

South Asian Muslim women with disabilities

An Exploration of the Impact of Disability on the Lives of South Asian Muslim Women in
Winnipeg

by

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A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba
in partial fulfillment of the requirements for the degree of

Master of Arts

Department of Disability Studies

University of Manitoba

Winnipeg, Manitoba

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Acknowledgements

I would like to express my deepest appreciation to my Thesis Advisor, Dr. Nancy Hansen, for all her unwavering support, expert guidance, understanding and encouragement throughout the research study.

I also express my appreciation to the members of my Thesis Committee, Dr. Diane Driedger and Dr. Laura Taylor for their valuable feedback on my thesis. Their thoughts and comments were valued greatly.

I humbly extend my appreciation and gratitude to all the participants in this study. Their discussion of their everyday experiences was a most valuable contribution to this study. I also wish to thank them for their time, patience and kind support, without which I could not have written this Thesis.

Lastly, I would like to thank my family, my parents, brothers, and sister for their continuous support, encouragement and unconditional love; without which I would not have been able to complete this thesis.

Abstract

Understanding how disability is perceived from a cultural perspective, helps create knowledge about the issues related to disability in a particular culture. It helps to understand how much cultural beliefs impact the social status of a person with a disability in a society (Coleridge, 2000; Ingstad 1995). In addition to culture, religion also plays a significant role in most South Asian people's lives. Often both culture and religion of that culture are essential when planning interventions for community development in a society (Hasnain, Shaikh, & Shanawani, 2008; Harris, 2004; Miles, 1996). Cultural practices in the South Asian community are influenced by religion but many cultural practices reflect ancient traditions.

This thesis explores the lives of South Asian Muslim immigrant women in Winnipeg with various disabilities in order to obtain a specific cultural as well as religious perspective on disability in the form of personal stories.

Table of Content

Acknowledgements	i
Abstract	ii
Chapter 1: Introduction	1
Locating myself as a researcher	3
Research questions.....	5
Research objectives.....	5
Significance.....	6
Chapter 2: Literature Review	8
Purpose of the literature review	8
Method of review	9
Women, disability, and Islam	9
Impact of culture on disability	12
Traditional gender roles and status of south asian women with disabilities.....	14
South Asian muslim women with disabilities negotiating western societies	18
Chapter 3: Research Methodology	21
Research design	21
Participants in the study	22
Participant recruitment.....	23
Interviews.....	26
Ethical considerations	27
Data analysis	29
Chapter 4: Themes	33
1. Perceptions of disability.....	34
<i>Self-perceptions of disability</i>	36
2. Community encounters	40
<i>Sympathy or empathy</i>	40

<i>A dualistic approach towards disability</i>	42
<i>Lack of awareness creates negative attitudes towards people with disabilities</i>	44
3. Marriage and disability	46
<i>South Asian women’s struggle with body image issues</i>	48
<i>Absence of family-support on the prospect of marriage</i>	49
4. Religion and culture: An interesting mix.....	52
5. The support system	63
<i>Family and community support</i>	64
<i>Government support</i>	69
Chapter 5: Conclusion -----	75
Limitations of the study	80
References -----	83
Appendix I: Letter of Introduction and research description -----	94
Appendix II: Invitation letter to organizations -----	96
Appendix III: Consent form -----	98
Appendix IV: Interview guide -----	103

List of Tables

Table 1.0. Key words and phrases.....	9
Table 2.0. Participants' background information	22

List of Figures

Figure 1.0. Factors influencing perceptions of disability.....	34
Figure 2.0. Factors influencing cultural norms	52
Figure 3.0. Impact of immigration on South Asian cultural dynamics.....	63

Chapter 1: Introduction

Culture is often defined as a way of life. Cultures are customs that are based on people's common beliefs. It gives its people a sense of identity and belonging (Moran, Abramson, & Moran, 2014).

The broad definition of the term South Asians comprises various specific elements like culture and religion. However, irrespective of different religions, they all share some cultural similarities that give them a single collective identity as South Asians (Hussain, 2005). The South Asian population is comprised of various cultures and religions. However, Muslim South Asians are often perceived as having a strong affiliation with their cultural values and religious beliefs. Most of them may even avoid assimilation into the Western cultures (Azmi, 1997). Issues concerning South Asians and especially women from South Asia have long been missing from the disability discourse on ethnic minorities (Hussain, 2005). This research study specifically sets out to understand the impact of culture, gender, and religion on the lives of South Asian Muslim immigrant women with disabilities. It explores how disability affects the lives of women in fulfilling family roles and responsibilities, and how their families perceive disability.

Society has often adopted varied ways to maintain social control over women, and women with disabilities, in particular (Begum, 1992). By exploring how disability in women is perceived by members of a particular culture or religion would bring forth knowledge about the lives of women with disabilities. This research study aims to collect personal narratives about the lived realities of South Asian Muslim immigrant women with disabilities. These realities lead to new knowledge resulting in the development of policies specific to various cultural needs. This may also help to create a society which is more sensitive to various cultural needs of women

with disabilities. Dossa (2009) suggests that giving participants an opportunity to share their stories offers them some social visibility. South Asians are an ethnic minority community in Canada and Muslim women with disabilities within this ethnic minority are thought to be marginalized for multiple reasons. First, they are women. Second, they have a disability and third, they belong to an ethnic minority. Vernon indicates that disabled women within an ethnic minority may face negative attitudes from friends, employers, colleagues, teachers, and even from their families (as cited in Jenny Morris, 1996).

Many Western feminist disability researchers advocate the premise that disability is a social construct, similar to race and gender, and the meanings associated with the concept of disability are all culturally shaped (Smith, & Hutchison, 2004; Garland, 2005). Studies also maintain that the concept disability is socially constructed and may differ from culture to culture. Hence, how disability is understood in one culture may not be understood in the same way in another culture (Ingstad, & Whyte, 1995; Bickenbach, 2009).

Muslim cultures are generally viewed as separate ethnic groups. These groups are often perceived as a male-dominated, violent and oppressive societies for women (Suleiman, 1999). Studies indicated that religious beliefs usually have played a positive role in the lives of people with disabilities. However, the impact of different religious orientations on people's attitudes towards disability is yet to be explored (Selway, & Ashman, 1998). This research study attempts to explore the impact of both religion and culture on the lives of women with disabilities.

Often, cultural and religious beliefs are so fused together that it may become difficult to explore a society's attitudes towards disability exclusively based on either cultural or religious beliefs. It is maintained that the challenges to women's rights may vary among religions and

across regions. The impact of culture or religion on gender rights, specifically for women, is seen as a major international issue (Raday, 2003).

Non-disabled feminist researchers have often ignored the bodily experiences and issues facing women with disabilities. Many feminists still believe a highly athletic body and an active mind represent a good feminist, not a mind and body with any impairment or illness (Morris, 1996; Wendell 2001; 1996; 1993). Whereas, many feminist disability researchers indicate that disability is just another human experience, although, it varies in types and degrees. It represents the social and cultural interpretations of human variation (Thomas, 1999; Garland, 2004; Smith, & Hutchison, 2004).

In feminist disability studies, disability is again a cultural interpretation of bodily differences (Garland, 2005). Morris (1991) noted, “Surely the representation and exploration of human experience is incomplete as long as disability is either missing from or misrepresented in all forms the cultural representation takes” (p.85).

Garland (2005) notes,

Disability is a story we tell about bodies. It is a received yet pliable story that changes over time and across places. Representation structures rather than reflects reality. The way we imagine disability through images and narratives determines the shape of the material world, the distribution of resources, our relationships with one another, and our sense of ourselves. (p. 523)

Therefore, by collecting the narrative accounts of the participants, this study explores and aims to counter many forms of misrepresentation that may exist about how disability is perceived by the South Asian community in the West.

Locating myself as a researcher

I am a Muslim woman. I also identify myself as a non-disabled feminist academic. I grew up in a small middle-class Muslim family living in the city of Karachi, Pakistan. I obtained

my primary, secondary and post-secondary education in Pakistan. Pakistan is one of the developing countries in South Asia. All four major provinces (Sindh, Baluchistan, Punjab, & Khyber Pakhtunkhwa) have different ethnic representations and languages. In Pakistan, Islam is the religion that influences all social values, beliefs, and cultural traditions (Hakim & Aziz, 1998). Culture is often defined as a way of life. Cultures are customs that are based on people's common beliefs. It gives its people a sense of identity and belonging (Moran, Abramson, & Moran, 2014). In Pakistan, however, Islam has a significant influence over people's daily lives. It impacts many important aspects of everyday life such as: marriage, education, food, cultural values, and traditions (Wilber, 1964).

Growing up in an Islamic, male dominated society of Pakistan, I believe I can relate closely with most Muslim South Asian women. It is our society's narrow-minded approach toward women, and especially toward women with disabilities that puts us all in a single marginalized/disadvantaged group (Singal, Bhatti, & Malik, 2011; Sen, & Ostlin, 2008). My South Asian background, personal experience as a Muslim woman from Pakistan, and my perceptions of the status of women and women with disabilities in Pakistan are motivating factors that led me to conduct this qualitative study.

Through my experience with Disability studies in Canada I learned about the history and struggles of Canadian women with disabilities, their participation and contribution to the disability rights movement. My studies in Canada led me to explore whether living in Canada had any influence on the lives of South Asian Muslim women with disabilities.

I was aware of the possibility that my South Asian Muslim background or my experience as a South Asian Muslim woman would influence the interpretation of data. However, the data interpretation is strongly supported by the participants' direct quotes and relevant studies. My

South Asian background and my personal experiences as a Muslim woman enable me to provide a deeper, more meaningful interpretation of the data.

Like many qualitative research studies, this research study is not completely devoid of subjectivity. Although, I belong to the South Asian Muslim community, I situate myself in the role of explorer in the research study, and only information which the participants consented to is shared in this study. Being a member of the South Asian Muslim community increases my sensitivity to participants, and it also strengthens my integrity as a researcher.

Research questions

Generally, South Asian society is assumed to be a male dominated society. Traditional cultural norms seem to marginalize both disabled and non-disabled women from all public spheres. Thomas, M., & Thomas, M.J. (2002) maintain that gender equity is a major issue for women, particularly in the South Asian social framework. This research study explores the following:

- How do South Asian Muslim women with disabilities belonging to an ethnic minority deal with living in a larger Western social context?
- How does disability impact their lives as women in the South Asian Muslim community?
- How do families influence the distribution of family obligations based on socially expected gender roles?

Research objectives

The following are the objectives of the research study:

- To explore how disability of women is perceived by members of a particular culture or religion.

- To find out how disability and gender impact the lives of women with disabilities on intersecting with their culture and religion.
- To explore how disability affects the lives of women in fulfilling family roles and responsibilities.
- To counter many forms of misrepresentation about disability and Muslim women with disabilities through their personal accounts.

Significance

The research study is significant in many ways:

- The research study attempts to create awareness about the perceptions of South Asian Muslim women with disabilities about gender relations and other life choices.
- It aims to increase knowledge about how cultural perspectives shape certain people's lives.
- It provides an opportunity for South Asian Muslim women with disabilities to voice the issues and challenges that they experience in life. As a result, the outcomes from the study also present an opportunity to other women with disabilities in the South Asian Muslim community to relate to the participants' life experiences.

The literature review reveals that very little research has been conducted with South Asian Muslim women with disabilities living in Canada. Many of the studies involved analysis of the provision of culture specific services to these individuals. For example, the work of Parin Dossa (2009) mainly addresses the discrimination and racism against South Asian immigrant Muslim women with disabilities in relation to Canadian policy and services. Therefore, this qualitative research study is a pioneering attempt to explore the lived experiences of Muslim women with disabilities from South Asia and their ethnic differences in the Canadian cultural context. It helps to create new knowledge about disability in a specific cultural context that will

interest other researchers to explore further in the area of policies and practices in Canada limited to a specific cultural context, particularly women with disabilities from an ethnic minority.

In conclusion, a feminist disability research study not only aims at collecting personal narratives of women with disabilities, but it also adds to disability knowledge about all inequalities and discrimination they experience (Garland, 2005). Unfortunately, it appears that not many feminist disability writers have explored the impact of various cultural interpretations of disability on the lives of women within ethnic minorities in the West (Nancoo, 1993; Fine & Asch, 2009; Dossa, 2009). Therefore, this is a pioneering study that aims to explore the cultural as well as the religious aspect of the lives of Muslim women with disabilities from South Asia living in the West.

Chapter 2: Literature Review

Purpose of the literature review

Most of the research to date about immigrant women with disabilities is directed toward service providers and the availability of culturally appropriate services. There is much work to be done to reveal the lived experiences of immigrants with disabilities with varied ethnic or racial backgrounds (Stienstra, 2002; McDonald, Keys, & Balcazar, 2007). For the purpose of exploring existing knowledge about women with various disabilities in the South Asian Muslim community, various research studies have been reviewed. The literature in the study addresses knowledge about different forces that are perceived to be at work in the South Asian Muslim communities such as religion, culture and gender. The literature reviewed is divided into four parts.

First, it attempts to cover the historical aspect of Islam, disability, and women, touching on the status women have had during pre and post-Muhammad era. This part of the literature attempts to understand Islam's perspective on disability and women.

Second, it attempts to unravel the impact of culture and religion on disability. It sheds some light on the impact of different interpretations of Islam on people's understanding of disability.

Third, this part of the literature attempts to discuss the traditional gender roles of South Asian Muslim women with disabilities.

Lastly, with the limited literature available, the fourth part attempts to point out the oppression that South Asian Muslim immigrant women with disabilities may often experience in their community.

Method of review

Key words and phrases signifying the concepts of the research questions were used to search the existing literature (See Table 1.0 for key words and phrases.). A systematic review of the literature produced by numerous researchers and scholars was performed. Articles published in various journals were reviewed. Reference lists of articles were reviewed and articles were selected based on their relevance to the research questions. A literature search was conducted using several electronic data bases such as Google scholar, Google books, and Scopus. Published articles from numerous journals were reviewed. For example, the following journals were consulted: *Journal of the Society for Disability Studies*, *Journal of Disability Policy Studies*, *American Journal of Community Psychology*, *Journal of Ethnic and Migration Studies*, *Journal of Religion, Disability*, *The Journal of social psychology*, and *Journal of Holistic Nursing*.

Words and phrases framing the research questions	Related words
South Asians	South Asian women, South Asian Muslim women, South Asian Muslim community.
Islam, disability and gender	Islam and women, Islam and disabled women, Islam and disability, disability and gender roles.
Religion, culture and disability	Disability and cultures, ethnicity and gender, cultural and religious identity.

Table 1.0. *Key words and phrases*

In addition to online and hand searched articles and reports, a number of books comprising content relevant to the research questions were reviewed.

Women, disability, and Islam

With the advent of Islam in 610 C.E., it appears that the status of women in society gradually began to improve. Women were still facing challenges, but they were able to

contribute to politics and community development. However, after the Prophet Muhammad's death, conditions for women in the community changed and were no longer conducive for them.

Women were isolated and restricted to their homes (Sechzer, 2004).

Sechzer (2004) elaborates on the challenges women faced in the post-Muhammad era,

Women were isolated, secluded, forced to pray at home-not in the mosque, and exclusion was put into practice. Women were essentially removed from most sectors of society. Veiling of women included covering specific parts of their body to prevent enticing men. Women's status declined rapidly and freedoms they had were essentially abolished. (p.263)

Restrictions and discriminative practices against women appear to have been adopted by most Muslim countries. In South Asian countries like Pakistan, India, and Bangladesh, the status of women varies significantly. (Niaz, 2003). In the modern Muslim world, discrimination against women may begin from the time they are born. Their social status may further deteriorate on giving birth to a girl (Douki, Zineb, Nacef, & Halbreich, 2007).

