social Accessibility**

One mother originally from Asia explained how inaccessible her home country can be for people with a physical disability; the way of life does not support people with disabilities:

Mother: …. it very hectic the city so you cannot really stop by on the road and have wheelchair, take out the wheelchair to load Jane and things, so everybody is honking and the road is very busy. So it’s very busy we think she needs a lot of medical appointments this is a very hectic life for both the caregiver and Jane.
By contrast this mother observed that the Canadian government tried to make things inclusive for people with disabilities which facilitated their abilities to participate in everyday life:

Mother: They will find the Canadian government prepares these people with appropriate work and things are adapted for the blind. Everything puts them (the blind) into consideration. Ok, they (people who are blind) know that they are part of the community. That’s why I do not think others are looking at them inappropriately.

Yes, that’s my feeling.

Consequently this mother felt this integration meant people in general were more tolerant and did not view people with disabilities as an oddity.

These selected interview responses highlighted significant issues that were important to families who had relocated from other countries. The data have helped to illustrate the significance of life in Canada for these families with a child with a disability or CHC. Immigrant families not only wanted access to care they also were seeking a safe place to live; they also wanted to live in a community that was responsive to and supportive of people with a disability or a CHC.

These accounts also begin to help us understand the uniqueness of the Canadian context for some immigrant families and what is perceived to be available to them as they attempt to care for their child with a disability or CHC. Such services include universal health care; availability of some forms of technical support; societal commitment that recognizes individuals with disability and how they are situated within family life. These
accounts help to situate the particular experiences of immigrant parents caring for a child with a disability or chronic health condition. In what follows I build upon this context to examine how these perspectives influenced the families’ current healthcare decisions for their children with CHC. In particular I will explore what influenced these immigrant families’ access to services?

**Families’ Experiences with Accessing Services in the Canadian Context**

**The Advantages and Challenges of Early Diagnosis in British Columbia**

The complexity of the Canadian healthcare system can be confusing for anyone trying to access services. All families who participated in the study had children who showed delays in their development that required the children to be followed and assessed by healthcare professionals.

Only one child arrived in Canada with an identified health condition (autism). Nonetheless, the story of his journey to diagnosis was similar to the other children. Initial concerns about the child’s behavior or development were raised early in the children’s lives. Families with more than one child were able to compare children’s development with a sibling. Such observations alerted the parents to potential concerns with the younger child’s development which prompted parents to seek an assessment. In all the families included in this study such consultations resulted in a disability diagnosis or identification of a CHC. One family had three out of their five children affected by CHC:

Father: They don’t exactly know the genetic cause they don’t exactly know, nothing shows through but it just looks like it hit the boys. That’s one part, they born most of them like that. I mean when some of
them born right away they figure out there’s a problem.

Three days or actually during the first week showing

the brain issue maybe the small brain and it causes

them the feeding problem.

This family’s situation was an interesting one, which left me with unasked questions for fear I may offend the father and be perceived as judgemental. On reflection I thought about whether there had been genetic counselling to help parents understand the risks associated with future pregnancies? I wondered if these parents were hoping for a boy unaffected by the gene. I realized that my own questions and the assumptions inherent in them reflect the views many people in society hold about people with disabilities particularly disabilities that appear to be preventable. Which also prompted me to wonder what attitudes they had faced from others, such as myself, wondering why they continued to have children who were profoundly disabled?

In the majority of families in the study the child’s health condition was not predicted and diagnoses occurred at different points following birth. For example, one mother whose daughter was born here, explained that although she had a normal, healthy pregnancy a traumatic delivery meant her daughter’s issues were identified at birth and the child needed to be followed closely by healthcare professionals:

Mother: No the doctor tell me at her birth. He said she

has brain damage, but what they don’t know is

how big the damage. So we don’t have to wait

until she grow up, cos the doctor says some of

them (children with brain injury) when they grow
up they get better but some get worse.

Another child received a preliminary hearing loss diagnosis within 72 hours of his birth, however the diagnosis of autism came later when he was demonstrating delays in his milestones and language skills. His mother explained:

Mother: Actually there was a screening test when he was 3 days old in the hospital, for the hearing test.

So we got a \textit{(confirmed)} diagnosis when he was about 4 months old. So he is bilateral profound hearing loss. Initially there were no other issues.

By the time he was 2 years old, er actually he got a cochlear implant after his first birthday but after a year of therapy, he still no language. So his teacher notice that and remind us that he may have something else, he may have other issues. I didn’t think anything wrong. I think probably he couldn’t hear and he got new things \textit{(cochlear implant)} & probably taking him a little bit longer to learn speech because I’ve no knowledge about autism.

The early interventionists involved in this child’s speech and language therapy recognised that this child may have autism and encouraged the family to ask for an assessment from the Provincial Autism Resource Centre in Vancouver. This mother later expressed her gratitude that these professionals were persistent in their recommendation for further assessment because she (mother) was in denial that anything else could be
wrong with her son. Her hesitation would have resulted in further delay of early intervention services that are important for a child with autism. In fact many families had been connected with numerous healthcare professionals early in their children’s lives. This professional involvement was required to confirm a diagnosis, address any issues as they arose, mobilize supports and hopefully result in a positive health outcome for the child:

Father: When they (his sons with CHC) were born they go into children’s hospital. Then they (healthcare professionals) become involved in the beginning of their lives. The children have big investigations, a lot of doctors involved, a lot of clinics involved, neurology, pediatrician. Then the doctors go more in depth, check the children’s hearing, eyes, and check what they can do or not do. This father’s description provides a glimpse into the complex array of specialized services that families gained access to in the hospital centre.

Another family explained their sons were born prematurely and although appeared fine at birth still required follow up by healthcare professionals to observe their development. This follow up was important because one child has a significant facial deformity and although his parents have been told it’s “just cosmetic” he is followed by a specialty team at the specialist centre. :

Mother: ……an MRI (Magnetic Resonance Imaging), several CAT (Computerised Axial Tomography) scans, they checked his
vision to make sure nothing is impaired, checked

hearing and everything, so nothing was positive.

The family explained infant development consultants were involved when the boys were younger to ensure they met developmental milestones; now they are school age further developmental assessments have been suggested.

All the families interviewed appeared to appropriately access and utilise healthcare services. Usually referrals were made on recommendation of healthcare professionals who recognised a concern and required a specialist’s follow up for diagnosis or treatment. The children clearly received care, attended appointments and as much as possible participated in community and family life. However when a child was born with no obvious reason to be concerned i.e. normal delivery, no genetic predisposition; some families expressed a frustration in the healthcare system which does not always take a family’s concern seriously. One mother explained:

Peter was born normal, he developed normal.

The only thing I can say he lacked was suckling,

he could not suck very well, So I give him a bottle

and the bottle was hard too........I didn’t think

anything of it. He was fine, he sat down, and he

stood up. He was actually good because he was

my 4th child, I didn’t think anything of it.

However this mother went on to explain when Peter was 14 months old he was having problems walking. She took him to several doctors who did the usual developmental screening checks and could find no indication anything was wrong.
However by age 2, this mother explained “Peter lost his ability to walk and was falling everywhere. Still no doctor would transfer me to a referral to a neurologist.” The family chose to pay for a magnetic resonance imaging and neurology assessment in the United States, where the child received a diagnosis of cerebral palsy. On return to Canada the mother went to her family doctor with the new information and was immediately given a referral to a neurologist at a tertiary care hospital. When her daughter was born and presented in the same way as her brother with CHC, the mother’s concerns were immediately addressed and investigated by the neurologist still involved in her son’s care. Both children have since been diagnosed with a neurodegenerative disorder and have a team of healthcare professionals closely involved to monitor and treat the children’s ongoing CHC needs. These services include physical and occupational therapy, social work, at home caregiver, a range of subspecialists, nursing, etc. In order to attend school each child also has a special education assistant who provides direct care and adapts the environment so they can participate in various school activities. The mother described these professionals as advocates and recognises many go above and beyond what she felt they should do.

Mother: they did everything they can to help me, everything they knew they could provide: how to access a van for the kids, how to access financial aid for respite services, how to access community group to have a ceiling lift or an elevator or ramps in the house. I don’t know anything about that….. I was one of the lucky ones, believe me.
These interview vignettes demonstrated the willingness these families had in regards to accessing services for their children. It also illustrates that the journey to assessment and diagnosis can vary significantly from family to family.

Children identified early in their lives with a disability or CHC were flagged in the system as requiring a variety of healthcare services. Even those with “late” diagnosis had families willing to demonstrate a persistence to access what the children required for a diagnosis and to manage their ongoing health care needs. These services included however were not limited to: specialist assessments, ongoing therapy and nursing support services.

However, one family chose not to enrol their daughter in school and limited her interactions with others outside of the family. The mother did not express this isolation in terms of cultural beliefs rather she spoke of a need to decrease her daughter’s exposure to infections and thus reduce her child’s risk of becoming ill which could be detrimental. Reflecting on this explanation, I wondered if there was something else going on for this mother and was it related to an underlying cultural component to these decisions or an ongoing “shame” or the mother’s own difficulty coping with the diagnosis. As I reread this family’s transcript I was reminded how emotional this mother had become during the interview. The sadness in her voice as she shared how she has not told her friends in her homeland about her daughter’s CHC:

Mother: And to me when I was in Asia lot of people ask me about my daughter I did not say, tell them about her condition. I know it’s difficult for people who have never had children to respond to news that your
child has a disability or CHC, it’s kind of odd…….

I never share much (about her daughter) with friends.

The mother chose not to disclose a lot of information during the interview because she found sharing this personal information too distressing, at one point the mother began to cry. Therefore I was unable to probe further to try and understand why she was so alone in managing her child’s condition. The decision not to have Jane attend school has meant limited services being available to this extended family, thus increasing the burden of care on the relatives.

Mother: Later on we find out a lot of services was related
to the school program. Only when Jane go to school are we entitled to physio. We are entitled to hire a full time person to take Jane there, keep at school for the whole day.

