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UNDERSTANDING HEALTH LITERACY REGARDING THE CANADIAN HEALTH CARE SYSTEM UPON SETTLEMENT OF ISMAILI MUSLIM CANADIANS: A NARRATIVE STUDY

(Spine title: Understanding Health Literacy: A Narrative Study)

(Thesis format: Monograph)

By

Farzana Haji

Graduate Program
In
Health & Rehabilitation Sciences

Thesis submitted in partial fulfillment
Of the requirements for the degree of
Master of Science

School of Graduate and Postdoctoral Studies
The University of Western Ontario
April 2011

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Understanding Health Literacy Regarding the Canadian Health Care System Upon Settlement of Ismaili Muslim Canadians: A Narrative Story

is accepted in partial fulfillment of the
requirements for the degree of
Master of Science

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ABSTRACT

Health literacy is an individual's ability to read, understand, and use health care information to make informed health decisions for treatment (Kwan, Frankish, & Rootman, 2006). Health literacy studies worldwide have increased dramatically within the past decade in response to concerns about the populations that are at risk and the need to target effective interventions for them. Canadian censuses have utilized the International Adult Literacy and Life Skills Survey (IALLS) to examine Canadian health literacy rates and found that the most high-risk populations are older adults, immigrants, and the chronically unemployed. However, when researching the topic of health literacy, there was little information from the high-risk population themselves, few longitudinal studies, little research about possible interventions, nor was there consistent use of a single definition of health literacy. Being an Ismaili Muslim and understanding their history of migration, I wanted to ground my study through my family's experiences of having to move from East Africa to Canada in 1972. My goal was to gain a better understanding of the post-immigration experiences of the Canadian health care system in comparison to the pre-immigration expectations among older Ismaili Muslim adults, to discover how health literacy affected health seeking behaviours during immigrant settlement in Canada for this group, and to explore the effects of cultural capital, or the non-financial resources that assist in social and economic means, to determine how it assisted or hindered the successful settlement process of Ismaili Muslims within Canada.

The research was a narrative inquiry using in-depth, semi-structured interviews to get thick descriptions of the experiences of four Ismaili Muslim older adults who moved to Canada in 1972, their experiences of using the Canadian health care system for the first time, and their thoughts on the topic of health literacy. Their experiences and suggestions, detailed in their stories to live by, expanded the knowledge on the topic of health literacy by explaining possible interventions that have yet to be mentioned in research.

As a result of the study, four key considerations emerged: communication strategies applied in health literacy are not successfully targeting the immigrant population; there was confusion about the Canadian health care system, especially relating to the tiers of health care and the limits of OHIP coverage; the Ismaili population utilized the resource of cultural capital to assist in their settlement experiences and stressed the importance of comfort, trust, and sensitivity when taking advice from individuals about the health care system; and knowledge exchange about health literacy is vital for health professionals and patients, as well as other groups, to understand the importance of this topic.

The key considerations from the study have important implications for newly arrived immigrants and the Canadian health care system. The study suggests supplementing the typical quantitative surveys with rich, qualitative literature and targeting interventions particularly to the groups that require immediate attention. This study displays the importance of providing the immigrant population with a voice and an opportunity to describe their experiences about the health care system and the topic of health literacy.

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Mahatma Gandhi once stated, "Strength does not come from physical capacity. It comes from an indomitable will". The strong determination I have comes from hard work, and my indomitable will comes from the following individuals who have provided their support throughout the completion of my thesis:

My family and friends for their continuous love and support. I would like to thank my parents for being my role models and believing in me every step of the way. Thank you for all that you have sacrificed to get me where I am, I will be forever grateful. Mom, thank you for the endless nights you spent by my side helping me study and editing my papers. You showed me that nothing can replace an education. To my dad and my brother Alim, my deepest gratitude for your continuous encouragement and faith in me. Many thanks to my cousin Noorin who has always been there since our preschool days when we traded letters about missing each other, exchanging clothes, and chickens. To my grandmother Bhabhi, without you, I would not have had the inspiration for the topic of my thesis. Thank you for being such a big influence in my life and inspiring me each and every day

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CHAPTER ONE

Narrative Beginnings

My Journey with Understanding Health Literacy

Beginning of my Research Journey: Bhabhi's Story

Ever since I was a little girl, my grandmother, or "Bhabhi" as I have referred to her, related stories of her journey to and of her early days in Canada, and she always ended her story with discussing how lucky our family was to be living in such a multicultural and safe environment. Bhabhi's story almost always begins with a tribute to her country, Tanzania, East Africa where she grew up in a warm, temperate climate most of the year, surrounded by an abundance of flora and fauna and very warm-hearted, friendly people. Her conversation was also laced with memories of the beach, which was walking distance from her home, and recollections of her teaching days when she took her class on fieldtrips, or "safaris" as she liked to refer to them. Bhabhi mentioned that her daily routine involved walking with her family of eleven brothers and sisters to Jamat Khana (mosque) and going for walks to the beach or visiting with friends after the daily service. Being an Ismaili Muslim was essential to my grandmother's identity and was one of the main reasons why she decided to become a theology teacher. Another story she enjoyed relating to me was how she met my grandfather, or "Nana". Nana grew up in Kisumu, Kenya, and when he was on holidays in Tanzania, he saw Bhabhi, who had unusually long hair, which reached her knees, that my grandfather noticed immediately. He was struck by her and decided he wanted to marry her. Nana had his aunt approach my great grandfather formally for Bhabhi's hand in marriage, because he was very strict, to which my great grandfather eventually agreed after investigating Nana's background.

At this point in the story, I generally asked, "Then why would you move here Bhabhi?" She then mentioned the political changes that began in the early 1970s, when the government of the country where they had lived for many generations decided that the wealth of the country should be distributed

evenly amongst all peoples. The government began nationalizing the wealth and assets of the people, from land and buildings to privately owned schools, hospitals, and other institutions. People began leaving the country and, within a short period of time, there was a lack of skilled professionals, such as teachers, medical personnel, and businessmen. With the uncertainty and unrest in the country, my grandparents sought refuge in the western world, especially when President Idi Amin began forcing all non-Africans out of Uganda, and it was generally felt that Kenya would eventually follow suit. My grandmother explained that, when people left their countries to immigrate to countries like Canada, they arrived here with hopes and dreams for a better life for their children and themselves and a refuge from the country they had left behind.

When my grandparents and their children arrived in Canada, they felt lost and insecure in an unknown country. Their first winter was an absolute shock to their systems, but they quickly learned to wear the right gear and to walk and drive in the snow that they had never seen before in their lives. For the longest time, my grandparents could not eat chicken bought from grocery stores, because they thought it tasted like plastic. They were used to eating nothing but fresh fruits, vegetables, chicken, and fish that Africans sold as they travelled with their wares in each of the neighbourhoods. My parents are both skilled and educated and, consequently, did not have too much difficulty in adapting themselves to the new culture and obtaining work, however this was not the case with my grandparents, because they were not fluent in English. Bhabhi explained that the process of immigration and settlement in Canada did not go without a struggle, and they had to overcome a multitude of issues such as housing; employment; learning new customs, traditions, and laws of the country; building social support networks; as well as get over discrimination and prejudices, insecurities, and stress, which created a considerable tension in the form of depression.

My grandmother's stories have been very inspirational for me, and I have always had a desire to learn more about immigrants and the struggles they encountered in their new home, Canada. When I hear Bhabhi mention their struggles, I always think about the excerpt of a famous poem by Emma Lazarus engraved on the base of the Statue of Liberty, which reads, "Give me your tired, your poor, your huddled masses yearning to breathe free" (Young, 1997, p.3) The Statue of Liberty is recognized as a symbol of freedom throughout the world. Changing environments and political unrest have caused the movement of thousands of families out of their homelands. Whether forced to make such decisions or doing so because they wanted to have a better life for themselves and their families, all immigrants have had to survive the physical and psychological challenges. Many have found only hardship and experienced the destruction of their hopes and dreams. I believe that packing up and leaving one's home is one of the hardest things a person can experience. The injustice that my family, and others like them, had to endure was devastating to all of them. I do not think my grandfather ever recovered from his difficulties with health, searching for employment, and adjusting to new customs.

My grandparents' experiences has ignited my desire to describe the way the Ismaili population dealt with the health care and settlement challenges when initially arriving in Canada. This information may be useful for other immigrant communities in their struggles, making it easier for new immigrants to settle and form fresh roots in their host country. My thesis is consequently a tribute to my grandparents and people like them, who encountered struggles and faced discrimination, in the hopes that the information uncovered from my research might inform future policy development.

Reflection of my Journey as an Ismaili Muslim

The Shia Imami Ismaili Muslims, also known as the Ismailis, belong to the Shia branch of Islam. The Shia forms one of the two major branches of Islam, with the Sunni being the other. Growing up within the Ismaili Muslim community provided many opportunities for volunteering. From a young age, my friends

and I could not wait to turn 8 so that we could officially become “junior volunteers”. This was a very important position in our Jamat Khana because we were now allowed to assist the older adults, help with set up and wrap-up of Jamat Khana, as well as participate in event planning for the entire community, and the most exciting aspect was that we were old enough to wear the appropriate uniforms. At the age of 13, I became a “Big Sister” where I was able to mentor the 8-13 year olds, and when I turned 16, I became the youngest “Lieutenant” responsible for a group of volunteers and a member of the Youth and Sports Club where I could organize events such as the annual Youth Olympics and the annual Youth Camp in Minden, Ontario for children aged 8 -15. As I grew older, I continued assisting in Jamat Khana, however I was anxious to do more. I began assisting with charity food drives, working with FOCUS Canada, an affiliate of the Canadian International Development Agency (CIDA), helping with the Annual Partnership Walk and 10K Run. Overall, volunteerism has always played a major role in all Ismaili activities, whether local, national, or international, and it provides an inclusive network of social support for all individuals (Dossa, 1994). Volunteering gave me the opportunity to form lifelong friendships, and whether I am in London, Ontario, Toronto, or somewhere in Europe, there will always be an occasion to volunteer in Jamat Khana. I believe that each Ismaili newcomer to Canada, like my grandparents, has not only played a role in strengthening the community by volunteering but also in building Canada, and like them, I hope to make the country and community proud.

The statistics denote that more than 14% of Canadian Ismailis are over the age of 60 (Statistics Canada, 2008b), and in order to meet their needs, the Ismaili community formed the ISAT committee (Ismaili Seniors Action Team committee) to educate the older adults. In addition, the ISAT committee develops a range of initiatives to meet the needs of the aging population, which include an Ismaili older adult health centre at North York General Hospital in Toronto, Ontario, that provides services such as care for the elderly and programs such as meals-on-wheels (Institute of Ismaili Studies, 2009). I became a member of the ISAT committee after serving my year as Lieutenant and on the Youth and Sports

Board, and in that capacity, I was able to support the older adults in the community by developing programs, such as trips to places of interest like Niagara Falls and music nights.

Being a member of the ISAT committee provided the opportunity to utilize my educational knowledge and implement health promotion activities, such as Eat Right seminars for diabetics, Healthy Heart seminars, and exercise programs for the older adults, with the assistance of a local Ismaili physician who monitored the information I presented. With the ISAT programs, I sought my grandmother's assistance to recruit her friends to attend these sessions and to spread the message through word of mouth. On the first day of the exercise seminar, twenty older adults participated, which provided motivation for other seminars that are still being utilized in Jamat Khana today.

I have also participated and volunteered with a variety of other services that are available to community members. Advice and information pertaining to marital issues, parenting, financial security, youth development, and aging, as well as short term financial assistance, are considered the community's responsibilities (Janjuah-Jiveraj, 2003). I organized annual children's camps and participated in the first International Ismaili Sports Festival, held at York University in Toronto in July 1993, which has continued to be an annual tradition ever since (Institute of Ismaili Studies, 2009). During these events, participants from Canada, the United States, and other countries compete for prizes, share their common Ismaili heritage, make lifelong friends, and broaden their socio-cultural networks. Another project reflecting participation within the community was the completion of the Jubilee Gardens Housing Project in Toronto (Institute of Ismaili Studies, 2009). Completed in 1992, this development continues to provide affordable housing for Ismailis as well as others who are in need of immediate assistance (Janjuah-Jiveraj, 2003). For newly arriving immigrants, a National Settlement Committee arranges support for immigrant families in the resolution of immediate problems and refers immigrant individuals to agencies both within and outside the community that will facilitate their initial

integration and settlement into Canadian society (Institute of Ismaili Studies, 2009). With all these facets of the Ismaili community being addressed, the community gains more knowledge and refines its skills to assist others.

The first time I realized that I had a very special upbringing within my community was when I was in a palliative health care class in my Undergraduate career. Before this point, I assumed that everyone had their own communities outside of school to which they could turn for help, advice, or just social gatherings. In my class, we were discussing funeral rituals from various cultures, and everyone in the class spoke about their experiences with funerals they had attended. When I compared my experiences with theirs, I realized that the social support and community support we had within the Ismaili community was not necessarily similar to others. Funerals in the Ismaili Muslim culture involve allowing the family to grieve while the volunteer committees in place plan the entire funeral on the family's behalf. We also have bereavement committees, which are comprised of trained volunteers, who counsel the family of the deceased and assist in the grieving process.

In class, I provided the example of my grandfather's passing and explained our personal experiences. Everyone was taken aback by the support and mentioned that I was very fortunate to have a community of people who voluntarily offer their services for others. This is when I realized that my community was indeed special and how very blessed we are to be working as one 'family'. I wanted to share information about my community with others regarding our 'one for all and all for one' concept of an extended family in the community.

Middle of my Research Journey: Factors that Influence Health

As my knowledge of the health system grew over the years, my curiosity and questions increased because I wanted to learn more. My grandfather had been a chain smoker for as long as I could remember, and towards the latter part of his life, he was constantly in and out of the hospital. When I

began my Undergraduate studies in health science and learned about the social determinants of health, I reflected on my family's experiences and attempted to see how they corresponded with their health issues and what they could have done to improve their lives. I would question my family about what they remembered about Canada when they settled here initially, and how they dealt with all the social and economic changes, including the weather and finding employment.

Both my grandfathers were businessmen in East Africa, and it was customary to communicate in different languages with people of varied socio-economic and ethnic background, therefore it did not matter if they did not speak perfect English. However, when they came to Canada, they had to overcome a multitude of social determinants of health including housing, employment barriers due to scarcity of jobs, economic anxiety, foreign job experience, learning the customs, local traditions, and laws of a new country, building a social support network, as well as getting over discrimination, prejudice, and insecurities. These struggles created a considerable amount of tension, stress, possibly depression, and a lack of fluency in spoken English added to these anxieties.

When my maternal grandfather applied for a job at Bata Shoe Company, he was told he did not have Canadian experience or the necessary education, even though he had worked with Bata Shoe Company in Tanzania for over thirty years and had been well-respected in the business and Ismaili community. Instead he purchased a grocery store and once again dealt with ethnic customers where he could maintain his self-respect and was able to communicate without difficulties. My paternal grandfather, on the other hand, found a job as a security guard and worked nights until he retired. Difficulties with finding meaningful employment could have contributed to the emotional and psychological stressors my grandparents were already experiencing.

A vital area where my grandparents, and immigrants like them, encounter humiliation or loss of face is when they are rejected for a job after having had respectable jobs in their own country where

they were highly regarded both inside and outside their home. This resulted in both my grandfathers making a downward shift in career, even though they had the necessary experience. Immigrants, like my grandparents, felt there is "hidden discrimination"(Dossa, 1994) in Canada, especially when there are limited job prospects, and it is very easy to lose confidence and self-worth, however they upheld their self-respect, worked extremely hard, and brought up their children with the "proper" values and a pride in their new country without giving up hope.

The social determinants of health, such as the change in physical and social environments, difficulties in language, and employment stressors that came along with the migration process, affected my grandparents and their personal well-being. These psychological and emotional stressors reflected in negative health effects, because both my grandparents required medical assistance within months of arriving to Canada. Their ill health came at a time when I was learning about the "healthy immigrant effect" in school and how immigrants start off healthier when migrating to a new host country, and then suddenly, their health begins to decline (Health Canada, 2008a). At this point, it became evident to me that there was a strong association between the stressors of migrating, the social determinants of health, and the overall health of an individual. Compounded by the stressors of migrating, the social determinants of health either assist or hinder an individual in staying healthy (Health Canada, 2008a).

Coming to the Research Puzzle: Health Literacy

When I began my studies in my Masters program, I commenced linking concepts related to the social determinants of health, stressors, and immigration. I felt strongly that if I could conduct research in this area, I could perhaps offer my views and be able to propose some changes, whether it was something very small or more substantial. I could now integrate questions I had about my family with individuals who had experienced the same sort of issues when migrating and being confronted with changes.

Researching these puzzle pieces resulted in a linking concept - health literacy. Health literacy is a fairly new concept that has been recently adopted by the Canadian government (Kwan, Frankish, & Rootman, 2006) to examine how individuals learn to access the health care system. Health literacy was recently added to the list of the social determinants of health because learning to understand and access the health care system can prove to be a difficult process that affects the overall health of an individual. The British Columbia Health Literacy Research Team outlined a working definition of health literacy to be;

> "The degree to which people are able to access, understand, appraise, and communicate information to engage with demands of different health contexts in order to promote and maintain good health across the life course" (Kwan et al., 2006, p. 5).

This definition, in particular, incorporates a multitude of ideas that make health literacy not only a term that is employed worldwide, but one that is associated with and typically characterized by subcategories, such as access, comprehension, health care navigation, and individual and social factors (Canadian Public Health Association, 2008). Along with older adults and the chronically unemployed, immigrants have the lowest health literacy rates in Canada (Health Canada, 2008a). Discussing the topic of health literacy with my grandmother provided further evidence that the Canadian health care system is quite daunting. She explained that my grandfather only began utilizing the health care system when it was absolutely necessary, and then he was required to seek assistance because he encountered health literacy problems.

I decided health literacy would be an excellent topic to explore in relation to the immigrant population, like my parents and grandparents, as well as how they learned to navigate the health care system, in combination with several other factors they experienced when they initially migrated to Canada. Findings of the National Population Health Survey indicate that immigrants have more health

care needs than non-immigrant residents, thereby placing them in a high-risk category (Rootman & Gordon-El-Bihbety, 2008). Findings from such research would allow me to examine in-depth why this is the case with the new immigrant population. I could interview and research immigrants from the Ismaili Muslim culture and learn about their initial experiences with the Canadian health care system and potentially be able to apply this information to other new immigrant groups.

In addition to the experiences of my grandparents, further research indicated that the immigrant population also faces distinctive health care barriers that can affect their access to the health care system, such as awareness of health care coverage, cultural and communicative competency with health care staff, and lack of a regular source of care (Canadian Public Health Association, 2008). It became evident that the inability to understand aspects of the existing Canadian health care system makes a significant contribution to the poor health of the immigrant population, in addition to migration stressors and the social determinants of health (Canadian Public Health Association, 2008). I also asked both my parents' and grandparents' opinions, and they agreed with these findings, however they also shared the Ismaili Muslim cultural history that played an important factor in the settlement and migration process. They explained to me that, although moving to a new environment can be daunting, knowing that they had support from friends and family regarding any issues made the experience slightly easier to manage.

My family updated me about the historical background of the Ismaili Muslims. Transnationality has been identified by some as part of the history of the Ismaili population (Dossa, 1994; Institute of Ismaili Studies, 2009). Migration and resettlement of the Ismaili population occurred in 1840 from Persia; in 1900 from Bombay, India; and finally in the 1970s from East Africa to Canada, the United States, and the United Kingdom (Dossa, 1994; Institute of Ismaili Studies, 2009). When focusing on their

specific settlement in Canada, it has been suggested that most of the basic struggles of migration were overcome through the adaptive nature of the Ismailis themselves (Clarke, 1978).

The sociological concept of cultural capital is essential when discussing the process of social mobility and transition (Dumais, 2002). The term can be described as non-financial social assets such as cultural knowledge, skills, and education, and has been associated with power, status, and assisting populations in settling through economic and social relationships (Dossa, 1994; Dumais, 2002). The Ismaili population has been known to utilize cultural capital in their transitions, which has assisted in their adaptation by providing them with skills and education to help other Ismaili Muslims become familiar with the new environment to excel in their businesses and settlement process (Dossa, 1994). The cultural capital of the Ismaili population, through the financial, housing, and health care committees that were established in Canada, helped provide other Ismailis with the support, knowledge, skills, and education they required to understand the complex Canadian social systems.

Equipped with several puzzle pieces of information on health literacy and the Ismaili Muslim population, I thought it would be a good idea to consider conducting interviews with the members of the Ismaili community to acquire information on their initial experiences with the Canadian health care system. I also believed that, with the resilience this group has exhibited over the course of their history regarding transnationality and cultural capital, they would be able to provide an invaluable resource for my research. Although the pieces of the puzzle were present from the beginning of my research study, I was unsure how I would utilize and align them strategically to fully grasp the connection between health literacy and the Ismaili population.

Figure 1-1. My Research Puzzle Pieces That I Encountered When Creating My Research Question

Reflecting on the Impact of Health Literacy

The multidimensional nature of health literacy becomes clear when exploring its effects on individuals and their experiences within the Canadian health care system. Patients are faced with complex information and treatment decisions, as well as specific tasks such as interpreting test results, calculating medication dosages, and locating health information. To accomplish these tasks, individuals may need to be visually literate, information literate, or numerically literate (Health Canada 2008b). In addition, patients are expected to articulate their health concerns and be able to accurately answer pertinent questions and understand medical advice or treatment decisions, all tasks that can be problematic if there are language barriers (Health Canada, 2008b). I believe that, in this day and age,

health care has now become a shared responsibility between health care providers and patients, whereby patients require strong decision-making skills and the confidence to take charge of their own health management. If communication between health care providers and patients becomes unclear, difficult, or confusing, it could result in untreated or misdiagnosed patients and financial stress on the health care system, because patients continue to seek medical attention until their health concerns are resolved.

The fiscal impacts of the effects of the social determinants of health, including health literacy, on the health care system have been significant in Canada. For instance, the additional health care expenditure due to low health literacy skills was estimated at approximately $73 billion in health care dollars in 1998 (Canadian Council on Learning, 2008). What makes this relationship between financial inefficiency and low literacy levels even more clear is the contrasting evidence that exists in the presence of higher levels of health literacy. Cancer treatment, asthma management, and the treatment of diabetes are some of the most costly forms of health care, and research has found that higher levels of health literacy are shown to improve these conditions (Canadian Council on Learning, 2008), and thus likely contribute to a decrease in health costs.