Sechzer (2004) indicates,

The family and the woman's role in Muslim societies has been affected by various laws and cultures in different countries in addition to the social, economic, and financial factors including an increase in industrial and technological development and urbanization in societies. (p. 270)

In various Islamic texts, men are deemed superior to women, and women must be submissive to men. Therefore, Islam is often perceived as patriarchal. Often in Islam, both women and disabled individuals are classified together as disadvantaged (Turmusani, 2001).

Most Islamic texts and teachings are derived from the two original sources; the Quran, and the examples extracted from the life of the Prophet Muhammad (Bazna, Hatab, 2005). In order to understand the Quran in the best possible way requires an understanding of Hadiths. Hadiths were the examples collected from the life of Prophet by the Prophet's contemporaries

and were verified by scholars such as Al-Bukhari and Muslim, most revered by Sunni Muslims (Bazna, & Hatab, 2005). However, it appears that there are many different interpretations of Islam.

Lang (1997) points to the different Islamic interpretations,

Interpretations and translations [of the Quran] to other languages, while numerous, are considered to only represent the interpreter's understanding of the Quran and are, therefore, neither the Qur'an nor a translation of it. (as cited in Bazna, & Hatab, 2005)

There are various sects within Islam based on different interpretations and ideologies. Sunni and Shiite are two major sects of Islam and there are further subdivisions under each of these major sects. Sunni ideology is more state-focused than any other sect of Islam. Hadiths in the Sunni sect are adopted mainly from four schools of law "Hanbali, Hanafi, Shafi'i, and the Maliki". Shiites follow only one, the Jafari School of law. Yet, there are many other sects of Islam with various interpretations (Khuri, 2014).

It is important to note that often Shiite Hadiths may differ from Sunni Hadiths. Sunni Hadiths are the Islamic traditions (about the life of Prophet Muhammad) mostly passed on by Islamic scholars belonging to a Sunni sect with limited exposure to Shiite traditions. Whereas, Shiite Hadiths may also include sayings of the 'imam' who is not only a leader but who is blood kin to the Prophet Muhammad (Newman, 2013; Armanios, 2004). Therefore, literature discussing the Islamic perspective on disability may sometimes reflect a particular Islamic ideology. However, in many Islamic societies, disability is still viewed as a punishment or a sin. Studies indicated these negative views are based on cultural and social beliefs rather than Islamic teachings (Bhatty, Moten, Tawakkul, & Amer, 2009).

In the Quran, the term disability has not been used. Instead, the Quran has used the term disadvantaged people at many places to refer to people with disabilities. The Quran consistently seems to encourage Muslim society to help disadvantaged people improve their life conditions (Bazna, & Hatab, 2005).

The Quran clearly dismisses the perception of disabled people being 'impure' or 'evil'. It views disability as part of human existence. Physical appearance does not evaluate morality but piety (Bhatty, et.al. 2009). Prophet Muhammad's comment clearly implies this notion (Muslim, 2564), "Verily, God does not look at your bodies or your appearances but looks into your hearts" (as cited in Bazna & Hatab, 2005).

However, Turmusani (2001) argues that in traditional Islamic society, disability was considered to bring shame to the family who had someone with a disability. The family used to hide their disabled family members from society, particularly women with a disability who lacked autonomy. According to Turmusani (2001), no direct reference exists in the Quran about women with impairments. Although, there are Hadiths referring to those women found in hell to have varying physical deformities. It appears that the lives of most Muslims are often governed by Islamic teachings and traditions from the past. In addition, there may be contradictions among varied interpretations of Quranic meanings and Islamic teachings about women and disability.

Impact of culture on disability

Cultural representation of disability often forms the basis of all injustices and discrimination towards people with disabilities. Coinciding with varying religious interpretations, there are different cultural understandings of religion.

Miles (1996) notes,

What is perceived as ‘morally and ethically correct behavior with disabled people’ may vary sharply between three families on one street, where each belongs to a different religious or cultural community. (p. 490)

Disability in Pakistan is perceived differently across the country. A study suggested that some people in Pakistan still believe it to be a curse and others a punishment. Others also believe disability brings shame to their family (Rathore, New, & Iftikhar, 2011). Another study about Asian families with children with a mental disability suggests that both culture and religion influence families’ attitudes about disability. In addition, families often lack knowledge about disability (Fatimilehin, & Nadirshaw, 1994). The literature often suggests that the Asian community particularly views disability negatively. However, there is a strong possibility of community stereotyping. As Nasa Begum (1992) notes caution should be taken when interpreting the findings of a study as there might be other factors involved too. Interwoven religious and cultural beliefs often cause misunderstandings. The perception that; “Muslims believe disability is a punishment from God indicates a cultural, not a religious belief” (p.62). There are varied cultural beliefs about disability among Muslims, and often these cultural beliefs contradict Islamic teachings.

Often studies discuss the impact of culture and religion on people’s attitudes towards disability in Muslim communities. Groce (1999) argues that it is not only disability but also differences in how the concept of disability is perceived and interpreted cross-culturally that have a profound impact on the lives of disabled individuals. Therefore, it is also important to understand that in addition to perceptions about specific disabilities, there could be other forces at work too that may determine how a society interprets disability.

Groce (1999) maintains that “the lives of individuals with disability around the world are usually far more limited by prevailing social, cultural, and economic constraints than by specific physical, sensory, psychological or intellectual impairments” (p.756).

Researchers also argued that although, society’s perception about disability changes with time, often, social perception about disability is entirely associated with the social, cultural, and economic situation (Bhatty, et.al. 2009). It is often difficult to exclusively consider either culture or religion as the main force behind people’s attitudes toward disability. Al-Aoufi, Nawaf & Norbavah (2012) note, “People’s behaviors and attitudes might reflect their own understanding of their religion, but not necessarily the exact meaning of its values, where culture contributes in forming views of disability” (p. 213).

Al-Aoufi, et. al. (2012) clearly indicate,

Cultural perspectives, mixed with religious values, often lead to several courses of action, which may be falsely attributed to religious faith, such as embarrassment at having a child with a disability, attempting to explain the cause of the disability, and looking for fast solutions [a cure]. (p. 214)

The theories discussed in this part of the literature seemed to suggest that people’s attitudes often reflect their own understanding of what is right or wrong. This ultimately leads to the formation of a culture. Whereas, even religious beliefs are often seen to be influenced by culture.

Traditional gender roles and status of South Asian women with disabilities

Lorber (1994) notes, “Gender is a human invention like language, kinship, religion, and technology, like them, gender organizes human social life in culturally patterned ways” (p. 6). She further maintains, “In social interaction throughout their lives, individuals learn what is

expected, see what is expected, act and react in expected ways, and thus simultaneously construct and maintain the gender roles” (p. 32).

In South Asian societies both men and women are often expected to perform traditional gender roles. Men are expected to provide financial support to their family, whereas women stay home, are expected to take care of their children and the rest of the family members. They are expected to perform all in home chores such as cleaning, washing and cooking (Thomas, 2002). Does being financially dependent on men lessen their status as women compared to men? Fikree and Pasha (2004) indicate that women in South Asia are often placed at a lesser position to men. They may often be economically dependent on their men and may often be deprived of their right to make any decision on their own. Daughters in many families are often viewed as a liability as the traditional dowry system still prevails. It is important here to note that if disability affects women's ability to perform traditional roles, what status would they have in these traditional societies? Where would such a society place a woman with a disability when a non-disabled woman is considered an economic liability?

In the developing countries, studies indicate that the status of disabled women may even be less than disabled men. They often have limited or no access to resources like health care, education, employment, and special care services specific to their disabilities (Watermeyer, 2006; Joseph, & Nagmabadi, 2003).

Estimates from a 1995 study indicate higher male disability rates than female disability rates in Pakistan and India. This could be because women often die sooner due to less care and support; or because disabled women who are able to fulfill household responsibilities may not be counted as disabled (Elwan, 1999).

Furthermore, Mehrotra (2004) seems to highlight another important issue often linked to South Asian women with disabilities,

Their [women with disabilities in India] prospects in marriage and motherhood seem to be marred by the presence of physical disabilities as society constructs such women as incomplete. They are perceived to be in need of care themselves and as being unable to fulfill a caring mothering role. (p. 5640)

Ghai (2003) describes the condition of disabled women in South Asia, “In a cultural scenario, where the birth of sons is privileged, being born a disabled girl can be considered a fate worse than death” (p. 25). For example, women with disabilities in India face double discrimination due to the prevalence of traditional gender roles and expectations. Thomas and Thomas (2002) note, “She [a disabled woman] is perceived as one who is unable to perform her traditional roles of wife, mother and homemaker because of her disability, even if she may be able to do so in reality” (p. 2). Many South Asian families may not accept their females with disabilities in parental roles. They may not accept them in marital relationships. Such families may also avoid topics like sexuality or marriage for the female disabled members of their family (Yoshida, Li, & Odette, 1999).

Khanna (2000) indicates, “The general image of a woman with a disability in South Asia is a helpless and weak individual” (cited in Josep, & Nagmabadi, 2003). Women with disabilities in India and Indians who migrated to countries outside India seem to have lower marriage prospects since women’s worth is often determined on the basis of their physical appearance. Women with lighter skin color who appear healthy and physically attractive are considered more desirable by men (Glen, 2008).

In addition, inadequate government services, scarcity of medical supplies, lack of access to education, and lack of trained professional support make it worse for people with disabilities

and particularly women with disabilities. As a result, many of the individuals with disabilities seemingly become a burden on their families (Hosain, & Chatterjee, 1998). This situation gets worse with poverty as disabilities seem to increase the burden on the families (Hosain, Atkinson, & Underwood, 2002). Women with disabilities in rural regions across South Asia may be more affected by poverty as they are not often considered the breadwinners of the family. Often, women with disabilities and their families do not seem to be very concerned about their future (Foley, & Chowdhury, 2007).

Hosain, *et al.* (2002) in a study about disability in rural Bangladesh argue,

Females in Bangladesh generally have a lower status and are not as actively involved in income generating activities as males, and neither do they control family resources. Thus, disability apart from being negative is also a potential barrier to marriage, especially for women. (p.301)

Mehrotra (2004) also points out that the patriarchal system in the rural society of India places women at a lower position than men in the family and in society as well. Physical disability further lowers their status. Ghai (2002) argues, “In Hindi the phrase, ‘Women with disabilities’ (*Ek to ladki oopar se aapahij*) means, ‘one, a girl, and that too disabled’. This intermingling of disablement and gender marks the reality of a woman with disability in India” [sic] (p. 53).

In Pakistan, cultural understanding of disability still precludes integration of people with disabilities into the mainstream, and rehabilitation is often not considered an option by health care professionals (Rathore, New, & Iftikhar, 2011). Many children with disabilities in Pakistan, and also in India and Bangladesh are killed at birth, or left to die (Rock, 1996).

Overall, the literature suggests that disability may seem to drastically affect individuals’ ability to perform traditional gender roles. However, in developing countries, it appears that most

women with disabilities have limited access to rehabilitation services and other resources (Rock, 1996; Thomas, 2002).

South Asian Muslim women with disabilities negotiating Western societies

In the last few decades, 'exile groups, overseas communities, ethnic and racial minorities' have been referred to as 'diaspora' (Tölölyan, 1996). Studies indicate that diasporic communities give their people a sense of identity, unity, and self-awareness and cultural consciousness. Diasporic identity has led many young Muslim South Asian women in Britain, unlike their elders, to see a distinction between religion and culture. They have become self-aware disentangling religious and cultural knots (Knott & Khoker, 1993; Clifford, 1994).

Questions arise: does diasporic identity help Muslim South Asian disabled women to address inequalities they may experience? And does it have any impact on the right to have an independent life within their local community in the West?

South Asian women often have not been part of any disability discourse on ethnic minorities. A study on South Asian disabled women in Britain maintains that their lives are shaped by both culture and religion. There are also many family and community influences on their lives (Hussain, 2005). Some families of young disabled South Asian people interviewed in Britain view disability as 'tragedy' and their disabled son/daughter as vulnerable. Therefore, parents seem to be overprotective specifically with females since South Asian communities believe that a family's honor is at a higher risk for females than males (Hussain, Atkin, & Ahman, 2002).

In addition, living in an extended family, which South Asian families often prefer, involves less support but more monitoring of the lives of women with disabilities by family members as compared to men with disabilities in Western society (George, & Ramikissoon,

1998; Dwyer, 2000; Peach, 2006). They may experience inequality in obtaining an education (both academic and religious), finding employment and other opportunities which their male disabled or other non-disabled siblings receive (Hussain, et.al. 2002). Asch and Fine (1981) argue that social inequalities, economic situation, and negative self-image, all result in disabled women's 'systemic rolelessness'.

Dossa a Canadian scholar (2005) notes,

The onus is on the individual to adapt to society in a way that minimizes the difference. The less the person is seen as not doing things the mainstream way, the less is she accepted, the end result of which is being sheltered and rendered dependent. (p.2531)

Fine and Asch (1981) note,

Societal perceptions of disabled persons tend to be influenced entirely by the disability. Whether born disabled or having become disabled, the non-disabled world insists that disability is the predominant characteristic by which a person is labeled. (p. 237)

Another point to consider is that ethnic minorities may also experience racism and social injustices in the West. As a result, their communities may form firm standards based on both their respective culture and religion in order to maintain and strengthen their ethnic/religious identity.

Vernon (1999) indicates,

A fundamental dilemma rooted in oppression is that there are very few pure oppressors or pure victims. Even those who are themselves oppressed often consciously or unconsciously engage in the oppression of others who deviate from the established norm in a different way from them. (p. 389)

For instance, South Asian women with disabilities in Britain mostly follow their parents' religious and cultural traditions in order to maintain their cultural and religious identity.

Simultaneously, they explore and may even challenge some of their own traditional values and

customs while maintaining their diasporic identity as British South Asian with disability (Hussain, 2005).

However, limited literature is available addressing challenges of South Asian Muslim women with disabilities in Canada. Dossa (2005) maintains that the status of white women with disabilities seems to be lower than white men with disabilities, however, the status of women of color with disabilities seems even lower than white women with disabilities.

In Canada, people with disabilities and particularly women with disabilities have long been struggling for their equal rights as Canadian citizens. In 1980s, as a result of the Canadian disability movement, disability (cognitive and physical) was included in the *Canadian Charter of Rights and Freedoms*. This disability movement gradually began to grow and now there are multiple disability movements working to resolve various issues concerning individuals with disabilities (Kelly, 2013). The disability movement was initially led by men with disabilities and issues concerning women with disabilities were not addressed. Therefore, a group of women with disabilities from across Canada decided to create a network which is run by and for women with disabilities separate from men or non-disabled women. The disabled women's group DAWN (DisAbled Women's Network) Canada works for equal rights and integration of women with disabilities in Canadian society. DAWN Canada has been addressing issues of interest to women with disabilities for many years now. DAWN Canada, the Council of Canadians with Disabilities, and many other non-profit organizations have been addressing issues of women with disabilities such as gender and disability based discrimination in the workplace, accessibility issues, poverty, violence, parenting, sexuality and health. In addition, DAWN reaches out to visible minority women who are often neglected by mainstream society, such as Aboriginal women, Asian women, south Asian women, immigrants and other women of color (Stone, 1989).

Chapter 3: Research Methodology

Research design

A qualitative research methodology was chosen for this study, in order to explore the life experiences of Muslim women with a disability from South Asia. Qualitative research is a conventional approach concerned with "meaning" and "interpretation"(Barnes, 1992). This study attempts to explore how South Asian Muslim women with various disabilities perceive disability; and how disability and gender impact their lives when intersecting with their culture and religion. It also attempts to highlight how much living in a Western country like Canada has influenced their lives as Muslim women with disabilities.

Denzin and Lincoln (1994) note that, “Qualitative research involves the studied use and collection of a variety of empirical materials- case study, personal experience, introspective life story, interview, observational, historical, interactions, and visual texts- the described routine and problematic moments and meanings in individuals' lives” (as cited in Newman, 1998).