This family’s situation highlighted the assumptions that inform policies related to caregiving services and the allocation of resources within the Canadian healthcare system. These families’ experiences also illustrate the variation in the families’ experiences and the complexity of their decision making process, sometimes in the face of limited information. I wonder how different life may have been for this child and her extended family had they had proactive professionals involved like the previous family; willing to advocate on the family’s behalf to access funds or services.

**Managing Relationships with Healthcare Providers**

Relationships with healthcare professionals can have a lasting influence on people’s future interactions and behaviours even if the initial encounter is totally
unrelated. In addition an experience not related to healthcare could affect how a person interacts or even makes certain decisions. I discovered having professionals involved in a family’s life does not always result in positive outcomes. During one interview I was intrigued to hear about a family’s assigned settlement worker and the role this person played in assisting the family. In clinical practice I had encountered many families who had such assistance. Based on these encounters I had a preconceived idea the family would have benefited from this help. However as I listened to the father’s story it was evident this was not always the case. When I had asked father if they had a settlement worker he responded:

Father: Yes I have one but she’s a meanless girl (reference to the fact this father does not like the settlement worker due to her country of origin), she’s Bangladeshi.

Actually we don’t like because it’s another discriminatory; the Bangladeshi people they think they have a country, we are stateless (referring to the fact family had fled their country of origin and had live as refugees in Bangladesh) it’s a different view. Actually I don’t like (the situation) but still I am going to see her (settlement worker). But it’s not really helpful, she’s not effective. She’s less educated than me.

Further in the transcripts this family’s story highlighted how a family’s view may differ from a professional’s view which in this case led to a lack of follow through on
recommendations intended to meet the child’s care needs. This father expressed frustration that the settlement worker would suggest a care option which the father felt made no sense:

Father: This settlement worker she’s very stupid not talent. She’s looking for him (son with disability) a daycare person. So daycare person they can take ordinary kid. So I don’t have any kind of education to look after my son? (Sarcastic tone in father’s voice). How do I take care him, it is impossible (not to think father’s capable) because he is my son, I see him since birth that’s why (Father feels capable). Another woman coming to look after him needs a long time to understand him so I don’t understand what she is saying? (Referring to settlement worker suggesting another person cares for his son).

While this father felt the settlement worker was prejudiced based on where the family came from another father described his experience with a social worker who he believed withheld services due to the family’s religious beliefs:

Father: If nobody tell me about it how can I ask & how can I know that?, I know he need and he need and he need but in the end can he get or he can’t. I need somebody sometimes to tell. And so it’s sometimes always about who you are dealing
with. We dealt with a social worker, we had a bad experience in the end, I talked with her for a long time then we find out she has something against the Muslim people because four families, all Muslim have some problem with her. So then I went to talk to her supervisor and she replace her with another social worker. And it was totally different. We know after that from that social worker so many extra things he can get. She told us about, the wheelchair. We learnt the at home program can provide for him a wheelchair and other stuff she told us about.

In contrast to these two families’ accounts, about information being withheld was the notion embedded in other families’ stories about an understanding of care or resource inequities which existed for people in the families’ countries of origin. This concept added an additional layer of complexity as to what influences immigrant families’ decisions as they decide what services they access and use to meet their child’s needs. Several families were mindful that since arriving in Canada they had already received considerable help and many expressed the wish not to further burden Canadian society. Rather they hoped for autonomy and independence from others which included sponsors, extended family or healthcare professionals/services.
A Desire for Autonomy and Independence

Resourceful and Capable

The majority of families interviewed came from countries where there are limited resources or services available to the population regardless of whether the person has a disability or CHC. Although all families were eligible for at least some Canadian health care resources, the families in this study varied in the extent to which they were willing to draw on these resources. One family expressed the desire to only receive enough help necessary to allow the child with a disability to be in school. The father felt while his son was in school he, the father, could do extra training or find a job. This father expressed his desire to independently support his family:

Father: I can look after my son properly and at the same time earn a little money for survival here for my family (reference father’s wish to self-sufficient).

So I’m still eating on my sponsors (reference family is still reliant on sponsors). They (sponsors) have a one year agreement and that is why I’m going to take the course because after one year I must have to settle myself. I don’t know I don’t like to beg money from government. I’m not a beggar. They gave me the opportunity to come Canada, this is enough for me.

Other families drew on resources outside of the health care system. Some families spoke about extended family members’ willingness to help out when children
with disabilities or CHC were younger. However as the children got older this generally became less and less available to the families with children requiring additional care. When the family with three sons who have a CHC was asked if the extended family helped at all with the children with CHC, the father just replied “no.” He further stated “We don’t want someone to give us a favour. In the beginning, yes they helped with first boy. They are also getting older and you know the same old story, they have their own family.”

While this family’s two younger boys remain at home, the older boy lives with a foster family. However the father spoke about not wishing to over burden the foster family and even though this foster family is paid to provide care to the child with CHC, the father did not want to cause the foster family to burn out.

Father: ….. we say if they (the foster family) need respite, we care about them. Sometimes they need one day, 5 days, we take him (son with CHC) a lot, we take him in the summertime, at Christmas, any holidays, they want to leave the boy with us, no problem.

This last comment demonstrated the tension that exists for many families who have a child with disability or CHC; an appreciation for help of others coupled with the frustration of a complex system and the never ending burden of caring for a child with CHC. The next section discusses a different form of appreciation demonstrated by the other study participants.
Expressing Gratitude

Some families compared their situations here in Canada with people they knew in their countries of origin, emphasizing their gratitude for the resources they could now access. They described how thankful they were for the care their child receives living in Canada and how different life would be in their countries of origin. One mother spoke emotionally about knowing a mother in Southeast Asia who had a child with CHC. The mother interviewed explained the difference between life here and life there.

Mother: I see somebody here (in Canada) even if you don’t have a child, if you don’t have a job at least you can get the money from welfare to help you: they (welfare) pay for rent and food. But back there (Southeast Asia) they don’t have money available to those in need. Take me for example, if I don’t have a job, welfare will help me by giving me some money to buy food or pay rent. But over there (Southeast Asia), they (government) don’t have to do that. So they (general population) have to go work hard, they have to earn a living. Therefore they don’t have much time to take care of a child with special needs. And the government, the social services, they don’t have respite home, or somewhere else to take care of the child. So it’s very hard.

This mother further described a conversation between herself and a mother in Southeast Asia who had a son with CHC.
Mother: I see one lady who has a child similar to Penny.

I asked her what care she got from the government.

She said she gets about $10 a month. But you know $10 is very little. It’s not enough for anything. Her child is very sick and has seizures. The medicine to control seizures is very expensive. So there are times she (other child’s mother) cannot do anything. It’s very tough, it’s very hard there (referring to other country).

Acknowledging the advantages and supports she has in Canada this mother explained when she visits Southeast Asia she will give money to the other mother so she can buy food for her son. The mother (participant) further explained as she started to cry:

Mother: I know what it’s like because I have a child like hers.

I know how she (other mother) feels, so it’s very hard.

This mother’s recognition that others are sharing their resources to support her also extends to others. For example frequently this mother (participant) will pay for her daughter’s medication in the hopes that it leaves money in the healthcare system to offer support to someone less fortunate.

Mother: if it is something I can afford, I pay for it myself.

I know if it’s a medical item, the government and social services could pay however they have already helped me a lot with Penny’s care. So if it’s something I can do myself, or I can afford to pay for I will, I think
there are some children and families who need the help
and that money can go to help those people. I’m lucky
I have a business, so I have money, I pay for this and
that for Penny.

Another mother also seeks to ‘give back’ and share her own resources which in
her case is her expert knowledge related to navigating the health care system. She
volunteers to provides advocacy support to other families who have children with
disabilities or CHC. While attending medical appointments with her children, she
frequently meets other families who have children with CHC. This mother is aware that
professionals caring for her children with CHC have gone over and above their regular
daily work to ensure these children receive the equipment or care they require. As a way
to pay this kindness forward this mother explained she tries to help other families.

Mother: So believe me they (therapists) went above and
beyond to help me. I’m so grateful for that assistance
because now knowing what they did for me I can help
other families who don’t know what they are eligible
for and how to access it.

This mother explained she met a family whose son with a disability didn’t have a
wheelchair or adequate bed therefore transportation and sleeping arrangements were
difficult for him. She was able to help the family learn what steps to take to access the
healthcare system and how to ask for financial assistance.

Mother: I met a family who said their son (who’s disabled)
doesn’t have a hospital bed so he sleeps on the floor.
Their son doesn’t have a wheelchair so he goes on a trolley because the wheelchair he needs isn’t funded (by the government). The family don’t have enough money but they can apply to a charity for financial assistance, but they’ve never been told this information.

So I tell them “you can do this step, and that step.” I write letters and when I can I go with them to appointments to tell professionals this is what they (the family) require. I’m going to tell you this is how we can help these families.

One family talked about the community help they received when people discovered they had had twins. It’s an example of how other Canadian citizens want to help regardless of whether they have a child themselves with CHC:

Mother: Since we came to Canada, Canada has been very good to us. People are friendly and very helpful. The community itself when the people know I had twins, even in the hospital and I don’t know them, they give me clothes (for the babies). Even his (husband’s) colleagues at work they would know I was pregnant and offer us toys, clothes, coupons for baby milk and stuff like that.

These participants’ accounts demonstrated varying degrees of insight and appreciation as they strove to become autonomous and independent in their Canadian life.
It highlights how their child(ren) with a disability or CHC have been accepted by some people in Canadian society as being worthy of having resources or funding provided to their families in order to improve the child(ren)’s health and wellbeing.

However as their stories unfolded feeling of frustration was beginning to emerge. I was intrigued because at the beginning of the interviews everyone had spoken about the Canadian healthcare system offering better treatments or services to their children with disabilities or CHC. However as the interviews progressed people started to express frustration about the inequities or inadequacies they were identifying within the Canadian system. While the mothers seemed to accept these issues and spoke about assisting individuals either by limiting their own access to resources or advocating on others behalf; the fathers were more vocal in sharing their thoughts about how to improve the Canadian healthcare system. These paternal reflections were interesting because it appeared the longer a family lived in Canada the more disenchanted they became with the Canadian healthcare system

**Frustration About Available Resources and Perceived Inequitable Distribution**

The father who has three sons with same CHC was dismayed to think that technology is available which could detect brain abnormalities in utero however its use is limited.

