Stroke Prevention in Middle-Aged and Older Arab Immigrant Women: Emphasizing Strengths and Identifying Challenges.

by

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#### Abstract

Arab immigrants constitute a minority group that is increasing in Canada. Minimal literature exists on Arab immigrant women's experiences of ageing while managing health concerns. The evidence suggests that stroke risk factors are on the rise in this population with a lack of supportive resources to address stroke prevention. The aim of the dissertation research project was to better understand middle-aged and older Arab immigrant women's experiences of engaging in health-promoting practices in the context of stroke prevention. A life course perspective that incorporates elements from feminist and transnational theory was used to look at the social, economic, personal, and structural influences that shape women's experiences across different migration contexts. Sixteen women from the Levant region living in an urban Canadian center were recruited from a mosque and an Islamic community center. An interpretive descriptive approach was used by a bilingual researcher to guide data collection and analysis in the Arabic language. Data collection involved administering health and demographic questionnaires and conducting semi-structured interviews. Audiotaped interviews were transcribed verbatim, followed by thematic data analysis. Final themes and exemplars were translated into English by a certified translator.

The dissertation is composed of five chapters: an introductory chapter, three core paper chapters and a concluding chapter. Chapter one and five, the introduction and conclusion, present an overview of the study process and theoretical approach, implications for research, education, and practice, and study limitations and dissemination goals. Chapter two is a reflection on ethical tensions encountered in the research process, with a focus on issues of identity, social positioning, and discourses about Arab Muslim communities. Study findings are discussed in chapters three and four to include a transnational life course analysis of social dimensions of

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health and an intersectional analysis of women's experiences with stroke prevention. In chapter three social dimensions of health are addressed in relation to social roles, social support, and transnational connections. Women's stories extend beyond specific practices of stroke prevention to include experiences of maintaining physical, mental, and emotional health across the life course. Chapter four focuses on women's experiences with stroke prevention in relation to expanding health literacy, making healthy lifestyle choices, and managing chronic illnesses. An intersectionality lens is used to highlight structural barriers and the discourses that reinforce these barriers within the Canadian context. A fourth paper is included in the appendices as a work in progress that describes considerations and challenges for data collection and analysis in research with Arab immigrant populations. Overall the dissertation presents methodological and ethical approaches used in the research process, recounts narratives of Arab immigrant women's health concerns while ageing in Canada, and draws from these narratives to identify multi-level, multi-dimensional influences on Arab immigrant women's health.

## Preface

This thesis is an original work by Jordana Salma. The dissertation research component received research ethics approval from the University of Alberta Research Ethics Board, "Stroke Secondary Prevention: Facilitators and Barriers in Middle-Aged and Older Arab Immigrant Women", no. Pro00044841, February 26, 2014.

Chapter two: "A Bicultural Researcher's Reflections on Ethical Research Practices with Muslim Immigrant Women: Merging Boundaries and Challenging Binaries." is accepted for publication in Advances in Nursing Science. Authorship: Jordana Salma, Linda Ogilvie, Norah Keating, & Kathleen F. Hunter. I was solely responsible for data collection, analysis, and manuscript composition. The three co-authors contributed to multiple revisions of this paper, including development and re-structuring of concepts.

# Dedication

To my mother, Linda, who supported me in countless ways along this journey...

Me: Mom I have to study for an exam tomorrow.

*My* mother: I know you will do great, let's spend the day at the beach instead.

Me: Okay mom.

#### Acknowledgements

I am grateful to all the women who so graciously supported and participated in this study. I feel privileged to have had the opportunity to share your stories.

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I thank my grandmother Souhaila and my mother-in-law Layla for showing me how to be a strong and proud Muslim woman. You will always be the voices in my head that remind me to pray, to be honest, and to stay strong. Finally, my love and gratitude goes to my father, Maher, who ignited the spark that set me on this journey of learning. Your love of reading and writing was contagious at a young age, leading me to always ask and try to answer difficult questions.