The qualitative research approach helped to analyze and interpret participants’ personal accounts on how disability impacted their lives as Muslim women, for example, role and status of women, family dynamics, and cultural and religious perspectives, by acquiring information directly from the participants themselves. Participants were Muslim women with various disabilities originally from South Asia age ranging 30 to 60. They were well able to articulate their views on issues and misconceptions about disability in South Asian Muslim community.

South Asian countries have a variety of cultures and languages. South Asian countries mainly include India, Pakistan, Bangladesh, and Afghanistan. South Asian people include individuals from around the globe who have a subcontinent origin. The research approach used in this study allowed the participants to share their experiences with disability in the context of

being from a community, which may be assumed to be influenced by cultural and religious factors. Descriptive data was collected using an audio recorder, and field notes. Themes were generated while reviewing and analyzing the descriptive accounts of participants. This research methodology attempts to give voice to Muslim women with various disabilities having a South Asian origin living in the West. The main purpose of this research was to increase knowledge about the issues women with disabilities face from a different cultural perspective.

Participants in the study

Table 2.0 illustrates the background information of the participants who were recruited and later interviewed.

Age range	Participants	Education	Participants	Employment
30-40	1	Grade 12 in Canada. Child Care Certificate.	1	Never employed.
41-50	2	Grade 10 in Pakistan.	1	Never employed.
		Bachelor's degree in Arts from Pakistan.	1	Never employed.
51-60	4	Bachelor's degree in Arts in India/ Pakistan.	2	No longer employed, 1 on medical leave.
		Post graduate degree in Teaching from India. Child Care Certificate.	1	No longer employed.
		Bachelors of Science majoring in Chemistry from England.	1	No longer employed.
	7		7	

Table 2.0 Participants' background information

It appeared that the majority of the participants had at least an undergraduate degree in various areas. Only one participant was on medical leave at the time of her interview and was waiting for her full recovery from surgery. There were 3 participants who have never worked since they migrated to Canada and 3 participants were no longer employed as they could not continue their jobs because of their disability.

The participants in this study were from the two marginalized strata of the general population in Winnipeg, Canada. First, they were (Muslim) women who belonged to the South Asian community, a minority ethnic group. Second, they identified themselves as disabled women, no specific type of disability. They were approximately 30 to 60 years of age and were able to communicate on their own.

Participant recruitment

A list of disability organizations in Winnipeg was contacted via email regarding the study and a letter of invitation (Appendix II) was sent to these organizations via emails. In addition to the letter of invitation, a letter to the potential participants describing the research study, (Appendix I: Letter of Introduction and research description, an interview guide (Appendix IV: Interview Guide), and a consent letter (Appendix III: Consent Form) were also attached in the emails sent to the organizations.

The organizations were invited to participate in the research study by identifying potential participants in their network and circulating information about the research study among the potential participants. The lists of organizations contacted include;

- Immigrant and Refugee Community Organization of Manitoba.
- Independent Living Resource Centre (ILRC).
- DisAbled Women's Network Canada (DAWN).

- Canadian Multicultural Disability Centre (CMDC).
- Canadian Muslim Women's Institute (CMWI).
- Canadian Council of Muslim Women (CCMW) - Winnipeg Chapter.
- Manitoba Islamic Association (MIA).
- Association of Pakistani Canadians (APC), Winnipeg.
- Islamic Social Services Association (ISSA).
- University of Manitoba Pakistan Student Association – Facebook.

The prevalence of South Asian Muslim women with disabilities appears to be limited in Winnipeg. Being a member of the South Asian Muslim community, getting access to the population of South Asian Muslim women was not so difficult. However, locating women in the South Asian Muslim community who identified themselves as having a disability was comparatively challenging. Many of the above listed organizations replied saying that they had distributed the information sent to them about the research study to the possible participants. However, representatives from APC, CMWI and ISSA were able to share the information with some of the people in the South Asian Muslim community who located a couple of potential participants with various disabilities in the South Asian Muslim Community. The snowball sampling approach was quite effective in locating the potential participants in this study. The snowball sampling method is used to target a population which is geographically dispersed, dealing with stigma, or consists of small hard to access networks in contrast to the general population (Heckathorn, 2011). Therefore, the participants interviewed helped to locate more participants in their [South Asian] community.

Simultaneously with the snowball sampling method, the judgment sampling approach was used in order to select the most productive research samples. The judgment sampling

approach is used in qualitative research studies (Marshal, 1996). Judgment sampling is used when participants in a research study are supposed to have the relevant knowledge or information about the topic of the research. This is accomplished by the researcher identifying samples or letting participants nominate others who they believed to have relevant knowledge and experience about the subject of the research (Procter & Allan, 2006).

It was quite difficult to locate any South Asian Muslim woman who self-identified as being a woman with a disability, in any organization even in organizations representing Muslim immigrant women. Therefore, it became necessary to directly approach women with disabilities within the South Asian Muslim community using judgement/purposeful sampling method.

The other challenge was that some of the participants were initially rather apprehensive about their identity being revealed in any form in the study; even if the documents shared clearly explained that confidentiality will be strictly maintained. Therefore, with their permission they were personally contacted on the phone by the primary researcher to clear up any confusion regarding confidentiality or any other matter related to the study. Language and cultural similarity were instrumental factors which enabled the primary researcher to build a trust relationship with the participants prior to the interview session.

A total of 10 potential participants were invited to participate in the study and 7 participants agreed to participate. Upon receiving consents from the participants, interviews were scheduled. One of the three remaining potential participants could not participate due to her health condition and the other two simply refused to participate.

Of the 7 participants, one was from Afghanistan and the 6 remaining participants were from India and Pakistan. All the participants interviewed were able to articulate their views on how disability impacts the lives of South Asian Muslim women. One of the participants from

Pakistan asked to respond to the interview questions in Urdu (national language of Pakistan).

The remaining participants occasionally spoke in Urdu, or Hindi (the Indian national language).

Her interview transcript (translated into English by the researcher) was sent to her email address for review. The participant approved the final transcript after suggesting a few changes to it. The remaining interview transcripts were also shared and approved by each interviewee. Pseudonyms have been provided throughout.

Interviews

Documenting participants' experiences in the form of their narrative accounts relating to the specific theme(s) is a conventional method of data collection used in most ethnographic studies. This approach gives the participants enough room to reminisce and narrate their experiences.

Jochelovitch and Bauer (2000) described “narrative interviewing” as a qualitative research method that allows its participants to share their experiences related to the theme(s) in the form of conversation. It is to reconstruct the participants’ experiences in society from their perspective as directly as possible.

The interview questionnaire included semi-structured and open-ended questions designed to retrieve relevant information on the topic. The questionnaire comprised questions about the impact of disability on their lives, their role in the family, and the impact of religion and culture on their lives as Muslim women with disabilities. Overall, the interview questionnaire served as a guide for the participants and it ensured that the participants were well aware of the topic of discussion prior to their interview session. They were also made aware that if they did not feel comfortable or are not willing to participate, they could leave the interview or the research study at any time.

All the interviews were scheduled based on the participants' convenience and availability. The interviews were conducted, in consultation with the participants, at the place of their residence. Therefore, there were no accessibility requirements specific to their disabilities. Each interview session was about one hour in length depending on the participants.

The interviews were recorded with the participants' written consent. Later, the transcripts were shared with the participants for their approval. Field notes were written and maintained throughout the interview process. Field notes included observations made at the interview sessions.

At the end of the interview, each participant was rewarded with a Tim Horton's gift card worth \$5 as a token of appreciation. Finally, upon completion of the study, a copy of the final thesis or a summary will be shared with the participants on request.

Ethical considerations

There are certain general as well as specific responsibilities on researchers and institutions engaged in conducting research studies. The following were the ethical considerations that were practiced throughout the study. These ethical considerations were in accordance with TCPS2 (Tri-Council Policy Statement, 2nd edition) guidelines.

One of the most important ethical considerations for this study was to protect the participants from any form of exploitation. Hoonard (2002) emphasized that some of the suggestions enforced by Research Ethics Boards (REBs) include signed consent, maintaining confidentiality, and availability of adequate research information.

Signed consent letters were collected from the participants, and it was assured that their consent to participate in research was voluntary. All the information on the consent form was

read and explained to the participants. Participants were allowed to ask questions at any stage. They were also allowed to refuse to answer any question or withdraw from the study at any time.

Data in the form of interview transcripts, field notes, and backup electronic files were all treated as confidential documents. To protect the identity of the participants, pseudonyms were used in place of their real names. All the participants were assured that confidential information such as their medical records was not accessed throughout the study. Any unique identification characteristic that may reveal participants' identity was removed from the final thesis, field notes, summary of findings, and presentation. Audio files were kept on a secure password-protected computer and were used with participants' consent. All the forms, notes, and transcripts were kept in a locked drawer and were destroyed on completion of the final thesis.

This study includes observations, but also information intended to create new knowledge about the lives of Muslim women with various disabilities obtained directly from them. Sufficient information about the research and implications of participation was provided to the participants. Participants were informed well ahead of time about when and where they would be interviewed. As Hoonard (2002) argues, "Ethical Conduct for Research Involving Humans require that both the researcher and the participant know in advance what may happen both during the research and as a consequence of it" (p. 17-18).

Participants' accounts of their experiences were transcribed with clarity. Their lives' narratives were written with caution as there is a possibility that they may get mixed up with the data interpretation. Transcripts were shared with the participants before the data from the transcripts was used in the data analysis. Any part which the participants did not wish to include in the study was removed the research study.

Although there was no anticipated risk or harm to the participants for their participation in this study, it was assured that the safety of participants' emotional, psychological and physical state was not at risk. In order to minimize the risk of any emotional distress caused by reminiscing about a particular life event, the participants were allowed to opt out of the interview or to leave at any stage of the study. Interview questions were semi-structured and were designed based on a general conversational pattern.

Data analysis

Data analysis is a crucial part of a research study. It enables a researcher to develop an understanding and deeper meaning about the subject being studied. It is a complex process as it requires a researcher to manage a strategic analysis very systematically.

According to Morse & Field, (1996),

On the part of the researcher, creative and solid data analysis requires astute questioning, a relentless search for answers, active observation, and accurate recall. It is a process of fitting data together, of making the invisible obvious, and of linking and attributing consequences to antecedents. (p. 103)

All the interview questions in this study were designed in such a manner that creating themes from the content was no longer a very complex process. The interview questions covered key concepts like the interpretation of participants' individual experiences with disability, their community's perception of disability and impact on their culture, religion on their lives as women with disabilities.

The most effective analytical strategy used in the study was creating themes based on the nature of the data collected. Patton (2002) explains inductive analysis as a process of extracting data and creating meanings to identify the core themes of a research study. The inductive analysis is an analytical strategy that entails a complex process of analyzing the interpretation

and perspectives of the research participants (Glaser & Strauss, 1967; Strauss & Corbin, 1994). For that purpose, at the outset, interview transcripts, field notes, reflections, consent forms or any other written observations were all organized in separate folders. Pseudonyms were used to identify each participant's folder separately and also to maintain confidentiality. All the files were printed and a soft copy of each file was saved on a password-protected computer. All the notes, reflections and written observations from each interview provided guidelines for the next interview session with another participant. The data gathered was carefully read to have an understanding of the meaning of the content shared by the participants. Therefore, the interview transcripts were read thoroughly and every sentence was underlined and labelled. All the labelled sentences represented important information relevant to the research questions. The underlined and labelled sentences were carefully read the second time to cluster data that represented specific aspects of participants' experiences with disabilities under major categories and subcategories. The categories and subcategories were used in the final development of themes and they were named based on the content and information they represented. Finally, four major themes and some subthemes were developed. A thematic map was manually drafted to identify all the major themes and subthemes. It was assured that all the themes and subthemes developed were connected to the overall research objectives and information underlying each theme fit the description of the particular theme. The data under each sub or major theme was read and analyzed thoroughly a third time in order to ensure that all the important information underlying each theme has been processed thoroughly.

Finally, a written report comprising description of the participants' accounts was created. Simultaneously, a reflective journal was maintained which helped understand the meaning of the results and linking the themes to the research questions and to overall research objectives. The

final written report also included the primary researcher's observations and reflections about the participants. In ethnographic studies, this is termed as 'reflexivity'. It is based on a researcher's observations and experience of the settings in which the investigations took place and its participants (Reeves, Kuper, & Hodges, 2008). Field notes and a reflective journal were also used to keep a track of the findings and the final presentation of the results.

At every stage of the data analysis process, all the information was shared with the study supervisor and it was assured that no important information was missed in this process. This study attempts to voice participants' interpretation of their individual experiences with disability through descriptive themes that are created on the basis of the substantial knowledge shared by the participants about their lives in specific socio-cultural context (Strauss & Corbin, 1994). To maintain the trustworthiness of the research study, credibility was maintained by interviewing participants who fit the criteria of selection of the study (through purposeful sampling); information on the topic of the study was obtained directly from the participants in the form of participants' personal accounts; a semi structured interview questionnaire was used which gave the participants an opportunity to explicitly share their perceptions and views about the topic of the study; and also continuous supervision from the research supervisor was maintained throughout the study.

Initially, interacting with the women of a similar cultural background as myself seemed not so difficult. However, I was apprehensive about whether they would see me as an outsider because I was meeting them for the first time, whether they would perceive me as someone who may have difficulty understanding their situations and experiences since I am a non-disabled woman. I overcame all my anxieties gradually by engaging in conversations with participants. To maintain rapport, I dressed very informally for the interviews and I initiated with casual

introductory conversations when meeting the participants. Comfort levels were also maintained by interviewing participants in their own homes. They were also given the opportunity to leave if they did not feel like continuing at any stage of the interview. Participants' eagerness to share their views and experiences, and often quite personal information, indicated that they felt comfortable with me. This ultimately enhanced the quality and trustworthiness of the study.

Transferability is another strategy that ensures trustworthiness of a research study. It refers to the applicability of the findings of a research study to other contexts and situations. All the participants invited to participate in this study were mature and they all were able to articulate their views on the topic of the study. This study hopefully contributes in building a strong connection among South Asian Muslim women with disabilities and it would also provide an opportunity to all South Asian Muslim women with disabilities to relate to each other's experiences with disabilities.

Chapter 4: Themes

The descriptive data obtained from the transcripts and field notes was carefully reviewed and analyzed. Thematic analysis was performed on data which led to the development of five major themes. The following are the five major themes and various subthemes under some of the themes.

1. Perceptions of disability

Subtheme: Self-perceptions of disability

2. Community encounters

Subthemes: Sympathy or empathy

A dualistic approach towards disability

Lack of awareness creates negative attitudes towards people with disabilities

3. Marriage and disability

Subthemes: South Asian women's struggle with body image issues

Absence of family-support on the prospect of marriage

4. Religion and culture: An interesting mix

5. The support system

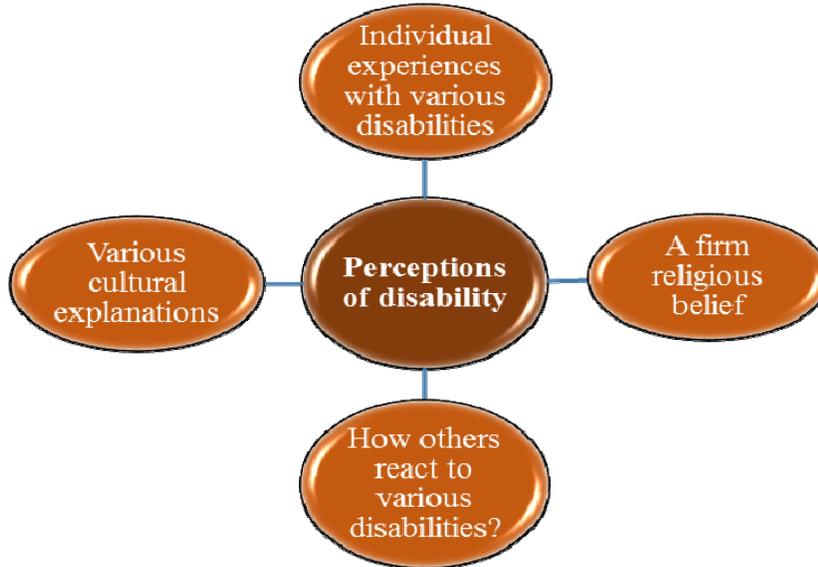
subthemes: Family and community support

Government support

All these themes discuss concepts describing different aspects of the lives of South Asian Muslim women with disabilities supported by participants' direct quotes. In addition, diagrammatic illustrations under some of the major themes reflect the descriptions in these themes.