Father: If you *(referring to doctors)* have the MRI in your hand and the technology in your hand use it because you are human. To control disability in this country for example I might suggest the government spend the money to give every pregnant lady an MRI so you can see if there’s a
problem or not. Then the family can decide if they keep the baby or not. To give good service you have to start in the beginning and I know many things. I know about rules, the Canadian government pays a lot of money for ladies to go to US to terminate pregnancies at later stages.

This father also discussed his sense of unfairness about services and resources available to other populations. He compared the services offered to drug addicts at safe injection sites or training programs for young offenders in youth jails to what is available to families with children requiring additional supports. This gentleman was very vocal in his disagreement with the government’s view to allow immigrant families entry into Canada with their children who are disabled or have a CHC. He felt Canada should look after its own citizens first before offering help to other countries’ citizens.

Father: They (government) bring lots of families from different places in the world even if they have disabled kids with them. That’s wonderful, that’s very nice however I’ve given you examples of people born here with disabilities who need help as well. If you help other countries, but cannot help your own citizens, we don’t want show the world we are ok. If you have the last bread at home, you give to your kids first and then offer what’s left to the neighbour.

This parent’s accounts illustrate the challenges of reconciling service provision for individuals’ within the context of broader social policy.
When there are more people requiring assistance or services it’s inevitable there may be delays or limited resources available. Families shared stories about the delays in services and their frustration especially when they couldn’t understand why there would be a delay. One family talked about the delay to have their twins assessed by a psychologist. As I listened, I realised at time of the referral the boys would not have been developmentally age appropriate for certain psychological assessments. So a delay would have been reasonable if the healthcare team hoped for optimal assessment results to guide recommendations to meet learning needs or therapy services. But, parents do not always see the limits of the professional services that are available.

Father: Sub specialty team at (tertiary care centre) referred him (son with CHC) to (assessment centre) that was I think 2 years ago.

Mother: They (the sons with CHC) were still in preschool, but it took a long time to get into (assessment centre) just to make sure they were ok.

When asked if the delays were due to child not been developmentally age appropriate the father replied:

Father: yes, but at the same time they (healthcare system) have limited resources of doctors especially for case like my son and other kids. They need very specialised doctors and I think they have a shortage.

His son with CHC also had to wait for an MRI which concerned his parents because they felt all they could do was wait and see if he was going to develop normally:
Father: Well they (Healthcare team) said “we don’t know”
so until he got his MRI we had to watch and compare his
progress to his brother. This wait for MRI took almost
2 years because it wasn’t an emergency so they don’t
schedule it sooner. There is I think 30-40% chance of brain
damage for the condition he has, so we were scared because
we wanted a normal kid. So for 2 years all we could do
was watch him and compare to his brother.

At the other end of the age spectrum was the interview with the mother from Asia.
Her daughter (with CHC) required a psychologist assessment to determine eligibility for
adult services as the healthcare team prepared to transition the child’s care from
children’s services to adult services; a process that needs to start at age 14 years. The
family had spent two days at a pediatric speciality center so their child with CHC could
undergo the necessary assessments. When the mother was asked why the assessments
were required she explained:

Mother: Mainly the request is from (organisation providing community
care services) to see if Jane is eligible for their program. The
doctor has to assess Jane on her basic needs and whether she’s
able to respond to other stimulation, that she’s aware of the
outside world. Something like that.

Although her child with CHC is preparing to transition to the adult world, this
mother is concerned about what the outcome will be:

Mother: she is still a child, a small baby to us. Her mental age
is still below one year old. But society will think she is an adult. Even when I go to Sunny Hill the doctor, social worker said I should apply as much as possible because the government is more kind to child than when she is a grown up.

This family’s story highlighted the processes a family needs to go through in order to justify the need for services or help. This child with a CHC is still functioning as an infant however the healthcare system expects her (the child with CHC) to participate in assessments in order to prove she needs supports. Although not part of this study, I wondered what affect this situation may have on a mother’s mental health as she has to retell the family’s medical and social history during these assessments. What feelings or thoughts are reopened for a mother as she retells her story in order to justify her daughter’s need for supports? This story also highlights the feelings of many families who use services funded by the ministry of children and families. The necessary arrangements, assessments and paperwork required to have their child transition to adult care services; a world that brings different challenges because services to adults are greatly reduced. Regardless, the families I spoke to were convinced life anywhere other than their country of origin would bring about improvements for their child with a disability or CHC. Even healthcare professionals in other countries were seen in a negative way. Some families had had a negative experience that impacted their views on healthcare and services in other countries. A family shared the following encounter which left the mother very emotional and adamant she would not put her children through the experience again.
Mother: there was one time I went to the Persian Gulf,
I took the kids and they were little ……….. I
didn’t want them to miss their physiotherapy…..
so we found a centre. ……….. The physiotherapist
I believe I don’t know his ethnicity but he was
speaking in Arabic, I don’t speak Arabic but my
husband speaks Arabic so he translated for me.
While we were there the therapist was more concerned
about the kids’ drooling than doing anything about it.
He was concerned about the drool touching him. So I
literally got mad and told my husband I was never going
to go back and I didn’t care what happened because the
therapist was offensive and he was not hiding it.

The mother further explained:

Mother: The system is like the handicapped is taboo. That was
2004 so I haven’t been back there, no way, no how,
I’m not taking my babies there.

This demonstrated that preconceptions were not only held by community
members but in some instances also by health professionals. This negative experience
had a profound effect on her desire not to return to that country even though her husband
still lives and works there. There was an unspoken desire for her children to be treated
with respect and dignity regardless of their disability.
These participants’ accounts and reflections on their experiences allowed me a more in depth understanding of the complex array of considerations for families as they immigrated to Canada. Their overriding concern was to create a better life particularly for the child with disability or chronic health concern. They longed to be in a place that would accept their child in a more favourable light. The next section will focus on two central concepts identified in this study: Creating a future and Personhood. An analysis of these concepts hopes to enhance our understanding of the findings.

**Creating a Future**

**Balancing Act**

The families in my study spoke about wanting to make a positive contribution to Canadian society. However as they establish a life here they are tasked with balancing family life, employment, caregiving and maintaining their own health and wellbeing. This is not dissimilar to other researchers’ findings about families who have a child with a disability or CHC (Lingren, 1993). Two fathers discussed how they once owned businesses and were employers to a number of people. However the burden of caregiving and supporting their child(ren) who have significant health problems and require frequent hospitalisations, has meant the fathers could not focus on their businesses. The inability to focus on their businesses in competitive markets has had a detrimental effect resulting in the fathers losing their businesses and becoming employees in other people’s companies. One father spoke openly about his frustration that if families decide to keep the child with a disability or CHC at home there is limited resources and money available to the biological family. There was a sense of unfairness, that the system was perceived
as punishing parents who are willing to care for their disabled or medically compromised child at home.

Father: There’s a lot of families trying to care for their child themselves. However it places a lot of pressure on the family and in my experience a high percentage of these families who have children with disability end up divorcing or separating because of the pressure. Is it the pressure because not receiving a good service (referring to funding) from the government?

One mother explained how she had to terminate her employment because she took too much time off to attend her children’s appointments:

Mother: I used to work, my previous company they know (about her son’s issues) because I have to take day(s) off, I have to bring him to see doctor. However, I take too much day off. (Employer) was accepting. But company very busy, (mother had to leave) so I’m just looking for a part time job, maybe few hours a week. Looking say in September when the kids back in school. Very hard to go back full time. Have to think what’s the best for kids.

When the move to Canada meant improved healthcare or access to services, the child with a disability or CHC was undoubtedly the recipient of a positive outcome. However, the stories shared in the interviews contained positives and negatives aspects to
relocating the family to a new country. Consequently, for some families the desire for a better life brought issues that affected not only the affected child but also the family unit as well as individual family members. Some family members may have also gained improved healthcare, educational opportunities and safe living environments. While others may have sacrificed much for the opportunity to create this better life of which they may not have benefited as much in the long term.

**Sacrifice on a Personal Level**

One family demonstrated many sacrifices by coming to Canada. This family were refugees and demonstrated characteristics listed by Sotnik and Jezewski (2005) “loss of most of one’s belongings, lack of personal emotional and physical preparation; no choice of one’s next destination” (pg19). They left behind “rooted memories, achievements and love for their abandoned homeland” (Sotnik & Jezewski, 2005, pg. 19). They were separated from their mother/wife who had been relocated to a different country and due to misfiled paperwork was unable to join the family in Canada. However to move to the other country and reunite the family would mean the daughter, unaffected by a disability, would be unable to complete her studies. Her father felt to move again would mean losing what she had accomplished so far. In addition his son who has a disability had already been waiting several months for a developmental assessment needed for school attendance:

Father: I can live, I can do anything without knowing the language, because I can use body language. She (daughter) need to study to make her future that why we not choosing to go there (country where
wife lives). And you know the five months already needed to process my son’s case. If we go there (country where mother lives) maybe another year spoilt for him. That’s why I’m not willing to go there. Still we are in the contradiction. My wife thinks she’s in heaven that country much better than Canada. It’s farcical thing, Canada is the most beautiful place and the second largest place.

During the interview the father failed to acknowledge the missed opportunities for his children, growing up away from their mother meant they were denied the ability to form a bond with their mother. Indeed the daughter had the educational opportunity here in Canada which would be needed to establish a career. However it also meant she was denied a relationship with her mother and opportunities to learn life lessons from such a close female relative. The father did recognise the continued separation meant he was the only other family support available to his children in Canada, however he was also sacrificing a relationship with his wife; something he chose not to discuss during the interview. In addition this father was now primary caregiver to his son with a disability; a role usually undertaken by the mother:

Father: That’s my duty, that’s my duty, that’s my natural duty I have to carry on. Actually the duty is not only belong to me, his mother also has to take the responsibility. But when she’s not here so he’s hanging with me it’s very natural so I can’t avoid
my duty as a father.