The three most vulnerable populations in terms of health literacy are the older adult population, immigrants, and the chronically unemployed (Health Canada, 2008b). The recent Canadian Council on Learning Report, *Health Literacy in Canada: A Healthy Understanding* (2008) emphasized that, due to their lower levels of health literacy, these specific high-risk populations experience poorer health (Health Canada, 2008b). The report suggests that these groups "lack the necessary skills to manage their health and health-care needs adequately" because they possess the lowest levels of health literacy compared to the average Canadian (Canadian Council on Learning, 2008, p. 9). In particular, the

immigrant population has additional barriers of language and culture, which can inhibit their literacy scores by up to 65% (Canadian Council on Learning, 2008).

Reflecting on Health Literacy Research

One challenge in studying health literacy is assessing the health literacy rate of a nation or population. Health literacy has typically been assessed by quantitative measurements (Jahan, 2000). The Canadian government has taken steps to assess the level of health literacy of the Canadian population through the introduction of the International Adult Literacy and Life Skills Survey (IALSS), questions from which were incorporated in the 2006 census. The Canadian Council on Health literacy, in association with the IALSS, developed a framework of five levels of health literacy to analyze the nation's results. Within this framework, the first level represented the poorest level of proficiency, or under a grade two reading level, and individuals attaining level five had strong literacy skills and could read at least at a grade eight level (Canadian Council on Learning, 2008). The levels addressed various health activities and categories including health promotion, health protection, disease prevention, health care activities, and health care system navigation (Canadian Council on Learning, 2008). Surveys and census data have been analyzed to produce a numerical conception of the number of people who have difficulty understanding the Canadian health care system (Gillis, 2004). Results demonstrated that 60% of the general Canadian population were considered to be at or below level two, therefore lacking the capacity to obtain, understand, and act upon health information and services to make appropriate health decisions on their own (Canadian Council on Learning, 2008).

Although Canada has opted to use the IALSS to assess our nation's health literacy, there are several other ways it can be, and has been, measured. There are numerous existing health literacy assessments and as research in this area grows, newer assessments continue to be introduced. The

most recent trend in assessment of health literacy has been related to specific diseases or conditions, such as diabetes and cancer (Moody & Rose, 2004; Rootman, 2006).

However, there appears to be a gap in the available literature and research. The voices of individual users of the health care system are absent (Fetter, 2009; Moody & Rose, 2004; Rootman, 2006). Many researchers in this field have drawn attention to the fact that population surveys and percentages can only provide numerical representations of the number of individuals requiring help, the populations most affected, and potential barriers that exist (Gillis, 2004; Jahan, 2000; Rootman, 2006); little or no research has been directed at qualitatively understanding the reasons why certain populations are affected differently than others, the possible interventions or improvements that should be considered, or the ways in which the health care system can be amended to accommodate the unique needs of vulnerable populations.

Reconsidering the Research Puzzle

Because my family utilized the services of the Ismaili community and its cultural capital in their health literacy struggles, I wanted to explore if the Ismaili community influenced the settlement experiences of other Ismaili Muslims. Listening to the stories of the Ismaili Muslim immigrant experiences and their struggles with the health care system in 1972 might assist other new immigrants groups in ways that surveys cannot accomplish. This information could help other immigrants feel they are not alone in their struggles and assist them in discovering where assistance can be uncovered.

It will be challenging to put the four puzzle pieces (stressors, social determinants of health, the healthy immigrant effect, and health literacy) together to understand their impact on the health of individuals. It involves discussing and reliving experiences of almost four decades ago with individuals who have extensive memories of fleeing East Africa and settling in Canada, and in terms of this study, specifically in Toronto, Ontario. I believe that speaking to members of the Ismaili community would

provide them the opportunity to tell their stories, like my grandmother did, regarding their migration experiences when leaving East Africa for Canada in the early 1970s. Furthermore, the participants could experience comfort and trust in me as a researcher and elaborate on their poignant but emotional experiences (Beiser, 2008), because both my parents and grandparents also experienced similar hardships.

As I reflected on the stressors my grandparents experienced and their relation to the social determinants of health and the healthy immigrant effect, I came to an drive that determined my research purpose and questions. The purpose of this research project is to understand the experience of being a part of a community that adopts a particular system of support for first time users of a health care system. In addition, this project aims to explore the idea that there is a relationship between cultural capital and health literacy. The research objectives are, specifically:

1. To gain a better understanding of the post-immigration experiences of the Canadian health care system in comparison to the pre-immigration expectations among older Ismaili Muslim adults,
2. To discover how health literacy affected health seeking behaviours during immigrant settlement in Canada within the Ismaili community living in Toronto; and
3. To explore the effects of cultural capital to determine how it assisted or hindered the successful settlement process of the Ismaili Muslims within Canada.

CHAPTER TWO

Scoping Review: Bringing Theoretical Concepts to Conceptualize Health Literacy in the Immigrant Population

Conceptualizing Health Literacy

Understanding the concept of health literacy in greater depth was the most prominent change in my appreciation prior to conducting the interviews. Previously, my only knowledge of the term health literacy involved the aspect of accessing the health care system. The term 'health literacy' was developed in 1974 where nurses and health care professionals in the United States noticed a gap in treatment instructions and subsequent behaviours from patients arising from minimum health education standards for all grade-school levels (Rootman, 2006). Since then, collaboration across several disciplines has led to the adoption of the term in fields such as education and psychology; and what has arisen in this cross-disciplinary study of health literacy is recognition of the need to understand patient perspectives (Rootman, 2006). These collaborations brought about several definitions and confusion in the actual meaning of the term, 'health literacy'. This made comprehending the process of health literacy from an immigrant's point of view difficult, because it was necessary to grasp how individuals make appropriate health decisions that lead to health seeking behaviours, or the personal actions that promote optimal wellness, recovery, and rehabilitation (Canadian Council on Learning, 2008). Along with older adults and the chronically unemployed, the immigrant population is identified as a vulnerable group and are all considered to have the lowest health literacy rates worldwide, which require significant improvement (Health Canada, 2008a).

Although a growing body of peer-reviewed studies has demonstrated the importance of increasing the level of health literacy within the immigrant population, little attention has been focused on developing a common definition of the various dimensions or measures of health literacy. A scoping

review was conducted on the topic of health literacy and the immigrant population. A scoping review is a way of mapping the existing research literature in a given area and is used to identify research gaps (Arksey & O'Malley, 2005). The purpose of this scoping review is to identify and summarize previous studies that define, explore, and assess health literacy as it applies to immigrant populations.

Both qualitative and quantitative studies were explored in this literature review. Electronic databases, including EMBASE, SCOPUS, CINAHL, PUBMED, PsychINFO, MEDLINE, and Social Science Citation Index were searched individually using health literacy*, or health education*, or health knowledge* and older adults* or aging* or elderly* and immigrant* or immigrants* as key words. Publications were limited to those published in the English language between 1972-2010; and both peer-reviewed literature and grey literature, such as reports by the Canadian government, have been incorporated in this literature review.

Boundary Maintaining Mechanisms

To be eligible for inclusion in the review, the studies had to: (a) focus on health care and immigrants; and (b) describe one or more of the following: definition of health literacy or health education, dimensions of health literacy, health literacy measures and/or intervention(s), and progress in the study of health literacy. Publications were excluded if they were: (a) published before 1972; (b) written in languages other than English; or (c) lacked information related to the specific inclusion criteria.

The final search yielded 40 articles. Of these, a total of seven unique abstracts were rejected because they did not meet the inclusion criteria. This resulted in the retrieval of 33 full-text articles that provided information on health literacy within the immigrant population. Of these 33 studies, two reports included cross-referenced information and grey literature that I incorporated.

This review is organized by major themes, namely: perspectives on health literacy; theoretical underpinnings for research in health literacy; dimensions and measures of health literacy; factors

influencing immigration and settlement; and efforts to improve health literacy within the immigrant population through interventions. Because the topic of health literacy is not documented in great detail in Canada, it was essential to review international articles and studies on health literacy. Of the 33 articles reviewed, most were from the United States (n=22), but there were also articles from Canada (n=5), Australia (n=4), and some European countries (n=2).

Perspectives on Health Literacy

A number of authors agree on the definition of health literacy including an individual's ability to read, understand, and use health care information to make informed decisions and follow instructions for the purpose of treatment (Canadian Public Health Association, 2008; Health Canada, 2008a; Rootman, 2006). However, there seems to be considerable variation in the operationalization of the term health literacy. This may be because health literacy includes both the health literacy demands made by the health institutions, media, and internet and the individual skills that are brought to the situation, for example, an individual's ability to understand the directions given by health care professionals (Nutbeam, 2000; Ratzan, 2001). For these reasons, the term 'health literacy' can be misunderstood or misconstrued.

The majority of Canadian publications (n=5) seem to adopt the definition of health literacy provided by the British Columbia Health Literacy Research Team (Kwan et al., 2006) that encompasses the term health care navigation, which is defined as, "identifying all aspects of the health care system that can be utilized to benefit the individual" (Canadian Public Health Association, 2006, p. 23).

Most American and international journal articles (n=19) employ the definition of health literacy advanced by the Institute of Medicine (IOM, 2006), Ratzan and Parker (2000), or the World Health Organization (WHO, 1998). Several studies (n=8) did not define the concept of health literacy at all. Table 2-1 offers some of the most commonly cited definitions of health literacy in health care that are

utilized internationally.

Table 2-1

Most Commonly Cited Definitions of Health Literacy of the Studies Reviewed

Original Authors	**# of times cited in current review**	**Definitions of Health Literacy**
Kwan, Frankish, & Rootman, 2006	8	The degree to which people are able to access, understand, appraise, and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-span (p. 4)
IOM, 2006	9	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Health literacy is also a result of interaction between the individuals and the different health contexts in which they seek or receive health information (p. 3)
Ratzan & Parker, 2000	4	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (p. 210)
WHO, 1998	3	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health (p. 1)

Because health literacy is a multidimensional construct, a more robust view of health literacy might encompass the ability to understand scientific concepts; skills in spoken, written, and online communication; critical interpretation of mass media messages; navigating complex systems of health care and governance; and knowledge and use of cultural capital and resources, in addition to utilizing cultural and indigenous knowledge in the process of health decision making (Nutbeam, 2000; Ratzan, 2001). These various elements of health literacy make defining the term complicated, hence the lack of

international consensus about the concept. Without an understanding of the term health literacy, it proves difficult to delve further into the topic and its implications.

Theoretical Underpinnings for Research in Health Literacy

Because of the differences in historical, political, social, and cultural backgrounds of immigrants, additional theoretical perspectives have been used to understand health literacy in this population. Within this review, 19 studies discuss the importance of either Social Network Theory, Social Capital Theory, or Cultural Capital Theory. Other models used to describe health literacy include the Conceptual Model of Health Learning (Wolf et al., 2009), the Outcome Model for Health Promotion (Nutbeam, 2000), the Individual Patient Journey (Jordan, Buchbinder, & Osborne, 2009), the Andersen Model (Schillinger, Grumbach, & Piette, 2002), and the Pathways Between Patient and Health Literacy Model (Ishikawa & Yano, 2008). For the purpose of this study, the Social Network Theory/Social Capital Theory/Cultural Capital Theory, the Conceptual Model of Health Learning (Wolf et al., 2009) and the Pathways Between Patient and Health Literacy Model (Ishikawa & Yano, 2008) will be discussed further, because they were most frequently cited throughout the health literacy studies reviewed.

Social Network Theory/Social Capital Theory/Cultural Capital Theory

Cultural Capital Theory is an umbrella term used to encompass both the Social Network and Social Capital Theories by several authors, where it can be generally described as the skills that provide a person with a higher status, power, and economic and social relationships in society with cultural knowledge, skills and education (Dumais, 2002). Social Network Theory purports that relationships within the networks of individuals are more meaningful than individual relationships themselves (Jahan, 2000); and research shows that health literacy rates are higher when there is a network of social support available for individuals (Fetter, 2009; Ishikawa & Yano 2009; Rootman, 2006). Social networks, and the people who comprise them, may be useful in increasing awareness of and positively affecting health

behaviours, in particular for immigrants whose individual skill sets may not be adept enough (Jahan, 2000). According to Health Canada's Health Policy Research Bulletin (as cited in Rootman, 2006), social capital refers to a network of social relations that may provide individuals and groups with access to various *resources* that facilitate access to the health care system (Statistics Canada, 2008b). Social capital is formed by social groups within a community to obtain the necessary resources needed to achieve health care goals (Jahan, 2000). These concepts assist in facilitating health literacy and provide avenues of alternative information for new immigrant patients.

Social Network, Social Capital, and Cultural Capital Theories assist in understanding that health literacy can be improved with and by the people around you. Authors who address these theories propose that most people who are new to the country believe that they can relate to others in their situation (i.e., other newcomers) and trust their friends and families to provide an alternative source of reliable information, which makes the Social Network, Social Capital, and Cultural Capital Theories important in understanding the topic of health literacy for immigrants (Fetter, 2009; Ishikawa & Yano 2008; Rootman, 2006).

Conceptual Model of Health Learning

Wolf et al. (2009) consider the use of the Conceptual Model of Health Learning essential to elaborate on the contextual issues affecting the settlement process and, specifically, to understanding how immigrants learn to navigate the Canadian health care system through their past experiences. The model emphasizes the importance of social network and social capital as essential assets when settling in a new country (Wolf et al., 2009). The Conceptual Model of Health Learning brings together several fields of study, such as education, psychology, and cognitive science, to provide a more in-depth explanation of the various abilities that every individual must utilize when obtaining, processing, and understanding health information in order to ultimately, make health decisions. This model was

proposed to inform the health system of the challenges individuals must face, and the strategies they must employ, in order to understand and use the health treatment information provided by health care professionals (Wolf et al., 2009).

Wolf et al. (2009) suggest that health-learning capacity involves a cognitive and psychosocial skill set necessary to obtain the appropriate health knowledge, which leads to health behaviours, and eventually, health outcomes. Within this holistic model, collaboration between the fields of education, cognitive science, and psychology is utilized to help understand how health professionals can guide patients towards obtaining and understanding health information to their highest potential (Wolf et al., 2009). The Health-Learning Capacity Model separates health literacy into its individual parts and highlights the various demands immigrants face when dealing with the health care system initially.

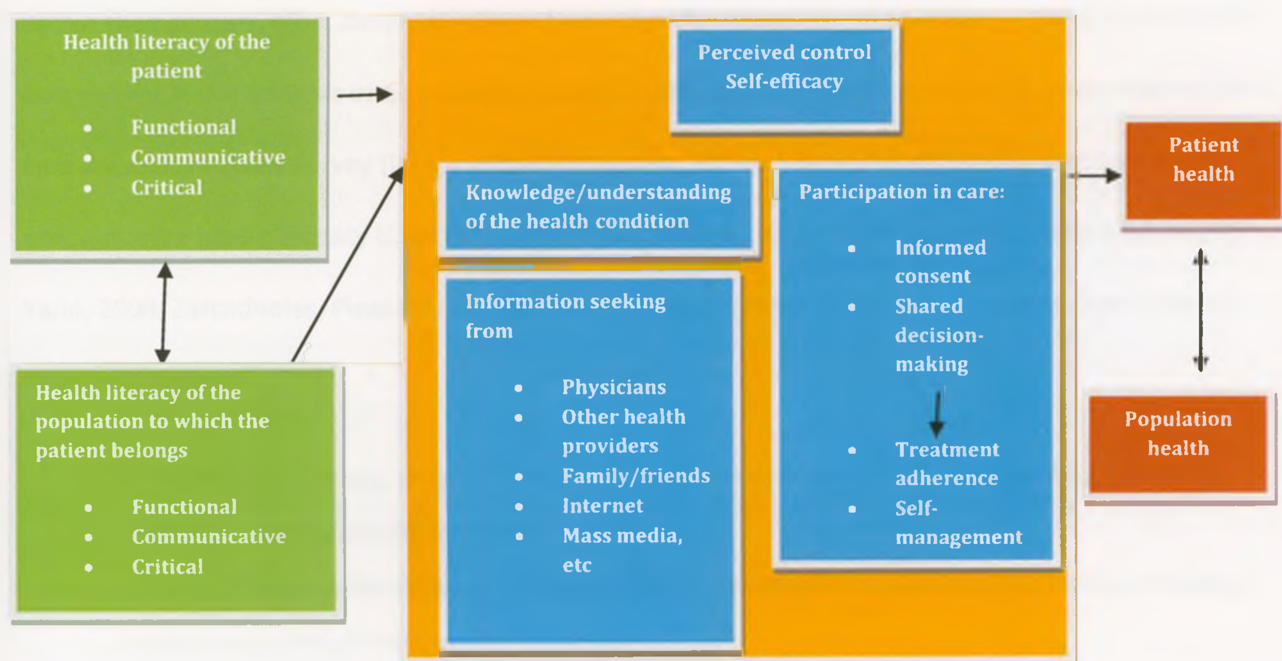
Pathways Between Patient Health Literacy Model

Ishikawa and Yano (2008) proposed the Pathways Between Patient Health Literacy Model because studies had demonstrated that a lack of adequate functional health literacy contributes to poorer levels of health and well-being (Ishikawa & Yano, 2008). The Pathways Between Patient Health Literacy Model proposed a conceptual framework that links health literacy to health status and health service use by incorporating four intervening factors as pathways: (i) disease and self-care knowledge, (ii) health risk behaviour, (iii) preventative care and physician visits, and (iv) compliance with medication. Ishikawa and Yano (2008) incorporated the results of the Rapid Estimate of Adult Literacy Measure (REALM) (Davies & Crouch, 1991) and the Test of Functional Health Literacy Assessment (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995) surveys when developing the model. Ishikawa and Yano (2008) elaborate on the types of health literacy and discuss the gaps in literature surrounding the conceptual definition of health literacy and its application by providing an overview of health literacy and its dimensions that goes beyond examining functional literacy (see Figure 2-1). The authors argued that the

Pathways Between Patient Health Literacy Model was the most comprehensive perspective on health literacy (Ishikawa & Yano, 2008). However, this model was rarely utilized in the health literacy research studies reviewed.

Figure 2-1

Model of Patient Participation in Health That Influences Health Literacy (Adapted from Ishikawa & Yano, 2008, p. 119)



Dimensions of Health Literacy

Health literacy is multifaceted, incorporating several aspects, such as access to health institutions and being able to take and use medical instruction (Health Canada, 2008b). In most cases, health professionals and researchers adopt a model of health literacy that features multiple dimensions (Ishikawa & Yano, 2008). Many researchers and health professionals introduce the dimensions of health literacy to help operationalize the development of health literacy questionnaires. However, much like the disagreement in the definition of health literacy, authors include differing health literacy dimensions within their studies. Most dimensions have been identified from literature reviews, questionnaires, and subsequent factor analysis of quantitative health literacy questionnaires, such as the International Adult Literacy and Life Skills Survey (IALLS) (Statistics Canada, 2002). These dimensions have become a way to conceptualize health literacy (Canadian Council on Learning, 2008; Health Canada, 2008b; Ishikawa & Yano, 2008; Zarcadoolas, Pleasant, & Greer, 2006). Health Canada (2008b) lists 4 dimensions of health literacy, including:

- Fundamental literacy, which refers to the skills and strategies involved in reading, speaking, writing, and interpreting numbers
- Scientific literacy, which refers to levels of competence with science and technology, including some awareness of the process of science
- Civic literacy, which refers to abilities that enable citizens to become aware of public issues and to become involved in the decision-making process
- Cultural literacy, which refers to the ability to recognize and use collective beliefs, customs, world-views and social identity to interpret and act on health information

Measures of Health Literacy

During this literature review, it became clear that health literacy in health care settings is typically assessed through quantitative questionnaires that are based upon combinations of the dimensions of health literacy previously mentioned. Thirteen studies utilized quantitative methods in the form of

population surveys, and three of these also used a mixed methods approach, using both surveys and interviews. Among the articles reviewed, only six utilized qualitative methods to assess health literacy. Of these, two used informal interviews, one employed formal interviews, one utilized observation, one used focus groups, and one made use of a collaborative tool as its methods of data collection. The remaining studies (n=14) did not employ any methods to measure health literacy and simply utilized the term and explored the effects of health literacy within certain populations.

The health literacy scale, derived from the International Adult Literacy and Life Skills Survey (IALLS) survey tool, ranges from 0-500 and allows for comparison of differences in average health literacy among different groups of adults (Nutbeam, 2000; Shohet & Renaud, 2006; Wolf et al., 2009). These 500 levels can be translated into 5 categories utilized to compare assessment findings with other individuals. Table 2-2 outlines the levels of health literacy described by Nutbeam (2000), where the five levels of health literacy are used to understand functional health literacy, interactive health literacy, and critical health literacy, with level five being the highest level of health literacy achievable.

Over the course of this literature review, I identified over ten different tools to measure health literacy. Although one study suggests measuring health literacy to assist in diagnosing the underlying levels of health literacy within a population or group (Derose, Escarce, & Lurie, 2007), other authors warn against aggregating survey data, because health literacy often varies between groups of individuals (Ishikawa et al., 2008; Wolf et al., 2009; Zanchetta & Poureslami, 2006). Some studies suggest focusing on one specific population and assessment of health literacy, because every cultural group or local population varies (Jahan, 2000; Lee, Arozullah, Cho, Crittenden & Vicencio, 2009).