1. Perceptions of disability

Figure 1.0. Factors influencing perceptions of disability



One of the themes that emerged in the study is perceptions of disability. Disability is often defined in terms of the two models: the medical model and the social model. The medical model describes disability as a health condition requiring medical care. The social model of disability views disability as a socially created problem. It includes social stigma and discrimination experienced by people with loss of function of any organ or body part. It requires integration of people with disabilities into society and changes within the social environment to accommodate people with disabilities in all areas of social life (Emmett & Alant, 2006; Ahmad, 2000).

Social stigma and lifelong discrimination in all areas of social life may often lead individuals to internalize all the misconceptions related to disabilities resulting in their negative self-perceptions. For example, disability causes dependence, asexuality, life becomes useless

with a disability, and so on. All of this may brutally affect one's confidence and self-esteem (Nosek, Howland & Young, 1997; Esmail, Darry, Walter, & Knupp, 2010).

The level and nature of discrimination towards disability may often vary in different cultures, and within cultures, the manner and the extent to which individuals respond to discrimination may also vary. Some individuals may seem relatively more responsive to discrimination than others. For example, some women with disabilities internalize negative societal attitudes towards disability and believe that it is their fate no matter how badly they are treated. They basically give in to the cultural devaluation of women (Nosek, Howland & Young, 1997; Esmail, Darry, Walter, & Knupp, 2010). Most of the participants in this research study also seem to firmly believe that their disability and all disability-related challenges are from Allah. They believe that they will be rewarded in their afterlife for courageously facing all the disability-related challenges in this life. They seem to be grateful to Allah for their lives and how He created them. However, in another study, it also appears that a few families of young Muslim South Asian women with disabilities in Britain were not happy with Allah giving the family a child with a disability which brought shame to their families (Hussain, Atkin & Ahmad, 2002). Some women with disabilities seem to respond to social discrimination differently.

A study shows that many South Asian young Muslim women with disabilities in Britain seem to live overprotected lives as their reputation is believed to be more at risk than men with disabilities in their families. This leads to women with disabilities being deprived of their basic rights and freedom more than the men with disabilities in their families, and to which some of the young Muslim women with disabilities seem to mostly oppose (Hussain, Atkin & Ahmad, 2002). Perceptions of disability emerged as a theme in this study, which explored the extent to which social disparities influence an individual's self-perceptions of disability.

Self –perceptions of disability

Studies show that there are two views that explain the self; an independent, and an interdependent view of the self. An independent view of the self is when a person has control over her surroundings and is in less need of receiving feedback on her behavior from others [people apart from the individual herself in the specific social contexts] in the form of their thoughts, and feelings. This reflects autonomy and independence in a person. It is assumed that more individuals in the Western cultures hold this view than in non-Western cultures. An interdependent view of the self, on the other hand, is when a person is more conscious of others so she attempts to fit into the specific social contexts. This rewards the individual with a feeling of connection and helps the individual avoid unpleasant feelings such as shame (Markus, Kitayama, 1991).

Most of the participants in this study appear to have positive self-perceptions of disability in the face of the South Asian Muslim community's discriminatory treatment towards women with disabilities. For example, Maryam claims, "Disability has affected my life very positively. It depends on how you take your disability and how you use it. My disability actually has made me a better human being". According to Maryam, she could have been a different person if she had not acquired disability,

In the beginning, after I had the accident, I thought oh God! I can't do anything, I can't bend down and I can't make chapattis [roti/bread] like all the nitty-gritty things. I was very depressed. After 10 or 15 minutes I thought and realized that no, I am not useless. I still got a brain. I can speak English. I can help people who are less fortunate; whoever needs my help, who can't speak English, who are new here. I can help people in so many different ways, not physically but mentally, by giving them advice so that's what I used after that. Maybe if I didn't have a disability I wouldn't have considered all these things because you are unaware then.

Maryam further adds, “After my disability, I have become useful to everybody, to the whole community. It has made me a different person altogether. Before that, I was tied to my household and my children”.

Shazia also feels very positive about her life with a disability but at times, she gets depressed because her health condition does not allow her to continue her job.

Shazia says,

I have a very positive outlook on life. I don't have anything negative in me. I never give in or lose hope if I experience something bad in life. I never degraded myself if I ever feel that I can't do something, I don't lose hope in any situation. Some days are depressing as I used to work, and now I am at home all week because of my health condition.

Susan Wendell (1989), a disabled feminist writer referring to the Western cultures notes that pain and suffering caused by bodily illnesses often result in individuals with illnesses experiencing hate, pity, and fear. It appears that participants in this study are unwilling to give in to these experiences. Fatima claims, “I don't see myself as a patient. I am not a patient. I think one should keep one's courage to the highest level and always be positive”.

Similarly, Raisa appears to contest that society generally assumes that disability leads to dependence.

I am a strong person. I want to stand on my own feet. I don't want to become dependent on anyone. I don't want to give pain to anyone. I don't want anyone to say I am dependent on them. I want to take all the pain myself. I have home-care but I do as much as possible.

The stigma associated with a disability often makes it hard for individuals with an illness to talk about their experiences. Therefore, individuals with certain illnesses find it hard to relate their situation to anyone.

Shazia shares her experience when she first discovered she was depressed,

When my doctor recommended me medicine for my depression, I was so concerned, as no one in my family has ever had it before. Some of my friends advised me to do yoga, they said it was temporary and it will go away with time.

Participants in this study also seem to firmly hold the belief that Allah [God] gives them life and all that they experience in life involves the will of Allah.

Shazia declares,

I have immense trust in Allah. I believe everything comes to us from Allah. We should courageously accept it. If we are now going through some difficulties in life, we might be rewarded later only we need to accept all that courageously. I perform my daily prayers regularly. My strong faith in Allah has given me courage.

Raisa not only holds the same belief as Shazia, but she expresses her gratitude to Allah for making her life relatively less challenging than the lives of other people with severe disabilities. Raisa shares,

I am grateful for everything in my life. I don't have any regrets. Allah has made me as I am and I am happy with that. I believe I am not the only one with a disability. When I see other people with severe physical disabilities, I feel more confident that at least I am still capable of doing so many things. I always think that I have everything I ever asked for in my life, and I am grateful to Allah for everything. I pray that may Allah doesn't give anyone of us a disability that would completely restrict our movements.

Raisa seems to believe that life is worse for people with severe physical disabilities. She appears to express her fear that severe physical disabilities may restrict one's movements and make one completely dependent on others. It appears that the meaning of disability varies depending on individual experiences with disabilities.

Shazia shares,

In the past, I used to think that with a disability one becomes completely useless and the meaning of disability for me was when an individual is not capable of doing anything. After I came to Canada, I realized that being disabled is not like that and here people with disabilities are trained in a way that they become capable of doing things on their own.

However, Parveen seems distressed about her experiences in life with disability,

I feel helpless most of the time. I can't do much can't use stairs myself neither can't go to the market. I can't go to my doctor on my own... I am living a more stagnant life compared to rest of the family members without a disability. I feel so dependent on them for almost everything. I get into a depressive phase at times but my family supports me and helps me feel fine again. I don't think I could survive without my family. Disability has influenced my life in many ways; I can't move freely on my own, I can't grasp things in my hands, and I can't stand for more than a few minutes. My disability has affected my life badly, and it has done it in a big way.

A majority of the participants in the study seem to hold a positive view of their lives with a disability. They appear to accept for all the challenges they face with their disabilities. It seems that they often try to connect with their religious faith and they seem to firmly believe that everything in their lives is from Allah. This enables them to sustain their hopes for the future.

However, individuals' self-perceptions of disability are often shaped by varying individual experiences with disability. It seems that for most of the participants, their experiences with disability have made them better individuals; but for some, life with a disability makes them feel helpless and dependent on their family. Participants appear to find their lives with disability challenging, but in their view, life becomes much harder and way more challenging with severe physical disabilities. Therefore, some of the participants seem to view themselves in a relatively better position than individuals with severe disabilities. It appears that these participants may covertly refuse to be viewed as disabled persons, who often in the eyes of people in their community are dependent and helpless. Perhaps they are simply attempting to highlight the varying degrees of challenge which the individuals experience depending on the type and severity of disabilities.

2. Community encounters

Often individual experiences with various disabilities are shaped by how others in a variety of social contexts react to various types/forms of disabilities. (Markus, Kitayama, 1991). Participants in the research study share their experiences of their interactions with people in their community. South Asian communities in the West seem to share some cultural similarities. People in the South Asian communities seem to feel connected with other people in their community or in society as a whole. Participants in the study seem to share their stories about their interactions with people in their community both in their country of origin and in Canada. Raisa shares her story about the attitudes of people towards disability,

Here in Canada, people look at both people with disabilities or without disabilities as equals. Here everyone has equal value and worth. People make disabled people stronger. They support them and encourage them. In Pakistan, Afghanistan, India, people would have given me different names. They make fun of people with disabilities. They do not give any value to such people. I saw a man in Pakistan once, leaving a blind old man in the middle of a busy road to die. The blind man had only asked him to help him cross the road. My father saw the blind man. He went and helped the blind man cross the road. The man who had left the blind man in the middle of the road to die started cursing at my father for helping him. That is very sad. Here, in Canada, they do not even kill a stray dog like that [stray dogs in most of the Muslim South Asian countries are often killed by city officials].

Community encounters emerged as a major theme in this research study and it discusses how people in the South Asian Muslim community react to disability in the light of participants' accounts on disability.

Sympathy or empathy

Participants in this research study preferred empathy over sympathy. In their opinion, empathy is a feeling of living through others' experiences and being understanding of other

people's needs. Whereas, sympathy in their view was feeling sorry for people with disabilities for their apparent "suffering".

Maryam shares generally how people in the South Asian community respond to disability,

Our community perceives disability very negatively. What people do is they sympathize. They will feel very sorry for you if you have a disability. Awe, you poor thing! [Oh, Bechaari!] They don't empathize with you. They will not encourage you. This kind of attitude does not just exist in Pakistan, but here as well. Once I went with my husband to Niagara Falls. My husband dozed off while sitting in his wheelchair. Someone came and put some money in his hand...when I picked up the money I saw that it was Pakistani currency. This shows our people are being sympathetic towards people with disabilities.

Whereas, Raisa seems to prefer sympathy over empathy and states,

I believe sympathy is better than empathy. Every human being should have sympathy in their heart. Without sympathy one becomes evil. Sympathy leads to respect and care for people with disabilities. Sympathy is when someone embraces your pain and helps you. Whereas, when someone empathizes with you, he will only hear you not listen to you and will simply go on with his life.

Fatima appears displeased with people in the community who sympathize with her and treat her differently.

Fatima argues,

The community people don't show much concern to you, but they sympathize with you more and treat you differently. I don't need anyone's sympathy. I only want sympathy of God. Most of the people in xx community start sympathizing with you once they hear about your health condition.

Parveen seems disappointed as well in how people in the South Asian Muslim community treat disability,

People I know in the community have become used to my condition. When I meet people for the first time, they show sympathies and pretend as they are very concerned about me. They look down on you as you are not a human being worth living. I have felt people's hidden hatred for the dependent individuals like me because they don't want to see them around. Pain and illness scare them away.

A dualistic approach towards disability

People often seem to adopt a dualistic approach toward disability. First, individuals with visible physical disabilities, for example, people in wheelchairs, using mobility aids, missing limbs, and so on are categorized as disabled. Therefore, based on the traditional attributes associated with disability, people with visible disabilities are not expected to function the same as everyone else. Second, individuals with invisible disabilities are not seen as disabled. They are expected to maintain behaviors conforming to the traditional norms of customary behavior (Dale Stone, 2005). Hence, people with visible disabilities often receive sympathy, whereas, people with invisible disabilities are often expected to function at the same pace and manner as everyone else.

For instance, Maryam seems to feel that people with chronic illnesses are often met with disbelief,

People mostly see and react to visible disability only, because our people you know they never even bother to see what lies inside. They can see me apparently healthy, they think I can do everything. They don't realize that the way I am doing things. Like this morning, I woke up with so much pain and I had to take so many painkillers, and then I was able to walk or do something. They would say, Oh, Maryam, you are fine you can make us one pot of Biryani [a traditional Pakistani cuisine] for the Mosque. ... I couldn't even cook for myself at home. I had so much pain. I couldn't lift my arm even. I couldn't stir so I modified all my cooking techniques and everything. They did not care because people only see visible disability.

Fatima agrees that a dualistic approach regarding disability does exist. Fatima indicates, "In our community, if you are missing a limb, people think only that is a disability. As long as you can perform a job physically, they don't see a disability."

Sana says,

We have not seen anyone with a visible disability among women in our community. Those with health issues do not share much and they are not getting any support from anywhere.

Fatima makes an important point that it is not widely understood that disability impacts every individual's life differently. Non-disabled women in the South Asian community often make comparisons between two women with similar chronic conditions and end up blaming women with chronic illnesses for not taking good care of their health.

She shares,

If you don't have a visible physical disability, people even use examples of a third person saying if that person with so and so disability can perform so and so job, you can do it too. People often say you should take care of yourself and if you take good care of yourself you won't get sick.

In addition, people without disabilities often seem to avoid listening to or talking about the pain caused by some chronic illnesses. One of the reasons they avoid talking about pain or illness is that they are often fearful of becoming disabled or sick themselves. They fear weakness and dependence that are traditionally attributed to chronic illnesses and disabilities (Vickers, 1997). Maryam points out that often people avoid listening to other people sharing their experiences of pain.

Maryam shares,

If you complain all the time people will run away. They will not sit and listen to you. Who wants to listen to someone who is complaining about their pain all the time? But that's normal human behavior and that can happen to anyone in any community.

Maryam shares a story about one of her friends who passed away due to cancer,

I had a friend who had cancer. She passed away two weeks ago. She was Christian. Every time I called her and asked her how she was feeling. She always said that she was doing fine. She used to say, 'I had chemotherapy, in fact, I feel

so strong. I cleaned my house and I cooked'. She used to surprise me. Maybe she was fine. I felt very bad after she passed away that she never complained about her pain or anything to me. At least she could have talked to me and told me about it... This is because people don't want to listen to you. It actually bothers me. The only thing I feel is that she should have known that I am a very good listener, and I listen to people. I listen to their pain as I feel pain and I understand pain.

Lack of awareness creates negative attitudes towards people with disabilities

Shazia seems to suggest that usually, it is the lack of awareness about disabilities that results in people's negative behavior towards persons with disabilities. People's expectations may also change with different disabilities. People with visible disabilities are often not expected to perform the same as everyone else without disabilities, in any of the traditional, social or family roles (Albrecht, Devlieger, 1999).

Shazia points out,

Some people irritate me because they excessively probe into my personal life and repeatedly suggest me the Do's and Don'ts about my current health condition. Often, repeated advice from people is not very helpful, but I rather find it discouraging. They make me feel that I am incapable of doing things on my own because of my health condition. However, when I began to understand religion I have learned to ignore and forgive people, and focus on life and things that will help me in my afterlife.

Fatima claims,

They [people in the community] will simply neglect you if you are not able to take part in the community activities because of your disability. If you are not being active in the community, they will show no interest in you. I think they should support and encourage us as one might be able to do other things, work that involves only mental work like some computer work.