This caregiving role meant the father was limited in his ability to gain employment and become the family’s main “breadwinner” a role usually held by the male family member. As this case suggests decision making about the best way to secure a future for immigrant families is not a straightforward process. There are a number of factors to consider some of which will affect individuals or the family unit as a whole.

**A Different Kind of Sacrifice**

The family’s decision to remain in Canada while the mother was forced to live elsewhere was in contrast to a family from Asia who made a predetermined choice for their child to remain in Canada with extended family. The mother explained this enabled them (the parents) to return to Asia for business and career opportunities in order to provide financial assistance to the relatives remaining in Canada who were now the primary caregivers to their daughter with CHC. This family’s situation intrigued me because I have spoken with other parents who decide to remain in Canada and have their child raised by grandparents in their homeland. This family’s situation appeared to be the opposite. In fact I wondered if this family had chosen to have the child remain in Canada as a means to segregate the child from the Asian community. As Sotnik and Hasnarin (1998) explain “the disability represents a wrongdoing by the parents or ancestors and is considered a source of disgrace” (as cited in Sotnik & Jezewski, 2005, pg. 27). In this family’s case the parents are first cousins and due to the consanguineous relationship they were aware they had a 25% chance of conceiving a child with a disability. The mother explained she and her husband had studied in Canada and on graduation returned to Asia to work and start a family. After their daughter’s birth, she explained Canada’s
healthcare system and acceptance of those with significant health concerns were reasons for their family’s return to Canada:

Mother: ….. we have Jane and we thought overall everything is healthy during her checkups. So we decide to have Jane raised back in Canada so we moved back. So after about a few months we learnt Jane is not responding well as a (typical) 4 to 5 month old girl so we start doing investigations & we find that she has significant visual impairment and CHC. So we moved to Canada (permanently) because we know Canada has a good medical & also has pediatric specialty centre & also the service is more leaning to these children. That’s the main reason that we raise Jane here.

In many ways this mother’s situation was similar to family #1’s mother. Two mothers living away from their children and having their child with a disability cared for and raised by other family members. This adds another burden of care onto families as well as providing another reminder to them that their child is different and may not be valued in the same way as a typically developing, healthy child transitioning into the adult world. This leads to the second concept to be presented, personhood.

**Personhood**

All parents in this study, regardless of personal circumstance, wanted their child(ren) to be valued as a person by the family and society. As a child gets older parents all express the desire that their child will make a contribution to society.
However, for a child with disability or CHC these contributions may be limited or different because of their health issues and developmental abilities. Nevertheless the parental wish for the child to establish or maintain their personhood may continue throughout the life span; especially if the parents have spent much of their own life advocating for their son or daughter with a disability or CHC to receive the same recognition as a person as any other member of society.

**A Life to be Valued**

The families interviewed shared many examples of how they or their child(ren) have been perceived and for some there has been the need to redefine who they are within the family as well as the larger communities. One family shared the following experience:

Father: Actually it was so complicated when

he was first born, you know they (*Doctors*)

gave us a hard time... by the time they found

out......... they started to send messages (*indirect*)

to just let him go. He was having trouble breathing,

he almost died, his colour changed. Almost died

and this I thought was one of the messages especially

the way they were telling me, it was like they

explained to me, he was like he was going to be

like a meal in front of me on a table, just breathing,

like up and down and that’s it. So I say again,

really it was not nice and I told them “you don’t

know anything about me, about our culture, about
our background, about our religion, so no matter
what he is, as long as he’s here you are not going
to be the one to decide to let my son die.”

This child was viewed by the family as a gift, specially selected for the family by Allah. The family viewed the child as valuable and worthy of receiving the appropriate medical attention to ensure he survived the traumatic birth event which has left the child brain injured and in need of total care. This family couldn’t even conceive the thought that their son wouldn’t be given the necessary care to allow him to live.

Another mother explained that the family was content to have the child with a disability as part of their family. And while they did not like the fact that she was atypical in her development and had health issues, they felt “happy” to have as a family member and included her as much as possible in family activities:

Mother: So I’m sad anyway it’s like we hopefully

the medical can help her or whatever, but

there’s nothing we can do. Because er, she’s

sick, so we know, I feel bad for her because

she cannot have a life like a normal kid. But

we know she come to the family so what we

have her like we are happy. We not really happy

because she’s sick. But we happy to have her

around the family, we only wish she’s ok.

We are very happy we have her.
It was the desire to keep these children within the family unit that had one father explain how he has tried to gain supports at home for his family to care for his children with CHC rather than choosing residential or foster care:

I’ve been to the member of parliament.
I’ve been everywhere to keep the boy under my roof. When you care about baby to keep him alive because if you don’t here is the reality; baby doesn’t live. Anyone if you are not eating anyone dies, so when you force someone to eat to keep him alive you have to care about how’s his life go with his family, not I just want to support the baby & leave the family.

This father was very passionate about how his son should be allowed to remain within the family home. He felt his son should have the right to be care for by his parents and grow up with his siblings. These vignettes echoed similar parental’ views in other studies with immigrant families residing in other countries (Maloni et al, 2010; Bryant, Ahmed, Ahmed, Jafri & Raashid, 2011). And affirms how professionals cannot always know or predict how a family will accept their child with a disability or CHC. None of the families in my study spoke about their atypical child being a burden on the family whether from a caregiving perspective or contributing to financial hardship because a parent could not work due to providing care. However, it does highlight the ambiguity of a family’s situation; how it can vary depending on life circumstances, family histories,
values and beliefs. All of which contribute to how people define themselves and others within a family unit or the larger community.

**Re-Defining Self**

The families talked about their status as immigrants or refugees and how this negatively influenced their experiences. They did not wish to be known by the labels of immigrant or refugees because for some families the labels held negative connotations.

One family described their experience of living as refugees in a country they felt vulnerable and described being treated as second class citizens in their country of refuge:

Father: kind of hateful society (*reference to fact as refugees they felt oppressed, unable to travel freely, etc.*).

Daughter: Because we are Burmese and he (*brother*) shouts.

Father: The neighbours look down on him.

Daughter: Throw water at him when he shouts, so very heartbreaking. I cannot do anything because we cannot go tell the police what did he do. It’s very heartbreaking, yes very stressful at that time.

For this family, everyone felt “like second class citizens” and the societal stigma of either being a refugee or a person considered different because they acted in a way not acceptable to the societal norms. The daughter/sister’s comment that she couldn’t do anything to help her brother revealed an expectation that siblings often feel the need to be protector, caregiver and advocate for their siblings who are disabled or affected by a CHC. However, the father later stressed he doesn’t wish to over burden his daughter with
a caregiving role to her brother. This father was very aware his daughter needed to develop her own identity as a young adult.

Father: Yes, I don’t like to waste her time because (points to his daughter) she has a future, she has to build her future herself. I can’t help now she is 19 years old she has to do it herself. So she has to try hard so I don’t like to waste her time with him (pointing to his son).

However this young woman was required to attend school during the day and return home to look after her brother as well as participate in household activities such as cooking and cleaning. I wondered if she felt a loss of her own identity as a daughter and sister, as she became a care giver to her father and brother.

In fact other families also spoke about the siblings taking on alternate roles. The twin brother of a child who was struggling with self-esteem due to facial deformity was described by the mother as “really helping us” even though the child in question is only 6 years old:

Mother: And his brother is really helping us, very protective.

……..Yes, he’s like his guardian angel. His brother helps him out. He says “James lets go” & yes he’s with him. We always felt that because he (child with facial issue) always gets depressed & like, feels sad. He feels sad & his brother is always like “if anyone bothers my brother I’m here for him.”
Interestingly this mother’s next comment didn’t speak to the fact that her 6 year was taking on this new identity of protector. Rather, she described the need for James (the child with the CHC) to “stick up for himself”.

Mother: But I know it’s wrong we don’t want his brother to
do this anymore. He (James) has to stick up, like
stand up for himself. So we are trying to tell his
brother to stop doing that.

The interviews highlighted other family members shifting their identities from being a close relative to establishing themselves as the child’s primary care giver. One family has the sister in law taking on the caregiver role. This woman is the child’s aunt and even though the child is a teenager, due to her disability and CHC, she requires 24 hour care; something the aunt does with minimal additional support. The mother explained:

Mother: OK so that’s Anne my sister in law, my husband’s
sister and Nanny (elderly relation). Anne also lives
downstairs so they (Anne & Nanny) rotate to look
after Jane during day time. So after about 10 years
ago we received some respite so we can have some
in home service. A caregiver comes in to relieve
Anne so she can go & do her own things. Yes, so
we received about 30 hours a week for almost about
for 10 years…… Anne sleeps in same room as Jane
to give her every night rotation so to roll her from side
to side & turn her around. Also in the past Jane was
on continuous feeding during the night time. So have
the feeding finish by about 4 or 5 o’ clock she (Anne)
would get up & flush the feeding tube or change
diaper.

This account illustrates ways families re-organized to manage caregiving for the
children with disabilities or CHC. In this case the extended family living in shared
accommodations the caregiving role appeared to become a caregiving career for the
child’s aunt.

The challenges of family caregiving, particularly when siblings are involved, has
been explored by Aldridge and Becker (1999) who suggest that “some degree of caring in
childhood is both routine and to be valued and encouraged as a part of ‘healthy’ child
development” (pg. 304). However if a caring role during childhood becomes excessive
and the child begins to fit the definition of a ‘young carer’ then the caring may have
detrimental effects on the child providing care (Aldridge & Becker, 1999). When the
sibling with a disability or CHC care needs have a substantial effect on the family’s
resources then the parents may require the ‘unaffected’ child to take on some of the care
tasks; especially if the family has limited or no extended family support which maybe the
case for many immigrant families.

As the preceding accounts indicate a child’s CHC or disability impacts all other
family members and, in most cases in this study, different family members added
caregiving to their previous roles. Over time this caregiving role seemed to extend
beyond just taking care of the physical needs and moved into the realm of advocacy.
Especially as the caregivers recognised gaps in service or negative societal views towards these atypical children.