Table 2-2

Levels of Health Literacy Adapted From Nutbeam (2000), p. 266

Health literacy level and educational goal	Content	Individual Benefit	Community/social benefit	Examples of educational activity
Functional health literacy; communication of information	Transmission of factual information on health risks and health services utilization	Improved knowledge of risks and health services, compliance with prescribed actions	Increased participation in population health programs (screening, immunization)	Transmit information through existing channels, opportunistic inter-personal contact, and available media
Interactive health literacy; development of personal skills	As above and opportunities to develop skills in a supportive environment	Improved capacity to act independently on knowledge, improved motivation and self-confidence	Improved capacity to influence social norms, interact with social groups	Tailor health communication to specific need; facilitation of community self-help and social support groups; combine different channels for communication
Critical health literacy; personal and community empowerment	As above and provision of information on social and economic determinants of health and opportunities to achieve policy and/or organizational change	Improved individual resilience to social and economic adversity	Improved capacity to act on social and economic determinants of health, improved community empowerment	Provision of technical advice to support community action; advocacy communication to community leaders and politicians; facilitate community development

Different countries utilize various measurement tools, which adds to the confusion around health literacy, because there is no international standardization. All Canadian quantitative studies include the revised version of the International Adult Literacy and Life Skills Survey (IALLS), also known as the Adult Literacy and Life Skills Survey (ALLS), which was used in the 2006 census (Canadian Council on Learning, 2008; Nutbeam, 2000). The Expert Panel in Canada asserts that the IALLS is the survey that most

accurately measures and embodies the definition of health literacy expressed by the British Columbia Health Literacy Team (Canadian Council on Learning, 2008). Surveys and questionnaires as well as health literacy surveys relating to specific diseases such as diabetes and cancer are utilized in the United States (Fetter, 2009). Many disease specific survey-based health literacy measurements are used in the United States on a daily basis by health professionals as a way to diagnose patients (Rudd, 2007). The most popular form of health literacy measurement is the Rapid Estimate of Adult Literacy in Medicine (REALM) test (Canadian Council on Learning, 2008).

Although surveys can provide an understanding of population health literacy and the general issues faced by individuals regarding the health care system, it has been recommended by several authors that we begin to supplement this quantitative data with richer qualitative data through interviews, focus groups, and/or observations to gain a better sense of the individual experiences involving health literacy within the Canadian health care system (Canadian Council on Learning, 2008; Nutbeam, 2000; Wolf et al., 2008). In addition, narratives have been proposed as a means to study health literacy within a population, because this would be a strong method to elicit the voices of those experiencing problems within the health care system (Nutbeam, 2008). Gaining a deeper understanding of health literacy requires intensive, long-term studies, using interview and observational techniques longitudinally, an approach that has not been attempted in the existing studies (Ishikawa & Yano, 2008; Nutbeam, 2000).

Factors Influencing Immigration and Settlement

The immigrant population experiences a range of challenges and complications when entering a new country in relation to their health and well-being (Statistics Canada, 2008a). Within three months of settling, the health of the new immigrant population gradually declines, which is described as the healthy immigrant effect (Statistics Canada, 2008a). At their first health crisis, access to health and social

institutions is essential (Statistics Canada, 2008a). Given that health care is an early need for the immigrant population, government policies require cultural sensitivity and should address the heterogeneous populations, which is not what the immigrant literature demonstrates.

The literature on immigrants and health reports that ineffective government policies, lack of cultural sensitivity, and language barriers impede communication between immigrants and health care professionals and, consequently, negatively affect their access to health care support and decrease their quality of care (Beiser, 2008; Fetter, 2009; Statistics Canada, 2008a). In addition, research on the immigrant population notes that all different immigrant populations do not necessarily view health care practices in a similar manner, which governmental policy has yet to take into account (Beiser, 2008). All these factors contribute to lower health literacy levels for immigrant populations who have trouble accessing health institutions and understanding health information upon their arrival in a new country.

An intercollaborative form of research has been applied to explore the effects of settlement experiences and integration of new immigrants, including their psychological and emotional states. When experiencing such a drastic change in lifestyle, several psychological needs, which are not typically assessed, arise in attempting to find social networks as well in grasping the differences within the physical environment (Beiser, 2008; Derose et al., 2007; Statistics Canada, 2008).

Furthermore, immigration research in the field of psychology recognizes that immigrants are a heterogeneous population and, consequently, have differing needs, values, and cultural backgrounds that need to be addressed (Beiser,2008). Given this variation, studies have examined the strategies that new immigrants of different cultural backgrounds employ, either successfully or unsuccessfully, to help in the integration experiences of other immigrants (Fetter, 2009). When settling in a new country, factors such as social support and guidance play a large role in determining successful integration (Fetter, 2009).

Other factors, such as governmental policies and regulations, affect power relations and cultural constraints that are experienced by immigrants in a new environment (Beiser, 2008). This could negatively affect the way the immigrant population learns about health and health literacy in relation to their race, gender, or class (Beiser, 2008; Fetter, 2009). It is necessary to understand the influence these factors have on the settlement and integration experience, which can vary depending on the social and political context of the immigrant population. Beiser (2008) explains that the diversity of individuals is not taken into account, because there are no policies in place that attempt to maintain the health of individuals after their arrival. Moreover, health care programs for new immigrants are, in the majority of situations, designed from the perspective of the health care professionals, which can lead to miscommunication and confusion regarding the unique needs of the immigrant population (Beiser, 2008).

In relation to health care practices, it is essential that health care professionals are thorough in taking patient histories, in particular documenting the social and political contexts of the individual as well as the potential barriers he/she may confront in accessing health care and treatment options (Health Canada, 2008a). Discussing these topics would also allow health care professionals to assess the language skills of the individual and introduce them to additional health literacy resources, if necessary (Beiser, 2008; Fetter, 2009; Jahan, 2000).

Efforts to Improve Health Literacy within the Immigrant Population

Despite the rise in health literacy assessments, description alone cannot improve the health literacy of specific groups of individuals, such as the immigrant population, let alone that of an entire nation. Instead, improving health literacy is most frequently accomplished by implementing a number of interventions, often targeting one or more dimension of health literacy at a time (Rootman, 2006). A number of studies (n=14) discuss complications of health literacy and implications in practice within the

immigrant population but do not propose future solutions. Similar to other aspects of health literacy discussed so far, several different interventions to improve health literacy exist, and some have become more prevalent than others. Ishikawa and Yano (2008) proposed a stepwise solution to improving basic health literacy: (a) respect, (b) establishing a health literacy culture, or a team of health care professionals that utilize health literacy evaluations in patient visits, (c) using the survey data to drive programs, (d) identifying and developing health literacy training and evaluation resources, and (e) advocating for school-based programs targeting literacy and health literacy (Ishikawa & Yano, 2008). Other interventions that have been suggested regarding the general population include teaching patient skills across the lifespan beginning in elementary school, developing health literacy training and education resources for health professionals, using data to drive programs with newer surveys, developing a portable personal health record, and advancing communication practices for health professionals to enhance patient history taking (Canadian Council on Learning, 2008; Jahan, 2000; Nutbeam, 2008). A systematic review on the effectiveness of health literacy interventions has not been published to date.

Innovations focused directly on immigrant populations are few in number. For the purpose of this review, the interventions regarding immigrant populations will be discussed in detail. Among these studies that do propose solutions, Kreps and Sparks (2008) suggest that the first step in improving health literacy is to establish a health literacy agenda or culture by involving all health professionals in collaborative research, making them aware of standards, technologies, tools, measurement, and expectations. But first, they indicated assessing the current status of health literacy within a population, which is normally accomplished through the use of surveys (Kreps & Sparks, 2008). This would make health professionals more aware of the background health histories of immigrant populations in order to be more culturally sensitive towards their patients in terms of their abilities and levels of communication (Kreps & Sparks, 2008).

Jahan (2000) recommends improvement in health literacy by promoting a community-based intervention strategy targeted at specific immigrant populations. Jahan (2000) cautioned that a health education program will only be useful if it is specifically tailored to a given population, which requires: 1) Assessment of community needs; 2) Identification of achievable goals; 3) Information dissemination in a way the community prefers; 4) A behaviour-based monitoring system; and 5) Continuous adaptation of implementation of strategies (Jahan, 2000). Jahan (2000) proposed this solution as a result of the research he conducted in Bangladesh, through which he discovered that tailoring programs to fit the population and its needs, benefits local populations. In addition, community involvement would lead to the empowerment of community members to take leadership roles, which would be crucial to the program's sustainability and success (Jahan, 2000). Jahan's proposed program could take anywhere from 3 to 5 years to effect change in health literacy practices.

The most frequently cited health literacy improvement interventions that have been suggested for immigrant populations include: production of a health literacy culture and team (improving health literacy screening and education), alliance within health and education sectors, community-based educational outreach, and culturally competent and sensitive practices. Each will be discussed in further detail below.

Production of a health literacy culture and team (improving health literacy screening and education)

Of the articles that discuss interventions, two publications recommend the creation of a health literacy culture, or a team of health care professionals that would improve the communication of health literacy within a health care environment (Fetter, 2009; Wolf et al., 2009). This would greatly benefit the immigrant population by making available persons to aid in their communication of health issues to health professionals. These studies adopted the Cultural Capital Theory (Jahan, 2000) and Pathways Between Patient Health Literacy Model (Ishikawa & Yano, 2008) as frameworks. Knowing that there is

someone who speaks your language and understands your culture fosters an environment of trust, and the patients have assurance that they have support and someone to go to if they have questions regarding their medications or treatment plans. A health literacy culture would encourage all health professionals to recognize and understand the importance of health literacy, therefore allowing the team to aid patients on a daily basis and have evaluations of health literacy as part of their medical routine. By building a health literacy culture, health professionals would be conscious of the challenges faced by new immigrants, regardless of their health literacy levels, therefore improving their interaction with the health care system and their health care experience overall. In effect, new immigrants could become more familiar and at ease with the health care system and utilize it more frequently, as needed. A health literacy culture, if enacted, would be able to intertwine aspects of health care and education, as well as communication to better accommodate immigrant groups and improve their health literacy levels, with the help of educated health care professionals.

Health literacy education and screening programs targeted towards health professionals are another commonly implemented intervention (n=4). Though some studies report improved health literacy communication among patients after training in health literacy, others suggest that the best method is to educate the health professionals (Fetter, 2009; Wolf et al., 2009; Zanchetta & Poureslami, 2006). The health professional training techniques also include training regarding communication with patients who are new to the country and who require assistance (Fetter, 2009; Wolf et al., 2009; Zanchetta & Poureslami, 2006). Training topics include defining health literacy, measuring health literacy, various ways to measure health literacy with individual patients, ways to improve health literacy, directions for more information, event reporting and analysis, and the importance of teamwork and communication (Wolf et al., 2009). Some authors assert that health care professional training has the potential to assist immigrant groups by allowing them to feel more comfortable when discussing their health issues with these trained professionals (Fetter, 2009; Wolf et al., 2009). Trained health care

professionals would be able to direct the patients to someone who could assist them if any problems did arise.

Results of educational programs have not yet been reported in the literature because the topic is still emergent. The importance of continuous training is stressed, because change in practice and health literacy is not commonplace after only a single exposure to training. Multiple exposures to training would enable health professionals to better internalize the elements of a health literacy culture. Other researchers have recommended the implementation of health literacy curricula that promote learning from adverse events, especially for future care providers, adding that the ideal time for learning is during schooling (Fetter, 2009; Wolf et al., 2009).

In a health literacy culture, routine health literacy screening could help direct care. For example, the United States has employed the Single-Item Screener (Baker, Parker, Williams, Clark, & Nurss, 1997) and the Three Screening Questions (Jeppesen, Coyle, & Miser, 2009) on a regular visit basis (Davis & Wolf, 2004). Health professionals, mostly family doctors, are required to question their patients regarding their health histories-and background information to assess their health literacy and take appropriate steps to facilitate and advance their health literacy (Davis & Wolf, 2004). This involves directing them to others who can help them with this process, clarifying how they can contact the family doctor for more information, alerting other health professionals if there is a language barrier, and/or assisting the pharmacist by advising them on how to explain prescriptions (Davis & Wolf, 2004; Ishikawa & Yano, 2008). Unfortunately, because longitudinal studies have not been completed in this area, evidence as to outcomes of this protocol is lacking.

Alliance between Health and Education Sectors

Several publications (n=13) recommend the use of an alliance between health and education sectors to improve health literacy rates in the younger immigrant population. Most studies report using health

literacy as an outcome of health promotion by creating supportive environments for health leading to structural interventions 'by' or 'with' people, rather than 'on' or 'to' people, through empowerment (Nutbeam, 2000). This applies at local, national, and international levels by emphasizing, for example, the need for improved alliances between WHO and United Nations Educational, Scientific, and Cultural Organization (UNESCO), at the international level, and the need for a clearer discernment between agencies, at the most local level, of a common definition of health literacy (Rootman, 2006; St Leger, 2001).

An alliance with the health and education sectors will advance health literacy at all levels in future generations by increasing patient skills and, therefore, building health-learning capacity, leading to better health behaviours and outcomes (Rootman, 2006; Wolf et al., 2009). Rootman (2006) and Wolf et al. (2009) state that primary and secondary educational curricula should include content for building health-learning capacity. This would develop a psychosocial skill set described within the Health-Learning Capacity Model, and advance knowledge of common terminology, practical health care information, health system navigation skills, and age-related health issues (Rootman, 2006; Wolf et al., 2009). It would prepare young immigrants for the future and also aid them when confronting family-related problems regarding the health care system (Rootman, 2006). Ideally, this course of action would lead to more accurate expectations of one's current and future roles and responsibilities in managing personal health (Rootman, 2006; Wolf et al., 2009). The authors believe that if the quality of early education can be improved and health care can be simplified, the impact of low health literacy can be reduced (Wolf et al., 2009).

Community-based Educational Outreach

Three of the articles reviewed focus on the creation of community-based educational outreach programs for improving health literacy, using a grassroots movement within an immigrant population.

When attempting to improve health literacy within a specific population, such as the immigrant population, programs that are targeted towards these groups tend to have more of a positive result (Jahan, 2000). However, it is important that a facilitator, not an educator, works jointly with the community members to address problems successfully and motivate and empower community members to improve their understanding of pertinent health issues (Jahan, 2000; Sarfaty et al., 2005). This provides a sense of trust for the community members, and a person with whom they can consult for any questions or concerns (Ishikawa &Yano, 2008). The authors reiterate the importance of involving the community in every step of the process, so that they have a greater understanding of the issues they face and are empowered to take action to deal with them (Jahan, 2000; Sarfaty, Turner, H., & Damotta, 2005). The team involved with the community-based educational outreach should include members of both the health care and educational sectors, to enhance learning skills, and collaborate in an inter-professional fashion for a better end result (Jahan, 2000). These teams are a forum for ongoing problem-solving, providing support and training on topics of health literacy, monitoring the success of the program, sharing status reports, and disseminating findings tailored to the community (Jahan, 2000). However, because few studies have been conducted regarding community-based educational outreach, longitudinal results are still unknown.

Culturally competent and sensitive practice

Health care is one of the earliest needs of immigrants after migration (Health Canada, 2008a). Three specific articles discuss interventions regarding the need for health professionals to be culturally competent and sensitive towards the needs of their patients (Fetter, 2009; Ishikawa & Yano, 2008; Jahan, 2000). Being aware of cultural traditions will demonstrate respect and foster trust between the patient and health care professional (Jahan, 2000). Because immigrants generally face numerous concerns when entering a new country, health care should be tailored to their learning capabilities and understanding (Canadian Council on Learning, 2008). In addition, taking into account a patient's social

and political circumstance can allow the health care professional to take a more sensitive approach (Jahan, 2000). These aspects should all be taught to health care professionals within the health literacy culture to improve health literacy rates (Fetter, 2009). The literature does not mention how health professionals can improve cultural competency or sensitivity, however, Ishikawa and Yano (2008) suggest that, when taking a patient history, an individual's language skills and basic communication skills can be put to the test; and when treatment options are provided, the health care professional should explain then in a manner that best suits the individual and his/her health literacy skill set (Ishikawa & Yano, 2008).

Discussion

This literature review discusses several aspects of health literacy within the immigrant population that require improvement. Some publications have simply examined the term health literacy within the immigrant population but have not explored interventions in depth. Similarly, the various dimensions of health literacy rates have not been examined by many studies. Diverse tools to measure health literacy were identified, most often in the form of quantitative surveys; yet, researchers in the field indicate a need for more qualitative inquiry into health literacy, employing methods such as interviews, focus groups, and longitudinal observations (Ishikawa & Yano, 2008; Nutbeam, 2000). These in-depth studies would provide a perspective that would allow the reader to understand the concerns of the immigrant. Some publications suggest that the study of health literacy should focus on specific population groups, rather than an entire population, because health literacy is context-specific (Jahan, 2000; Rootman, 2006).

Although the quantity of studies on health literacy has risen dramatically in the past decade, the number of studies that have overlooked the importance of clearly defining concepts is surprisingly high. Whereas some studies derive models of conceptualizing health literacy from research in other

disciplines, such as education and psychology, many ways of considering health literacy and its dimensions have stemmed from factor analysis of surveys, such as the REALM (Davis & Crouch, 1991) or IALLS (Statistics Canada, 2002). I believe that adopting the Wolf et al. (2009) Health-Learning Capacity model offers additional direct guidance for helping the immigrant population and their families better comprehend health information, make appropriate health decisions, and take action. In addition, incorporating Ishikawa and Yano's (2008) conceptual framework of Pathway Between Patient Health Literacy Model and social support, would provide a more holistic perspective on the topic of health literacy.

Improvements in health literacy have been accomplished by implementing comprehensive interventions and simultaneously targeting multiple dimensions of health literacy (Ishikawa & Yano, 2008; Jahan, 2000). However, most innovations that propose to increase health literacy rates are not targeted towards high-risk populations: immigrants, the chronically unemployed, and older adults. The studies reviewed introduce a combination of interventions to improve health literacy, however no longitudinal studies have been conducted (Canadian Council on Learning, 2008; Nutbeam, 2000, Rootman, 2006; Wolf et al., 2009). Many studies indicate that a strong leadership commitment to health literacy improvement is essential to success (Rootman, 2006), whereas others suggest that the assistance of inter-collaborative health care professions will ensure better execution and effectiveness of novel innovations (Wolf et al., 2009).

The key messages that I gained from the literature review regarding improving health literacy in immigrant populations are represented diagrammatically in the following model (Figure 2-2). Defining, operationalizing, and conceptualizing health literacy is essential to proposing strategic changes in health literacy rates and, eventually, the establishment of a health literacy culture (Fetter, 2009). Because health literacy is context-specific, it may be best to focus on a specific population, such as the immigrant

population, rather than the entire nation (Jahan, 2000; Rootman, 2006). Focusing the improvement of health literacy in the populations that most require it will aid in the elevation of the nation's health literacy rates (Rootman, 2006). Improving individual group health literacy rates will ultimately contribute to enhancing the entire nation's health literacy understanding. Summarizing the information providing in this literature review, it became evident that the first steps in building and improving health literacy should consist of: (a) defining the term health literacy, (b) identifying areas for improvement in specific populations, (c) assessing health literacy rates through surveys, in-depth interviews, and observations (Jahan, 2000), (d) raising awareness of findings with health care professionals, (d) implementation of proposed interventions, and (e) continually monitoring the measurement, improvement and evaluation process. This can be visually represented in Figure 2-2 below.

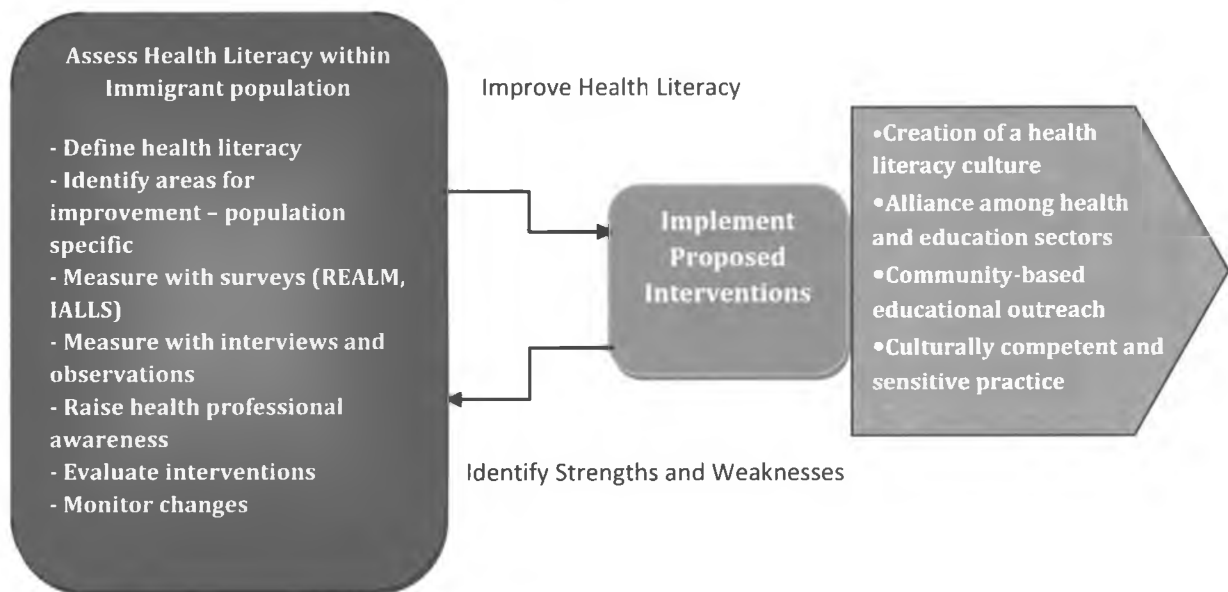


Figure 2-2. Model of Health Literacy Improvement Within the Immigrant Population Incorporating Concepts From the Literature Reviewed

Strengths and Limitations of this Review

Strengths: To the best of my knowledge, this review presents the first comprehensive summary of its kind of the existing research and knowledge of health literacy within the immigrant population. It was evident when I researched the topic of health literacy that longitudinal findings were lacking. Because

health literacy is a fairly new concept, the research surrounding its dimensions, measurements, and interventions is limited. My literature review summarized the extent and range of the research activity of health literacy, provided as full and systematic review as feasible of the information available, summarized the research findings, and identified the research gaps in the existing literature (Arksey & O'Malley, 2005).

Limitations: Although this review of the literature provides a detailed compilation of the topic of health literacy in the immigrant population, as a scoping review, it does not purport to assess the methodological quality of the studies reviewed.

Recommendations for Policy and Research

Based on my review of the proposed interventions on health literacy and the immigrant population, I propose the following recommendations for future research and policy development.

Define the term health literacy

Despite the increase in peer-reviewed studies on immigrants and health literacy in the past decade, many studies vaguely define the concept of health literacy, and there has been significant debate over how health literacy should be defined and operationalized. The terminology and ideological concepts connected to the various definitions of health literacy within the literature speak to the sheer diversity of approaches and perspectives used within the subfield of immigrant health research. I believe that the definition of the term must be agreed at an international level for the term, 'health literacy' to be used optimally in comparative research and policy development.