Whereas, Maryam claims,

I have never been left alone by community people. It depends on the person's attitude that what does he or she want from others and how one treats oneself first. I have always been very respected by people. When I had the accident, people were concerned. I feel so embarrassed that even people older than me would give their seat to me at the mosque.

Shazia also appears to have a fairly positive experience with how people generally respond to disability, except some people in the community who maintain an indifferent attitude towards people with disabilities.

Shazia explains,

I feel generally people in our community would treat people with disabilities nicely and are kind to them. Our Muslim community in Canada has become more aware of disability. They have gained social awareness from non-Muslims [referring to non-immigrant Canadians] seeing how they support individuals with disabilities. They realize that what our religion teaches us about how to treat such individuals is actually being practiced here by non-Muslims in Canada. They are now beginning to understand how a society could support people with disabilities to help them to live life as independent as everybody else.

Maryam is pleased with the gradual increase in the social awareness of people in the Muslim community. She shares what she often witnesses at the mosque,

Over here [in Canada], it is so much better. People are very considerate and are well aware. Even at the mosque, people will open the door for me. They will even remove snow boots for us as they are too long and because of disability we can't take them off. All this is more because of social awareness and awareness about disabilities, not just because of religion. Yes, in our religion, people also say that this (kind of attitude) towards disabled people is a good deed, but mainly it is because of social awareness.

In summary, it appears that people in the South Asian Muslim community often sympathize with people with visible disabilities or illnesses. Though, they seem to neglect people's invisible disabilities or illnesses. As indicated by the participants it appears that people, in general, avoid people who often seem to complain about pain and suffering. It appears that people without disabilities often seem scared of disability as disability is often associated with dependence and helplessness. It also appears that people with disabilities and particularly women with disabilities do not even want to confide in others about their experiences with disability.

Raisa claims, “My personal experience has taught me that trust is very important before you decide to share anything personal with anyone other than your family members”.

Sana argues,

Women do not want to share because they are scared that if they open up to someone about their illness, that someone will tell someone else and the news about their illness will spread in the community in no time.

It suggests that women with disabilities do not share feelings and/or experiences because of the social stigma associated with disabilities.

Maryam notes,

Women are unwilling and reluctant to speak up on any social issues related to disability because disability is still a taboo in our culture. In our culture, we women are not supposed to express ourselves. We are not supposed to talk about our pain.

This seems like women with disabilities in South Asian communities are still secretly struggling against the social stigma attached to disabilities.

Most of the participants maintain that due to social awareness, attitudes of Muslim South Asians are gradually changing towards women and disability. All the participants seem to feel positive and appear quite hopeful.

3. Marriage and disability

Marriage and disability emerged from the participants’ accounts on perceptions of disability. Marriage is often seen as an institution shaped by socially constructed rights and responsibilities (Bell, 1997). Traditionally, in South Asian Muslim families, marriage is arranged by parents or elders. These days, both parents and youth get involved in the decision but in the end parents’ approval is still vital (Bhopal, 1999). Evidence from a study performed in India shows that in many South Asian countries, including India, changes have been taking place

with the traditional family-arranged marriage. Although parents and family members' approval continue to be important in the selection of a spouse, the daughter/ son's approval of the partner selected is also given importance. Sometimes, young people even get to select their own spouse independent of parents and family members (Jejeebhoy, Santhya, Acharya, & Prakash, 2013).

It appears that the South Asian traditional arranged marriage system is gradually changing in South Asian communities particularly those that are living in the West. Young South Asians are assuming new cultural reforms by restructuring their parent's old cultural norms. They are frequently seen participating more in decision making and they often demand to be consulted during the arrangement of their marriages (Ballard, 1982).

According to the participants in this study, parents here appear to participate in the decision making process concerning their children's marriage as compared to taking decisions for them like they traditionally used to do.

Sana shares her experience,

Children raised in Canada do not usually lie to their parents. They are more confident now. If they are going out with someone, they will tell their parents. In India, Pakistan mostly people have double standards. They indulge themselves in everything, but they hide from everyone. My son told us right away that he wanted to marry a Hindu girl. We told him we have no issues but she has to convert to Islam and only then she could marry you. The girl first converted to Islam and then my son and she got married.

Shazia says,

Marriages used to be arranged by parents, but now both men and women choose on [their] own who they want to marry. In Pakistan, parents on either side want to know each other's family background so they meet and greet with each other's relatives, but this is not very common here. They don't probe much into each other's family background.

It would also be interesting to examine the impact of the restructuring of the conventional norms on the lives of South Asian women with disabilities in the West.

Shazia states,

A growing trend in the West among young educated [South Asian Muslim] individuals these days is that they prefer mental compatibility over physical beauty and even this trend is spreading in Pakistan now.

South Asian women's struggle with body image issues

Studies show that the body image issue is something that affects all women including South Asian women. They often feel pressured to meet the demands on physical appearance. One of the aspects where South Asian women appear to struggle most is against prejudice against their darker skin color. Often they feel pressured to conform to the Western ideals of beauty to be considered for marriage that is, tall, thin and white skin (Sahay, Sarita, Niva, 1997; Sahi, Dana, 2003).

Bano is from Pakistan. She has been living in Canada for several years now. She shares,

Pakistani people in Canada have not changed their narrow thinking. They carefully assess a woman's physical appearance before considering her for marriage. People often prefer health and physical beauty in women, even over education.

Shazia argues,

Having a disability does not seem to be a big hurdle for [South Asian] women when it comes to marriage. I have seen a couple of my distant female relatives with a physical disability who got married. They both are living a happy married life with their children and husbands.

Other participants seem quite explicit in their responses about how women with disabilities in South Asian Muslim communities are treated. Maryam, a Pakistani-Canadian woman remarks, "Disability in both boys and girls is treated the same way. Though, disability in females receives worse treatment. It is seen as a curse". Sana an Indian Canadian, participant notes, "When a woman has a disability then her life is no more the same. Marriage in her case is absolutely not possible". Sana knows another Indian Muslim girl from Toronto who has a

physical disability as a result of polio. Being a Muslim she wanted to get married to a Muslim man. Unfortunately, with her disability she could not find any Muslim man who would marry her. Eventually, she found an Italian Christian boy and she got married.

Sana mentions,

Her mother was worried that her daughter got married to a Christian guy. Well, I say she should not be complaining about it now, as no one among our Muslim brothers showed interest in getting married to her because of her physical deformity.

All the participants in the study, but Shazia, seem to agree that no matter what part of the world they are living in, disability lessens the possibility of marriage for South Asian women.

Absence of family-support on the prospect of marriage

Raisa indicates, “In most cases, chances of Muslim women with disabilities getting married is either very low or close to zero”. Raisa is in her late 30’s. She recently got married to a man from Afghanistan. Raisa’s husband now lives with her. Finding a marriage partner was not the only challenge Raisa faced. She was also fighting against her family’s misperception that women with disabilities could not have a successful marriage. Raisa obtained support from one of her close friends.

Raisa shares,

My family did not want me to marry, they didn’t come when I was getting married. They just came to see me and my husband. They could not believe that I found a man who is so handsome and highly educated.

It appears that families do not consider their daughters with disabilities suitable for marriage as they are doubtful and apprehensive about their daughters with disabilities having a successful married life. It also appears that often families believe that their daughters with disabilities are at risk of being exploited. Considering people’s discriminatory treatment

particularly towards women with disabilities, families fear that probably only someone with some hidden interest would be willing to marry their daughter with a disability. They fear that she might be abused by her husband or in-laws as disability causes vulnerability.

Raisa indicates how people from Pakistan, India, and Afghanistan living in the West view a woman with a disability and marriage.

Raisa shares,

Family members of a woman having a disability perceive her as being dependent and useless. They don't want that woman to get married because they think that a disabled woman could not live a happy married life. They think that she will not be able to take care of herself, and she will not be able to fulfill her family responsibilities after marriage. A man will only want to marry her for his own benefits like only to get a foreign nationality.

However, this might not seem to be the case every time. Maryam shares,

There are wonderful people in this world as well. I have a Pakistani friend. She lives in Toronto. My friend's family has got Muscular Dystrophy (MD). It is a hereditary condition. There is no cure for MD. It runs in the family. Her son has it and all their females in the family have it. All the females are now married. They got married to their cousins. Therefore, before marriage, their husband already knew about their condition. And there was no cultural or family pressure involved in their marriage.

Bano is a Pakistani-Canadian who has been living in Winnipeg for 7 years now. In 2003, her 16-year-old daughter met with an accident while returning home from school. Her accident left her physically disabled. Bano is in her 40's. She has diabetes and chronic joint pain. Bano has been taking care of her daughter since her accident.

Bano expresses doubts about her daughter's future,

I don't see any future for my daughter getting married or raising a family unless she gains enough independence. No one will accept her because she is dependent. She is dependent on me for every little thing, dressing, eating, toileting.

Parveen is another Pakistani Canadian. She is in her early 40's. She has been living in Canada for 10 years. Parveen often feels that her disability has made her completely dependent on her family members.

Parveen notes,

A man with a disability could easily find and marry a girl without a disability. If he is financially sound, he can also find a girl without a disability, who is a lot younger to his age. Marriage is not even an option for a woman with a disability. Most of the disabled women spend their whole life at their parents' home where mostly they are not treated well. Their family sees them as a burden.

Bano informs how Canadian Pakistanis interpret disability in women,

Most Pakistanis in Canada don't change their narrow mentality. Their attitudes remain the same no matter where they live. I have never heard any Pakistani family accepting a disabled girl for their son's bride. Families see their own disabled daughters as burdens. Families do not consider them for marriage as they see them as dependents and not able to take care of themselves.

Some women seem to rationalize the disparities women with disabilities experience throughout their lives. For instance, Bano surprisingly seems to justify the negative attitudes of people towards women with disabilities.

Bano candidly admits how she herself feels about disability in women,

I don't blame people for their negative attitudes towards disabled women as I being a mother of a daughter with a disability I understand them. I will not accept myself a girl with any disability for my son.

Likewise, Sana admits,

Everyone seeks his own benefit in life. Most of us are selfish. Now, who will marry a *Terri bakri [a twisted goat]*? If someone asks me to allow my son to marry a girl with a physical disability, I will definitely not allow it, though I know it is wrong.

Overall, it appears that most of the South Asian Muslims in Canada still hold on to their traditional approach when it is about marriage. As Bano, referring to the narrow perspective of

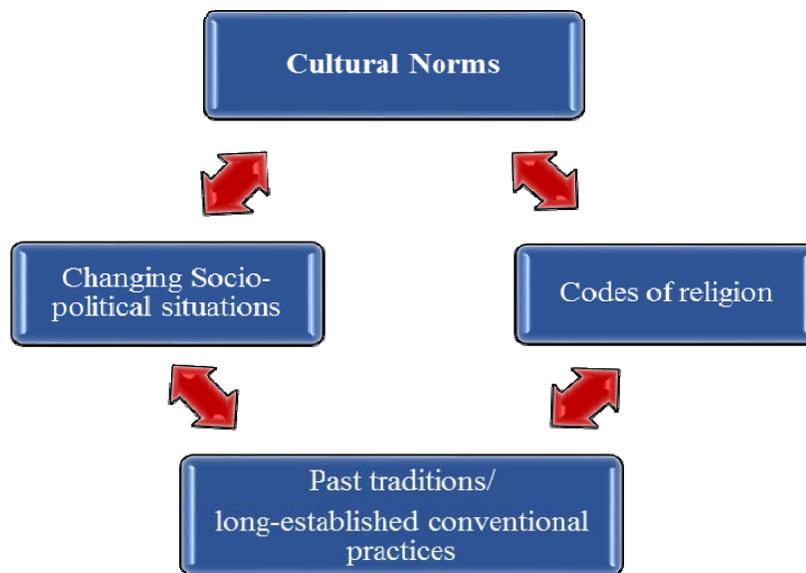
many Pakistani Canadians, says, “They carefully examine a woman’s physical looks when it is about marriage. People look for beauty in potential brides, sometimes, they even prefer beauty over education”. Marriage does not seem to be considered a possibility for women with disabilities, particularly by their own families. It appears that their families fear they will not be able to run their own family home and they are at a risk of getting exploited in the process.

In addition, some of the participants themselves were not in favor of considering a girl with any physical disability as a possible bride for their own sons. Over the years, myths surrounding disability and the majority of people’s negative attitudes towards disability have left some lasting adverse effects on some women with disabilities.

However, it also seems evident that with the increase in social awareness about disability in the West, attitudes towards women with disabilities appear to be gradually changing in South Asian Muslim communities.

4. Religion and culture: An interesting mix

Figure 2.0. Factors influencing cultural norms



This theme discusses some interconnected factors that appear to affect cultural practices in the South Asian community (*Figure 2.0*). Studies show religion as a key element in understanding a culture. A society's cultural values, norms, and traditions are greatly influenced by its religion. The impact of religion varies with society's changing social and political situations (Hinnells, 2005). Raisa seems to support the argument that cultural norms are often influenced by religion.

She says,

Culture is important. For me, it is what I have been taught since my childhood. Most aspects of our culture are influenced by our religion. For example, when I was young my mother taught me to keep myself covered up, but this is also what our religion teaches us [women] to do. Many times, we follow our religion and culture both at the same time.

It appears that religion encourages people to combine general ethical ideals with culturally valued morals. For example, a religious concept that God created the world motivates its followers to make united efforts towards protecting the environment to preserve life. Religion interprets and rationalizes behaviors that are ethically acceptable with reference to religious principles. Therefore, people become more motivated to incorporate ethical ideals into their cultural norms (Gardner, 2006). It would seem that cultural practices in a specific social context often reflect a common religious belief system, which allows people to interpret their lives (Reder, 2010).

This theme emerged from participants' accounts of how they interpret their lives with a disability with reference to their specific belief system. Participants seem to share how much influence their religion and culture have on their lives.

Bano shares,

Religion has helped me in coping with all the challenges in my life. It has given me immense strength. I believe if we are determined to achieve something good for ourselves, Allah will definitely help us. It is my firm belief in Allah which keeps me going in life.

For Parveen, her faith in Islam has given her strength to endure her pain,

My faith in Islam creates a healing effect on me. Religion I feel has power with miraculous impact on my life with disability. Initially, I was unable to bath on my own but now for last year and a half, I am taking a shower on my own by the grace of almighty Allah. I have strong belief that when Allah gives us pain and hardship, He also gives us immense strength to endure all the pain.

Maryam claims that her religion has given her a new and positive perspective on life after she acquired her disability. Her faith in her religion has given her inner strength.

She states,

Religion in my life has played a role to help me understand the needs of other people. It has made me stronger inside. I am a bit lazy to pray, or sometimes I am busy, or because of the pain sometimes. I pray to Allah to enable me so I can pray five times a day. One thing is that I never complain because I always think *Inn Allah Ma' As'sabireen* that God is with those who have tolerance and *saber [patience]*. When I hear people complaining, sometimes, I even hear my friends complain, 'oh I have a knee pain or oh, I have a shoulder pain'. I look at their faces and think that if I start complaining that I have pain from my head to toe, they will run away, and I have severe pain. That is the strength which religion has given me.

Fatima seems to share the same sentiments about her faith as other participants in the study,

My belief is that everything that is going on in your life is already written in your fate. Allah gives you everything and I strongly believe that Allah helps you a lot. Remembering Him gives me satisfaction and peace of mind. When I read Quran I gain a lot of inner strength and that keeps me going in life. If our women with disabilities have the courage and inner strength, disability is not something they can't live with.

Raisa expresses her gratitude towards Allah and says, “I am grateful to Allah for everything in my life. I don’t have any regrets. Allah has made me as I am and I am happy with it”.

Studies show that Islam appears to give a sense of identity to the Muslim South Asian minority in Britain. They believe that all the aspects of their lives should be guided by the teachings of Islam, and ethnicity should be treated as secondary in their lives.