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### **Chapter One**

## The Origins of a Question

A global increase in aging populations, especially evident in Western nations, has propelled the issue of healthy aging to the forefront of policy and research agendas (Marmot, 2005). The Canadian government continues to voice its commitment to funding research and supporting policy initiatives that increase the quality of life of older Canadians. Such government initiatives include building age-friendly communities, supporting active ageing, and funding older adults' health and social services (Government of Canada, 2009). These initiatives have not, however, adequately acknowledged the needs of older immigrants (Newbold & Filice, 2006). Immigrant women ageing in Canada are increasingly ethnically and linguistically diverse, emigrating from countries in Africa, the Middle East, Asia, and South America (Hudon & Milan, 2016). With the increase in number and diversity of older immigrant women comes the need to focus on healthy aging in this population. One aspect of healthy aging relates to chronic disease management, which is concerned with both decreasing the burden of chronic disease and improving the quality of life of older adults living with chronic illnesses (Chappell & Hollander, 2011).

Many immigrant groups in Canada and other Western nations experience a decline in health over time with rates of stroke increasing to mirror or exceed that of the general population (Sohail, Chu, Rezai, Donovan, Ko, & Tu, 2016). Stroke is the third leading cause of death in Canada (Statistics Canada, 2011) and the economic burden of stroke remains high where Canadians lose 3.6 billion dollars a year to the costs of stroke treatment and lost productivity (Public Health Agency of Canada, 2011). As a registered nurse with a background in acute stroke care, I was acutely aware of the debilitating and life changing effects of stroke in older adults. I began to wonder about my patients' future experiences with ongoing health management and secondary stroke prevention when discharged to the community. I was involved as a nurse in the stroke prevention clinic and saw patients for follow-up post stroke or post-diagnosis of conditions that significantly increased stroke risk. I noticed the lack of healthpromoting resources that were culturally and linguistically tailored to diverse populations. The literature mirrored this observation where discrimination, economic instability, language and cultural barriers, and social exclusion continue to influence access to and utilization of healthpromoting resources (Scheppers, Van Dongen, Dekker, Geertzen, & Dekker, 2006; Valderrama, 2011). Such challenges can be amplified for older adults from culturally and linguistically diverse backgrounds (Bukman et al., 2016; Tummala-Narra, Sathasivam-Rueckert, & Sundaram, 2013; Ypinazar & Margolis, 2006). Awareness of the literature and experiences as a nurse in stroke services propelled my interest in stroke prevention in diverse older populations as a research question.

I lived and worked in the Middle East early in my nursing career. I was aware of the lack of health promotion initiatives targeting healthy ageing and management of chronic health conditions. I can remember frequently participating in technically advanced acute and emergency care interventions. I can remember less frequently engaging in discussions with patients around prevention and management of chronic illnesses. Overall, the Arab world lacks infrastructure and commitment at a policy level for health promotion initiatives (Al Jardali et al., 2010). What does this mean for immigrants coming from the Arab world to Canada? I chose stroke prevention in Arab immigrant populations ageing in Canada as a dissertation project. I chose to focus specifically on Arab immigrant women because of my social positioning as a bicultural Arab woman. This positioning resulted in greater awareness of the challenges women in the

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community experienced in the context of maintaining health. I was initially interested in women's personal experiences and interpretations in regard to stroke secondary prevention. I planned to target a high risk population that had already experienced a stroke or transient ischemic attack [TIA] to allow a better understanding of the pathways of risk that lead to stroke development and the subsequent experiences of secondary prevention. Recruitment was challenging as the available Arab population in the local urban location was small. Finding women who lived in the community and had experienced such an event meant an even smaller pool of potential participants. During the first two interviews it became evident that primary prevention was a serious area of concern for the women who explicitly stated that they had not been aware of their stroke risk profile and had minimal stroke knowledge. Difficulty with recruitment and insights from the first interviews propelled me to expand recruitment criteria to include women who had not experienced a stroke but were at a high risk for occurrence.