Insist on longitudinal studies on community-based educational outreach programs

Community-based educational outreach programs have been proposed and/or implemented in the immigrant population, but there are no data on the outcome of such programs. Longitudinal studies are necessary to build an understanding of not only the impact of having an active facilitator within a

community on community members' health, but also of the effects of a facilitator on raising health literacy rates and awareness overall. Without these studies, the effects of empowerment within the context of health literacy will never be known and the most effective programs cannot be identified or replicated. Further, the execution of these studies will likely require a move to more qualitative research that uses the voice of the immigrant population to develop and implement necessary strategies to overcome existing challenges. By allowing immigrants to explicate and clarify their hardships, their voices will be heard from their own perspectives, and policy development can then be centred on the issues of the population in question.

Facilitators and coping strategies

Researchers in health literacy among immigrant populations should take an asset-based perspective. Fetter (2009) calls for research that focuses on the resilience of immigrant groups rather than the challenges facing them. Using an asset-based approach can allow research to frame solutions to the challenges that immigrants face, through the lens of the resourcefulness and determination that this population embodies when settling in a new country.

Final Thoughts

I believe that a shared set of concepts may enable researchers to exchange information, strategies, and interventions in order to improve health literacy rates within a population. However, there is a gap between the conceptual definition of health literacy and its application. Improving health literacy in the immigrant population involves more than the transmission of health information, although that remains a fundamental task. Cultural competence, sensitivity and helping people to develop confidence to act on health information will best be achieved through more personal forms of communication support and through community-based educational outreach. The first steps in accomplishing the goal of improving

immigrant health literacy, and eventually national health literacy, is to mend the epistemological and methodological fallacies that have, to-date, limited research in this area.

I believe that my research study will be able to help address the research gap identified by this literature review. Utilizing qualitative, in-depth, semi-structured interviews will provide more holistic information about health literacy and provide thick descriptions, which the quantitative survey-based studies were lacking. Interviewing the Ismaili Muslim immigrant population can help close the gap in the research by addressing a high-risk health literacy population. My work will also take an asset-based approach by examining the use of cultural capital to enhance health literacy. Finally, my research study employed the definition of health literacy provided by the British Columbia Health Literacy Team, in an attempt to standardize the definition.

CHAPTER THREE

Methodology and Process of the Study

Methodology of the study

What is Narrative Inquiry?

Our individual lives are composed of lived experiences, and in order to understand a person, we need to study his/her experiences (Chase, 2005). Narrative inquiry is the study of a person's experience in the form of a story (Chase, 2005). Drawing on Chase's (2005) working concept for narrative inquiry, narratives are essential in understanding the various points of transition in the stages of a person's life (Chase, 2005). Oral histories explain the perspectives of the participants regarding their experience of leaving one country and entering another, essentially providing memories and meaning to those who have lived through these events (Chase, 2005). Chase (2005) and other philosophers, such as Crites (1997), conceptualize experiences as a storied phenomenon and storytelling as one of the most important cultural expressions. They argue that the formal quality of a person's experience through time is inherently narrative (Chase, 2005; Crites 1997). Similarly, MacIntyre (1981) expresses a narrative as a process that is drawn from our experience and a way of understanding our life when he explained, "we all live out narratives in our lives, and we understand our own lives in terms of the narratives that we live out" (p.212).

Narrative inquiry is consequently a necessary tool in immigrant research, passing down a lifetime worth of experience and allowing others to learn. Immigration literature suggests that using the narrative method and collecting stories of immigrants' experiences with both the health care system and the overall migration process, has provided in-depth, rich, and thick descriptions for data analysis (Beiser, 2008; Oberg, 2003).

I chose to focus on the lived experiences of four older adult Ismaili Muslim immigrants and their respective stories about entering Canada and utilizing the Canadian health care system for the first time. I was assisted in the analysis by the three commonplaces of narrative inquiry outlined by Connelly and Clandinin (2006,p.479), including *temporality* (continuity), *sociality* (interaction), and *place* (situation), which all specify dimensions of a narrative inquiry space. These terms can be further understood when considering *continuity* brings together the past, present, and future; *interaction* involves personal and social interaction; and *situation* represents a place or location (Connelly & Clandinin, 2006).

In addition, Clandinin and Connelly (1994) suggest that stories and narrative inquiry have four major directions: *inward, outward, backward* and *forward* that help create a three dimensional narrative inquiry concept. The concept of *inward* refers to internal conditions, such as feelings; *outward* relates to the environment; and *forward* and *backward* represent the past, present, and future (Clandinin & Connelly, 1994). Through the three dimensional narrative inquiry concept, I constructed questions that looked inward and outward relating personal and social issues and addressed temporal issues by observing the past, present, and future (Clandinin & Connelly, 1994). The concept of *place* was addressed by introducing a poem entitled, "Those who left East Africa, feel as if they have left their souls behind" (Kassam, 2005). The poem assisted in situating the participants in the study, both metaphorically and physically to their migration in 1972 from East Africa to Canada.

Narrative inquiry acknowledges that a person not only focuses on his/her own individual experience but also on the social, cultural, and institutional narratives by which their individual experiences are shaped (Clandinin & Connelly, 1994). My storied experiences through the journey of learning about health literacy and settlement through my grandmother's eyes is an example. For

instance, my grandmother's story of entering Canada was not only composed of her own personal circumstances about her struggle in finding a job and getting sick, her hopes that her daughters would have a good education, and her desire to be a good mother and provide for her family, but her feelings were also shaped by social conditions, such as cultural concepts and social status compared to "back home" in East Africa. The concept of the three dimensional narrative inquiry space and the four directions has enabled me to be reflexive and conceptualize my lived experiences along with those of my participants. This was essential to enable my development as a researcher.

Why Narrative Inquiry?

In my narrative beginnings, I imparted stories of my grandparents and their experiences when emigrating to Canada from East Africa. Through reflection, I came to understand and formulate meanings of these experiences and was able to apply them to other people's stories. Thus, I personally understood the significance of relating stories of these lived experiences in my own research. I also believe that there is a strong need for narrative inquiry in immigrant research, especially because the art of communicating stories is one of the main behaviours of our species. Sharing these stories, I suggest, may make others understand and relate to immigrant experiences.

The stories composed in my narrative beginnings helped inform my understanding of who I was in the past, who I am in the present, and who I am becoming in the future (Clandinin & Connelly, 1994). What makes this project even more personal for me is that the 1972 immigration into Canada is also part of my family's history, which has framed my perspective with an entrenched, personal interest and understanding. My family has gone through the experience of not only having to leave their home country of Tanzania when they came to Canada but has also faced the challenges in accessing and navigating through the Canadian health care system upon their arrival in this country. Hearing my grandparents and parents discuss their settlement in Canada has shaped my need to be

more sensitive and empathetic to their situation as well as those of the participants who went through similar hardships. The stories passed on over the years by my family, particularly my grandmother, regarding their process of settlement and integration has led to the topic of this study.

At the end of this project, I hope to be able to assist other immigrant populations by describing the way specific members of the Ismaili population dealt with the health care and settlement challenges when initially arriving in Canada. This information may be useful for other immigrant communities in their struggles, making it easier for new immigrants to settle, and possibly inform future policy development.

How is my Study Narrative?

In-depth, semi-structured, open-ended interviews were selected as the method of choice for the qualitative narrative data collection (Chase, 2005). The interviews allowed the participants to elaborate on their experiences with immigration and the health care system, as well as the barriers and facilitators to their health literacy experiences. The interviews were audio recorded and transcribed verbatim for further narrative data analysis. The semi-structured interview guide can be viewed below (Table 3-1).

Table 3-1

Semi-Structured Interview Guide

Interview Guide

Semi-Structured Questions	Prompts
Context (population)	
- How did the poem make you feel about "back home"? - Describe who you are within the Ismaili Community	- Did you agree or disagree with the author?
- What does the Ismaili community mean to you? - How was your life in East Africa prior to 1972?	- Committees - Leisure time, work, family
- Why did you migrate to Canada? - Did you have any views of Canada at that point? What did they consist of?	
Settlement	
- Tell me about your moving period	- Stress? Children? Family?
- How was your health affected?	
Concept of health literacy	
FIRST HEALTH CARE EXPERIENCE	
- How long after you settled did you require access to the health care system?	- Immediate health problems? - Barriers - Medical instructions - Treatment (behaviours)
HOW DID YOU ACCESS THE HEALTH CARE?	
- Where was your first health care experience?	
- How did you know where to go? - Did the community play a part in this?	- Positive or negative experiences?
- Are there any ways you can think of now that would have been easier to comprehend the health care system? - What aspects did you find confusing, if any?	- Communication - Doctor's instructions - Changing healthy behaviours - Literacy, learning experiences - Did you have access to brochures, other types of information that aided in this process?

Semi-Structured Questions	Prompts
EXPECTATIONS	
- How was your health care back home in East Africa?	- How was the health care system in comparison? - Navigation comparison
- How do your expectations of the Canadian health care system pre-immigration compare to when you settled in?	
HOW TO COMMUNICATE HEALTH LITERACY	
- How do Ismaili Muslims communicate health issues among themselves? Do you believe this to be different in other societies or immigrant groups? - How do you feel health literacy will be most effective to other Ismaili Muslims and immigrant populations?	- Group immigration process, did social support aid in this process? - What alleys of communication? Internet? Brochures? Presentations? Conversations?

Narrative and immigrant literature suggests that the participants should be relaxed and comfortable and interviews should, consequently, take place in familiar surroundings (Beiser, 2008; MItton, 2008). In this study, participants were given the option of being interviewed in their own homes or at the local Ismaili, Muslim community centre that is located in Toronto, Ontario, where all Ismaili social events are held. However, all participants chose to have the interviews conducted at their homes in Toronto, Ontario.

Process of the Study

Entering the Field: Finding my Participants

Due to a perceived lack of trust within the immigrant population, existing immigrant narrative literature suggests that recruiting a small number of participants is appropriate (Beiser, 2008). It is more important to focus on establishing a strong bond of trust between the researcher and a small number of participants (Beiser, 2008; Chase, 2005). Chase (2005) asserts that, when engaging in a

narrative approach, the rigour and quality of data collection and analysis outweigh the number of participants (Chase, 2005).

Four individual participants were selected due to the amount of in-depth information that was collected until saturation during each interview. Focusing on just four participants creates the opportunity to devote an unlimited time period to each in-depth interview. Two men and two women were selected in an attempt to obtain participants with a variety of backgrounds, settlement experiences, interactions with the health care system, and diverse perspectives. The following criteria were used to recruit participants: (i) all individuals had to be English-speaking and of Ismaili, Muslim decent; (ii) informants were subject to the 1972 expulsion or forced to leave from East Africa (either Tanzania or Uganda), after which they relocated to Toronto, Ontario, Canada; (iii) all participants had the required verbal and cognitive capabilities to complete the interviews; and (iv) the individuals ranged from age 70 and over, so that they would have been roughly age 40 upon entering Canada. As adults of about 40 years old when they came to Canada, their memories of the settlement process, including interactions with the health care system, would be classified as 'flashbulb memories,' or memories of a significant and extremely emotional moment or event (Weaver, 1993). Due to the extreme and personal nature of flashbulb memories, it is much easier to recall these experiences during discussion in the interview process (Weaver, 1993). Using these criteria to recruit participants ensured that all participants arrived in Toronto, Canada under similar circumstances with access to similar support systems.

Participants were recruited using purposeful sampling and a homogeneous method, with the help of a gatekeeper. In qualitative immigrant studies, researchers advise that the recruiting process be facilitated with the assistance of gatekeepers, because they are trusted by the participants (Aroian, Katz, & Kulwicki, 2006). The gatekeeper in this case, a minister at the local Ismaili Muslim

Community Centre in Toronto, ON, contacted a sample of ten individuals whom he felt fit the inclusion criteria of the study. The role of ministers within the Ismaili community is significant, because they perform the role of a counsellor, friend, and they also direct and guide individuals in their spiritual and secular lives. Due to the very personal and established nature of the relationship between the minister, as a gatekeeper in this study, and the Ismailis with whom he interacted and has known for a long time, he was able to easily and accurately select participants he felt were appropriate for this study. From the ten individuals referred by the gatekeeper, I selected four participants through purposeful sampling. This decision was based on the availability of the participants for interviews, and the information I felt that the participants could provide in relation to this project. By selecting only four of the ten referred individuals, the gatekeeper was not aware of the exact identity of the research participants, and the confidentiality of the participants was enhanced.

Letters of information were distributed to each of the initial ten individuals by the minister at the local Mosque (see Appendix A). The gatekeeper advised potential participants to contact the primary investigator of this study if they wished to volunteer as a participant. All ten individuals expressed interest in participating in the study and followed up by contacting the researcher. Four participants (two men and two women) were contacted and invited to participate in the interviews and at this time, I answered any questions they had regarding the study. These participants were advised to contact me if they had any further questions or required additional information.

Coming to Know my Participants

At the beginning of the interview, each participant was asked to provide a range of demographic information to gain an understanding of their pre-immigration context in comparison to their lives in Canada at present. The participants were informed that I was of Ismaili Muslim descent as well, to

foster a sense of trust and a level of comfort. All individuals had children, except one female participant who was single and had never married. The participants had a thorough knowledge of the health care system in East Africa and were all devoted members of the Ismaili community who attended the local Mosque on a regular basis, whether it was for prayers or social purposes.

The four participants ranged in age from 70 to 81 years and all had experience with the Canadian health care system early after their arrival in Canada (Table 3-2). At the beginning of each interview, all participants were asked to provide a nickname that was utilized throughout the data collection and analysis, in order to preserve confidentiality. In the following table, relevant details of the participants are listed, including their background and initial health care experiences in Canada.

Table 3-2

Participant Demographic Information

Name	Age	Number of Children	Education Level	Year of Arrival in Canada	First Health Care Experience in Canada
Bhebla	81	3	Univeristy – Teacher's college	1972	Required health care within a month after arriving
Khamru	77	5	High school – businessman	1979	Immediately
Pyarali	70	2	High school – Businessman	1973	Within three months of arrival
Merun	70	0	University – Masters in Nursing	1971	Within three months after her arrival

were aware of the availability of health care, they required help to learn how to navigate Canada's intricate health care system.

Khamru:

Khamru grew up and lived in a city in Tanzania called Mpwapwa, with his wife, four daughters and one son. In the 1960s, Khamru and his family moved to the larger city of Dar-es-Salam. He mentioned that, in 1972 when the nationalizing began in Tanzania, there was political unrest and distrust of the government and its policies. Khamru's business and one house were seized by the government, and he was forced to pay rent on the business he had once owned. Khamru's business began to suffer with the socio-political shifts in the Tanzanian culture, which lead to electrical and water shortages. The quality of education diminished, and people started to flee the country because they were afraid that all their possessions would be confiscated. Khamru watched as, in the neighbouring country of Uganda, citizens who were not native to Africa were given 24 hours to leave the country, so he decided that, for the sake of his children and family, they should leave Africa and move to India. Khamru sold all his belongings and left everything else behind during his transition to India.

Upon moving to India, his son contracted jaundice and required a lot of medical attention. Due to the lack of medical facilities in India, in 1979 Khamru and his family relocated to England, where his brother had resided for many years. Khamru's son and family received the medical treatment necessary, and they settled in England, where his children were educated. However, Khamru and his family decided to move to Canada after his daughter got married and moved to Toronto. He enjoyed visiting his daughter in Toronto, which he seemed to prefer over England because he found Toronto was not as damp and "roomier", with its wide open countryside.

Khamru was also pleased that he had the opportunity to live in Canada, although with his family's multiple migration experiences, he became ill and required the use of the medical system almost

immediately upon his arrival. While adapting to the new climate and barriers, Khamru and his family faced difficulties in adjusting and finding work. Natural challenges like climate, language, and employment were compounded when Khamru encountered health problems that he had not experienced in Africa and India. Because he was not familiar with which health institution to attend and had questions regarding the Canadian health care system, Khamru turned to the Ismaili community for assistance.

Pyarali:

Pyarali lived in the capital city of Dar-es-Salam in Tanzania, East Africa with his wife, daughter, and son. He owned a business and was, therefore, affected when the government, headed by President Julius Nyerere, began nationalizing people's possessions in the early 1970s. During the nationalizing process, both of Pyarali's business and his home were taken away from him. He felt he could not adequately provide for his family and that the safety and security of his family was jeopardized. Pyarali was worried about his children and asked his brother and sister-in-law to sponsor him and his family so that they could immigrate and settle in Canada.

Pyarali and his family were sponsored a year later, and his whole family relocated to Toronto, Canada with the bare essentials they were permitted to bring with them. Pyarali and his wife were forced to fly back to Dar-es-Salam periodically to tie up some loose ends, because they had left the country as soon as they had received their sponsorship papers. This "uprooting" of the family was difficult, especially for Pyarali and his wife, because they had to start from scratch in a new country with just enough clothing and money to get by until they found employment. However, Pyarali and his family consider themselves very lucky and are exceedingly grateful for the opportunity to live in Canada and the fact that they were afforded a fresh start.

Within the first few months of their arrival, Pyarali and his family experienced several health challenges during their settlement process. The entire family encountered respiratory problems and ended up with asthma due to pollution. They also began to suffer through regular colds and allergies every time the weather changed. Arriving from a tropical environment, where the temperature did not go below 15°C, to a country where temperatures can range from -40°C to 35°C within a matter of six months was a difficult adjustment for Pyarali and his family.

Merun:

Merun lived in Dar-es-Salam, Tanzania, in East Africa with her brother, sister-in-law, and their family. Merun had completed her post-secondary education and was working when the process of nationalizing by President Julius Nyerere began in the early 1970s. Her brother and his family decided to move to Toronto, Canada for the safety and well-being of his family and because of the decline in education standards, which negatively affected his children. Because Merun did not have any family other than her brother, he sponsored her so that she could join them in Canada. Merun was single at the time and did not have any children. Her decision to relocate was based solely on her desire to be geographically close to her remaining family. Merun only brought necessities with her. Merun was thankful for the opportunity to live in Canada, but she had some difficulties adapting to the weather, food, and to the different culture overall. Merun required access to the medical system within the first three months after migrating to Canada. When she attempted to use it, she encountered several challenges, such as trying to distinguish which health institutions to consult, what were the limitations and requirements of OHIP coverage, and grasping the process of how to confer with medical specialists.

Kinds of field texts

I came to recognize and appreciate my roots through reflecting my own and my family's personal experiences. With this personal drive, I was able to understand thoroughly and identify with each of the participant's narratives with the assistance of various field texts. I utilized three types of field texts throughout this research process, including the audiotapes/transcripts, a personal reflexive journal, and a poem entitled, "Those who left East Africa, feel as if they have left their soul behind" (Kassam, 2005).

First, the audiotapes and transcripts provided a record of the, "informal nature of the conversational space [that encouraged] the participants to reflect upon their previous experiences and share these more comfortably as opposed to the formality of an interview conversation bounded by specific questions" (Mitton, 2008, p.23). I analyzed, interpreted, and understood their stories and the unspoken emotions of the participants' experience by listening to their voices, silences, pauses, and making notes about their facial expressions and body movements whilst being empathetic through their painful emotional journey.

Second, concurrent with the data collection, a personal reflexive journal was used to record personal thoughts and experiences relating to the research process. This provided me with what Chase (2005) calls a narrative voice and allowed me to elaborate the details of the narrator-listener relationship by explaining and communicating all aspects that were not mentioned in the interview. Situations such as meeting the participants for the first time, discussions that were encountered either before or after the interview, or interpretations of body language were included in the personal reflexive journal. Because I had personal ties with and insights into the Ismaili community, the committees, social support, social networks, and cultural concepts, were easier to explain and discuss.

Lastly, introducing the poem entitled, "Those who left East Africa, feel as if they have left their soul behind" (Kassam, 2005), at the start of each interview became a source of rich, personal information. Initially, the poem was not intended to be a field text; it was simply intended to facilitate discussion of "back home" and the participants' pre-immigration experiences. However, it became a reflection of the participants' sense of longing. I asked my participants to share their feelings after they had read the poem about East Africa, and it triggered memories of important events, special moments, feelings, and their relationship with people, before I asked about their experiences of settlement or learning about the health care system. The poem brought forth discussions ranging from sand, family, food, beaches, to the smells of East Africa.

Those who left East Africa, feel as if they have left their soul behind

I left Dar-es-Salaam, island of raha (happiness),
To emigrate to Canada, land of opportunity.

Forsook the tropical sun
For cold frigid weather.

Left behind the warm ocean breeze
For the windchill of winter.

Abandoned white pristine beaches
For brown muddy shores.

Turned away from a turquoise ocean
For polluted lakes.

Gave up mangoes, papaya, mabuyu, achari and sunflower
For processed apples, pears, peaches and cherries.

Gave up white snapper and king fish
For boxed cod and sole.

Gave up mishkaki, nyama choma maambri and bharazi

For cereal, bagels, cheese, and salads

Gave up drinking coconut water straight from the coconut

And settled for bottled water.

Left behind the street coffee seller (Kahava)

For the office coffee pot.

Left behind the exotic fragrance of phapa and langi langi

For the pungent smell of sulfuric emissions.

Deprived of hearing the call to prayer

For the sound of police and fire sirens.

Deprived of seeing women clad in mysterious black buibui

For women dressed in jeans and miniskirts.

Deserted a slow relaxed pace of life

For the fast lane.

Gave up afternoon naps

For gym workouts.

Gave up riding a bicycle through the narrow streets

For driving a car on the highways.

Discontinued a course on the coral marine life

For a course in stress management.

Discarded mud and thatched dwellings

For concrete and steel.

Left behind a community-based life

For a human zoo.

It makes me wonder

If I have also left my soul behind in Dar-es-Salaam.

(Kassam, 2005)

Because the poem was so influential in interviews, it deepened my understanding of my participants emotions and experiences. Thus, I came to consider it a field text because it led to further insight into my research project.