Ethnicity shapes many aspects of their lives but is not seen as central to their identity (Jacobson, 1997; Hussain, Atkin & Ahmad, 2002; Jeldtoft, 2011). Many people often choose to wear traditional clothes to maintain religious identity. It also depends on how an individual views him/herself. Some view themselves as being more religious and some view themselves as not very religious, whereas, the majority of Muslims appear to view people who are not very religious as not true Muslims (Hinnells, 2005).

Sana indicates that generally, people in the South Asian community perceive others as religious based on their traditional appearance. It looks like appearance often influences people’s perceptions.

Sana argues,

Religion helps me to remain strong and praying gives me peace of mind. I am religious but I do not wear a scarf. There are often women with scarves who will point to other women not wearing scarves to cover their heads. It depends on how religious you believe you are. Some people are really very religious, they strictly practice religion and some are not very religious. I say religion is personal. You live your faith. You help someone in need and you show compassion to other human beings in need. That is religion for me.

In addition, many South Asian Muslim parents often fear that their children, particularly their daughters will become Westernized. They could completely adopt Western values which the parents often perceive as being morally corrupt (Ijaz & Abbas, 2010). Therefore, in the West,

South Asian Muslim parents seem to greatly stress transferring their cultural and religious values to their children. Over the years, young people in the South Muslim Asian community living in the West are exploring new ways to avoid any conflict between their parent's values and the Western norms (Hussain, Atkin & Ahmad, 2002).

Shazia also seems to express similar concerns while she shares how Canadian South Asian Muslims view religion,

I think religion has more impact on the life of Muslims here in Canada than back in Pakistan. It is sad to say that in Pakistan there is a gradual deterioration occurring in people's moral standards...As far as religious belief is concerned, there are people here in Canada who have completely become Westernized. They think that religion hinders their progress, but there are people who fear that their children will lose their identity as Muslims and they might get carried away with the Western lifestyle. Therefore, they make their children hold on to their religious beliefs and practices.

Shazia adds to her comments,

In the past, people used to even hesitate to dress up in their traditional clothes and some South Asians even used to avoid speaking in their first language in public with other people with the same origin. Over the years, this has changed. Our people now have become more aware and have gained more confidence through education. It is in our religion how a woman should maintain *satar* [modesty]. With an increasing number of Muslims in Winnipeg and with more awareness, now they don't hesitate to put on their traditional dress according to what our religion teaches us. I have even seen women fully covered walking in public.

Shazia seems glad that with gradual awareness in the West, many Muslims are now reverting to their traditional and religious customs.

Fatima also states,

We have to make sure that our children are aware of our cultural values and religious beliefs. We must refrain [sic] them from adopting a Western lifestyle. My children are not allowed to go to any friend's house or also their friends Muslims or non-Muslims are not invited to our house.

Shazia remarks that for anyone culture is easy to adopt but religion is hard to embrace.

She claims,

Culture is very easy to adopt and people adapt to a culture very easily. What is hard to accept is religion. Religion comes from within oneself. It is a commitment to oneself. It depends on an individual how much religion impacts someone from inside.

Parveen elaborates on it further and makes an interesting comment,

I think Muslims from South Asia living in Canada follow their cultures and traditions all their life. Their children follow Canadian society and its norms, but their parents make sure that their children are fully aware of their own cultural traditions. Many people strictly follow their cultural traditions but some are very flexible. My family lives with our cultural traditions and that is where our family values come from. Our lifestyle, caring for elders, practicing faith and all family members living together represent our cultural traditions. Most of our cultural traditions are according to the Islamic teachings and that's why we refer to our cultural values so that we follow Islam even if we are not strictly practicing our faith.

It appears that South Asian Muslims living in the West seem to hold on to their religious values and cultural integrity according to Parveen.

Shazia indicates how Islam requires women to seek permission from men on most aspects of their lives,

In Islam, men are expected to take responsibilities outside home and women to take care of responsibilities at home. If women have to leave their home to work in order to make ends meet, they can do so after seeking permission from their husband if married, father or brother if unmarried. Men cannot force women to work outside against their will but this sort of decision should be made with mutual consent.

Raisa seems content that even with so much freedom in Canada, she lives according to her cultural and religious customs of her own free will.

Raisa says,

There is a lot of influence of the Western society on our people as it allows freedom. I personally like to follow my culture as I love my culture and my religion. My conscience does not allow me to go out uncovered. Even If I did, no one would mind. I have no religious pressure on me and my husband does not impose anything on me but it is my conscience that does not allow me to completely adopt a Western lifestyle.

It is important to note here, that Raisa, like other participants in this study, immigrated to Canada some years ago. She grew up in Afghanistan and lived in India and Pakistan for several years before immigrating to Canada in her late twenties. Therefore, she already had become accustomed to the Islamic and traditional South Asian norms before arriving in Canada.

However, it appears that for South Asian Muslims, and women in particular who grew up in the West, maintaining a balance between their traditional norms and their western identity may have become an ongoing struggle but they still manage to achieve it without causing any sort of conflict (Dwyer, 2000).

Bano shares her story about growing up in a traditionally conservative community in Pakistan,

Culturally, in Pakistan and India, women are obligated to fulfill their husband's and children's wishes. They are responsible for all the household chores and also looking after their children. They are often not allowed to leave their homes without a male family member. My family used to live in a small village in Punjab [province]. There was a school in our village which was up to grade 10, and to study further one had to travel to other big cities of Punjab. In our village, only sons would travel to other cities for higher education, but daughters were not allowed to travel that far. In my family, my father never allowed me or my sister to travel outside the village for education. Therefore, my sister and I could not continue our education after grade 10. My sister went to a local religious teacher who taught her to read and memorize the Quran.

Bano claims that this conservative cultural approach is not common in Canada among people from Pakistan and India.

Bano adds,

No woman in my family or in my relatives in Punjab works outside the home. They are allowed to obtain education but not allowed to work. People living in the cities are relatively open-minded and allow their women to work outside the home. Yet, there are many people from India, Pakistan living in Canada who do not mind sending their women outside the home to work. I think it could be because in Canada, mostly our people do not live close to each other in the same locality. People from their community may not know much about you if you are not in contact with them.

Bano seems to point out that many South Asian Muslims in Canada appear to hesitantly adopt many aspects of the Western life. According to Bano, reluctance exists only because unlike people in the West, people from South Asia are more concerned about how others in their community would react to their behaviors. She also indicates that South Asian Muslims still seem to adopt Western lifestyle because South Asian Muslims in Canada often do not live in proximity to each other. This reduces the possibility of any rumors spreading around in the community.

Maryam comments about how past traditions influence cultural norms and religion often become secondary,

Some of the South Asian Muslims use religion as a shield. Some even kill for their own ulterior motives and use religion as a shield. Both cultural values, as well as religious beliefs, are twisted. In our Muslim South Asian community, culture is stronger than religion. Religion should come first but unfortunately, people prefer culture over religion which is often twisted as well. People are more worried about what other people will think about them, even if they are doing something right, according to the religion, because religion does not teach you wrong, it is our made-up culture which leads us to wrong things. For example, female circumcision is a custom in many Muslim countries. There was a Muslim lady [from Ethiopia] who worked for me. She was herself a victim of circumcision. I was shocked to learn about that. It is their custom that two or three weeks before the girl gets married, the circumcision is undone.

Studies reveal that the traditional patriarchal practices may still exist and may vary in form in relation to different social contexts. For example, patriarchal practices in South Asian

communities may even escalate after migration to the West. Women may give in to patriarchy to access economic resources resulting in more dependency on the male head of the family, or to find refuge against overt or covert racism in Western societies (Walton-Roberts, Pratt, 2005). This indicates that varying socio-economic situations in different countries also impact on cultural norms influenced by past traditions.

Maryam says, “Religion does not say, you don’t respect women. Prophet (Peace be upon Him) himself used to stand up for his own daughter, his wife Khadija and his mother Bibi Halima”.

Raisa claims,

Religion pretty much influences our culture, our attitudes and how we live. The difference between religion and culture is that our religion belongs to our prophets and Islam specifically to Muhammad (PBUH). Whereas, culture depends on oneself, our lifestyle. For example, the way I have decorated my house clearly represents my culture. I respect all religions. In my eyes, only humanity matters. I like to live in a multicultural society. I believe that we learn from each other’s cultures.

South Asian Muslim communities in the West have often been stereotyped as being patriarchal communities. Participants in this study seem to contend this negative impression of South Asian Communities in the West.

Shazia argues,

There have been a lot of misconceptions in the West about how Muslim men treat their women, such as in Islam, men are allowed four marriages and to force their women to stay at home and wear certain kinds of dresses only. Yes, there are a few who have come from some of the interior provinces of Pakistan who do not allow their women to work outside the home and are controlling. The majority of the Muslim women, however, are acquiring education and even many have career jobs. In Toronto, there are small scale industries run by ‘Dessies’ [common term used by South Asians to refer to themselves] where women work and where language is not an obstacle. Islamic Circle of North America [ICNA] also works to clear these misconceptions about Islam and its teachings to non-Muslims in the West.

Maryam points out an important aspect of South Asian community that seems to affect its cultural practices.

Maryam shares,

There are different races with different cultures in Pakistan. People of different races may have a different understanding of culture and religion. For example, Sindhi people [people from Sindh- the province of Pakistan] there is a custom where girls are married to Quran. What the hell is that? I know people who are prejudiced towards daughters. They say that they don't want daughters. They are so narrow-minded. Most of them come from small towns. This only happens in families in rural areas where illiteracy is very high.

Maryam seems to claim that conservative people are not just in South Asia. South Asian Muslims when they migrate to the West they bring along their traditional customs with them.

Maryam shares,

Ignorance can be seen anywhere. People can have a Ph.D. but their mindset is like that. I have even seen Muslim South Asian doctors and PhDs here in Canada when they talk, they drive me crazy. There are still people here who have a very narrow approach when it is about their daughters. It is not because of religion. It is a cultural thing and unfortunately came from Hinduism [Hindu culture]. We have a lot of cultural things in Pakistan that came from Hinduism like dowry.

Shazia claims that Islam encourages people to respect each other and help people in need.

She states,

Religion [Islam] teaches us to respect everyone's dignity and self-respect. It teaches us to help people in need and encourage such individuals so that they can live their life as everyone else in society.

Raisa remarks,

I do not like people who think badly about other people, hate and look down upon people with disabilities. They are not obeying Allah and they do not fear Allah. People who do not fear Allah scare me the most. Afghan people mostly are driven by worldly greed. People who fear know that one day we all have to leave this physical world and die.

However, Shazia seems to stress the importance of education. She says,

Negative attitudes towards women and especially towards women with disabilities are because of some of our cultural norms which we created ourselves or sometimes because of old conservative family traditions. All of it is because of ignorance and lack of quality of education. Education gives people awareness and broadens their vision. Our educational curriculum needs modification. Education should allow people to have open minds. It should enable them to see others as human beings like themselves and to respect each other's basic rights. That is how people become considerate to other people's needs.

All the participants in this study seem to agree that both culture and religion together play a vital role in shaping people's attitudes in life. Most South Asian Muslims appear to hold culture as the root cause of all negative social behaviors like patriarchal practices that are often linked to South Asian Muslim communities. It appears that lack of access to quality education and social awareness result in ignorance which makes the lives of women, particularly women with disabilities more challenging.

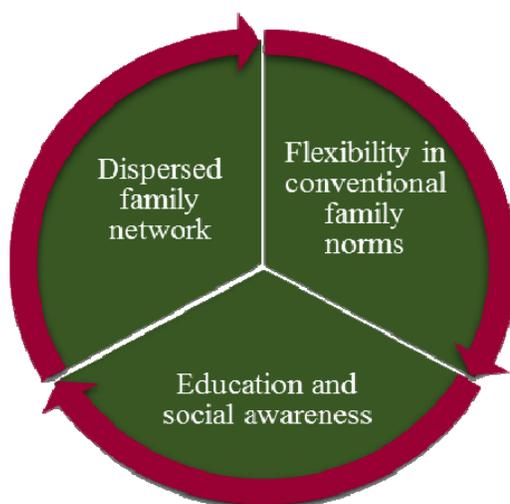
Maryam conveys a message to other South Asian women saying, "My message is to the families that women need to be educated in every which way. They need to be educated both academically and socially".

It seems that some of the South Asian Muslim families from rural areas who migrate to the West often hold onto their old patriarchal traditions. However, many South Asian Muslims seem to have developed social awareness and they appear to integrate into the Western community while remaining within the bounds of their cultural norms and religious principles. Yet there are also some who fear the negative influence of western culture on their youth growing up in the West. They fear that it might lead them away from their culture and religion. Therefore, parents keep their children from socializing with their friends outside their religion and culture.

Most of the participants appear to identify themselves as being not very religious but surprisingly they all seem to acknowledge that they gain strength from their religion. Participants also believe that their disability is because of their fate. Allah [God] has made them who they are and they seem content by what Allah has given them in their lives. In the end, it looks like participants in this study seem to emphasize that some of their old cultural traditions need some reformation and religion should not be used as a shield for negative social behaviors.

5. The support system

Figure 3.0. Impact of immigration on South Asian cultural dynamics



People with disabilities experience many challenges in different areas of life including: household responsibilities, education, or employment. In addition to their physical limitations, society's negative attitudes towards people with disabilities often impede their full participation in the community (Deegan & Brooks, 1985).

It seems that family support, community support, and support from the government are important elements in the lives of people with disabilities which allow them to live and participate as fully as anyone else in society. The support system is a theme that emerged in the

study from participants' accounts on the support provided to people with disabilities, specifically women with disabilities living in Canada.

Figure 3.0 illustrates the impact of Immigration on South Asian conventional family norms and support system in Canada. This theme discusses different kinds of support which South Asian Muslim women with disabilities receive in Canada. It also discusses some of the effects of immigration on South Asian Muslim cultural norms in the light of participants' accounts on the different support they receive.

Family and community support

A study of two groups comprising sixty-two women with and without physical disabilities revealed that women with physical disabilities are often more at risk of being abused most commonly by their husbands or live-in partners and the duration of abuse also seems to be longer than for women without physical disabilities (Young, Nosek, Howland, Chanpong, & Rintala, 1997). None of the participants in this research study mentions any experience of abuse towards women with disabilities by their own family members in their community. In fact, they appear to appreciate their families for their support.

Studies about South Asian families show that in nuclear families, spouses, children or siblings with disabilities are cared for by both male and female non-disabled family members. For example, husbands are often responsible for watching over their children with disabilities, dropping them off at school, taking them to their medical appointments, and so on. Whereas, mothers' responsibilities are often focused on the intimate care of their children with disabilities and they are often left struggling on their own. If the child is a son and he approaches adolescence, fathers may assume the responsibility of helping their wives with caring for their adult son with physical disabilities (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004).

Bano argues that it is women's religious duty to take care of all the household responsibilities of her family.

Bano shares her story about how she fulfills all her family duties,

I am a housewife and I take care of the needs of my children as much as I can. I believe that it is every woman's duty to fulfill the needs of her children and husband. I have pain in my knees and I have diabetes, but still my children and husband come first. I believe it is my duty to serve my children and husband. I have always served them fresh food. My husband always praises me so much that I always get him a cup of tea whenever he wants it before he even asks for it. This is our religious duty to look after our children and husband. My responsibilities increased after my daughter's accident. She came home from hospital after 8 months and after that I have been taking care of all her personal care needs.

It appears from participants' accounts that in South Asian nuclear families, often women are expected to perform all the household work including caring for the disabled family member. It only becomes challenging for families if there is a female family member with a disability who requires assistance with personal care as in Islam women are forbidden to have any physical contact with any man except her husband. In such cases, a female support is required particularly if no other non-disabled female family member is available to assist her (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004).

Bano notes,

Both women and men with a disability suffer in our [South Asian] countries. They don't receive any support from anywhere. It becomes more challenging for a woman when she requires assistance with her personal care. She has to rely on one of her female family members.