In McKeever and Miller’s (2004) research parents who advocated for their children were often viewed as “the squeaky wheel” (McKeever & Miller, 2004). Others have described such parents as “needing to become adversarial or difficult with service providers in order to obtain desired services for their child” (Larson, 1998, pg. 867). One of the fathers who participated in this study explained how he had confronted physicians who in his mind were “writing his child off” as being not worth saving:

Father: it’s as simple as somebody who loves you, maybe your husband, your boyfriend, if he gives you a gift & you don’t like it because you think it’s cheap & you throw it up in his face, how is his feeling? So my God gave me him as a gift, I’m not going to return him back, and I’m the one who has the right to take his life. That’s why as long as he has life, I’m going to keep that chance for him to live. And I told the doctor, “ok if anyone of you brave enough too, all of you can do a surgery, don’t just remove his tube take your knife cut for me his neck. Don’t tell me it’s a merciful death, it’s a crime. What’s the difference both of them is killing.” So at the end they start asking us, the social worker starts to communicate with us, so the doctor he starts dealing with us while we were there.

Although this father explained he did not undertake the day to day care activities for his son unless his wife was ill or unavailable. He felt proud that he could undertake the role of spokesman for his family and in doing so garner the necessary care his son required.
Green (2007) discovered in her study with mothers of children with disabilities “over
time mothers begin to gain skills in advocating for their children. These skills and the
accompanying confidence can spill over into other areas of life and become a source of
self-esteem” (pg. 158). I would argue this also applies to fathers as evidenced by a
number of fathers in my study who spoke about fighting for services. One father in
particular described how the healthcare and social system should be changed to allow
parents to become the paid care givers for their child. By doing this the father felt parents
could remain at home rather than delegating the responsibility to others and then having
to go to work to earn a living in order to maintain the family’s standard of living:

".....let’s give the family the chance. They have
the baby born, ok, you want to keep the
baby with you (parents)? We (government)
give the money, $2000, to help you live.
And we’ll say one of you (parents) can leave
the work to care for the baby. They (government)
don’t do that, they don’t do that. They prefer
to give $6000 for example to special care or
give $3000 to foster family but they don’t give
the choice for the family. I want to keep my
baby like any family, keep the baby under
my roof.

While not all parents were engaged in advocacy outside of the caregiving domains
they all recognized that their children’s unique circumstances required that they develop
the ability to explain their child’s needs to the healthcare providers in order to ensure that
the appropriate care and services were made available.

In addition to managing their children’s health challenges, all of the study
participants were trying to establish themselves in their new homeland. For some
families how other people viewed them was important because they wish to be seen as
capable and contributing to family life or society. While the day to day caregiving role
may have fallen to the female members, the fathers wanted to share their contributions to
the family whether as the financial provider or as an advocate. However some interviews
highlighted the fact it was not only family members who were redefining their identities
whether positively or negatively. Some families’ stories described how their child with
disability or CHC was situated within the family to demonstrate attempts to reaffirm
these children as valued members of the family. In doing so there appeared to be a desire
to positively establish the child(ren)’s identity other than a child who is flawed or
devalued.

**Defining the Child’s Identity**

In the following quote/exemplar one mother describes how her extended family
views her child with a disability and do so with a desire that others will see the child in a
positive light. The mother from Southeast Asia shared how her daughter is accepted by
the family and “spoilt” by her (the child’s) older sister who no longer lives at home but
frequently visits and will bring her younger sister gifts:

Mother: Everybody love her. Everybody love her. Her cousin,
her niece, her auntie, brother everybody. They spoil her,
they buy a lot of stuff for her. So my daughter she just
bought this for her *(hold up a Hello Kitty blanket)* last month…… Anytime they come back, they buy her lots of clothes for her. She has a lot of clothes. All the teachers say “Angie you have a lot of beautiful clothes.” So you can see she even bought her, see her shoes. *(opens two drawers full of shoes)*. Lot of shoes, alot of stuff, see. They bought her a toy computer, everything. She has lots of things, they spoil her a lot.

This mother proudly showed me her daughter’s clothes and shoes. It was a touching example that the family was seeking to recognise the child’s personhood especially because this young girl is developmentally compromised. Her mother was attempting to define her child’s identity as a “normal” teenager despite her disability. By making sure this child has the “beautiful clothes” and “lots of shoes” it gave the child worth because isn’t this what all teenage girls desire? The positive comments from teachers highlighted the fact the family would be seen as taking good care of this child who was very medically compromised. The material items whether clothes or toys served as a natural “hook” for others to want to interact with this child who was limited in her communicate and abilities. Her situatedness in the family was described by her mother:

Mother: We feed her like the family with healthy food. Sometime we give her some special medicine, we take care of her good. She lives around a family, who’s loving her,
taking care of her. You know, it’s very important for her because she very happy, like when everybody around her, play with her. Or we bring her out she very excited, happy we have a very big back yard. The kids take her out, like I show you. So here we buy the plastic pool we put in & then the kids they go swimming. She sit there we bring her bath chair & I put her bikini on & she sit there with them, they play with her……..she enjoy it.

This family’s interview comments echoed the sentiments in other researchers’ work whereby “mothers invested enormous cost and effort to ensure their children were dressed well and fashionably” the intent to “symbolically signal the ‘worthiness’ of children with disabilities by dressing them well” and worked hard at ensuring their children with disabilities attained “the status of person” (McKeever & Miller, 2004, pg. 1187).

The mother of child being raised in Canada by extended family, shared information about life when her daughter was younger. She talked about the outings and activities they did together when the mother visited. She talked about her daughter, Jane, smiling, demonstrating some response to stimuli, and small enough to be easily carried or transported in a car. The photographs around the family’s living room were testament to this fact however were in stark contrast to the older Jane who showed no response on my arrival at the home. As Jane gets older, she gets bigger and her Canadian caregivers are
aging. Her mother explained “Auntie is older and the physical work is a strain as she looks after Jane, who is also growing bigger and bigger” and “going out in the wintertime is cold for Jane, we don’t have a big wheelchair van so it is difficult to carry Jane.” The mother’s earlier memories of her child are what help this family continue to see this child as a valued member of the family. This child’s disability has led to her isolation from the larger community because she doesn’t attend school. Her family rationalised this segregation as a way to limit the child’s exposure to potential illnesses that could have a devastating effect on this young girl due to her precarious health status. Consequently this is another example of a family valuing the child and demonstrating the desire to keep her safe and well.

**Summary of Findings**

In this chapter I have documented my findings of the participants as they described their experiences and perceptions as an immigrant family raising a child with a disability or chronic health concern (CHC). As I listened to the families’ stories I was able to identify three main processes. These processes helped me gain a new perspective as to why these immigrant families chose to access and use certain healthcare services. I categorize these processes as: desire for a better life and healthcare; families’ experiences with accessing services in the Canadian context and desire for autonomy and independence. The second part of this chapter focused on two specific concepts chosen after further reflection and interpretation of the data. These concepts were creating a future and personhood. In chapter five I will discuss my findings further and consider the implications of these research insights for practice.
Chapter 5 Discussion

In this chapter I will discuss how the findings confirm and advance current knowledge about immigrant families who have children with disabilities or chronic health concerns (CHC). Through this study I hoped to gain an understanding as to the families’ perceptions as they attempted to access and utilise health care services for their children. In addition, I intended to identify influences that may have informed their decisions when meeting their child(ren)’s health care needs. A synopsis of the findings will be presented and implications of the study findings for practice and future research will be explored.

Synopsis of Findings

The purpose of this study was to describe and explain immigrant families’ experiences of accessing and utilising healthcare services within British Columbia for their child(ren) with a disability or CHC. A total of eight families were recruited to participate in this qualitative research study. There were six mothers and four fathers participating in the interviews with two families choosing to include additional people: one family asked an older daughter to participate and another family requested the interviewer allow a family friend to be present and answer questions if appropriate. Between the eight families there were 13 children who had a disability or CHC. Eight children had complex healthcare needs which required significant medical intervention to help keep healthy within their primary diagnoses. The other five children required intensive cognitive and developmental assessments as well as ongoing therapy services to address any intellectual and developmental delays.

During the interviews the families shared a wealth of information that helped inform my present knowledge about families who have children with a disability or CHC.
Consequently, the information gleaned helped expand my knowledge and promote a better understanding about what services they utilised as well as any barriers they encountered on their healthcare journey. I was challenged to reflect on what else influenced these families’ thoughts and feelings as they establish a home and raise their children in Canada. In addition to gaining insight into these families’ experiences I identified two core concepts/processes that characterized their experiences: creating a future and fostering personhood were processes that prompted me to reflect upon these families’ experiences and consider the ways their perspectives shaped not only their goals for their children and their encounters with the health care system but also influenced the decisions they made about their family life.

The families who participated in this study have lived in Canada between a year and 27 years. They all described countries of origins which had limited resources to provide ongoing care and treatment to their child(ren) with a disability or CHC. The relocation to Canada was in the hope that a better life and healthcare could be provided to their children. Yet their stories resonated with issues and challenges the families faced as they established themselves in their new homeland. However, if you remove the ‘immigrant’ label some may say what these families face is no different to any other family who has a child(ren) with disability or CHC; a complex healthcare system which for some populations can be frustrating to navigate, inequitable in resource allotment and limited in service provision. In addition these families may suffer with the burden of caregiving just like other families with children or dependent adults. However, I would suggest immigrant families may have additional factors that would be worth considering.
Through analysis of the identified concepts and processes I was able to recognise how the families’ histories and experiences informed their beliefs, values and decisions. This type of information may help healthcare providers understand the family’s context and ensure an effective treatment plan can be developed. In fact the interviews conducted for this study probably only touched the surface and if follow up interviews had taken place additional data may have unearthed even more new learnings. The families I spoke with, wanted to tell their stories and have them heard not just listened to. Sometimes this type of information may not be possible to collect in the time allotted for busy medical appointments designed to address the salient health issues of the episode of care. Yet it is these stories behind the immediate medical interactions that can have a profound effect on how a family responds to treatment options or care recommendations.