From field texts to research texts

The analysis consisted of three steps: constructing chronological narratives, analysis of each narrative, and the cross-narrative analysis. While completing each step of analysis, I concurrently listened to the audio recordings and read the transcripts to ensure focus on the stories. In addition, I was conscious of each story in terms of the *three dimensional narrative inquiry space*, taking into consideration the *temporality, sociality,* and *place.*

Initially, I constructed chronological narratives where I organized the stories presented in the interview according to a timeline. This exercise assisted in creating a comparison between the experiences "back home" in East Africa and in Canada. This strategy helped me reflect on the participants' stories narratively, as I kept in mind the association with the three dimensional narrative inquiry space (Clandinin & Connelly, 1994), particularly temporality.

I then composed an analysis of each narrative by reflecting on the chronological narratives and the thoughts the participants were conveying in terms of the 'narrative coherence' (Chase, 2005). I also considered the three dimensional narrative inquiry space by thinking in a narrative fashion throughout the interviews, particularly issues of sociality and place. I explored my participants' lived stories and experiences individually, which offered a greater personal understanding about each of them. Through the progression of the interviews, I learned that narrative inquiry opened the path for me to attain respect, love, and a greater understanding of the mutual and common roots between

me, as a researcher, and the participants who shared their lives through stories (Clandinin & Connelly, 1994).

Finally, in light of Bateson's (2000) citation, "wisdom is born of the overlapping of lives, the resonance between stories" (p.243), I was able to complete a cross-narrative analysis by reflecting on all the stories as a whole. To realize the key considerations, I studied these narrative accounts and extracted what I perceived to be overlapping themes related to my research puzzle.

Throughout the entire process of forming research texts from field texts, I reflected on my reflexive journal and my personal experiences, because my place within the community provided me with unique insights into the stories of my participants. I was able to relate my family's stories with those of my participants, which allowed me to better understand how I was a participant in my own study. My reflexive journal assisted in clarifying what my experiences meant to me, and I formed a bond with my participants. In addition, always being conscious of the three dimensional narrative inquiry space made me aware of the overlapping findings in relation to my own family's stories.

Quality criteria

In accordance with best practice methods, the interviews in this study were complimented by three forms of field texts, which gave the data confirmability and credibility. The quality criteria for narrative studies created by Whittemore, Chase, and Mandle (2001) were applied and the creativity of the study was preserved. The primary and secondary criteria ensured detail and balance between creativity and rigour. Utilizing these considerations greatly improved the research study. Please refer to Table 3-3.

Table 3-3

Quality Control - Considerations For a Narrative Study (Whittemore et al.,2001)

Quality control techniques	How quality was maintained in the study
Primary Criteria	
Credibility and authenticity	• Stories of the participants reflected the meaning and experiences that were lived and perceived by the participants because the data provided came directly reflect the experiences of the participants. This gave the data both credibility and authenticity.
Criticality and Integrity	• Both aspects were important in reflection and reflexivity – a personal reflexive journal was maintained to allow and acknowledge my personal/family involvement in the study (integrity) while allowing me to critique my potential over-involvement (criticality) • Interpretations were trustworthy because participants varied in background and were hand-chosen by the gatekeeper from the community • Standard research procedures were incorporated and integrated • Researcher's position was discussed during the interviews and in the thesis • Peer debriefing was completed with my advisory committee members as well as my supervisor who were all removed from the research process. Following each step of the analysis, we all met and discussed my assumptions, possible interpretations, how my own subjective experience was affecting the analysis. The group had critical and sustained discussion of findings at each stage to ensure consistency throughout the analysis
Secondary Criteria	
Explicitness and creativity	• Presentation of data was completed verbatim from the stories related by the participants, therefore, there was explicit presentation of results • A poem was used to evoke emotions about East Africa, which brought back "flashbulb" memories (Weaver, 1993) of all aspects of their lives "back home". This also addressed vividness, below.
Vividness and thoroughness	• Thick and faithful descriptions, imagination, and clarity were displayed through the utilization of the

	poem, which provided the features of the emerging themes • Each narrative was analyzed and organized chronologically first, with each participant's themes and categories woven through their stories including direct supporting quotations from participants to substantiate themes • Data came from the stories of the participants themselves • Saturation was attained for all participants because all aspects were elaborated on thoroughly by the end of the interview. All participants felt they had adequately related their story
Congruence and sensitivity	• Methodological congruency was achieved through the research question, the method, the findings, and between the data collection and analysis and they all aimed for a similar goal • Logical congruency was achieved through discussing the methodological processes with the advisory committee • Sensitivity was accomplished by allowing the voices of the participants to be heard through audio recordings. I also attempted to stay true to their thoughts by reviewing all interpretations of the themes with the advisory committee.

Ethical considerations

In this study, the appropriate ethical research standards involving humans, detailed in the Tri-Council Policy Statement (CIHR, NSERC & SSHRC, 2004), were addressed. Ethical approval was received from the Non-Medical Research Ethics Board at the University of Western Ontario on December 3, 2009. There were no known physical risks to the participants from the study.

Immigrant literature suggests that being sensitive and empathetic builds a sense of trust, commitment, and respect with participants (Beiser, 2008). As a researcher, I believed that it was not my place to judge my participants but to engage in conversation to understand connotation in the meaning of their stories. Although there were no known physical risks to the participants from this

study, preparations with support services were made with a counsellor who spoke English, Gujrati, and Kutchi, because there was the possibility the research study could evoke painful memories and emotions among the participants. The participants would be able to speak to a trained professional if they felt uncomfortable, uncertain, or emotional when discussing their settlement and health care experiences with the Canadian health care system. Furthermore, participants were able to stop and leave the interview at any time, with no consequence to themselves. In addition, I created a safe space for the participants to fully engage in conversation by having the interview take place in a location where the participant felt comfortable.

Confidentiality was further maintained because I chose my four participants from the ten potential candidates selected by the gatekeeper. The gatekeeper thus was unaware of the four final participants, and further, even if he were to deduce the identity of specific participants from their stories, the role as lay minister carries an obligation for confidentiality that he would not violate. In addition, throughout the data collection, analysis process, audio recordings, and transcribed documents, pseudonyms chosen by the participants, maintained discretion. The master list of was kept separate from the coded electronic and hard copy versions and was stored in the office of the researcher through a password protected computer electronic file, which was only accessible to the researcher and members of the thesis advisory committee.

CHAPTER FOUR

Narrative Accounts of the Adventures of Settling in Canada

Before migrating to Canada, Bhebla, Khamru, Pyarali, and Merun fled political unrest in their homes in East Africa. The President at the time was in the process of revolutionizing Tanzania and his reign was characterized by an abuse of power, political repression, ethnic persecution, nepotism, corruption, and gross economic mismanagement (Ullman, 1978). He was in the process of nationalizing homes and businesses, a concept commonly referred to in the interviews as the act of changing the ownership of personal property in favour of the government. As a result, families now had to pay rent to the government for businesses and houses they once owned. During this course of action, many British citizens who had lived in the country, especially teachers, began to leave, and as a result, the quality of education also deteriorated. All four participants chose to settle in Toronto, Canada for safety. They encountered several barriers such as health care, housing, employment, and finances. Their settlement challenges and triumphs will be examined in each of the participants' narrative stories, including their encounters with the Canadian health care system.

Utilizing a narrative interpretive and descriptive analysis, all narrative accounts will be examined using Connelly and Clandinin's (1994, 2006) components of narrative inquiry, including *temporality* (continuity), *sociality* (interaction), and *place* (situation), and keeping the four directions in mind: *inward, outward, backward, and forward.* With corresponding analysis, discussion on topics such as settlement, confusion with the health care system, the Ismaili community, and barriers and facilitators to the concept of health literacy will be presented. Within the analysis, portions of my personal reflexive journal, as well as the participants'

thoughts regarding the poem entitled, "Those who left East Africa, feel as if they have left their souls behind" (author unknown), will be discussed.

Narrative Account 1: Bhebla's Stories to Live By

Bhebla's Journey to Canada

I met Bhebla at her house for the interview and rang her doorbell at 10 a.m. on a Sunday morning. I saw a small frail lady with a warm smile opening the door as she introduced herself. Bhebla was very welcoming and immediately asked if I was thirsty or hungry and offered me food and a drink. The Ismaili community in general, places a great emphasis on food, and it is an insult to refuse, so I asked for a glass of water and ate some homemade tumbua ndizi, a traditional East African bread made from plantains, coconut milk, cardamom, and flour.

Bhebla was eager to talk about "back home" and had pictures in her house of her family and life back in East Africa, as well as current pictures of her grandchildren and friends. I noticed one picture, in particular of, Bhebla and her husband standing with their children beside an elephant in an endless field. It was almost as if their life in East Africa was surreal, with the natural beauty of the backdrop, and the first thought I had was, "how could anything go wrong in such a beautiful place?"

When I remarked about the exotic picture, which one could only dream about, Bhebla began discussing her family. She was very proud of her daughters and could not wait to tell me about their successes and her six grandchildren. She offered to share some pictures so that I could use them for my research, which I gladly accepted. According to the Lay Minister at the Mosque, or the Gatekeeper, I would not have any problems interviewing Bhebla for my research project, because she was very friendly, smart, and well-spoken, and these attributes were confirmed when I met her.

When we began our interview and discussed the poem, Bhebla opened up about her past experiences and her upbringing in Tanzania. Bhebla lived in Dar-es-Salam, Tanzania, in East Africa with her husband and three children, and her extended family all resided nearby. Bhebla loved "back home" and laughed constantly as she read the poem, thinking about the exotic and fresh food, aromas of the food and exotic flowers, and the general lifestyle of Dar-es-Salam. She elaborated on how the poem made her feel, how it brought back her memories of East Africa. She touched her arms when speaking about the warmth of the sun. When we discussed how you can purchase coconut water in juice boxes in Canada, it made Bhebla laugh, because she was used to getting fresh coconut from a tree, and she could not believe how drastically different her life was now in comparison. She also explained how they were used to eating everything fresh, whether it was fruits or any kind of meat. To make me understand better about the impact on the taste of these foods, which could not be replicated in Canada, she stated,

We also had a lot of exotic fruits that we used to enjoy that we do not get over here, and the ones we do get over here are generally not fresh, or generally the sweetness or the juiciness of the fruits are not as similar to what we enjoyed back in Africa.

Everything from chicken to fish, it was all fresh. If you wanted to have or enjoy a chicken, basically somebody would pass by our house and the locals there would sell it that way, and we would ask them that we wanted. We would pick and choose a chicken and then we would have help. They would cut up the chicken. So when we ate it, it was fresh, it was actually a live chicken that we would get cut up and we would get fresh. In the same way, fish would be like somebody actually went fishing that morning and then afternoon, you would be buying fresh fish and making fresh curries, or you know, stews you know. So it was

everything you ate that was fresh, that we weren't used to when we first came to Canada. Chicken that we ate was from a supermarket, and we couldn't get used to the taste because it felt like we were eating plastic or rubber, because the taste just was not there.

Bhebla brought up the word "fresh" several times throughout the interview, insisting that the products shipped over to the supermarkets here were not the same, did not taste the same, simply looked the same. She mentioned that even foods made with the same products did not taste the same. The taste of fresh and home-cooked food was just not there. I sensed that Bhebla associated the taste of foods in Tanzania, to her memories, which could never be replaced. Although Bhebla spoke about the transition being easier than expected, the way in which she described the simple changes in her Canadian lifestyle suggested that the settlement was difficult. The atmosphere and surroundings of Canada were significantly different than Dar-es-Salam.

Initially, I could not understand how the smells and textures of food could make the settlement process in a new country difficult, because to someone like me who has grown up in Canada, the food is the same: chicken, fish, and fruits. However, when I heard Bhebla's descriptions, I felt that I had not tasted "real" chicken or fruit before. It reminded me of my first trip to the Caribbean when I tasted a banana. The sweetness and the fresh taste of that banana made me feel as if I had never had a banana before, and I understood what Bhebla was talking about, and I almost felt cheated by not having experienced those flavours. I remembered that when I returned from my trip to the Caribbean, I did not eat bananas for quite some time, because I felt the difference in the taste of "real" bananas and that I was simply missing out. When contemplating this experience, I realized that Bhebla had undergone this process with her entire diet and that this transition must have been difficult.

While discussing the drastic change in her surrounding and its effects on her personally, Bhebla reflected on the incomparable difference in the fragrance of a rose grown naturally in Tanzania to a nursery raised one in Canada. She mentioned that there was no comparison to the natural surroundings “back home”, and I could see that Bhebla had left her heart in Africa. She described,

Over here, the first time I got a rose from somebody, that rose had no fragrance. And I could not believe that I had a rose in my hand that had no fragrance, because every rose that grew over there had a fragrance to it, so, like these were the things that were very very, uhh different for us. We couldn’t get used to it.

When discussing the level of respect towards others in Africa compared to Canada, there was hesitation in her voice. She had a harder time explaining to me what respect meant “back home”. Respect was a quality that was exuded through the individual – the manner in which people spoke to you, the clothes people wore, and the way family was treated. I felt that Bhebla sensed that, in Canada, the level of respect was somewhat different. She implied that respect towards family, through these actions, was not there, and this had an impact on her. She elaborated,

Culture shock and it was very difficult for us to get used to that. Over there, as well, there was a lot of...there was that level of respect where people, it mentions over here that, buibui. Buibui is that the attire that the Muslim women wear. They are covered from head to toe, but not everybody did that of course. You know, there were other people that wore their own clothing but, everything was based on respect. Like you didn’t find people going beyond that respect because, if you wore something that was not appropriate, you were not only insulting somebody who was watching you, but you were insulting yourself, because you

were not dressing appropriately. How can that person look at you and talk to you and or look in your eye and talk to you normally if you are not dressed appropriately. So that was the level of respect as well, was difficult to get used to.

The poem raised other memories in Bhebla's lifestyle and daily routine in East Africa and brought forth comparisons about the pace of life and the concept of time, to which she needed to adapt. The pace of life in East Africa was brought up numerous times, and each time it was illustrated with hand movements like soft waves. Bhebla's life in Africa was generally at a much slower pace, and this also brought smiles to Bhebla's face. The topic of pace of life also brought up a recurring theme related to her family, about having the time to relax, as well as to enjoy each day to the extreme. She smiled continuously when speaking about how their water even tasted sweeter, and that bottled water was a phenomenon that she learned about in Canada. Bhebla explained,

> *The pace of life, of course, was extremely slow. You came home for lunch. You went in the morning, whether you were working or you went to school, you left after your breakfast, you went to work or went to school and then lunch time, you actually came home. The distances were not that far, even though we lived in a city, the distances were not that far. Everyone would come home, have supper, have an hour's rest, and then went back to school or back to work and then the afternoon life resumed. You were home by, you know, 4 o'clock, and your evening life started and you would have your supper, go for walks, you would, you would have the whole evening to yourself. Over here, people are more concerned about going to the gym and working out and you know and taking good care of themselves, but to them it is not, you cannot compare a gym life to taking a walk at the beach or fresh air. You know, water for instance, the tap water,*

we didn't even know there was such a thing as bottled water. Everything came out of the tap, everything was you know...the water even tasted sweet. You know, and we found that over here again, you have to get used to drinking the water...So things were very very different. We found getting used to that kind of a lifestyle extremely difficult.

Overall, I feel that when researching the topic of health literacy within the immigrant population, most research studies fail to mention the effects of settlement on the individual and the process of adjustment to their new host-country, or rather the effects of changes in place and the major directions in the life of an individual. When discussing Bhebla's memories regarding her home of East Africa in relation to settling in Canada, it appears to be a difficult adjustment to the environment, food, and even smells.

When discussing Bhebla's settlement in Canada, she explained the political turmoil that arose with Tanzanian President Julius Nyerere around 1972, and that it was unsafe for Bhebla's children to remain in East Africa because there was a risk to their safety and well-being. Julius Nyerere, like Ugandan President Idi Amin, was favouring people who were born in East Africa to stay, all those who had emigrated a few generations prior, such as Bhebla's family, were living in danger and fear of being uprooted. Bhebla and her husband made the decision to migrate to Toronto, Canada when they had learned that all faiths and nationalities were accepted and they could practice their faith without any restriction. They knew that Canada would be a safe place for their children to grow up and establish a life without concern for their safety.

Bhebla and her family left everything behind and migrated to Canada with bare essentials to ensure a better life for them all. When discussing how the government nationalized their properties in Africa and their decision to migrate to Canada, Bhebla became sad as she described her main apprehensions for her family,

Our main concern was, at the time, since I come from an area where the Africans got their independence and they started nationalizing all our things. So basically, if I owned two homes, one was nationalized by the government, they took it away from us. If I owned two cars, they took away one of my cars, if I had more than one business, I was allowed to keep one business but they would take away my second business, and education for my children became very difficult because a lot of the community, the Asian community, the European community, the British community that were settled there, started leaving the country because of all these uncertainties and then...when they started leaving, the education level and everything dropped because the teachers were not there anymore. The schools were being run by staff that were not properly trained, and so I thought my kids would suffer as far as their education was concerned which why, that was our key thing. We didn't want the education of my three children to suffer and they were at that school age, which is why we decided to migrate to Canada.

Settlement becomes a more complicated concept within the immigrant population when it is connected to the search of employment, housing, and financial security. Immigration authors such as Jahan (2000) and Beiser (2008) note that the immigrant population is distinctive and vulnerable with their varying needs. Although Bhebla felt thankful for having the opportunity to live in Canada, there were difficulties adjusting, getting settled, and finding work after immigrating. Bhebla described her transition period as being "horribly traumatic". She discussed,

Basically, the first few years were horribly traumatic because we came to a life of great difficulties. We could not find jobs right away. I was a teacher back in Africa and over here when I came and we had to work, we could not live on the money we had brought with us. I

had to work in a factory where I had to sew the bags, I had to sew the bags, comforters, duvets, and what I didn't realize is that when I started working there, I had a lot of allergies. I suffered a great deal as far as health is concerned, and I couldn't understand why I was constantly sick. But that is what made me constantly sick, because I was really allergic to all these things that I was sewing and whatever they were using in the comforters and the bags and whatnot they made us sew.

Bhebla's experiences with finding a job were similar to those discussed in the literature. Originally in Tanzania, Bhebla was a teacher, but in Canada, she found a job at a factory. Beiser (2008) discussed ineffective government policies and language barriers that impede the communication between immigrants and their future employers. Taking any available job to provide for her family could have induced a large amount of stress and could have led to Bhebla becoming ill.

Bhebla described her job at the factory as being "very regimented", a way of life with which she was unfamiliar. She was unable to go home for lunches due to distances and time restraints. This adjustment to a different work culture was another difficult aspect as Bhebla attempted to integrate herself into the Canadian culture. Bhebla elaborated that,

The life in the factory was very regimented so that I wasn't used to. We had an easier life back in Africa, so to come to a 9 to 5 job where we had to work away constantly with a small break in the morning and a small break in the afternoon – your lunch hour, you were constantly at it at the sewing machine.

In Tanzania, Bhebla was able to go home during her lunch break, where she spent time with her family. Most people in Tanzania had a "siesta" time during which everyone was able to go

home, relax, spend time with family, and have lunch, and then return to work. The Canadian work schedule was difficult for Bhebla, because she was not only unable to see her family, but did not have a sufficient break to relax, resulting in stressful workdays.

Bhebla was exposed to unfamiliar ailments, allergies, and a change in pace of life at work, and she sounded distressed when discussing her feelings and experiences. Derose et al. (2007) discussed that psychological and emotional needs arise for immigrants in terms of their settlement experiences and found that factors such as social support and guidance play a large role in addressing these needs. At this point in Bhebla's story, she recounted how her support from the Ismaili community played a vital role in all the adaptations that her family was forced to make. The literature explains in great detail the importance of cultural capital when entering a new host-country for new immigrant families (Beiser, 2008; Fetter, 2009; Jahan, 2000), where their inner emotions are greatly affected by their environment (Connelly & Clandinin, 1994).

Bhebla's Experiences within the Ismaili Community

When discussing the importance of being an Ismaili, the look on Bhebla's face spoke volumes about the happiness and joy she felt. She sat up straight and her body language indicated that she prides herself regarding her community, and has no hesitation in seeking assistance from them or any of the committees within the community with her questions and concerns. Bhebla described the importance of being part of the Ismaili community as,

> *...it gives me that culture that I get and can actually associate with. I can turn to anyone in the community for assistance, I have that support system, if I needed help, if I needed information, if I needed to get advice, I can turn to members of the community or we have*

various committees within the community who help in any area you can think of, if I need any information or help.

To Bhebla, the Ismaili community and mosque was not only a place of faith and a bond she had with members of the community, but it also provided her with a social community, where she was able to participate in social events and discuss questions or concerns. Bhebla explained that,

Ok, for instance, in the seniors, we have a seniors' committee where they organize entertainment for us so that every now and then we might have a concert and get together and we chat and exchange ideas where we talk to people. We eat together or they may take us on a tour of a place...but they also, on the other hand, talk to us about health related things. They will talk to us about how important it is to eat right. If I am a diabetic, what are the symptoms I should be watching for, what I should be doing, and I am a diabetic. So basically, I need to make sure that I attend to all those events because it is very helpful for me.

Immigration literature suggests that having a support system to go to when there are questions relating to the health care system is a necessity for successful integration (Beiser, 2008). When arriving to Canada, Bhebla's husband required immediate medical attention and could not provide for the family. It became necessary for Bhebla and her family to access the Canadian health care system for the first time, and having the Ismaili community available for support and guidance was essential for problems being dealt with in a timely manner. Bhebla described this experience as,

...my husband, upon coming to Canada, within a few months, his elbows and his area in the shoulder – both shoulders and both elbows started affecting him and he was in a great deal of pain constantly. We talked to people in the community, the committees, and they suggested that we go visit a local health care centre and they advised us where we could find this place. Fortunately, the health care centre in our area was not too far and so we would go visit there and within a very short period of time, the doctors there suggested that my husband had to undergo surgery. So he went through a surgery in his two elbows and his two shoulder areas immediately after we came to Canada. So right away we ended up having to use the health care system.

Though Bhebla and her family knew health care was available, there was extreme confusion regarding which health care institution to attend, and from whom they should seek assistance in order to learn how to navigate Canada's intricate health care system. In addition, with the differing structures of the health care system from East Africa and Canada, Bhebla explained that the information she received from the community, clarified several of her questions. In Tanzania, one large hospital serviced the entire city; it was therefore, confusing for Bhebla and her family to be introduced to several tiers of health care. This is where the Ismaili health committees played a large role in assisting Bhebla and her family with their health care issues.