Some women with disabilities who could not perform their traditional responsibilities at home received support from their family members.

Parveen shares,

I have a son and a daughter living with me. My daughter is the youngest and she is the one who does all the work and also she helps me with everything. I feel I am not very helpful to her especially in the kitchen, but I try as much as I can. My husband is supportive too.

Studies show women revealing that their husbands provide little support with caring in many physically demanding areas, but the emotional support from their husbands keeps them going in their carer's role (Mir & Tovey, 2003).

Shazia receives both emotional as well as support with some of the household work from her husband. She seems to appreciate her husband for helping her keep her spirits up all the time. Her husband's support allows her to participate in the community as Shazia is also a member of a Muslim women's group named ICNA (Islamic Circle of North America).

Shazia shares her story about all the support that she receives from her husband,

I never give in or lose hope when I experience something bad or something very challenging in life. I have never degraded myself if I ever feel that I can't do something, I don't just lose hope in any situation. Actually, my husband supports me a lot and he continues to encourage me all the time. I cook sometimes and my husband can cook too. He cooks when he is home. He does laundry and vacuuming. I sometimes do dusting if I could and I also read. I am a member of ICNA (Islamic Circle of North America). Women come to my place and we get together and read Quran. My husband helps me with the housework and it makes everything easy for me at home. In Pakistan, it is the culture there that the husbands should go to work and women should take care of household chores. Men don't do any household work. When I came to Canada I started working here on and off so my husband has always shared household chores with me. In our families, it is not mandatory for only women to do the household chores. Men also take part in household chores.

Shazia's story seems to reveal that men also participate in household chores to support their wives which are often not seen as a common practice in South Asian Muslim countries.

Fatima shares her story,

My husband and I share chores like cleaning and cooking. My husband has health issues but he is still very cooperative and helpful. He drives so he takes me to my doctor's clinic on my appointments. Women in our culture are expected to cook and clean the house but because of my health condition I am unable to perform many of the household chores but fortunately, my husband is helpful and shares the chores with me as much as he can.

Sana also seems to share that household responsibilities are equally distributed between men and women especially when they are living in the West.

Sana shares her experience,

In my family mostly ladies look after household work but here men and women both share household responsibilities. No one minds that here. These days, women here in Canada as well as in India are no longer submissive. My husband says education has made us [women] rulers. I agree but I cannot say the same about women in rural India or women who are not educated.

Studies also reveal that in South Asian extended families, other non-disabled family members may also assume caring roles for the disabled as well as elderly family members but this may vary among families depending on their willingness to help and their own circumstances (Glendining, 1988; Qureshi & Walker 1989; Parker 1993). Bano states, "In Pakistan, people in your own family helps you if you need support, but mostly they stay away from you saying they are also struggling in their own lives". It appears that most of the families do not live close to their relatives or other family members. Most of the participants are living in nuclear families and many of their relatives are in other states or cities of Canada. Therefore, expecting direct and continued support from other family members or relatives does not seem possible.

Fatima shares,

My close family relatives don't live with me. One of my brothers lives with his family in Toronto. When I first began to have serious health issues some of my

close family relatives helped me. My brother and his wife came and stayed with me. After few months, it was not possible for them to continue living here with me as they have their own struggles in life. There are things going in everybody's life. They cannot be physically here to support me, they still pray for me. In Canada, the medical staff gives us training at the hospital to help us survive when living on our own.

Bano shares that people from Pakistan whether they live in Canada or Pakistan often maintain an indifferent approach towards their other fellow Pakistanis.

According to Bano,

Pakistan has a more self- centered society. People think that if someone has problems or difficulties in life, they themselves should be dealing with them. Our religion, on the other hand, teaches us to help people in need. Not only in Pakistan but also in our community in Canada, people do not [provide] much support for families like us who are going through such hard times.

Fatima shares,

People in our community neglect you if you are not with them. If you stay away from them for a long time due to illness or something, they will not show any interest in your whereabouts. To be seen in the community, one needs to become active in the community. We need support from our families and also from people in the community.

Maryam believes that people in the South Asian Muslim community usually express concerns for others in need and specifically individuals with disabilities.

Maryam shares,

I was never isolated by my community people. It depends on the person's attitude that what does he or she want from others and how one treats oneself. I am always very respected by people. I feel so embarrassed that even people older than me give their seats to me at the mosque. People still give me lots of respect. They always ask me how am I doing and show concern.

Shazia says,

In our Canadian Muslim community, people don't treat people having disabilities any different. They show their concern, exchange their contact numbers with them in case they need help. I feel generally people in our community would treat people with a disability nicely and care for them.

Participants in the study seem well connected with other people in their community. It looks like they do not socialize frequently in their community, yet they all seem to feel connected to people in their community. It appears from the participants' accounts that most of them receive support from their immediate family members, specifically from their husbands. It appears that since they do not live in close contact with their relatives or other people in their community, they do not seem to have any kind of pressure from their community or families to follow the conventional family norms. Since their relatives and other family members live at far distances from each other, most of the participants rely on support from the government.

Sana claims,

I have not seen any woman with a visible disability in our community. If there is one, I am sure she is getting support from the government, everybody does. The government in Canada provides support to people with disabilities. My husband could not drive because he had an injury so we asked for Handi-transit.

Government support

Participants in this study seem to be very appreciative of the Canadian government's support. Most of the participants appear to choose home care and to avail themselves of other community resources because their family relatives who would usually offer their support to them did not reside in the same locality, province or country. For example, Raisa needs support with her home chores and to an extent with her personal care needs. She seems glad that because of the support she gets from the government she could survive independently without depending on her friends and relatives.

Raisa is one of the participants who had traveled to many countries prior to settling down in Canada. She began receiving support since the time she arrived in Canada as a refugee.

Raisa expresses her appreciation saying,

Canada overall is the best. I am very proud to be here. I am so fortunate to be here. I have traveled to many countries, Australia, New Zealand, Germany, USA and more but Canada is the best for its welfare and support for people with disabilities. I tried to go to New Zealand but the government in New Zealand does not support people with disabilities. Canadians are very friendly people and kind too. Canadians have given me a new life. They are very kind. Canadian Government has supported me in all ways. I have homecare here with other support. After I got married, they brought my husband to Canada. Even with my disability, they allowed me to come here and gave me all kind of support. If I was in Afghanistan, I would never receive all this support like in Canada.

Maryam also receives home care support for herself and her husband. They both have physical disabilities and they both need continuous care.

Maryam describes a typical day in her life,

It is very unpredictable. Since last 26 years, my days have been unpredictable. We both have a disability. We don't know when we are going to Emergency like my husband is not feeling well today. Usually, I start my day with prayers then I go back to sleep. We have help, we have breakfast in the morning. There is less worry about home chores because we have help.

The majority of the participants seem to compare their lives with disability in Canada to what their lives would be like for people with disability in their country of origin. Interestingly it looks like participants due to their immigrant status seem to appreciate and view whatever form of support they receive not as their basic right as citizens but a kind gesture or favor extended to them by the Canadian government.

Raisa explains how she would be treated being a woman with a disability back in Afghanistan, India or Pakistan,

In Afghanistan, India, Pakistan, I wouldn't even be treated as a human being. First, for being a woman and second, for having a disability. The most important thing over there is money. People only value you and respect you if you have lots of money. In Canada, people even care about their animals more. They give value to disabled people, children, elderly people, and even animals. I have lived in

Canada for 12 to 13 years. There is no discrimination. They don't see you as black, white, or disabled.

Bano seems grateful to the Canadian government for providing support for her daughter. She says,

In Canada, there are all kinds of support available for disabled people and their families. My daughter has started going to school again. She is in grade 9. She loves her school and all her teachers. The school has provided her with an assistant. She receives professional help and she has improved so much now. She has started eating meat if we cut it into small pieces.

Bano shares,

Life of a woman with a disability in Pakistan is [a] lot harsher than one cannot even imagine. One of my relatives' daughter caught fever when she was only 7 months old and she was diagnosed with polio. She is now 16 years old. She doesn't speak [nonverbal] and fully depends on her mother and grandmother. She crawls on the floor in her home. Her mother or grandmother look after her. No one helps them and there is no support from the government. If she was here she could get support from the government just like my daughter or any other person with a disability.

Parveen states, "In Canada, people care for people with disabilities. They value life and the government supports disabled people."

Fatima further explains,

In Pakistan and India, family and relatives support persons with disabilities. There, the government does not provide support to them. In Canada, there are lots of opportunities for disabled people. I see that they make them feel as normal as everyone else. There are lots of wheelchair accessible areas, the Handi-transit service, and other disability support programs. There are agencies providing support to individuals with disabilities. You can also apply for the government support. You only need to fight to achieve government's incentives. It takes a long time. You submit your application and your doctor should be able to convince the officers that your case is genuine.

Bano notes,

There are government agencies in Canada that provide support to disabled people. I have received support from people in our local community where we are living. My daughter's hospital bills and treatment expenses after her accident were all

covered by the government. If we were in Pakistan, it would be impossible for my family to bear all these expenses. The government of Pakistan doesn't provide any support to disabled people in Pakistan.

Shazia feels she gains more strength seeing other people with severe disabilities being supported by the government.

Shazia shares,

After I came to Canada I realized that people with disabilities are being trained in a way that they are able to do things independently. I know a girl who was in grade 8 or 9 who had an accident. Everyone thought she's gonna die. She remained in the hospital in the ICU [Intensive Care Unit] for some months. She survived but now she has a severe physical disability. The government spent so much on her to support her. Government's aim is to make sure that she does not remain in bed the rest of her life and she is able to do things. She goes to school now and she has special transport facility. She is given a special computer device to communicate with other people. There is a lot of support from the government for people who have a disability.

All the participants in this study praised the Canadian government for providing unbiased support and services to people with disabilities. None of the participants appear to complain about the lack of cultural sensitivity in the provision of care services that would otherwise restrict their access to community resources.

However, a couple of participants seem to indicate that due to lack of awareness many immigrant South Asian women do not know what resources are available in the community and how to access them. Maryam says, "Women in our community need to be educated both academically and socially as they lack intelligence and awareness."

Fatima indicates that women in the South Asian community need education and they should be educated about their rights in Canada,

Muslim women with disabilities from India, Pakistan, and other countries need to be educated about their rights and how to access resources provided by the government to disabled. Women lack awareness and no one in our community shares information.

Participants in this study not only seem to praise the support from the government but also support and encouragement from some of their family members they live with, particularly their husbands. All the participants are married and seem glad that their husbands are very supportive of them. They even share household chores with them which is usually not the case in India, Pakistan, and other South Asian countries. Most of the participants receiving support from their husbands seem no longer burdened by their traditional roles of an obedient wife or a nurturing mother. However, one of the participants seems to believe that women are religiously obligated to be self-sacrificing in fulfilling all the responsibilities towards their husband and children.

The support the participants get from their husbands seems to enable them to participate in their community activities. It appears that if there is a family member with a disability in the family, men and women together assume carers' role in the family. Women appear to play the main role with caring responsibilities as they are often expected to perform all the personal care duties for the disabled family member along with the household chores.

Overall, participants seem to appreciate their families for their support and they seem to subtly challenge the long-established misconception about South Asian families being discriminatory towards women. However, some of the participants seem disappointed with their community's indifferent attitude towards people with disabilities and particularly towards women with disabilities. They seem to point out that people in Canada other than people in their Muslim community value and care about people with disabilities more. They seem to express fear that if they were still in their countries of origin they would not have received the same treatment as they get in Canada. They seem to feel fortunate that they are here in Canada. They have homecare, accessible places to visit, accessible transportation system, healthcare, and other

benefits. It also looks like that their lives with disability in Canada seem to be less influenced by how disability in women is perceived by South Asian people in their countries of origin. In addition, family support, support from the government and most importantly, their religious faith seems to strengthen them and enable them to have a positive outlook on life.

Chapter 5: Conclusion

This research study attempted to create knowledge about disability in the lives of Muslim women from a specific cultural context. The literature reviewed in the study revealed that in a multicultural society, it is crucial to obtain knowledge about different cultures because cultural beliefs often form the basis of societal norms. Different cultural practices reflect common beliefs and are representatives of their respective religions. Both culture and religion are closely connected with each other. Therefore, in order to understand a culture, its religion needs to be studied simultaneously.

Participants in the study were all practicing Muslims (praying five times a day, fasting, reading Quran) but they seemed quite modest about it. Religion plays an important role in their lives. According to the participants, their religion gives them peace and also the strength to face all the challenges in their lives. Participants viewed religion separate from culture. In their opinion, religion is a belief system and cultural practices are shaped based on how religious teachings are interpreted by people in different cultures.

The literature reviewed in the study indicated that Islam is divided into two major sects: Sunni and Shiite. However, the participants did not seem much concerned about different interpretations of Islam under the two major sects. They seemed to emphasize more how different cultures have different traditions that have passed on to their generations for years. These are traditions that have cultural roots and they have nothing to do with the Islamic belief. A participant shared a couple of examples such as marrying off young girls to the Quran is an old tradition in some cultures in Pakistan, and also in some Muslim countries in Africa, female genital mutilation is still practiced. All the participants seemed to view the lack of education and

social awareness responsible for the cultural devaluation of women and women with disabilities in particular.

Participants revealed that in South Asian Muslim countries, most of the limitations and challenges women in general experience are socially created. For example, in certain South Asian Muslim cultures, women are not granted educational opportunities, they are not allowed to work outside their home and cannot leave home without being accompanied by a male family member. These restrictions often vary in nature and degree within different cultures across different South Asian Muslim countries. However, there are also certain religious restrictions on women, such as they are not allowed to have any kind of physical contact with men other than their own husband, and they should dress with modesty.

Gender-based differences in family responsibilities were also viewed as culturally created. Some of the participants shared that it is a religious obligation for every Muslim woman to take care of all her husband's and children's needs. One participant's daughter has acquired physical disability after a road accident. The participant herself had been taking care of her daughter's personal care needs all by herself at home. She seemed very pleased with herself for being able to look after her and all her other family members individually by fulfilling her household responsibilities even when she herself has some chronic health issues. She believed that a woman is religiously obligated to accomplish all of this. Whereas, another participant seemed unhappy because of her inability to partake in the household responsibilities and therefore, she viewed herself as a burden on her family. This actually seemed to indicate that many South Asian Muslim women internalize some of the culturally driven oppressions directed at them all their lives in their countries of origin. Similarly, all 7 participants in this study were also glad that their husbands supported them. None of the participants were living in an extended

family setup. They did not receive any direct support from their close relatives, as their relatives were not living in close proximity. Whereas, participants indicated that in South Asian countries often people live in the extended family environment. Therefore, all the responsibilities related to a female family member with a disability are respectively distributed among the rest of the family members. All the participants seemed to appreciate the Canadian government for providing support to individuals with disabilities.

The study also attempted to explore participants' perceptions of disability and the influence of their community's perceptions of disability on their own understanding of disability. It was revealed in the study that the majority of the participants had a positive view on life with a disability. They seemed to accept their disabilities along with all the entailing challenges as their fate. They all seemed to share a similar belief that if they courageously endured the hardships in their present lives, they would be rewarded in their lives after death. The participants in the study seemed to interpret the meaning of their lives and their lives with various disabilities from a religious point of view. They believed that their faith in their religion has blessed them with enough strength to face all the challenges their lives with disability entail.

Participants viewed people in their South Asian communities to be indifferent towards the needs of people with disabilities in the community and particularly towards women with disabilities. Participants' claims that Islamic teachings instruct us to help and support disadvantaged individuals, not to isolate them from the rest of the community. They should be encouraged and given opportunities to live independent and dignified lives. The research study appeared to reveal that in Canada, the South Asian Muslim community, like many other ethnic minorities, has been experiencing a gradual cultural reconfiguration to fit into Western society. For example, most Muslim women obtain higher education and also work outside their homes.

This seemed to indicate that most of the discriminative practices towards women are culturally driven and present cultural practices are influenced by the Western societal norms.