**Revisiting What We Know in Light of What’s Been Learned**

**Service Needs and Utilization**

All the families interviewed are ongoing users of healthcare services. In fact their children required healthcare and social service resources in order to meet their basic needs as well as maintain their optimal health. This study’s participants will require ongoing engagement with both health and social services which will continue throughout childhood and into adult life. Thus they have much in common with other Canadian families with a child with a disability or CHC regardless of whether the family members were immigrants, refugees or national born citizens (Stevens et al, 2006); Yanti et al, 2006). As general literature indicates that many immigrants face challenges accessing services it was important to gain insight into the experiences of immigrant families with a child with a CHD or disability. This study aimed to fill this knowledge gap; by
undertaking this qualitative study I was able to hear from the families what professionals are involved, what role they played and how beneficial their assistance was in order to meet the children’s needs.

One insight is that immigrant families who have support workers or clinicians willing to advocate on the child’s behalf may be perceived as faring better than those who were attempting to navigate the systems alone. However, having access to support workers/services did not always mean that families felt supported. There were examples in my study that demonstrated families feeling some healthcare professionals’ behaviour was suggesting information and services were being withheld at the detriment of their child’s health and wellbeing. What I found interesting was families did not speak about the professionals being incompetent or inexperienced at their job. Rather they described these professionals’ attitudes towards the families as being racist and demonstrating discrimination. These comments about healthcare professionals being racist shocked me especially as many of the study participants described Canada’s citizens as accepting and inclusive of people with disabilities or people who would be considered different the societal norms. However, these remarks are similar to findings originating in studies from the US and UK (Burgos et al, 2005; Bywater et al, 2003; Guendelman et al, 2001) with families originally from Pakistan and Bangladesh. These observations draw attention to the need to build respectful relationships – ensure each person point of view is sought & considered as plans are made. It demonstrates the need for cultural safety to be practice within health care environments.

Cultural safety is a concept originally developed in New Zealand for working with their aboriginal people and is now used to gain clearer understanding about the
needs and relationships for other societal groups. De & Richardson (2008) explains that cultural safety allows healthcare providers to “question their cultural selves and the impact they have on the people with whom they work” (pg. 42). In addition cultural safety is “a way to work with highly diverse communities in a way that helps remove the barriers of ‘power’ and ‘authority’ and promotes equality” (pg. 43). The National Aboriginal Health Organisation fact sheet (2006) offers the following suggestions about cultural safety, it requires a healthcare professional to be “respectful of nationality, culture, age, sex, political and religious beliefs” and means “a person’s knowledge and reality is valid and valuable.” Therefore applying cultural safety to care encounters should reduce the use of generic care or treatment plans. Consequently it supports a family centered care approach to ensure recommendations are meaningful and appropriate for the family if they are to be successfully implemented and sustained.

**Barriers to Accessing Care**

**Complex System.** All but one child with a disability or CHC whose families participated in this study were born in Canada. The child who came to Canada with his family had been diagnosed prior to migration. However, due to British Columbia’s funding rules, he was required to undergo another assessment to ensure he met the diagnostic criteria for his health condition. This determination was critical for only after this assessment and confirmation of diagnosis would he be eligible for treatment and educational supports. In this case the parent was very accepting of this requirement, though expressed frustration at the length of time it took to get an assessment completed. Waiting meant that the burden of caregiving for the child rested solely on the family. This example prompted me to consider that in other cases of newly arrived immigrant
families, who do not know the healthcare system’s requirements the need for a reassessment may seem confusing and illogical particularly if their child already has been given a diagnosis and may have been receiving services in another country. Parents may view that the reassessment requirement may delay funding and therapy services which, for some children, may be detrimental to achieving a positive outcome.

It has been argued by critical scholars that the Canadian healthcare system is built on neo-liberalist principles which may contribute to structural conditions that privilege some groups over others. One manifestation of such principles is the notion of decentralization of services as the government reduces its role in economic regulation and social support (Morrow, Dagg & Pederson, 2008; Ramon, 2008). This role reduction occurs when a government transfers funds to local regions and empowers these regions to distribute funds according to identified needs of their given community and populations (Morrow et al, 2008; Ramon, 2008). This action means a government can distance itself from resource allocation and is not held accountable to meet the needs of disenfranchised groups. It has been argued that groups that may be disadvantaged by such decisions can include immigrants, refugees and families with dependants who are disabled or have CHC needs. The ideology of neo-liberalism is premised upon the view that people must take responsibility for their health and social determinants of health (Morrow et al, 2008). Such a stance operates under the assumption that all people have the ability to: understand their needs; make informed decisions; navigate a complicated health system and access resources. As this study suggests, this assumption does not necessarily hold for many individuals who, as a marginalised group, are limited in their control to compete for resources with the rest of society or are limited in their understanding, due language
barriers, to be able to make informed choices. The current fiscal climate means there are limited supports available and families are expected to take on more care at home. Even if a child is admitted to hospital for an acute care episode there is an expectation to have the child discharged as early as possible back home and into the family’s care. Thus, in the current socio-political climate, families who lack knowledge and or lack financial resources or who may be under employed because of their immigration status may be at particular risk for not receiving supports and resources to assist them in managing their child’s complex health condition.

**Burden of Caregiving.** In another era children such as those whose families participated in this research would have been offered or expected to live in a residential institutional setting. Not only because of the care these children needed but also the societal view of such illnesses did not suggest they had social value or potential. The parents who participated in this current study by working to capture their child’s personhood challenged this view. Additionally however, the shift from governmental care to community living has meant that institutionalised care is no longer an option. Children with disabilities and CHC needs now remain in their parents’ homes, sometimes into adulthood. This shift relies on the assumption that family members will provide the care to the individual and assist them to live within the community. However, as found in my study, the caregiving role usually falls to the female members and can place them in a difficult position as it is assumed they are capable and available to carry out the care tasks (Kirkham & Brown, 2006; Peter, 2004). These tasks can be challenging when there is no formal/professional support or training available to families. According to Peter (2004), “families often assume the responsibilities and attain skills of nurses but are not
give the remuneration or the regulated working conditions and protection of formal providers.”

Regardless of the child(ren)’s disability or CHC, the mothers in this study were the parent who met the majority of the child(ren)’s needs. This was also discovered in Yanti and colleagues’ work (2006), although in contrast to their work, in my study if the mother was not available then another female extended family member would take on the caregiving role. I pondered this situation and wondered if this alternate care giver was only found in specific immigrant groups. I have since learnt that some Chinese families will turn to family members first for help and care before requesting supports from the community or professionals (Lui, 2005). As revealed in my study’s findings this practise seems to still exist irrespective on how long the family has lived in Canada. Although it’s important to remember that a family’s beliefs and values can vary between generations (Lui, 2005). In my experience I’ve never known a Canadian born family to do this. In fact if the biological mother was not available then the family requested in home caregivers or the child went into a foster home. Yet as in my study, the immigrant families accepted another female family member taking on the caregiving role as the norm. However, as this alternate caregiver takes on the role it would be important to remember they potentially are giving up a lot of their own dreams or choices. This could create another form of burden on the caregiver as they suffer loss of self.

Yanti and colleague’s study (2006), also discussed mothers’ feeling stressed at trying to take their child out of the home. However in my study only one family expressed being overwhelmed with taking the child out into the local community. It was unclear if this was due to an underlining cultural belief about disability or indeed related
to the extra work entailed in getting the child ready or changing routines in order to leave the house. Yet when the outings were required to attend medical appointments all participants made the effort to leave the house and planned their activities accordingly to achieve this goal. I was curious if this was because many of the interviewed families had memories of how life could be for their child(ren) in another country and they were grateful to have such medical care available here in Canada so made every effort to get to appointments? In addition all the study participants’ whose child was in a wheelchair had their own transportation to get their child to appointments. However, this may not always be the case especially if families have limited resources to purchase wheelchair accessible vehicles especially if funding requests have been denied.

**Reconciling Contradictions: Being Grateful & Feeling Frustrated**

Many families’ stories demonstrated a tension between being grateful and feeling frustrated. Parents were grateful for what care and resources their child(ren) was receiving in Canada compared to what was available in their countries of origin. Nonetheless they were often frustrated because they were faced with waitlists, limited resources or inexperienced professionals. One family refused to accept the suggestion to remove care to their profoundly disabled son. This experience has stayed with the father and caused him to be suspicious of future healthcare interactions. This parent’s observations prompted me to consider if healthcare professionals make such suggestions because they were trying to be “kind?” Did they want to spare the family ongoing stress and care burdens associated with raising such a complex child? Or instead of taking the time to gain a clearer understanding about the family’s beliefs and values were these
professionals applying, what Daudji and associates (2011) warn against, generic and
generalised cultural beliefs? Or, did they not recognize the person within the child?

Health professionals and the systems of which they are a part also must reconcile
tensions associated with allocation of what are ultimately limited resources. How does one decide which patient groups will receive resources & what criteria will inform such decisions? In the current economic climate when either reduced funding or limited human resources means formal care supports may be minimal or non-existent are families being unfairly placed in difficult situations? With technology and ongoing medical advances we have the ability to save these children’s lives and keep them alive using medical interventions. Yet as a society we struggle to provide the families with sufficient means to care for the children at home. Minimal supports are offered and in the current funding and policy guidelines there is no ability to provide adequate monetary compensate to parents who have left their employment in order to care for the children.

As a nurse who worked in the community I witnessed the issues families faced. Many informal care givers were unprepared to perform basic tasks for a child with a disability or CHC. These tasks included feeding, bathing, toileting as well as more complex medical procedures. The child can become vulnerable to health risks if the caregiver is unable to competently complete these tasks. Relationships amongst spouses or other children can be affected because meeting the needs of the child with disability or CHC may take time away from other family members. This can be especially difficult for younger children who may not understand why attention is diverted elsewhere or focused specifically on their dependant sibling (Lubin, Schwartz, Zigman & Janicki, 1982). Within my practice area I frequently experienced moral distress as I identified the
additional support families required and witnessed the lack of resources available to meet their needs. A number of scholars have identified the prevalence of such ethical dilemmas among health care professionals (Peter, 2004; Rodney, Brown & Liaschenko, 2004).