Similar to immigration research that discusses the importance of social support in integration (Beiser, 2008; Fetter, 2009), Bhebla relied heavily on her community to advise her regarding all facets of Canadian life. Bhebla's story reflects immigrant literature that states that government policies and regulations do not assist with the health of immigrants after their arrival in Canada (Beiser, 2008; Fetter, 2009; Rootman, 2006). Bhebla explained that the

community guided her to resources and health care professionals and helped in accessing the various tiers of the health care systems.

When questioned about the health care system, Bhebla discussed the importance of being able to trust the health care professional she was visiting. Bhebla also explained the importance of discussing health issues with the Ismaili community. For example, Bhebla explained that, for her diabetes, the Ismaili community thought she should see an Ismaili dietician, because seeing someone from her own community who can speak her language makes the health advice "work better". She discussed that because "they can understand where I'm [Bhebla] coming from and the kinds of foods I eat, and it helps tremendously when they understand I eat a certain kind of food that the normal Canadians don't eat, and perhaps I'm not supposed to be eating". This way, the Ismaili dietician can recommend an alternative that Bhebla knows she can have and that is congruent with her cultural eating habits.

The idea of having a health care professional of the same culture was suggested frequently in the literature review as a potential intervention to increase health literacy by fostering trust with the immigrant population. Rootman and Gordon-El-Bihbety (2008) thought that having culturally competent and sensitive practitioners would allow immigrants to visit a health professional within their community, where they would feel a sense of comfort and trust. This would allow the health advice and treatment options to be better received and assist in future visits (Rootman & Gordon-El-Bihbety, 2008). I gathered the opinions of Bhebla and the Ismaili community, and it was explained that referring to health professionals within the Ismaili culture was a normal practice. The suggestion to seek out health professionals of similar cultural roots would be of use to other cultures if this information was available publicly, so that all

communities could access a database of health professionals and their background or language options (Beiser, 2008; Fetter, 2009).

Word-of-Mouth and the Ismaili Community

Throughout the interview, Bhebla mentioned the fact that all health advice within the Ismaili community occurred through word-of-mouth. For example, health information regarding the H1N1 pandemic was explained to the Ismaili community through health seminars held after religious ceremonies. Bhebla stated that the health committee was, “constantly advising people to go for vaccinations and to make sure we look after ourselves”. Because there was differing information from the media, a team of Ismaili doctors and nurses gathered information from government sources and informed the community of their opinions pertaining to the health care crisis.

Bhebla maintains that the Ismaili community is very tight knit and that health care issues, as well as other concerns, are discussed through seminars,

> *In the Ismaili community, I think because we are very close as a community, even though there are websites and there are, for instance, the telehealth I know about, where you can phone and all that and this is once again the information that is given to us by the health committee members for the seniors...generally right after they make announcements to let us know what is happening and that everyone should be aware and there’s more information from the health people like doctors and nurses within the community. Generally, they are there to help and assist us.*

When asked by what mode of information she preferred learning about the health care system, Bhebla mentioned that she thought the health seminars and word-of-mouth learning

techniques were effective, because other ways of communication, such as the newspaper, "are not very clear". Bhebla felt that going to the members of her community, especially when the health learning sessions are held, was better. "Information within the community...makes us understand a little better about it in our language and they go into a little more depth about it, I can actually relate to it and understand the impact of H1N1 for instance". Bhebla concluded her explanation by elaborating that learning these concepts in her own language is an important issue for her, because then she feels confident when acting out her health-seeking behaviours.

When Bhebla arrived in Canada, she wanted to provide safety for her family, and learning to access the health care system was an important facet of reaching her goal. The Ismaili community provided her with answers to her questions and assisted in her transition and settlement to a new country. Bhebla stressed the importance of seeing professionals of a similar culture within her health care experience, whereby a sense of trust is fostered prior to the appointment. Instead of deciphering brochures, Bhebla grasped information by attending health seminars or through word-of-mouth and learning from the stories of others members of the community, which is a novel concept in health literacy that has not been examined.

Ways of learning in immigrant populations were not discussed in the health literacy literature. However, the concept of how the general population associates their health-seeking behaviours with their overall health was discussed with the Health-Learning Capacity Model (Wolf et al., 2009) as well as in Jahan's (2000) community-based educational outreach intervention. In the Health-Learning Capacity Model, one's past behaviours and present learning abilities affect future actions regarding health (Wolf et al., 2009). Theories aside, the literature does not mention modern pathways of learning, because there have not been any qualitative studies that explore application of the theories about health care and health literacy.

Community-based educational outreach may assist in implementing community-based strategies towards specific problems (Jahan, 2000). If researched in a longitudinal fashion, community-based educational outreach could prove a useful method of educating immigrant communities regarding health, finances, and housing (Jahan, 2000).

After the interview, Bhebla thanked me and invited me for lunch. She also enquired about my family and where in Africa they were raised. Bhebla's commitment and love for her family was evident throughout the interview, and learning about Bhebla's experiences provided a perspective on health literacy that the literature has yet to provide.

Narrative Account 2: Khamru's Stories to Live By

Khamru: The World Traveler

When I met Khamru, he greeted me with a hug and invited me into his home, where he lived with his daughter and son-in-law. I noticed his apprehension immediately, because he was slightly hesitant to start the interview, and I could tell he did not know what to expect. Khamru ended up asking me quite a few questions about my research before the interview began, which I was happy to address.

Khamru asked me detailed questions about my parents, and in what part of Africa they had lived. This conversation generally takes place when Ismailis meet, because most of them have a theory: they all have someone in common whom they know, and this was definitely the case, because my parents and his children went to the same school in Tanzania. After enjoying some laughs, it appeared to put Khamru at ease, which is when I began the interview.

I began to read the poem aloud, and I could see Khamru smiling and laughing at the details described as he started to reminiscing about his past, his life in Africa, and his family. He explained that the author had captured his emotions about his lifestyle "back home". However, instead of concentrating on the positive aspects of the poem, Khamru began explaining some of the negative aspects of life in East Africa that the author failed to mention, such as the dirt roads. Moreover, Khamru explained electricity in homes and business was inconsistent and affected business, in particular, negatively.

> *I had a business over there, and I lived in a small town which is Mpwapwa, which is about four hours from the main city which was Dar-es-Salam, which is the capital of Tanzania. Because of the store, I had to travel once or twice in a month to go over and*

pick up goods that I needed to sell back again in my store. That meant leaving my kids and my wife alone at home and going and doing that, and the roads over there were not like they are over here, paved. They were muddy, especially when it was raining. The truck would get stuck and there's no CAA over there, so you need to get someone who passes by to help you get it out or you need a jeep where you were going. So, that's the difference there.

Khamru also mentioned the hardships everyone encountered when the government of Tanzania began nationalizing people's assets and how it affected his business personally. It became difficult for him to provide for his family, because all his profits went towards rent to the government for a property that he had owned. He explained,

Well, after all these years, working hard and actually had a building which we owned and we were renting it out and it was taken over by the government and we didn't have a penny that came back to us or anything.

Very different until things started to go crazy after 1972. This is when we decided that the education standards were falling, people were leaving because they were afraid that because the houses were nationalized and the businesses were nationalized, everything would be taken away. In Uganda, people were given 24 hours to leave the country with just the clothes they were wearing and nothing else. So we left, we went to India, thinking that we would settle there, since our ancestors came from there, but unfortunately, after living there for six months, my son became very ill, he had jaundice and because of that, I decided to go to London, England because I had my brother who had been in London, England since 1960 and one of my daughters was already in London.

There was sadness in Khamru's voice when he described having to leave everything behind and move to India, and then to London, England to ensure the health and safety of his son. His decision to leave Africa and India was based solely on providing the best option for his family, putting the needs of his family above his own.

After describing the painful memories, Khamru began to shift his discussion to the aspects of life in East Africa that he missed the most. Like Bhebla, Khamru talked about the taste of exotic fruits and the fact that they are not as fresh here as they were back home as well as going from hot weather to the seasonal changes in weather. During the process of settling in Canada, Khamru found adjusting to the temperature one of the most difficult aspects of the transition, which was emphasized through the way he stressed these experiences with his tone of voice. He mentioned that the seasons in Canada also provided a sense of change that he had never previously experienced,

> *But things are a little different over here, the weather is different. You have to dress accordingly and you cannot go out every day as you know with the freezing rain or snow it is difficult.*

Although several facets of integration were discussed in immigrant literature, Khamru raised a subject that has not been mentioned in the research: the change in weather is not only difficult to accept in itself, but it also affects social life, routine, and leisure time. Khamru's apprehension about not being able to leave his house every day due to the weather changes also affected his choices regarding his friends and social activities. The winter made Khamru apprehensive about going and driving to Jamat Khana, which limited his social options. Immigrant literature on settlement processes, such as Beiser (2008), Fetter (2009), and Jahan (2000), usually discuss government policies but do not address all aspects of immigrant

livelihood affected by change. Every immigrant is affected by adjustments in a different fashion, and it might be helpful in terms of health to understand the many difficult changes experienced by immigrants.

The International Experience

While Khamru was describing the experiences of moving to Canada, he also gave details about his shift from Africa to India, India to England, and finally from England to Canada. Through these transitions, Khamru and his family were confronted with several barriers. In the initial stages of moving to India, Khamru's son became ill with jaundice and through his experiences with the Indian health care system, Khamru felt it was unstable and less than satisfactory and that his son required further assistance. Because he had family in England, Khamru decided to uproot his family from India so that his son would be able to receive the best health care and his family would benefit from the many services that could be accessed in a developed country. After several years in England, when all his children were almost grown, Khamru decided to resettle in Canada where his other brothers, sisters, and one of his daughters were established. Khamru has enjoyed living in Canada with its multicultural environment and spacious clean spaces, as well as the ability to access some of the Canadian services available to him and his family, especially when his son encountered health complications in India and London. Khamru explained,

> *Well Africa to India was the hardest part because we were trying to sell ALL our belongings which meant the furniture and the excess clothes we had before we could leave for India. And India is one of those countries where nothing goes without bribes, so anything you want to do, there is a bribe that you have to give in order to get anything done and that was very unusual for us. It was a very different situation from back home*

in Africa. So as far as taking things were concerned, we only took a few clothes and that, we couldn't take any furniture and that so we had to start all over again there.

We didn't settle too much, thank God for that. We didn't have to worry about selling things because we were still trying to find out if we wanted to stay there and whether my kids would get proper schooling. And then because we were having problems and my son became ill, we decided to go to London, England and as soon as we landed in England in 1979, I took my son to the family doctor, my brother as I said was there in England, so he knew his own family doctor. So, I took my son there and the first thing the doctor said to my son was, "Young man, go back home, I will come and see you". So he didn't even treat my son over there, he sent us home and the doctor came home and that's when he told us that he had jaundice. It took about two to three months for the jaundice to go and then we joined him in school and they did their studies over there.

From England to Canada, we landed in Canada, it was a very different environment over here. Over here it was much more roomier, much more greener space, bigger cities and very spacious. As far as the accommodations were concerned, they were very good over here. In England, it was very damp, it was very cold, you had radiators for heating and every room had one. It wasn't like here, say for example you are in a house you have forced air, so you have a furnace in the basement running over there, but in England, it was very cold. Plus over here, the accommodations – the apartments and that are very good and the transportation is good as far as the subway is concerned and very close also.

Khamru's account detailed the need for transition and resettlement process due to health care and better education for his family. He wanted to provide stability in their lives so

that they were able to better prepare for the future, which is the reason why Khamru planned his life accordingly. His selfless act of providing his family with a safe and stable upbringing gave his children the opportunity to have healthy, successful lives, about which he elaborated at the end of the interview.

Experiences with Health Care

After settling in Canada, Khamru explained that he needed to use the Canadian health care system almost immediately for his son and wife, who both required surgery. With these concerns, Khamru turned to his sister and daughter for advice about the health care system, because they were both established and had lived in Canada for some time. For reassurance, Khamru also discussed these issues with the Ismaili community in Jamat Khana, and they provided him with information about the closest walk-in clinics he could attend and provided some guidance relating to the surgeries required for his son and wife. He explained that the brochures and write ups provided by the government were difficult to understand due to the language barrier, and even though he understood verbal English, he was a new arrival in Canada and felt a bit overwhelmed and did not seem to understand what they were attempting to communicate.

Unfortunately, with his family's decline in health, the stress affected Khamru. Khamru's instinctive tendency to care for family was clearly displayed throughout the interview. Although he was very fit for his age, went for two kilometre walks daily, and kept himself busy around the house, the cumulative stress of moving and his family members' health problems negatively affected him. Khamru explained,

> *...The problem that I had – I kept getting tired, my days seemed longer, I was out of breath, and it turned out that I had high blood pressure and didn't know that I had that. So, luckily I went to the walk-in clinic and they found out that this was the problem and I was given medication to control it.*

I got the feeling that Khamru was scared and seemed to be lost when discussing the topic of his personal health problems. He was used to taking care of his family and making decisions for them, but he was now in a vulnerable position, because he required assistance. It was vital that he looked after himself so that he could effectively care for his family. Beiser's (2008) explains that emotional and psychological states of new immigrants are so fragile during the transition to a new host-country that the health of immigrants can be greatly affected.

As the discussion continued, Khamru was apprehensive to bring up his negative comments about the health care system. I noticed that he became slightly fidgety while describing his first MRI appointment when he started having back pain. Khamru realized, through observing others in the hospital as well as the speciality doctors he had visited, that the health care system in Canada is not entirely equitable. Khamru explained,

> *The confusing part was only trying to find – for example, I needed my MRI done because I have a back problem right now, and MRIs took six months to get appointments unless you had a doctor that was pushy enough or had contacts in hospitals, then it would be that much of a longer waiting period. You would be in there within a few weeks or so. That to me was surprising, I thought everyone had access equally, but you have to know the right person to get the right treatment.*

This perception regarding the health care system is not prominent in the articles reviewed or articles discussing the topic of health literacy within Canada. However, when researching the topic of "problems with the Canadian health care system", several qualitative projects emerge that mention the issues of unequal access to services. With the immigrant population already receiving less than adequate health services, additional obstacles only negatively affect their efforts. I noticed that when he spoke of health care system "back home" in East Africa, it appeared to be more of a paternalistic model, whereby the patients listen and comply with the treatments provided by the health care professional. Khamru listened to the doctors orders and complied with treatment. However, I believe that in Canada, there is more of a shared responsibility between a patient and a health care professional. With this experience, Khamru became more involved in his health care practices and knew it was essential to question practices and appointments. Although Khamru learned this information through difficult means, I felt that he became more involved in his treatments and appointments from that moment onwards.

Improving Health Care Through Media

When discussing the avenues of learning that Khamru preferred regarding the health care system, he initially mentioned that he remembered receiving pamphlets and brochures about Canada's health care services. He felt the brochures he received from the government did not provide assistance to some of his more particular questions involving where to access health institutions close to where he lived. He also explained that the language barrier is always an issue, which is why he preferred receiving verbal explanation about the health care system. He stated,

I would have preferred if someone would have explained it to me, because when immigrants come to Canada, or any country, not all of them know English. First they do not all speak it and they have a problem in reading and understanding what's written. So it would have been better if we had been explained than the pamphlets.

The grey literature recounts many opinions of the immigrant population regarding health literacy, such as CBC interviewing immigrant families on their thoughts about the Canadian health care system in countless articles. However, peer-reviewed journal articles and research studies regarding health care professionals do not account for the voice of new immigrants. In addition, Khamru added that the various messages provided by other forms of media proved to be confusing. Many of the studies I examined assumed the immigrant's thoughts and behaviours, whereas newspapers and media channels actually provided input from the new immigrants themselves. Research should inform policy development, and it is vital that immigrant concerns/recommendations be taken into account.

Khamru went on to explain some practices of the Ismail health care committees and the development of health seminars for the community. He described the format of the seminars as similar to question-and-answer sessions, which included refreshments and snacks after the event. He described,

We have different seminars at different times and we are advised accordingly as far as – for example, we just had a health seminar the other day explaining to us about the H1N1 situation that is going on right now whether people should be taking it [vaccination] because in our community, there is a lot of talk happening, if you have odds like 1 to 10,000 there is a side effect, no one is going to take it. So, we had nurses, we had doctors, we had specialized community member people come over and explain to us the

advantages and disadvantages if you don't. Also, we have clinics every year, especially for seniors, for flu injections that are provided by the community, to the community people. And also we have other nurses, and sometimes doctors frequently visiting the seniors home or Jamat Khana or the mosque where they would explain and also help take blood pressure or find out who was diabetic and who needed help kind of like that.

The theoretical perspectives on health literacy that were described in the literature review, did not discuss specific avenues of learning, but did acknowledge the fact that the ways of learning vary from one person to another. Understanding the various methods of learning could increase health literacy rates, especially with the immigrant population. In addition, supplementing this information with local, community-based intervention strategies mentioned in the literature review (Jahan, 2000) could prove to be successful. Longitudinal, qualitative, in-depth research in the area of health literacy, presenting the thoughts and perspectives of new immigrants regarding settlement, would be extremely helpful to gain insight into the suggested community-based interventions.

When discussing learning health information, Khamru said,

What I do see now are pamphlets coming out in my own language where I can read them or in the TV programs we are watching, the community run or the community TV programs, they speak in our language so they explain it to us, which helps us.

At the end of the interview, Khamru hugged me and wished me well. His love for his family was evident through the way he communicated, and his family valued his opinion. Khamru was kind-hearted and extremely caring and provided excellent insight into the health care system that I would not have known from the literature. I asked him what Jamat Khana he

attended and promised him that I will make a point of visiting that specific location and that I would also attempt to visit him and his family in the future.

Narrative Account 3: Pyarali's Stories to Live By

Pyarali's Journey in "Uprooting" his Family

I met Pyarali at his house for the interview. His wife met me at the door and offered a welcoming greeting and immediately offered me something to eat or drink. Pyarali's wife began to discuss my thesis project with me in detail and what my future plans were. During this time, Pyarali appeared to be quiet but kept smiling, and he laughed at my jokes. East Africa's largest city, Dar-es-Salam, was very tight knit, so Pyarali's wife asked about my parents and in which town they were raised, because she felt she might know my grandparents. As through Bhebla and Khamru's questions, we learned that her children and my mother went to the same school and volunteered together in Toronto. After this happy discussion, Pyarali made a small joke about "getting down to business".

Pyarali was slightly hesitant to start the interview, and it appeared he was unsure of the questions I was planning on asking. I tried to calm him prior to the interview. I went over the letter of information and consent form and asked if he had any questions before we began. When asking about his demographic information, Pyarali almost seemed to be stuttering, but he became cheerful when I began to read him the poem regarding East Africa.

The poem reminded him of his childhood, and he admitted to missing Tanzania with its clean air and safe environment, although he mentioned that currently, several aspects of Tanzania have altered the country quite drastically. He started by describing how life was significantly "easier" in Africa.

> *Yeah, when we used to eat fresh meat, fresh fruits, fresh vegetables, the food was cooked at home, and sometimes through a servant, sometimes through my wife, but it*

was cooked fresh, all the ingredients were fresh – all of the ingredients were fresh so much so that you wouldn't have a freezer. We had a fridge for cold water and ice, but we would not have a fridge for food. We would buy fresh meat that day and then come home and cook it. That kind of helps your lifestyle, your health, because you don't need any of the food that is injected with any type of hormones or anything like that. So, it was all fresh. So that also influenced our lifestyle because we were healthier, we used to be active. There were no TVs, we didn't have a TV anyways so there wasn't really any time for TV. You come home, you eat, you sleep, you go to Jamat Khana, you go for a walk, sometimes to the beach, where there was fresh air – that was another thing that made a difference on our health.

We all had a job. We used to come home for lunch every day and we would eat, sleep for an hour or two, and then go back to work. So that I never see that happen here. Not only do we have fast cars and fast highways to get to your home, but even then, we are so far away from work that it isn't even manageable, we can't go home. So that type of lifestyle we will never get again, and I know that. But overall, it was a wonderful life, since I was born and even up to 1972. Even though it wasn't a life full of luxury, it was hard work, but it was not as hard as it is here, it wasn't as stressful. The stress levels were much lower, we weren't getting sick.

Pyarali appeared to equate the fresh food and the more relaxed lifestyle to his overall health and well-being. Altering one's lifestyle directly impacts one's daily routine and, in effect, one's health. Although these aspects are discussed in the literature, they are not described from the personal perspective of an immigrant or mentioned when exploring the difficulties in adjusting to a new culture. The magnitude of lifestyle changes that Pyarali describes could also

contribute to stress and poorer health. The literature on the 'healthy immigrant effect' needs to expand and include the perspectives of immigrant populations, to provide health care professionals with information to which they would normally not have access. This information could affect policies created for new immigrants that would assist them in maintaining their health when they initially settle in a new host country.

After describing the positive memories of "back home", Pyarali discussed how his family was impacted by the 1972 revolution. He explained that the political problems were not included in the poem and that the unrest caused him a constant feeling of stress, and due to this fact, he felt that "uprooting" to Canada would be beneficial to his family. He explained,

> *It didn't show or say anything about the political problems we were having there, or the educational system – although it was good at one time, it was deteriorating as we progressed, as the government was changing. I don't even know how to explain it, but the government was taking over businesses and nationalizing you know, they were taking over the houses. But just prior to that, we got out of it so that part was good but they are not mentioning that in the poem still. There was a lot of poverty and a lot of other issues they are not saying. They are only saying the good parts in the poem.*

Pyarali's tone of voice dropped at this point, as he described the turmoil he faced when deciding to uproot his family. At that time, his sister-in-law had already settled in Toronto because the rumours of nationalizing were just beginning. Pyarali explained that his sister suggested that he should also consider settling in Toronto for the safety of his children. The Ismaili community in Africa also felt that Tanzania was undergoing some drastic changes, and the community had to prepare itself for the future. He elaborated,

Well, at that time, my sister-in-law was in Toronto, she had immigrated about two years earlier. And we already knew that there was some nationalizing happening, not only rumours, but we could see things happening and we knew that it wasn't going to be good for the kids. So we were also told in our community and in the Jamat Khama that things were happening and our leader was somewhat guiding us, to a certain degree, to get us out of that country before things happen for the worse. Some of the people didn't listen to that and stayed. We had the opportunity for us, that my sister was already in Canada, and she sponsored us to come to Canada, which took a little time, but in a year or so, we migrated to Canada in the 70s.