Participants' everyday experiences in the community revealed that with the gradual increase in social awareness about disability and other aspects of life, people's behaviors towards individuals with disabilities are also gradually changing.

The study indicates some of the negative attitudes about women with disabilities that have been culturally ingrained in the South Asian Muslim community. For instance, disability causes dependence, women with disabilities are incapable of taking care of themselves and their traditionally assigned family responsibilities, only visible disability is viewed as a disability and much more. These negative attitudes have been so deeply rooted in their cultural practices that women with disabilities seemed to internalize all these negative attitudes.

In South Asian Muslim families, parents mostly get to decide who their sons and daughters will marry. Most of the participants claim that they would not approve a girl with any disability as their future daughter-in-law even though they themselves had disabilities. It was interesting to learn that even one of the participants with a severely disabled daughter refused the idea of accepting a girl with a disability as her future daughter-in-law. It is also important here to note that all the participants in the study acquired their disability after they were married, except one participant who was born with a physical disability. The participant who was born with a physical disability wished people to sympathize with people with disabilities and especially with disabled women. In her opinion, people who fear Allah have sympathy in their heart for women with disabilities. Therefore, people with sympathy in their heart for disabled women do not mind getting married to any woman with some form of disability. The rest of the participants seemed

to contend this notion as they preferred people to empathize and understand people with disabilities, not to sympathize with them.

Some of the findings from the study also indicate that often South Asian families in the West do not consider their female family member with a disability marriageable because of the fear that she could be exploited by a man for some hidden benefits such as to obtain a foreign nationality or to seek some kind of financial benefit. Though, some of the participants personally knew a couple of non-disabled men who were married to women with disabilities and the married couples were living a happy life.

In addition, an important concern raised by the participants was that often Muslim South Asian immigrant women with disabilities are unaware of the right channels to access services provided by the government to disabled people. None of the participants shared any experience of racism while living in Canada. All the participants praised the Canadian government and people for the kindness and support extended to them.

Overall, some of the findings from this study were in agreement with the literature, such as the marriageability issue, invisible disabilities not recognized as disabilities and how the South Asian Muslim community perceives disabilities. There were also findings that revealed new information about the South Asian Muslim community, such as gradual change in the traditional family-arranged marriage system, husbands sharing household chores, participants' self-perceptions of disability and the influence of past traditions rather than religion on how people perceive women and disability.

According to the participants in this study, they feel positive about their lives with disabilities in Canada. The reason that they feel positive about their lives with disabilities in Canada is because they receive support from the government and they find people in Canada

more socially aware than people in any of their South Asian Muslim countries. The other reason they emphasized on more is their faith in their religion from which they gain inner peace and strength. Participants indicated that the South Asian Muslim community is gradually progressing in terms of social awareness but many still hold the conventional views on disability of women.

The participants in this study indicated that in Canada, they do not feel any pressure from their relatives or any of their family members to fulfill their traditional gender based family responsibilities. Both husband and wife share their family responsibilities.

It appears that immigration to Canada is gradually directing them to reconfigure many of their conventional norms, such as the traditional family-arranged system, which has experienced some recent changes. This also indicates that people in the South Asian Muslim community are attempting to adjust to a different socio-political environment in Canada. According to the participants, they feel blessed that they are living in Canada because if they were still in Pakistan they would not have as fulfilling lives as they have here.

Limitations of the study

The findings from this study seem to answer the core research questions, however, these findings cannot be generalized to all South Asian women with disabilities living across Canada because this research study has limitations. It is important to note some of the study limitations.

First, the research study was performed on a small scale and it only included seven participants from Winnipeg, Canada. The majority of the participants were educated and belonged to middle to upper middle-class families. It would be interesting to explore the lives of women from other social strata and numerous cultures within South Asian Muslim community in Canada.

Second, the study mostly included participants who acquired disabilities later in their lives. Only one of the participants was born with a disability. Therefore, a detailed comparative analysis could be performed upon gathering information about women born with disabilities and women who acquired disabilities later in life.

Third, all the participants interviewed were mature and they were married. However, exploring the lives of young unmarried women with disabilities living with their parents would create knowledge with more clarity and depth in the subject area. This could be possible by examining a bigger geographically diverse pool of participants.

Although the small sample of participants somewhat limits the breadth of the analysis, the themes identified from the collected data are consistent with the existing literature relevant to the research study and allows further investigation into the subject area.

The findings and discussions in this study provide insights into the perceptions of people in the South Asian Muslim community about women with disabilities. This study helps to clarify many misconceptions about how disability of women is treated in the South Asian Muslim community. Since Canada is a multicultural society, it is very vital to increase everyone's knowledge about how different cultural perspectives shape certain people's lives.

This research study is a pioneering attempt to create knowledge about South Asian Muslim immigrant women and their lived experiences with various disabilities in the West which is guided by direct quotes from the participants. This study provides a great opportunity to the participants to express their solidarity with other participants and it also provides an opportunity for other women with disabilities from inside as well as from outside the South Asian community to relate to the participants' lived experiences with various disabilities.

As the primary researcher of this study, I believe I am making a small contribution to the vast field of Disability Studies hoping to create social awareness. According to the participants of the study, social awareness has so far brought gradual but positive change in their conventional norms. It appears that social awareness is crucial for social change.

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Appendix I: Letter of Introduction and research description

I am writing to request your participation in my Master's thesis research project. I am a student in the Interdisciplinary Disability Studies program at the University of Manitoba. I aim to explore the impact of disability on the lives of Muslim women with disabilities from South Asia living in Winnipeg. The criteria for potential participants for this project are as follows:

South Asian Muslim women approximately 20 to 60 years of age who identify themselves as having a disability, no specific type of disability, and who are able to communicate on their own.
If a participant wishes, a support person could accompany her during the interview.

Your participation will contribute in creating new knowledge about the issues women with disabilities face from a different cultural perspective. This study will explore how disability, gender, culture and religion impact the life of Muslim women with disabilities.

If you consent to participate, the researcher will ask you some questions during a scheduled interview. The interview will be scheduled based on your convenience and availability. I plan to conduct semi-structured in depth interviews, of about one hour in length depending on the participants. Opportunities of breaks will be provided throughout the interview duration. The interview questions will give you ample opportunities to share your life experiences being a woman with disability in your family and community. A copy of the Interview guide has been attached with this letter for your perusal. If you do not wish to share any particular experience of your life which you think may cause you some emotional distress, you may keep it general and share your own understanding about the perception of disability in your community and families within the community.

Please note that you will not be asked to provide any personal health information throughout the study. This study only aims to explore the general social issues women with various disabilities face in a particular cultural context.

If you are willing to participate, please let me know as soon as possible. If you have received this letter along with the consent letter and the interview guide from someone other than me, please contact me directly if you wish to participate. Under no circumstances, the participants will be asked to provide me with the contact information of other potential participants without their permission.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this study, you may contact Zahra Khan at khanz3@myumanitoba.ca, Tel. [REDACTED] or Dr. Nancy Hansen at Nancy.Hansen@umanitoba.ca, Tel. [REDACTED]. You may also contact the Human Ethics Coordinator at humanethics@umanitoba.ca, Tel. [REDACTED]

Thanks so much for your time.

Zahra Khan, MA student, Disability Studies, University of Manitoba.

Appendix II: Invitation letter to organizations

Hello,

I am Zahra Khan, a Master's student in the Interdisciplinary Disability Studies program at the University of Manitoba. I am writing this letter to request your support in recruiting participants for my research study which is about exploring the impact of disability on the lives of South Asian Muslim women with disabilities.

The Participants will be contributing in creating knowledge about the issues women with disabilities face from a different cultural perspective. They will have an opportunity to voice the challenges they may face because of their cultural traditions, religion, disability, or gender.

The participants I am trying to locate for this project are South Asian Muslim women who meet the following criteria:

Approximately 20 to 60 years of age,

Identify themselves as having a disability,

No specific type of disability required,

They are able to communicate on their own.

A written consent form will require the participants' signature. If participants consent to participate, I will ask some questions during a scheduled interview. The interview will be scheduled based on the participant's convenience. Participants' anonymity and confidentiality will be strictly maintained throughout the study and also after completion of the study. Please ask the participants who wish to participate to contact me directly at

khanz3@myumanitoba.ca or Tel. [REDACTED]

South Asian Muslim women with disabilities

Please consider referring individuals matching the above criteria in your organization for possible participation. I hope you would encourage them to participate by sending them a copy of the letter of introduction, the consent form, and the interview guide to inform all the potential participants about the study and their contribution in the study. I am enclosing all the aforementioned documents with this letter.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. If you have any concerns or complaints about this study, you may contact Zahra Khan at khanz3@myumanitoba.ca, Tel. [REDACTED], or Dr. Nancy Hansen at Nancy.Hansen@umanitoba.ca, Tel. [REDACTED]. You may also contact the Human Ethics Coordinator at humanethics@umanitoba.ca, Tel. [REDACTED].

Your cooperation in passing this information to the potential participants in your organization would be greatly appreciated.

Thank you for your time and consideration.

Sincerely,

Zahra Khan, MA student, Disability Studies, University of Manitoba.

Appendix III: Consent Form

Research Title:

An exploration of the impact of disability on the lives of South Asian Muslim women in Winnipeg.

Researcher:

Zahra Khan, a Master's student in the Interdisciplinary Disability Studies program at the University of Manitoba.

Email: khanz3@myumanitoba.ca, Tel. [REDACTED]

Research Supervisor:

Dr. Nancy Hansen, Professor and Director, Disability Studies, University of Manitoba.

Email: Nancy.Hansen@ad.umanitoba.ca, Tel. [REDACTED]

This consent form is part of the process which should give you the basic idea of what this research is about and what your role will be in this research study. Please take time to read this carefully and to make sure you understand what it all means. If you would like more information, feel free to ask. You will keep a copy of this form for your own records and reference.

What is the purpose of this study?

The purpose of this study is to find out how disability and gender impact the lives of South Asian Muslim women on intersecting with their culture and religion. It also aims to explore how disability is perceived by their family members, and how it affects their lives in fulfilling their family role and responsibilities.

Who will be interviewed by the researcher?

South Asian Muslim Immigrant women between the ages 20-60 with various disabilities will be interviewed. A maximum of 10 South Asian Muslim women with any disability not specific type of disability, and who are able to communicate on their own. If the participants wish, a support person could be present during the interview.

What would you find in your interview questions?

If you agree to participate in the study, you will be asked questions about how disability impacts your life, particularly, your role in the family. In addition, how religion and culture influence your life as a woman with disability. If you do not understand any question, feel free to ask during the interview.

How will the information I provide be used in this study?

This study aims to create awareness about the lived experiences of women with disabilities in a different cultural context. It is going to be a pioneering attempt to explore about the lives of South Asian Muslim women with disabilities in the Canadian cultural context.

A final report on the findings will be written and submitted in the form of a master's thesis at the end of the study. Prior to submission, the final thesis will be defended by the researcher in form of a presentation in the Department of Disability Studies at University of Manitoba. The participants will also be invited to attend the presentation on the final thesis. A copy of the complete master's thesis will be electronically stored in the University of Manitoba's library system.

I give my permission to include all the agreed upon information in the final thesis which will be electronically stored in the University of Manitoba's Library system.

Yes No

Can you opt out of the study any time you want?

Yes. If you agree to participate in the study, and later you decide to opt out of the study, you can inform Zahra Khan about your decision in person, by telephone at (204) 2303324, or by email at khanz3@myumanitoba.ca. During the interview you will not be put under any kind of pressure to answer a particular question which you do not wish to answer. You are free to end the interview at any stage. There is no penalty if you decide not to participate in this study.

What are the benefits of your participation in this study?

Your participation in this study will help create new knowledge about how disability is perceived in different cultural contexts, and how cultural perspectives shape certain individuals' life. It will also help to explore if religion has any influence on the perception of disability in a particular cultural context. The findings of this study might result in new policies and services specific to some cultural needs.

If there are any risks to you on participating in this study?

There are no anticipated risks to participants as a result of participating in this study. During the interview if you experience any emotional distress or discomfort, you may choose to stop participating at any time and refuse to answer any more questions. If needed, you may be able to contact Klinik Community Health for free drop-in counselling services at [REDACTED] or email at dropin@klinik.mb.ca.

An audio recorder will be used to record your interview as a result your voice will be recorded in form of audio files. My thesis supervisor and I will have access to these audio files. If you do not feel comfortable with your interview being recorded on a voice recorder, let me know so instead extensive notes will be taken during the interview. Interview transcript and notes will be shared with you for your review and approval before your responses are included in the final thesis.

I give my permission for an audio recorder to be used during the interview

Yes No

What steps the researcher will take to keep the information and your identity confidential in this study?

Pseudonyms will be used in the interview transcripts, field notes, presentation, summary of findings and final thesis to maintain confidentiality. Your real name will not be used anywhere in the study, but instead a pseudonym/fake name will be used to ascribe direct quotations from your interview in the study. Your name or any other identifying characteristics will not be associated with your responses. Any information that could reveal your identity will be removed from the interview transcripts, notes and final thesis.

Audio-files will be kept on a secured password-protected computer and will not be used except for this study without your consent. All notes and transcripts will be kept at Zahra Khan's home in a locked drawer. Zahra Khan and Dr. Nancy Hansen will have the access to data. Transcripts and notes will be destroyed upon completion of the study, no later than June 2016. Audio files will be deleted only after ensuring that all transcripts are accurate.

Your signature means that you understand what you have just read and that you want to participate in the research study. You can decide at any time to stop participating in this research study. You can also refrain from answering any questions you prefer to omit. Feel free to ask questions about the research and your role at any time during the study.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this study, you may contact Zahra Khan at khanz3@myumanitoba.ca, Tel. [REDACTED] or Dr. Nancy Hansen at

Nancy.Hansen@umanitoba.ca, Tel. [REDACTED] You may also contact the Human Ethics Coordinator at humanethics@umanitoba.ca, Tel. [REDACTED].

The University of Manitoba has established policies and guidelines that protect participants and provide support to members of the research community on the conduct of research involving humans. University policies are transparent and members of the research community are accountable to such policies when leading and participating in research.

What would you like to receive?

- Summary of the findings**
- Complete master's thesis**

Preferred mode of delivery?

Email: _____

Postal Address: _____

I _____ (print name) understand what the study is about and my signature below indicates that I consent to participate in this study.

Participant's Signature: _____ **Date:** _____

Researcher's Signature: _____ **Date:** _____

Appendix IV: Interview Guide

For Interviewer's personal use:

Age: 20-30 31-40 41-50 51-60

Marital status: Single Married Divorced/separated Widowed

Country of origin: _____

Number of siblings: _____ Brother(s) _____ Sister(s) _____

Rank in the family (by birth order): _____

Any other (immediate) family member with a disability? _____

Highest level of Education: None High school Tertiary Education

Post-secondary Other: _____

Education in Canada (if any): _____

Education in the country of origin (if any): _____

Occupation: _____

Employment: Paid Unpaid/voluntary None

1-How would you describe yourself?

2-Have you always had a disability?

3-What are your family responsibilities?

a- How do you see your responsibilities?

b- Are your responsibilities different from your other non-disabled family members?

c- What role does gender difference play in the distribution of family responsibilities in a typical South Asian Muslim family?

4- How would you describe a typical day in your life?

5- How do people from your ethnic community or people you associate with in your ethnic community perceive disability?

6- What role religion plays in your life and does it have any impact on your experience with disability?

7- Any interesting personal or social experience with disability you would like to share.

8- In your opinion, how much life with disability for a Muslim woman in Canada is different from any of the South Asian countries like Pakistan, India, and Bangladesh?

a- Are some of the stereotypes women with disabilities experience living in the West same as in any of the South Asian countries?

9- Explain, which one you think has more influence on the life of Muslim women with disability: culture or religion?

10- Is there anything else you would like to add or clarify?