#### **Study Question**

The research question emerged as: "What are the experiences of engaging in stroke prevention strategies in middle-aged and older Arab immigrant women living in an urban Canadian center in Alberta?"

#### **Study Objectives**

The dissertation research project involved recruitment of middle-aged and older Arab immigrant women with a history of a stroke or stroke risk factors to discuss their experiences of engaging in health-promoting practices in the context of stroke prevention. In focusing on the specific area of stroke, attention was given to the social determinants of health across the life course. This included attention to social and economic well-being, immigration history, and education as determinants of health that shape health behaviors, access to health-promoting resources, and exposures to health stressors. The objectives of the study were as follows:

- To understand middle-aged and older Arab immigrant women's experiences across the life course that could facilitate or limit the ability to engage in stroke prevention practices.
- To identify gaps in resources and knowledge that hinder middle-aged and older Arab immigrant women's abilities to engage in stroke prevention practices.

This project is a first step towards addressing broader research objectives that include:

- To identify facilitators and barriers to engaging in stroke prevention across groups of Arab immigrants.
- To identify and test strategies to enhance stroke prevention practices in Arab immigrants.
- To expand the focus on stroke prevention to include other cardiovascular conditions that share similar risk profiles and benefit from similar prevention approaches.

#### **Definition of Terms**

Middle- aged adult: A person aged 45 to 64 years of age.

Older adult: A person aged 65 years of age and above.

**Arab immigrant**: Arab immigrants are one of the largest non-European ethnic groups in Canada and immigration from Arab countries continues to rise (Statistics Canada, 2007). Generally, Arab Canadians are more likely to be educated at university level than the general population, to have a lower income than the general Canadian population, are relatively young in comparison to the general population, and include a high percentage (54%) of those who are foreign born arriving in Canada from the1990s onwards (Statistics Canada, 2007). Arabs come from 22

countries in the Middle East and North Africa [MENA] region: Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen. The majority of MENA countries are classified low to medium on the human development index with the exception of countries of the Gulf region, which have high indexes.

In this study the women were immigrants from the Levant region of MENA, specifically the Palestinian territories, Lebanon, and Syria. Criteria for inclusion were women greater than 45 years of age and who self-identified as being an Arab immigrant. All women in this study had been in Canada for more than five years. Most women had lived in Canada for the majority of their adult life, arriving as young brides or with young families. All women spoke Arabic primarily with differing degrees of fluency in English as an additional language. Education varied from illiterate to university level education. Income was low to high based on selfreported measures. All women were living in the community with family (spouses and/or children) except for one woman who was living alone. Ten out of the 16 women were housewives and six others had been employed at different periods in their lives outside the home.

**Secondary & primary stroke prevention**: Stroke prevention involves interventions that are designed to prevent, stop or slow the progress of stroke or stroke-related risk factors (Couttes et al., 2015; Meschia, et al., 2016). Risk assessment tools to identify potential participants were initially trialed and then abandoned for this study because women could not provide adequate health information to complete risk assessments and I did not have access to health records. Personal disclosure was used to identify women who had a stroke, TIA, or at least one health condition that can increase stroke risk, such as diabetes, hypertension (not able to always determine controlled versus non-controlled), hypercholesteremia, atrial fibrillation, or

myocardial infarction. The majority of women also had one or more modifiable stroke risk factor, such as obesity, smoking, and sedentary lifestyle.