I find myself asking if Canada has indeed offered the promise of a better life for these families. For those fleeing poverty, oppression, marginalisation and other stressors, have these stressors simply been replaced with other stressors? These new stressors could include lower economic status, loss of social support networks, language barriers, unexpected racism and discrimination (Chung, Bemak, Ortiz & Sandoval-Perez, 2008). For the families who participated in this study the overriding message is one of being recognised as people who come to healthcare encounters with different life experiences, histories and coping abilities. As one father explained, off audiotape, “I don’t expect you to learn everything about every culture that would be impossible. Just know we are human too but are different from each other even if we come from the same place.”

**Implications for Practice**

Varcoe and Rodney (2009) explain “western health care systems have a long history of unresponsiveness to the needs of patients, families and communities, particularly the needs of those marginalised because of age, race, gender, chronic illness, disability and so forth” (pg. 135). In our role of moral agents, nurses are called to take action to address this disparity. In fact families with children who have a disability or chronic health concern request help from health care professionals in advocating for their child’s needs in a service system that they perceive as very complex and often disjointed (Mackean, Thurston & Scott, 2005). The nursing profession familiar with ethical issues
and navigating the health care system is well suited as the health care providers to perform the task. Community or advanced practice nurses involved with these families can provide supportive care as the parents learn to deal with their child’s health issues and care needs. These professionals could also be the link between the family and other healthcare professionals or service agencies. The nurse can explain certain family characteristics, beliefs and values to others in the hope of demonstrating cultural safe care and help decrease judgements or barriers to care. As a moral agent, a nurse has an ethical duty to identify what is right and wrong and work towards improving the situation for the marginalised person (Rodney et al, 2004). This work would not only apply to immigrant families with children with a disability or CHC but any family living with these dependants. Engaging in processes and forums to develop and implement policy at the community level is nothing new to nurses. Since Florence Nightingale, nurse leaders have expected nurses to aid in community care and reform and if necessary take on leadership roles to move things forward (Sitzman, 2007). I agree with Storch (2004) that “nurses need to keep abreast of ethical issues impacting health care and to maintain a clear focus on the significance of those issues for nursing” (p. 11). However, it could be questioned whether nurses or any other marginalised group within society are able to support and advocate for another marginalised group? Furthermore it could be argued that nurses still need to work towards addressing their own disparities in a professional context.

It is important nurses are involved in discussions regarding different groups within society. Nurses are involved in people’s lives, listen to their stories and witness firsthand the effects of public policy (Sitzman, 2007). Nurses should raise issues of
inequity/ social injustice and be actively involved in how these issues can be addressed. For immigrant families with children with disability or CHC nurses need to actively participate in knowledge networks that share information between stake holder groups and provide opportunities to align with influential people. Frequently other health care professionals only see their piece of the situation. However, nurses see the bigger picture and take a holistic approach to complex issues. Nursing has a knowledge base that can bring meaning to the stories and experiences faced by immigrant families and their children as well as ensure the solutions are person-centered, meaningful and long lasting not just quick fixes which don’t address the deep roots of a situation. The study’s findings are helpful for nurses and other professionals as the families’ interview vignettes and subsequent analysis help raise awareness. In addition the information provides some additional understanding as to the actions or feelings facing immigrant families who have a child with a disability or chronic health concern. The findings emphasis how complex people’s lives and histories are and the significant impact these stories have on health care encounters. Reflecting on this study’s information will enable a healthcare professional to determine if there are knowledge gaps in their competencies to provide appropriate care this particular population. Certainly for myself, working in England and training in the Royal Navy, I was not exposed to the immigrant groups I’ve met here in Canada. As I reflect on my basic nurse training I don’t remember even talking about immigrant groups, cultural beliefs and values, or being introduced to any frameworks or models that would assist me in providing culturally safe care or services.
Implications for Education

As previously mentioned, Canada is a country built on immigration. Therefore, it is important healthcare professionals reflect on their practice and what additional education may be required to help in their professional development for working with different immigrant populations. However it is unrealistic to expect a healthcare professional to be competent in all aspects of different cultures (Groce, 2005). What is important is for healthcare professionals to appreciate there are “categories of human endeavour - among them: family, education, community and employment that are universal” (Groce, 2005, pg. 5). By understanding all immigrant communities will respond to these categories in culturally defined ways, the healthcare professional is better able to access and address the needs of the immigrant child and their families in systematic and rigorous ways. To assist healthcare professionals in this task it may be useful for them to review Dr Arthur Kleinman’s work. He developed a tool to assist care providers in learning about a person’s understanding of their health concerns. This tool will garner information necessary to assess the families’ cultural needs and in turn used to develop and deliver culturally safe treatment plans or services. The Kleinman questions (Kleinman, Eisenberg & Good, 1978), (some of which have been modified to fit the study’s participants’ situation) are:

1) What do you think caused the problem?

2) Why do you think it happened when it did?

3) What do you think the child’s illness/disability does to him/her? How does it work?

4) How severe is their illness/disability? Will it have a short course?
5) What kind of treatment do you think your child should receive?

6) What are the most important results you hope to receive from the treatment?

7) What are the main problems your child’s illness/disability has caused them?

8) What do you fear most about your child’s illness/disability?

These questions facilitate some basic skills of communication: listening, observation and empathy, which in turn allows a conversation to occur that will elicit information and assist another’s understanding of the parents’ explanatory model of their child’s disability or CHC. If this information is used in conjunction with a family-centered care model then as London (2008) suggests it “allows the (nurse) to come to the relationship without assumptions and prior knowledge of the patient’s culture. It allows for conversation, mutual exploration, errors and correction, and negotiations. The (nurse) does not have to be an expert at determining the best interventions but must know how to collaborate with the (family) to find them” (pg. 285).

**Implications for Further Research**

Although Canada is a country built on immigration, very little research, especially using a qualitative methodology, has been conducted with immigrant families who have a child with a disability or CHC. This study was a small sample of participants who were recruited from a tertiary care centre in British Columbia’s lower mainland. Further research is needed with larger, more geographically diverse groups as well as focusing on specific cultural groups. This study had participants from several different countries of origins therefore it is difficult to conclude if the findings related to the family from Asia is the same for everyone from Asia or only pertinent to this study’s family. In addition participants were required to speak and understand English; however it could be argued
that non-English speaking immigrants may face more barriers and challenges accessing and utilising the healthcare system than English speaking immigrants. Therefore further research would be important to carry out with non-English speaking participants so their voices can also be heard to determine to what extent language is a barrier to care.

However research involving immigrant groups can be challenging on many levels. I discovered difficulty with recruitment because people who have English as a second language may not read posters on bulletin boards or answer letters requesting their participation. Therefore researchers may need to rely on clinicians to select families for the researcher to contact. Again some may say these participants are better able to access services based solely on the fact that they are connected to healthcare providers who are proactive in advocating or bringing things to the potential participants’ attention.

Conducting longitudinal studies with these families would be valuable because it would garner findings that could address how immigrant families with a child with a disability or CHC manage across the child’s lifespan. We are all aware how different child services are to adult services and a longitudinal study would help determine how immigrant families’ access services for their child during this transition period, can they manage independently or do they need additional supports. A longitudinal study could also be conducted to follow the siblings of these families to glean information about how this specific group manage being raised in a household with a disabled dependant. Do they continue to take on a caregiving role as I discovered in my study? Or overtime as the unaffected sibling gets older are they able to enact their independence and reject certain expectations that may have been placed on them? However how feasible it is to carry out such longitudinal studies with immigrant groups is unclear. If the family
continues to receive services from one specific center then being able to locate the families for future follow up maybe easier than if the family no longer receives services and relocates themselves.

There has been a lot of research conducted with mothers of children with disabilities or CHC (Daudji et al, 2011; Green, 2007; Maloni et al, 2010; McKeever & Miller, 2004; Wahoush, 2009; Yanti et al, 2006). To date limited studies exist that address a father’s perspective about parenting a child with these issues. In my study there was one father who was the primary care giver for his son and I have also met other fathers doing this role in my previous community practice area. Therefore it would beneficial to learn from these fathers not only in the context of being an immigrant man but also from being a male caregiver, a role traditional viewed as “women’s work.” Could some comparisons be made to men working in nursing, again a historically viewed female profession? It would be interesting to discover how these fathers enact a caregiving role. Not because having a man do this role is wrong rather what differences are there and what could be learnt from different gendered ways of knowing and doing? As I listened to the fathers in my study speak about their children, I was left wondering what effect raising a child who was atypical had on these fathers’ mental health. What other issues should healthcare professionals be mindful about when dealing with immigrant parents? Again maternal depression has been studied in the context of mothering atypical children however I’m unsure about paternal depression. Certainly from my own practice, paternal depression was not a topic I thought about or screened for because many healthcare encounters occurred with only the mothers and I never met the fathers. However, if families are to be viewed holistically it’s important to be mindful of
what issues affect other family members and may need to be addressed if families are to be successful in providing care and meeting the needs of their children.

**Conclusion**

In this study I have explored immigrant families’ experiences of accessing and utilising healthcare services for their child with a disability or chronic health condition. Findings from this study explained the challenges many families face as they establish a new home and future in their new homeland. Using interpretive description as the research methodology allowed me to identify and describe three main processes embedded in the families’ stories: desire for a better life and healthcare; families’ experiences with accessing services in the Canadian context and desire for autonomy and independency. On further reflection and interpretation of the data, two specific concepts were later unearthed: creating a future and personhood. From the evidence uncovered it is clear immigrant families face a number of complex issues regardless of how long they may have lived in their new homeland. Immigrant families bring with them histories and life experiences many people living in a western country may never encounter or fully understand. Healthcare providers and policy makers are encouraged to become familiar with these issues so immigrant families can be assisted in accessing and utilising healthcare services in order to improve their children’s health outcomes. This study’s findings validate how multifaceted life for immigrant families maybe here in Canada especially if they have a child with a disability or CHC. The challenges of caring for these children may be compounded for immigrant families who are seeking to secure their family’s future in a new country at the same time as attend to the needs of other family members. Nonetheless, the data also showed that these children are valued by
their families who make considerable social and financial investments to nurture their child’s wellbeing.