At this point in the interview, I asked Pyarali how he felt when he had to uproot his family and settle in a new country. Pyarali's face spoke of an indescribable emotion that I would perhaps never understand. They had to leave most of their belongings and settle in a country where they had to get accustomed to a new lifestyle. He described his family as being "lucky", but that it "did hurt to leave, our feelings, it hurt to leave and move to this new country where all the customs were different". Pyarali reiterated that they were used to their own customs and routines, and moving to a country where every experience was new and extremely difficult. After reminiscing about these memories, Pyarali said he had made the right decision to come to Canada, even though it was a huge step for his family.

As mentioned in the other Stories to Live By, I felt that immigrant literature regarding settlement and health literacy does not go into great detail of the changes in lifestyle people experience when arriving in Canada. These experiences could supplement the quantitative results and have deeper meaning when understood through the perspective of a newcomer to Canada, especially for those who have not undergone similar circumstances, like myself.

Understanding the settlement experiences from the perspective of an immigrant allows one to understand their barriers towards the health care system, and why the 'healthy immigrant effect' occurs. In addition, the emotional and psychological stress placed on Pyarali was evident through his story. Beiser (2008) outlined new immigrant struggles, similar to those of Pyarali, in great detail. Pyarali went on to discuss how facets such as finding employment and confusion with the health care system provided further stress.

The Job Hunt and OHIP Coverage

When discussing his settlement experiences, Pyarali constantly brought up the topic of providing for his family. Arriving to Canada with a small amount of money, he felt it was crucial he find a job so that his family did not have to infringe upon his sister-in-law and he was able to provide a home for his children. The Ismaili community had workshops and seminars that he attended that assisted him when applying for Canadian employment. Although Pyarali was a successful businessman in East Africa, he found that his experience was useless in Canada, because Canadian businesses required Canadian job experience. He encountered several employment obstacles, which resulted in stress, and eventually he ended up with health problems. He stated that the language barrier was substantial; simple English was difficult to comprehend, and "it was mostly as we were new immigrants and it was hard to communicate, even for a job". He explained that companies required "Canadian experience first, so since you are new, you can't get that Canadian experience until you get your first job. It was like you were in a position that you can't move forward until you have Canadian experience".

This situation placed Pyarali and his family at a standstill. It resulted in Pyarali having to volunteer to receive a certificate of Canadian experience, before he could apply for other positions. In the meantime, Pyarali and his family had to rely on his sister-in-law for food and

shelter. Although the literature describes the hardships of employment, the accounts by Beiser (2008) in the literature review did not have an impact on me until I heard Pyarali describing his emotional and psychological state when he was unable to provide for his family. Suddenly it resonated with me, and I wondered how other families survived being in this position if they did not have family or friends to assist them?

Not long after Pyarali found employment, he became ill and had trouble breathing. Although Pyarali was used to the hospital system in East Africa, where a doctor generally made house calls, he was unsure how he could receive health care in Canada. Pyarali asked his sister-in-law for assistance, and she directed him to her Ismaili family doctor. Pyarali felt he could trust an Ismaili doctor and decided to meet with him, despite inconvenience, because he felt the doctor would be empathetic to his concerns. He explained,

> *My daughter also suffered from a couple health issues but it was nothing serious – a couple respiratory problems so I felt it was mostly pollution and the change in environment – the cold weather also. We came from a warm climate so yes, we were catching colds. I'm not blaming the weather or anything, but we were used to a tropical climate and then we were bombarded with severe deep cold temperatures*
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> *It was probably within a month or two after we moved [we needed access to health care] because my sister-in-law sponsored us, she had a family doctor that she used to go to, so it wasn't hard for us to find a doctor and she was comfortable with him because she was going there. But he wasn't close to our house, we had to travel by bus, change two buses to get to the doctor. But we got sick, I can't exactly remember when, but it was right away. We had an OHIP card already, but it was mostly just colds or coughs, sometimes fevers for the children and then we would just go to the doctor as needed,*

based on what my sister-in-law said; she was our guide, guiding us where to go and who to see.

After finally being able to visit a doctor, Pyaral required some allergy medication. Pyarali was under the initial impression that Canada had free health care, but he was mistaken. He also felt that being a new immigrant was difficult enough, but now he had to worry about paying for the prescriptions and making ends-meet. I could see that this topic was very stressful to Pyarali, because it appeared that he provided for his family financially, and therefore, felt strongly that he should be able to care for them in other ways. He explained his experience,

Well, as soon as we moved the costs seemed very high for us, because when you convert our money to Canadian currency at that time, it was high so we felt that it was very expensive. We did get jobs and at that time, we were making an average of $3 an hour, and that would have been a good wage. I'm just saying, based on a new immigrant, now that we have to pay for everything, except for health care which we didn't have to worry because we had the OHIP card, but prescriptions were extra. At that time, the company I worked for was a factory, and my wife got a job in an office where there was partial coverage where some of your prescription money would be reimbursed to you or deducted so you don't have to pay the whole thing. So that helped quite a bit, but the struggle was first to earn the money, put the food on the table, looking after two kids, and the rent, and then if someone gets sick, we would have to have the money to pay for that – not the OHIP or medical coverage but the dental and prescriptions were all extra. We would try and save every penny we had. Even though my sister-in-law had been here before and the community was there for support, it was still very scary to be in a new country.

I finally began to understand what my grandparents must have experienced when they first came to Canada. Being the head of his household, Pyarali felt it was his responsibility to not only understand the restrictions of OHIP, health care, and employment, but to ensure that his family had a place to live and food on the table. Although there are resources for new immigrants regarding health care and employment, this information does not explain how to balance economic hardships or provide alternatives in a manner that Pyarali and his family could understand. Allowing new immigrants to hear the struggles of others in the same situation makes them feel they are not alone. Pyarali had the support of his sister-in-law; however, other new Canadians should be given the opportunity to hear about not only the struggles but potential solutions for employment and OHIP confusion.

Throughout the first three stories, it is evident that immigrant literature regarding health literacy needs to be targeted towards the immigrant populations and health care professionals. Health information has to be presented in a manner that the immigrant population has no trouble understanding, that makes them feel confident in accessing the health care options provided.

The Media as a Resource

After the explanation Pyarali provided about the confusion he experienced when searching for a job and using the health care system and OHIP, Pyarali and I discussed possible solutions to help other immigrant populations facing similar issues. Immediately, he explained that the cultural programs on television would be a great tool to communicate the health seminars that are held in Jamat Khana to others, even if they have mobility or transportation challenges. He felt, like himself, others are more likely to listen to doctors and nurses when concepts are explained in their native tongue, because there is a sense of trust. He explained,

Yeah because at that time there weren't too many multi-lingual cultural programs on television. Now there are so many because there are so many diverse communities, there are too many different types of people from different countries and we have different channels like OMNI channels or CITYTV channels where they have different types or times for different cultures – sometimes Italian, sometimes Indian. They can give you a lot of updates and they tell you a lot about health care and the community overall, and your options so that you know where to go and what to do.

I think they are doing well with the TV, because there are a lot of seminars and a lot of things that are advertised where a senior person who is sitting at home, and usually they are watching TV quite often, they would know where to go and what to do, even if they were new immigrants they would know what to do now compared to when we came; it was a little harder for us.

Pyarali also explained that he felt strongly that the health seminars that occurred in Jamat Khana regularly would benefit other immigrant cultures, especially if they could be viewed on television. Pyarali's voice spoke with pride when he explained that the Ismaili community was "stronger and willing to help" and that the other immigrant cultures could learn from the established communities who help new immigrants settle in Canada. Pyarali added that he has been utilizing the Telehealth services, because he feels his English is getting considerably better. He felt that if Telehealth could provide assistance in his native tongue, other immigrant groups might be open to using this service. Telehealth could then be advertised on the cultural television programs and be utilized by immigrants in a comfortable manner. Furthermore, I believe that short documentary clips, movies, or television programs in native languages could provide individuals information on the health care system tiers, locations, how

to get there, where they can receive additional assistance, and the contact information of individuals from their respective cultures with whom they can discuss any questions.

After the interview, I thanked Pyarali and his wife for their time. Pyarali provided me with a different perspective of a new immigrant: he recounted his confusion over several aspects of the Canadian support system. Through trial and error, he was successful in providing for his family. In Pyarali's opinion, immigrant literature should incorporate the experiences of other successful immigrants and offer advice and guidance. Pyarali's commitment to provide for his family was evident throughout the interview, and learning from his success can provide other new Canadians with hope.

Narrative Account 4: Merun's Stories to Live By

Merun's Journey: Breaking Through the Gender Barrier

Upon arriving at Merun's house, she invited me into her home, which she shared with her brother and his wife. Merun was a very small woman, both in stature and size, but appeared to be very independent and strong for her age. She offered me a drink and was eager to participate in and discuss the study. While reviewing the letter of information, she exclaimed that she was very interested in this topic and began to ask me very detailed questions about the topic of health literacy. During the short dialogue prior to the interview, it was evident that Merun was well-educated. She explained to me that she was a nurse and enjoyed studying.

Arranging the interview with Merun was slightly difficult, because she was actually sick with H1N1 and was in the hospital for a month. She was released two weeks prior to the interview, but stayed in contact with me to let me know that she was interested in the interview and requested that I wait until she was home. She mentioned that she felt she could positively contribute to the findings and provide a perspective that would be essential to my work. I could not turn down her offer, so I gladly waited for her to recover.

At the beginning of the interview, Merun asked me to read the poem to her. She began to smile and I could see that she was reminiscing about East Africa. The first thing Merun mentioned was the fresh fruit, vegetables, and meat in her home town of Dar-es-Salam that she greatly missed. The discussion about food brought back memories of different scents and experiences with respect to nature and cuisine. Merun explained that buying fresh food was part of her daily routine, and it reminded her of her slow-paced lifestyle. She expanded,

> *Well, it definitely brought back many memories about the lifestyle we lived over there. Everything from the fruit and food was fresh and to the fact that you could probably buy any food you want on the side of the street., whereas here, you go to a restaurant and you eat food that has been processed and frozen and not necessarily fresh. It definitely made me think about how the lifestyle is so different over here – it is fast-paced and over there it was a lot more relaxing, it was not as stressful there as it is here.*

Merun also described that the poem did not mention the negative aspects of East Africa, such as the gender bias with which she struggled daily in her work environment as a nurse. She explained,

> *The poem did make me – the immediate way to think about the past is to think about it in a positive way, but of course, there were bad things, not necessarily bad things, but things that were worse there than they are here. Like the time when I lived there, which was up until the early 70s, there was a lot of – even though I was college educated and I had been in school and didn't have any family commitments, I felt that I was treated differently because I was a woman in the workplace. So that was one of the things that I would characterize differently over here. Obviously there is a little bit more development here, in terms of roads and buildings, technology, even in health care there is a different approach taken here.*

Merun did not expand on her experiences in East Africa in great detail, but what she did elaborate on was the fact that settling in Canada provided her with more opportunities in relation to her career. Merun was a new immigrant who benefited greatly with several aspects of her life in her transition to Canada. In Canada, Merun was able to utilize her higher education for her benefit and find a job that suited her talents. She explained that she felt she was "treated equally" in Canada and now has the same opportunities as men, which was not the

case in the job market in Tanzania. The immigrant literature discussing health literacy does not focus heavily on the positives when settling in a new country, but mostly the hardships. I feel that if other immigrants heard Merun's experiences with the job market and workplace environment, they would not always look at every hurdle as a struggle, especially if they knew there was a new immigrant who had succeeded and thrived.

In the early 1970s, Merun's brother was concerned for his children when the rumours of nationalizing began, and asked Merun to join his family in Canada, because she was not married and was living on her own. After much thought, Merun agreed because they were her only family, but she quickly realized after she had settled in Canada that she did not, "realize how different it [Canada] would be". Merun felt that moving to Canada would be to her benefit, because Canada was considered to be a "land of opportunity " and her gender would not hold her back in areas of study and employment.

Before arriving in Canada, Merun did not realize how extreme the changes in lifestyle, weather, and diet would be. Merun explained that she arrived to Canada during the winter, which proved to be a large shock to her system. She found that her immune system was greatly affected because she was prone to getting colds and the flu as well as becoming constantly sick with headaches. With the change in weather, she even had trouble attending Jamat Khana regularly like she did in East Africa, and she was unable to go home for lunch to have a relaxing, stress-free break to herself. When asked about her first winter, Merun stated,

> *I came in the winter time, so it was the cold that first got me. Coming from a warm climate, you're not prepared for the consequences of a cold climate – the headaches, fever, nauseating feelings – and you can't do anything if you are constantly sick. I guess the first person I asked was my brother, because I was living with him, his wife, and kids when I first*

moved here. But I also approached people in Jamat Khana before – they have contacts within them, they know Ismaili doctors, you know it was always a preference to go to an Ismaili doctor if I could get in touch with one, but initially I would go to a clinic that was around the corner of my house because it was close.

In the winter, it was a lot of colds and that type of thing, in the summer when it got hot, it wasn't the same type of heat that it was at home. There was a lot of pollution, so there was asthma and allergies that became an issue. I found myself having to take pills like regular Tylenol more frequently here to just control it.

On her first trip to the grocery store, Merun felt none of the produce was fresh, especially when she noticed the frozen food aisle. The fruit smelled and looked very different from the fruit she had once known. This change in lifestyle was the one of the largest adjustments Merun had to make. She explained,

I did come here during the winter which was of course a shock for anyone coming from a warm climate. It was something I was completely unprepared for and because of it, I found myself getting sick a lot more than I was before I moved here. Other than that, the weather was the most shocking part of the moving period and the idea that you can't just walk outside of your house and buy fruit, fresh fruit from the person standing right there, you had to go to the grocery store where you could buy fruit that were days old and shipped here from somewhere else especially because we don't grow fruit here in the winter, it was shipped and it had been on a truck and we never knew how old it was.

Merun had trouble adjusting to many facets of everyday life - the lack of taste in her food, the weather, and the lack of leisure time. Reading a journal article on the hardships experienced

by immigrants upon settling in a new country would never impact a reader because peer-reviewed journals simply state the barriers and struggles this population encounters. There are very few qualitative interviews regarding immigrants and health literacy and it is difficult to discuss issues such as adjustments made in daily life. Health literacy specialists could benefit from understanding the other important emotions enveloping a new immigrant, such as fear of finances and the fear about providing for their families. Simple changes, such as weather, can alter an individual's social activities and leisure time. Merun described that the winter and her new place of employment did not allow her the time to see her friends and to attend Jamat Khana daily as she once did. She was also unable to travel home for lunch hours and relax, because the pace of life in Canada was a more regimented. Beiser's (2008) explanation of the emotional and psychological effects immigrant populations encounter greatly mirrors Merun's experiences, however, there were no plausible interventions suggested, because the articles were not directed towards health care professionals or immigrant populations.

First Experiences with Fast Food = First Experiences with the Health Care System

Merun explained that after finding employment and attempting to begin her life without the support of her brother and sister-in-law, she found herself constantly busy with very little time to prepare food the way she had back home. When Merun realized that food in Canada did not taste the same as it did in East Africa, she decided to try something new: fast food. Fast food made her fast-paced life easier when she was in a hurry, and because it was not available in East Africa, Merun initially basked in the concept of ready food with no preparation required. However, the preservatives did not agree with Merun's stomach and caused gastrointestinal problems, which led her to accessing the health care system almost immediately upon her arrival to Canada. She explained,

I can't really remember what it was like to have the fresh fruit all the time but I remember thinking that it was a huge adjustment. We don't really think of food as something to adjust to, but it was an adjustment, where over here there are fast food places and it is just so much easier to pick up a burger and eat that way because you are constantly in a rush to go to work or to make it to Jamat Khana or do all these things. Whereas back home, it was just simpler and was not as overbearing.

Merun was unprepared for the repercussions on her body, and just like the other participants, had to access the health care system almost immediately upon settling in Canada. Merun also had some confusion regarding the differentiation of roles and doctors in Canada, because specialists were not common in Tanzania. Merun was not aware that in Canada she had to get a referral to see a doctor who specialized in gastrointestinal problems. She stated she was not provided this information when she arrived in Canada and only learned about these details once she consulted with the Ismaili community and her brother. Merun was also not sure which institution she should attend, especially due to the numerous "tiers" within the Canadian health care system. Merun stated,

However, the health care system was significantly different than here – doctors performed house calls, and when there was a problem, and got treated here. If you could afford a house call, sometimes it was preferable to do that. Compared to Canada, health care is standardized and there are many more places you can access care. The part I find confusing is, which institution do I go to for help? A hospital? Walk-in-clinic? Urgent care? CCAC? I wish someone would have explained it to me.

I think the one [health care centre] around the corner from my house I found it as I was going through my neighbourhood and that sort of thing, but my brother has recommended other

doctors to me, because when I needed specific care for specific problems, not just having to go to a GP, I would need to get a hold of someone who was a specialist. I would either ask my brother or people in Jamat Khana for information on how to get in touch with more specific doctors.

There wasn't the same type of specialization as there is here. Over here, it is very intense where there is one doctor for this and one doctor for that, and you'd have to get referred by a GP in order to see them. Over there in East Africa, you either called the doctor to your house for whatever illness you were having or you went to the hospital and whoever looked at you, looked at you. It wasn't the same type of intricate system it is here.

This is a problem that is not discussed within health literacy research, perhaps related to the lack of qualitative research in the field. Rootman (2006) and the Canadian government have concentrated on defining the term health literacy and discussing its implications on the health care system and the population as a whole. It is now commonplace that most new immigrants require access to the health care system almost immediately upon entering a new country, but the strategies in place to assist them with their search for a doctor or health care centre where they feel comfortable are few. For those individuals who do not have a support system, this process could prove difficult, and other forms of communication need to be designed for their benefit.

Health Literacy Communication Methods

The final stage of our discussion addressed the communication methods that Merun preferred for health literacy. Merun first explained something to me that I had not considered,

as a native Canadian: when people migrate to Canada, their priorities do not necessarily include the health care system, unless they become ill.

> *Well I guess when you're moving to a new place initially, you are leaving your home behind and pretty much everything. I guess your primary concern is not to read all the information when you enter the country – the pamphlets on health care, that sort of thing, it is not really a primary concern for you, because you are more concerned about getting your life in order. So, I guess perhaps if I wasn't handed a piece of paper telling me about the health care system, and if someone talked to me about it and emphasized to me that the health care here is not the same as it is back home, where you call the doctor and the doctor comes to your house. Over here, you have to go to the right type of clinic – either a hospital, walk-in clinic, a family doctor, there are so many different types of tiers or levels that you can go to, so it would have been nice to have someone clarify what all those levels meant.*
>
> *…When you're in the hustle and bustle of moving to a new country and you're an immigrant, you have so many things to worry about, like finding a job and finding a place to live, you know? Worrying about weather and food, the basics, I guess health care isn't the first thing you think about, and I can't say before I moved I asked – when my brother was living here first, I didn't call him up and ask him how the health care was here. I more came over here and learned about it and used it when I needed it.*

Merun's account provided an insight into why the immigrant population does not mention their confusion or reservations about government services when transitioning to a new country: they have more important concerns on their mind such as shelter, livelihood and other issues that are more important, and there does not seem to be a system in place to allow the new

immigrants time to comprehend the information they receive upon entering Canada. Canada's health care system is recognized worldwide for the services it offers. However, it also tends to be overwhelming and confusing for new immigrants. As a new immigrant, Merun's preference would have been to receive verbal communication and explanation of the health care system in Canada, especially because it was significantly different from what she was familiar with back home.

In my study, I learned that the participants preferred verbal communication methods rather than reading brochures or pamphlets that were, at times not very clear for them to understand. Resources need to be presented in a manner that new immigrants are able to understand, so they can navigate the health care system when they require it, as suggested by the community-based educational outreach intervention (Jahan, 2000). The Health-Learning Capacity Model (Wolf et al., 2009) and the Pathways Between Patients Model (Ishikawa & Yano, 2008) should be explored in further research. Like Bhebla, Merun preferred communication being offered through the Ismaili community and the people she knew. She felt that individuals who had had similar experiences regarding illnesses could be trusted with advice, because they could relate to her mental and physical state. Merun also explained that the information sessions within the Ismaili community, which are given in her native tongue, decrease the chance of misinterpretations and allow her further clarification during the question-answer sessions at the end of the seminar.

> *Ah, well we're a big – our community is very social, we are a big socializing community, we talk a lot so it is a lot of word of mouth. So someone will say, "I had this surgery, or I had this problem, or I got these pills" or whatever the case is, if you know that you've had a similar situation, you can easily ask them about who they talked to or what their*

experiences were, and they would easily help you out or get you in contact with someone who could help. We are just a huge word-of-mouth community, where we will talk about and also, I guess for seniors now they have sessions, information sessions where they will talk to us in our own language and give us information about how to take care of our health and safety in this type of society and where to go and what types of social behaviours and activities are best for our health.

According to Merun, the Ismaili community's committees are very important because, she explained, the information they provide is trustworthy. New immigrant research should incorporate preferred ways of communicating information and ensure that it is provided in the community's native tongue, which would decrease miscommunication. Merun added that the Ismaili community is very tight-knit and is a "constantly expanding network of people" whom you can approach for questions or concerns, and she commented that when they meet someone new within the Ismaili community, they get to know them personally and they are not just an acquaintance.

Merun also stated that teaching health literacy from a young age would be helpful with preventative health care, and by educating younger children, it will avert potential risks in the future and assist families when issues are being discussed in the home,

If I had read the pamphlets, they would have been helpful, but I think ultimately face-to-face is the most effective way to get a message across because if you trust someone you listen to them. I guess now, even though most of our community is not back home anymore, I think starting with health literacy at a younger age would help to add the preventative measure for illness that we seem to be encountering like diabetes, which is very prominent in the elderly community now. If we start educating children from a

younger age then maybe they would be better prepared, and I find that even though we are a very close-knit community that has the seminars and that sort of thing, they tend to target them towards elders rather than to the younger part of our community. So I feel like if we did that it would be more of a preventative measure.