#### **Study Significance**

In Canada, one to two thirds of individuals affected by stroke have minor to severe disability or impairment (Canadian Institute for Health Information, 2009). Women tend to have greater post-stroke disability and poorer post-stroke recovery in comparison to men, which is partly explained by older age of stroke onset, poorer pre-stroke functional status, multimorbidities, and poorer social support (Appelros, Stegmayr, &Terent, 2009; Persky, Turtzo, & McCullough, 2012). The occurrence of minor strokes or TIAs indicates the presence of underlying cerebrovascular and cardiovascular risk factors. These risk factors are precursors for the development of more severe stroke events and other adverse cardiovascular events that negatively impact quality of life and well-being (Couttes et al., 2015; Meschia, et al., 2016). Key strategies for primary and secondary stroke prevention involve dietary modification, exercise, diabetes and hypertension control, and use of pharmacological agents to reduce incidence of vascular events (Couttes et al., 2015; Meschia, et al., 2016). Delays in seeking stroke care lead to greater stroke severity, increased mortality, and increased post-stroke disability (Moser et al., 2006). Therefore, prevention also involves increasing stroke symptom recognition and response. There is ample evidence that the above prevention strategies work across ethnicities (O'Donnell et al., 2016). Yet, success in managing stroke risk is also shaped by personal beliefs and practices around health and by larger structural systems and processes that influence access to health resources.

Arab populations experience a high prevalence of undiagnosed and poorly controlled stroke risk factors such as diabetes and hypertension (Musaiger, & Al-Hazzaa, 2012; Tran,

Mirzaei, & Leeder, 2010), higher rates of smoking (Girgis et al., 2009), and higher rates of obesity and sedentary lifestyles (Qahoush, Stotts, Alawneh, & Froelicher, 2010; Liu et al., 2010) than a number of other immigrant and non-immigrant populations. There is a need for further attention in the context of minimal stroke prevention initiatives and resources specifically targeting the needs of Arab immigrants both in their countries of origin and destination (Berger & Peerson, 2009; Gholizadeh, DiGiacomo, Salamonson, & Davidson, 2011; Kamran et al., 2007). Immigrant women can be particularity vulnerable when faced with lack of social support, economic difficulties, immigration stressors, and inadequate culturally and linguistically tailored healthcare resources (Barn & Sidhu, 2004; Emami & Torres, 2005; Guruge, et al., 2010; Kokanovic & Manderson, 2006; Neufeld, Harrison, Stewart, Hughes, & Spitzer, 2012; Pavlish, Noor, & Brandt, 2010; Sethi, 2016). This research project aimed to increase understanding of Arab immigrant women's experiences with engaging in health-promoting practices that decrease stroke risk and pave the way for much needed future research in this area.

#### **Study Methodology**

Interpretive Description [ID] is a qualitative methodology, developed by Thorne (2016), which focuses on describing subjective experiences around phenomena of concern to nursing and constructing an analysis based on shared interpretations between researchers and participants. Interpretive Description moves from making visible individual experience to identifying patterns of commonality and difference across experiences. Interpretive Description also has a disciplinary goal, which is to formulate implications of research findings useful to the practice environment (Thorne, 2016). The goal of an ID is to answer two questions: what can I learn about this phenomenon, and how can this knowledge improve nursing practice. Sixteen women who met the inclusion criteria of this study were recruited from a mosque and a community

Islamic center using convenience sampling and the snowballing technique. Initially, I used recruitment posters (appendix A) but found this recruitment method unsuccessful. Advertising the study in community gatherings and use of community gatekeepers to recruit potential participants were successful methods of recruitment. The women were immigrants from the Levant region who were living in an urban center in Alberta, and who had either experienced a stroke event or had stroke risk factors. Recruitment and data collection occurred between June 2015 and May 2016. Data collection involved administering demographic and health questionnaires (appendix B) and conducting semi-structured interviews (appendix C). Interviews commenced in women's location of choice, usually their homes. Being bilingual allowed me to interview women in Arabic or a combination of English and Arabic. Interviews were two to four hours in duration. Consent was obtained in Arabic (appendix D) before commencement of the interviews. Interviews were audiotaped when consent was given and were later transcribed in Arabic. An Arabic-speaking research assistant helped with transcription of interviews. The research assistant signed an agreement (Appendix E) to ensure confidentiality of content in interview transcripts.