The study highlights how families navigate the system and show resilience as they settle into their new home and local community. The barriers or challenges to care due to a complex healthcare system or lack of funding and resources are just some pieces of the puzzle affecting immigrant families. This study highlighted how some immigrant families demonstrated an ability to be resourceful and capable in raising their child with a disability or CHC. However they need to have appropriate information, training or support to do so. In order for families to be successful in managing their child’s health issue there needs to be a collaborative partnership between the family and healthcare professionals. This partnership needs to be built on curiosity and a willingness to listen to families’ experiences, histories, beliefs and values brought with them into the healthcare encounter. At the end of the day, healthcare professionals come and go. However, it’s the family members who hopefully remain the same and therefore need to be empowered to become the experts of their child’s health issue and have an articulate voice to ensure the healthcare decisions are salient and meaningful for their child and family.
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Appendix A

Ms Fran Boyd
Director of Patient Services
Sunny Hill Health Centre for Children
3644 Slocan Street
Vancouver
BC, V4R 2C5

Dear Ms Boyd,

I am undertaking a research study as part of the degree requirements for my Master of Nursing degree at UBC. The study’s primary goal is to gain a clearer understanding about immigrant families’ access and utilisation of healthcare services within BC. The study will involve meeting with English speaking immigrant families who have a child with a disability or chronic health condition. The intent is gain a better perspective as to what barriers they face when trying to access and use healthcare services and supports for their child with complex care needs.

Sunny Hill Healthcare Centre would be a desirable site for this research because of the high percentage of immigrant families that attend appointments at the outpatient clinics. The research would require a sample of 8-10 family caregivers who are 18 years or older and have accessed services within the past 3 years. Each person would participate in a face to face interview with me.

If feasible I would like to ask the outpatient nurses to help identify perspective immigrant families who have had contact with their clinics (I will ensure no immigrant families that have been seen through my clinic area will be involved in the study). The perspective participants would be asked to sign an informed consent form, which will also be reviewed orally with them. Confidentiality will be strictly maintained. No name or identifying information will be written on any of the data collection forms. All data will be kept in a locked filing cabinet in my office.

I anticipate the research findings will provide healthcare service providers a more complete picture of what these families face as they try to access care for their child.

If it is possible, I would like to schedule an appointment with you so that we can discuss the possibility of me conducting this research at Sunny Hill. If you are in agreement I would need a letter of support to fulfill ethics requirement.

Thank you for your time in considering this request
Sincerely

Kimberley Tully
Kimberley Tully, RN, BScN
MSN Student
School of Nursing, UBC
STUDY FOR IMMIGRANT FAMILIES WHO HAVE A CHILD WITH SPECIAL NEEDS

Help us explore what barriers to accessing and using healthcare services exist for immigrant families who have a child with special needs.

ELIGIBILITY:
- Primary caregiver for child was not born in Canada
- Speaks English
- Has attempted to access services for the child in the past 12 months.

DETAILS:
Participants will take part in an interview lasting 60-90 minutes. An interview will be at a time & place convenient for the participant. There could be up to 3 interviews needed.

BENEFITS:
- Opportunity to share your experiences about accessing & using healthcare services in British Columbia
- Contribute to research that will help healthcare professionals better understand the challenges immigrant families face & why.

QUESTIONS:
Please contact Kim Tully (Researcher)
Tel: 604-xxx-xxxx
Email: xxxxx@xxxxx.ubc.ca
Appendix C

Permission for Initial Contact

Study: Exploring the Perspectives of Immigrant Families as they attempted to Access and Utilize Healthcare Services for their Children with Complex Care Needs.

My name is Kimberley Tully and I am a Registered Nurse who is studying towards my Master of Science in Nursing Degree. I am conducting a study in which I hope to learn about the experiences of immigrant families who have a child with a disability or chronic health condition and barriers they may have faced when trying to access and use healthcare services for their child.

This letter is to ask you to consider participating in my study. Please read the enclosed flyer and if you are interested in participating or have any questions, please contact me on 604-xxx-xxxx or email xxxxx@xxxxx.ubc.ca. Or my thesis chairperson, Dr Judith Lynam at 604-xxx-xxxx.

Thank you for considering participation in this study.

Sincerely

Kimberley Tully RN, BScN
Appendix D

Consent Form
UBC School of Nursing Letterhead

Study: Exploring the perspectives of immigrant families as they attempted to access and utilize healthcare services for their children with a disability or chronic health condition.

Principal Investigator: M. Judith Lynam, PhD, RN
School of Nursing
University of British Columbia
Contact Number: 604-xxx-xxxx

Student Investigator: Kimberley Tully, RN, BScN
School of Nursing
University of British Columbia
Contact Number: 604-xxx-xxxx

Co-Investigator: Gladys McPherson, PhD, RN
School of Nursing
University of British Columbia
Contact Number: 604-xxx-xxxx

Nancy Lanphear, MD
Department of Pediatrics
University of British Columbia
Contact Number: 604-xxx-xxxx

Becky Palmer RN, CNM, PhD
Professional Practice, Research, Learning & Development & Chief of Nursing
BC Children’s Hospital & BC Women’s Hospital
Contact Number: 604-xxx-xxxx

This research is for a graduate degree through University of British Columbia (UBC) and will be used for a Masters of Nursing thesis which will become a public document.

Introduction
You are being invited to take part in this research study because you are a member of an immigrant family who has a child with a disability or chronic health condition and you are the primary caregiver for the child.

Your participation is entirely voluntary. This consent form will help you understand what the research involves, why it is being done and how you will be involved.
If you wish to participate you will be asked to sign this form. If you decide to take part in this study, you can still withdraw without giving any reasons why.

If you do not wish to participate or decide to withdraw, you do not need to give any reason for your decision and your decision will not affect any medical care you or your family are allowed or are presently receiving.

**Purpose of the Study**
The purpose of this study is to explore immigrant families’ views about accessing and using healthcare services for the child who has a disability or chronic health condition. In particular what views you have about disability and what barriers you have found while trying to access or use healthcare services within British Columbia. More people are coming to live in Canada from other countries and need to access and use healthcare services. Therefore it is important that healthcare professionals know and understand what challenges immigrant families who have a child with disability or chronic health condition may face as they try to provide care to their child.

**Study Procedures**
If you agree to participate in the study you will be asked to meet for approximately 60 to 90 minutes with Kimberley Tully, there could be up to 3 interviews. The meetings will take place in a jointly agreed upon location and time. Each meeting will be audiotape recorded and you can ask questions during the interview process. No identifying information will be included when the interview is written out. There is no remuneration or reimbursement for participating in the study.

**Potential Risks**
You may choose to talk about issues that could cause you emotional discomfort. The researcher will attempt to limit this by being aware of signs of discomfort and stopping the interview if necessary. As well you can stop your participation at any time.

**Potential Benefits**
You will have an opportunity to share your experience about accessing and using healthcare services in British Columbia. You will also be contributing to research that will help healthcare professionals better understand the challenges immigrant families face and why.

**Confidentiality**
Your identity will be protected by code lettering rather than using your real names for example “family A,” “family B,” etc. This code will be attached to your family’s audiotaped interview, write up and demographic data. Also any persons mentioned on the tapes will not have their identity made known at any time. During the interview you can refuse to answer questions, ask for the tape recorder to be turned off or erased. Text and audio data will be stored on a password protected hard drive. Hard copies of this information will be kept in a locked filing cabinet in a locked office in the pediatric tertiary care centre and only the principal investigator and co investigators will be able to see this information. Any copies of the data will be stored on a secure server in the
School of Nursing with password protected access restricted to Dr J. Lynam. Data will be stored for the minimum of 5 years as required by UBC policy. It will be destroyed after this time if the investigator is not still drawing on it for her analysis.

**Contact**
If you have any questions or desire further information with respect to this study, you may contact Kimberley Tully at 604-xxx-xxxx or her supervisor, Dr Judith Lynam at 604-xxx-xxxx.

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or toll free phone number 1-877-822-8598, email address: RSIL@ors.ubc.ca.

**Consent**
I understand that my participating in this study is entirely voluntary and that I may refuse to participate or withdraw from the study up to the point of data analysis.

My signature indicated that I give permission for the information I provide on the tape during the interviews to be used in teaching materials, research journals, books or articles.

I have received a signed and dated copy of this consent form for my own records.

I consent to participate in this study.

__________________________________________________________________________
Subject Signature ____________________ Date ____________________

__________________________________________________________________________
Printed Name of the Subject ________________________________________________

__________________________________________________________________________
Researcher’s Signature ____________________ Date ____________________

__________________________________________________________________________
Printed Name of the Researcher ______________________________________________
Appendix E

Trigger Questions

1) Tell me a little about yourself.

2) Tell me about your family.

3) Can you remember when you found out about your child’s disability/chronic health condition? Can you tell me a little about that?

4) Can you tell me about your child’s condition and the care involved?

5) What do you think has caused your child’s problems?

6) Can you tell me what it’s like for you to care for a child with complex care needs?

7) Can you tell me who’s involved in the medical care for your child?

8) When was the last time you saw or spoke to a healthcare professional? Who was that person?

9) Can you tell me who’s involved in the daily care for your child?

10) What has been your experience with how people in your community interact with your child? How your family interacts with you & your child?

11) When you came to Canada can you tell me who helped explain the Canadian healthcare system to you or helped you find services for your child?

12) Can you tell me a little about the services your child receives?

General Probes:

1) Can you tell me more about that?

2) Can you give me an example of that?

3) How do you feel about that?

4) What did that mean to you?
### Appendix F

Demographic Tool Information

<table>
<thead>
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<th></th>
<th>Age</th>
<th>Occupation</th>
<th>Country of Birth</th>
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<tbody>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Father</td>
<td></td>
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</tbody>
</table>

Length of time living in Canada ________________________________

Family lives in _________________________________________________

Extended family members location _________________________________

Child’s disability / chronic health condition ____________________

Child’s Age ___________ Country of Birth _________________________

Language spoken at home _________________________________________

Family members able to speak English Y/N, read English Y/N, write in English Y/N

Healthcare services presently used: ________________________________

Healthcare services previously used: ______________________________