Merun's suggestions agree with most health literacy interventions, which discuss commencing exposure to heath literacy at a younger. Wolf et al. (2009) as well as Ishikawa and Yano (2008) discussed that providing children with health literacy information at a younger age can also help when their parents have questions or concerns. Conveying this information to the younger generation allows the term, health literacy, to become commonplace and utilized more often within the educational system (Ishikawa & Yano, 2008). Health literacy literature within the younger population also suggests incorporating health literacy within the health curriculum of the school system.

Merun's suggestions on communicating issues within health literacy provided insight into the experiences of a new immigrant. She discussed complex problems that the immigrant population encounters within a short time span after they have settled, which places their health, as well as the family's health, at high risk. Her suggestions regarding word-of-mouth techniques or having access to professionals when searching for assistance would indeed be helpful, in addition to Telehealth providing services in several languages. Research on new immigrants and their learning preferences has not been completed, and is essential to increase the health literacy rate within the immigrant population. Telehealth would be a useful means of providing confidential communication to the new Canadians and people who prefer a verbal resource. If Telehealth can provide this service in several languages, it is conceivable that

immigrant groups would seek assistance from it more frequently, in a comfortable setting, which is an important aspect to immigrants (Beiser, 2008).

At the conclusion of the interview, I expressed my gratitude to Merun for her profound comments and insight and commended her for shedding light regarding both Canadian and Tanzanian health care systems from the perspective of a health care professional. Because Merun did not have any children, her experiences differed from the other participants whose decisions were weighed in terms of the outcome on others. Not having children also allowed Merun to indulge in fast food on a regular basis because it suited her professional, fast-paced lifestyle. This led Merun to access the Canadian health care system and specialists for different reasons compared to the other participants. According to Merun, she also encountered several successes in her professional career due to her perception of the lack of gender bias in Canada, which was not the case with the other participants. Being a nurse allowed Merun to compare and contrast her experiences between the health care system in East Africa and Canada. In effect, she described her confusions about health literacy from a different vantage point. I thanked Merun again for consenting to the interview, even though she had not fully recovered from her illness.

CHAPTER FIVE

Reconsidering Health Literacy from the Ismaili Muslim Perspective

Key Considerations: Summary of Findings

The purpose of my study was framed around understanding four Ismaili Muslim participants' experiences in learning to navigate the Canadian health care system for the first time. Drawing on Clandinin and Connelly (2000), I thought 'narratively' to recognize and distinguish how the participants composed their stories in relation to their settlement experiences. There are numerous ways in which the findings of this research study can potentially contribute to the improvement of health literacy within immigrant populations.

Understanding the intricacies of the Canadian health care system has increasingly become a problem for many Canadians, with the percentage of low health literacy rates continuing to rise (Health Canada, 2008a). I believe that my research can help address some aspects of confusion about health literacy and suggest plausible interventions.

As I retraced my steps through my research puzzle, I had a better picture about the participants' experiences, because they described their personal experiences within the Canadian health care system. Listed below are the key considerations and main ideas, which I believe are central to the information uncovered through my research study:

1. According to the participants involved, communication tactics applied in health literacy are not necessarily targeting the immigrant population.
2. Secondly, as new immigrants, they were confused about the Canadian health care system, especially relating to the tiers of health care and the limits of OHIP coverage.

3. Thirdly, the Ismaili population utilized the resource of cultural capital to assist in their settlement experiences. They also stressed the importance of comfort, trust, and sensitivity when it related to taking advice from individuals about the health care system.
4. Lastly, the scoping review identified knowledge exchange about health literacy as vital for health professionals and patients, as well as other groups.

I will describe each key consideration below. After discussing each of them, I will explain how they assisted in increasing health literacy within the Ismaili Muslim population specifically, and potentially with other immigrant populations.

Key Consideration #1: Throughout the interviews, all participants mentioned that the information provided by the government in the form of pamphlets and brochures did not assist them in accessing health care. They had difficulties due to language barriers and differing choices in how they wanted to be informed about the health care system. Canadian immigrant literature on health literacy has identified very few communication strategies targeted to the most vulnerable health literacy populations: older adults, immigrants, and the chronically unemployed. Further, these strategies have not been evaluated over the long term.

With health literacy being a relatively new concept, there is more information to uncover, not only regarding its dimensions, but how to improve health literacy rates nationwide. To begin delving into this topic, studies need to examine the perspectives of the vulnerable populations and their preferred methods of learning (Wolf et al., 2009). Wolf et al. (2009) and Ishikawa and Yano (2008) both demonstrate the importance of health information learning preferences in health seeking behaviour outcomes. They also recommended that future interventions should

employ these strategies in efforts to improve health literacy rates (Ishikawa & Yano, 2008; Wolf et al., 2009).

The preferred methods of accessing, understanding, and using health information, according to the participants in my study, included media programs in their native tongue, face-to-face seminars with trustworthy individuals from the community, and Telehealth assistance provided in their native tongue. Studies have recently begun in the Greater Vancouver Area where culturally sensitive health care video clips were utilized within the Iranian community and aired on local television channels. The findings indicated that the Iranian community, like many immigrant communities, tends to exchange health information by word-of-mouth and emphasizes the importance of trust (Dowse, 2004; Osborne, 2006). The videos depicted short dramas in which actors, as members of the target community, engaged in solving health problems within the province of British Columbia (Bobal, Brown, Hartman, Magee, & Schmidt, 2007). Longitudinal studies are required to understand if these video clips have an effect on long-term health care behaviours (Bobal et al., 2007). By utilizing these suggestions, future health literacy interventions could target the appropriate vulnerable populations and begin to increase health literacy rates nationwide.

Key Consideration #2: All participants had difficulties in distinguishing the various tiers of health care and the limitations of OHIP coverage when utilizing the Canadian health care system for the first time. This confusion stemmed mainly from the structural differences in the health care systems between Tanzania and Canada. The participants came from a country where doctors made house calls, and if their doctor was not available, the hospital was the only location they could attend. Furthermore, citizens paid for the health care they received. The participants came to Canada with preconceived notions regarding health care coverage and

were alarmed when they realized the limits of OHIP, particularly in regard to prescription coverage. With the recent introduction of Ontario-based commercials regarding instructions accessing the tiers of health care, we can certainly understand the participants' confusion. If these commercials were translated, they could be helpful towards other populations.

Immigrant health literacy literature does not mention these confusions when entering a new country, however it does mention that most health care policy does not target the immigrant population (Beiser, 2008; Fetter, 2009). More detailed information regarding health care coverage needs to be readily available for the immigrant population when they are required to access the health care system, through the preferable ways of learning mentioned above. In this way, when the new immigrants are settled and require the use of the health care system, they would be able to utilize the form of communication they prefer and have their information needs met.

Key Consideration #3: Cultural capital made the settlement process easier for the Ismaili population because it promoted social mobility without economic means. They have used their community and social networks as a resource in adapting and providing them with skills to become familiar with the new Canadian environment. The committees formed by the Ismaili community assisted in providing resources on all aspects of Canadian life. With this information, the participants felt confident when accessing the resources that were shared by the community and they were not completely discouraged when navigating the intricacies of the Canadian systems.

When discussing accessing the health care system, Bhebla mentioned in her interview that she would rather visit an Ismaili doctor to discuss her diabetes, because he/she would understand her cultural values and lifestyle, and she felt he/she would be sensitive to her

decisions. Like Bhebla, Beiser (2008) strongly suggest that immigrant populations would prefer to communicate with a health care professional of a similar cultural background, because health care professionals could relate to and understand the diet the patients are accustomed and, consequently, recommend solutions that fit patients' lifestyle (Fetter, 2009; Jahan, 2000).

Not all immigrants can access health professionals of their own background. To make the immigrant populations more comfortable with their health care professionals, Fetter (2009) suggested that sensitivity training for health care professionals would be a suitable intervention and would assist in improving health literacy rates. Jahan (2000) mentioned that utilizing a cultural interpreter, an individual who is familiar with various cultures, practices, and lifestyles, would assist in the health literacy process and make patients feel comfortable. A cultural interpreter could potentially increase cultural competence and support efforts in delivering health literacy skills and programs effectively and efficiently. Furthermore, a cultural interpreter could also be utilized for Telehealth services. Longitudinal studies are necessary to understand if these interventions would be successful.

Key Consideration #4: The importance of knowledge exchange between immigrant, health care professionals, and researchers is essential. The resettlement experience produces new health challenges and new opportunities for knowledge exchange about health, family life, schools, and workplaces. Enhancing health literacy applies not only to communicating with physicians, but also to related situations such as knowing when to seek care, how to make health care appointments, and how to follow treatment instructions, which can assist immigrant settlement and integration (Zanchetta & Poureslami, 2006). In addition, the complex concept of health literacy involves disciplines from psychology and education, to sociology and anthropology. It is essential that there is intercollaboration among these professions to facilitate

interventions for health literacy, because they could provide a more holistic view, as well as demonstrate how immigrant settlement, access to health care, health literacy, and other social determinants of health are all linked to the health outcomes of the immigrant population.

Future Directions in Research and Policy

In the future, enhancing health literacy for the immigrant population in Canada will require the assistance of the public health and health promotion sectors. Quantitative information regarding health literacy has been provided through surveys, assessments, and censuses, but we need to supplement this information with qualitative literature to assist with the existing gaps, such as the stories provided in my study. The integration of health literacy initiatives into the settlement and integration programs within Canada would promote immigrant health and adaptation (Simich, 2009). I believe that it is important to note that increasing intercollaboration among all professional sectors will reflect how immigrant health, settlement, and integration are inseparably linked. For this to occur, all levels of government (national, provincial, and local) will be required to be involved in the process.

Suggested within the narratives and scoping review provided, specific areas that require immediate attention are:

- Assisting in health information needs for newly settled immigrants (Simich, 2009)
- Utilizing word-of-mouth communication initiatives targeted to specific immigrant groups and using participatory community-based education strategies
- Collaborating among the education, health, and media sectors to promote health literacy through the media and enhance immigrants' health literacy about health promotion and preventative health

- Supporting efforts to increase the cultural competence of health and social service providers to develop health literacy skills to deliver programs effectively to immigrants, which includes cultural interpreter services
- Funding more basic and applied research on specific immigrant groups in relation to health literacy and the effectiveness of community based-educational outreach programs
- Utilizing qualitative forms of assessment and research in the field of health literacy in order to address subjective aspects of health and wellness of immigrant population
- Ensuring good practice that supports health literacy between patients and health care professionals (Simich, 2009)

Strengths and Limitations of Research

Strengths: According to Clandinin and Connelly (2000), utilizing a small sample for the study was considered to be a strength, because it provided detailed, focused, and in-depth information from the Ismaili Muslim community as a specific group. Employing a narrative account was the most appropriate way to gather this information, because it provided thick, in-depth descriptions throughout the narrative accounts and analysis. In addition, because the topic of health literacy is relatively new, the scoping review brought all relevant material on health literacy and immigrant populations together, which had not yet been done. Furthermore, peer debriefing of the analysis was completed throughout the study. The thesis advisory committee provided their input into the analysis of each interview and their thoughts on the major themes within and between the stories. Finally, having membership in the Ismaili community provided the study with several benefits that could not have been achieved by a non-Ismaili researcher. Being an Ismaili Muslim allowed entrance into a normally close knit community, where the

participants felt cultural sensitivity from the researcher, along with comfort and trust. The participants might not have been comfortable elaborating on the details of their journeys with a non-Ismaili researcher.

Limitations: This study only involved members of the Ismaili Muslim population. Other immigrant communities might have differing barriers to health care and alternate perspectives regarding preferences for learning health care information. Moreover, the Ismaili population had differing circumstances in their settlement process from other immigrant groups, such as receiving access to OHIP immediately when entering Canada. For this reason, results of this study should be extrapolated to other new immigrant groups.

Final Thoughts

Results of this study were to be used to (1) gain a better understanding of the post-immigration experiences of the Canadian health care system in comparison to the pre-immigration expectations among older Ismaili Muslim adults, (2) discover how health literacy affected health seeking behaviours during immigrant settlement in Canada within the Ismaili community living in Toronto, and (3) explore the effects of cultural capital to determine how it assisted or hindered the successful settlement process of the Ismaili Muslims within Canada. The participants provided in-depth insight through their stories regarding complications with their settlement and integration processes, as well as their learning experiences with the Canadian health care system. I hope that, through this process, health literacy can be better conceptualized for the Ismailis and, hopefully, the immigrant population as a whole. The participants in my research study certainly opened my eyes to issues regarding the topic of health literacy that have not been previously discussed within the literature, such as the impact of climate, food, and changes in lifestyle on health. I hope that future health literacy

interventions, such as utilizing a cultural interpreter, media techniques, and word-of-mouth seminars will be implemented across the professional health care landscape. The participants' unique journey in approaching the Canadian health care system for the first time provided in-depth information that many quantitative studies have failed to provide. The similarities across the narratives highlighted several overarching themes that discussed aspects of settlement adaptation, problems with the health care system, the assistance of the Ismaili community, and barriers and facilitators to health literacy.

This information contributed to a broader understanding of how the Ismaili Muslim population learned to navigate the Canadian health care system, which emphasized the notion of being culturally sensitive and finding methods of health communication that better suit the target population. John Ralston Saul (2010) once mentioned that there are six pillars to Canadian citizenship; these involve: economic security, social networks, legal status, political participation, cultural identity, and public discourse. Being a Canadian involves the important relationship between individuals and their community, as well as their social and moral responsibilities as Canadian citizens. Integrating into Canadian culture, in this sense, is not only to be an active Canadian citizen, but also to incorporate one's own culture. He stated,

> *Canada welcomes more new citizens per capital than any country in the world. To build a modern and democratic society made up of people from around the world, Canadians have developed many initiatives to welcome new arrivals, help them adapt to life in a new country and encourage them to become active citizens. There are a lot of programs in Canada for immigrants, not nearly enough, not NEARLY good enough, but there are a lot of programs for immigrants and we have to work on more* (Saul, 2010).

As a proud Canadian, I want to assist other immigrants, just like my family, who love and appreciate being a Canadian as much as I do. Along with the emergent findings of this project, I strongly recommend that more longitudinal research should be conducted with other immigrant populations to gain a deeper understanding of health literacy within these populations.

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APPENDIX A

UNDERSTANDING HEALTH LITERACY OF THE CANADIAN HEALTH CARE SYSTEM UPON RESETTLEMENT OF ISMAILI MUSLIM CANADIANS: A NARRATIVE STUDY

Principal Investigator:

Dr. Lilian Magalhaes, PhD

Farzana Haji, MSc. Candidate 2010 (Student Researcher)

Faculty of Health Sciences, HBHSc, University of Western Ontario

LETTER OF INFORMATION - Interviews

Dear ____

I, Farzana Haji, am a Master's student in the Department of Health and Rehabilitation Sciences at the University of Western Ontario. I am working with Dr. Lilian Magalhaes on collecting information from this study in my Master's thesis. We invite you to take part in this study that will identify the facilitators and barriers for Ismaili individuals to navigating through the Canadian health care system upon immigration into Canada. This letter contains information to help you decide whether or not to participate in this study. It is important for you to understand why this study is being conducted and what it will involve. Please take the time to read over this material and feel free to ask questions if anything is unclear.

What is the purpose of this study?

The purpose of this research project is to understand how first time users of the health care system understand how to navigate and understand what the system entails. In addition, this project aims to explore the idea that there is a relationship between social support and health literacy, which involves learning to navigate, access, and understand the Canadian health care system.

Why have you been contacted?

The ministers at the Mosque have contacted you as you are considered an important stakeholder in the Ismaili Muslim community who immigrated during the1972 expulsion from East Africa. In effect, feel free to contact the student researcher, Farzana Haji, if you desire to participate.

What is involved if you choose to participate?

This research study will be conducted at your convenience – the interviews will take place either in the Ismaili Muslim community centre in Toronto, Ontario or at a location that better suits you. We would like to invite you to participate in an individual interview session that will continue as long as necessary considering the availability of the interviewees. In general each interview takes around one hour. Depending on the time required and the information presented, one or two interviews will be performed. During the interviews we will discuss resettling and learning to navigate, understand, and access the Canadian health care system upon immigrating to Canada. In addition, a poem about East Africa will be shared to invite discussion of the resettlement process and your individual feelings on the topic. Sessions will begin in November 2009 and will continue as long as necessary. . Interviews will be audio-recorded to analyze data later on. Audio-recording of interviews is mandatory in order to keep the accuracy of the data, if you do not wish to be audio-taped, you should not participate in the study.

What happens to the information gathered in the study?

Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Data collected in the interviews will be analyzed and eventually published in a scientific paper. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your explicit consent to the disclosure. Interview recordings will be transcribed in verbatim, and saved on a password protected computer to protect your identity, the researcher will replace your name with a unique code in transcripts and questionnaires. All hard copies of the data will be locked in a cabinet in a secure office at the University of Western Ontario, where only the investigators will have access. Any data taken offsite for analysis by the investigator will be de-identified, encrypted, and saved on password protected computers. Computers will be transported by the student researcher, Farzana Haji, and will be enclosed in a locked briefcase to ensure your identity protection. All data will be destroyed after 7 years.

What are the risks and discomforts to you if you participate?

Participants may feel uncomfortable, uncertain, or emotional when discussing their resettlement experiences and health care experiences within the Canadian health care system. The student researcher will endeavour to minimize this by clear explanations of the purpose and process of the research, along with conveying information regarding confidentiality for the participants. It is possible that there are particular events within the Ismaili community that you will not feel comfortable discussing and you should feel free to identify these. You may also stop the interviews at any time.

We are aware of the possibility that participation in this project may evoke painful memories and emotions. We are prepared to offer support services should you require counseling after interviews. English, Gujrati, and Kutchi speaking counselors at our partnering organizations will be available should you require them.

What are the benefits to you if you participate?

There are no known personal benefits associated with participating in this study, but your participation will provide us with an understanding of the facilitators and barriers to accessing the Canadian health care system upon arrival in Canada. The benefits of taking part in this study could include opportunities for increasing health literacy in future immigrant populations by discussing, identifying, and articulating the processes the Ismaili Muslim population discovered upon resettling in Canada. It is hoped that your participation will provide an understanding of the health literacy and health care navigation approach upon settling into Canada from and immigrant group perspective. However, you may not benefit personally from your participation.

Voluntary Participation

Participation in this research study is voluntary. You may refuse to participate or refuse to answer any questions and withdraw from the interviews at any time.

Other Pertinent Information

Please find the consent form attached to this letter.

If you have any questions or concerns regarding this study, please contact the Principal Investigator, Dr. Lilian Magalhaes at (XXX) XXX-XXXX ext. XXXXX. If you have any questions about your rights as a research participant or the conduct of the study you may contact The Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

This letter is for you to keep. If you agree to participate, you will be required to complete a consent form.

Farzana Haji, MSc (Cand.)
Health & Rehabilitation Sciences | Health & Aging
University of Western Ontario
Elborn College, London, ON

APPENDIX B

UNDERSTANDING HEALTH LITERACY AND NAVIGATION OF THE CANADIAN HEALTH CARE SYSTEM UPON RESETTLEMENT OF ISMAILI MUSLIM CANADIANS: A NARRATIVE STUDY

Principal Investigator:

Farzana Haji, MSc. Candidate 2010

Faculty of Health Sciences, HBHSc, University of Western Ontario

CONSENT FORM - Interviews

I have read the Letter of Information and have had the nature of the study explained to me. All questions have been answered to my satisfaction.

Name of participant (Print)

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Signature of participant Date

Name of person obtaining consent (Print)

-- --------------------------

Signature of person obtaining consent Date

APPENDIX C

Interview Guide

Welcome, Interviewer Intro (describe myself as an Ismaili Muslim), Letter of Information clarifications, Consent form and signature, Provide a copy of the Poem, Overview of objectives, Guidelines and ground rules, Start recording, ask participant to introduce themselves.

Objective: Describe the experience of resettlement and the concept of health literacy within the community.

Poem – East Africa

THOSE WHO LEFT E. AFRICA FEEL AS IF THE HAVE LEFT THEIR SOUL BEHIND

I left Dar-es-Salaam, island of raha (happiness),
To emigrate to Canada , land of opportunity.

Forsook the tropical sun
For cold frigid weather.

Left behind the warm ocean breeze
For the windchill of winter.

Abandoned white pristine beaches
For brown muddy shores.

Turned away from a turquoise ocean
For polluted lakes.

Gave up mangoes, papaya, mabuyu, achari and sunflower
For processed apples, pears, peaches and cherries.

Gave up white snapper and king fish

For boxed cod and sole.

Gave up mishkaki, nyama choma maambri and bharazi
For cereal, bagels, cheese, and salads

Gave up drinking coconut water straight from the coconut
And settled for bottled water..

Left behind the street coffee seller (Kahava)
For the office coffee pot..

Left behind the exotic fragrance of phapa and langi langi
For the pungent smell of sulfuric emissions.

Deprived of hearing the call to prayer
For the sound of police and fire sirens.

Deprived of seeing women clad in mysterious black buibui
For women dressed in jeans and miniskirts.

Deserted a slow relaxed pace of life
For the fast lane.

Gave up afternoon naps
For gym workouts.

Gave up riding a bicycle through the narrow streets
For driving a car on the highways.

Discontinued a course on the coral marine life
For a course in stress management.

Discarded mud and thatched dwellings
For concrete and steel.

Left behind a community-based life
For a human zoo.

It makes me wonder
If I have also left my soul behind in Dar-es-Salaam

(Kassam, 2005)

APPENDIX D

Office of Research Ethics

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. L. Magalhaes
Review Number: 16623S **Review Level:** Expedited
Review Date: November 09, 2009
Protocol Title: Understanding Health Literacy of the Canadian Health Care System Upon Settlement of Ismaili Muslim Canadian: A Narrative Study
Department and Institution: Occupational Therapy, University of Western Ontario
Sponsor:
Ethics Approval Date: December 03, 2009 **Expiry Date:** March 31, 2010
Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above named research study on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the study or consent form may be initiated without prior written approval from the NMREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the NMREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the NMREB.

Chair of NMREB Dr. Jerry Paquette

Ethics Officer to Contact for Further Information			
☐ Grace Kelly (grace.kelly@uwo.ca)	☐ Janice Sutherland (jsutherl@uwo.ca)	☐ Elizabeth Wambolt (ewambolt@uwo.ca)	☑ Denise Grafton (dgrafton@uwo.ca)

This is an official document. Please retain the original in your files.

cc: ORE File