Saturation was defined as the repetition of patterns of experiences that provided new insights into the research topic of stroke prevention in Arab immigrant women (Morse, Barrett, Mayan, Olson, & Spiers, 2002; Thorne & Darbyshire, 2005). Data analysis followed a thematic inductive approach with final themes and exemplars translated into English by a certified translator. An ID methodology relies on constant comparative analysis processes, originating from grounded theory, to understand human phenomena (Thorne, 2016). This involved going through four cognitive processes during the stages of data analysis (Morse, 1994): (a) comprehending, where one generates an understanding of the context and experiences of

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participants, (b) synthesizing, where one looks for patterns of commonalities and variations within these contexts and experiences, (c) theorizing, where explanations for the patterns are sought, and (d) re-contextualizing, where explanations are dwelled upon for their relevance and meaning to practice. I completed data analysis in Arabic to minimize loss of conceptual meaning that can occur with translation to English. Two interview transcripts were translated early on so that my English-speaking supervisor could provide feedback about interview techniques and development of initial categories. The first step, immersion into the data, consisted of reading and re-reading interview transcripts. Taking a bird's eye view of the data was followed by a coding process that involved generating categories and searching for connections across categories. Codes are descriptive labels designated to segments of a transcript; these labels were linked to form categories that summarize the different aspects of women's experiences with stroke prevention. Thorne (2016) encourages the use of manual data analysis practices for novice researchers to develop a personal style of inductive reasoning. I used a manual process of color coding segments of paper transcripts and organizing these codes into different categories. The last step involved the identification of themes. A theme is as an abstract conceptualization of patterns of experience that informs our understanding of a particular phenomenon (DeSantis & Ugarriza, 2000). The process of thematic data analysis involved searching for patterns of similarity and difference in experiences while simultaneously looking at the contextual factors that influenced the development of these patterns (Sandelowski, 2003). Audit trails, used to increase transparency in the research process (Meadows & Morse, 2001), were kept to record thought processes and approaches used from early data collection to later interpretation of research findings (Appendix F). The dissertation is a compilation of the research process and the

final interpretive outcomes and includes three core papers that address the ethical considerations of the research study (chapter two) and the resulting findings (chapter four and five).

#### **Conceptual Framework: An Emergent Process**

The dissertation research project aimed to understand Arab immigrant women's experiences of engaging in health – promoting practices related to stroke prevention as they age in Canada. Different theoretical perspectives informed the research process; from life course theory and intersectionality to transnationalism. Thorne (2016) refers to the term 'multiple truths' to describe knowledge outcomes of qualitative research processes. I use the term 'contextual truths' to frame the way I conceptualize the production of knowledge in the research project. By 'context' I mean the spatially and temporally contingent realities that shape experiences and interpretations of those experiences. I discuss context throughout the dissertation in relation to three contexts that I see influencing the research process: intra-personal, interpersonal, and extra-personal. The intra-personal context relates to the researcher's reflexive activities and the inter-personal refers to the relational dynamics between researchers and participants. Both the intra and inter-personal contexts are contingent on the social positioning of the researcher and researched community. These dimensions are discussed in chapter two and in appendix F, where the relevance of context is highlighted in relation to ethical and methodological research considerations. The extra-personal context centers on the external processes, structures, and practices that influence the way a particular phenomenon is experienced and interpreted in research. Data collection and analysis always involves a process of construction; I believe that ignoring context can lead to constructing in the dark. In chapters three and four, the study findings are situated in the context of geographical, social, political, and

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economic realities. Different conceptual frames allowed me to situate the findings of the study in context and to focus on different particulars.

The move towards integrating aspects of life course, transnational, and intersectional theoretical approaches during the research process was a result of the ways I came to understand the intersections of immigration, ageing, and health. I saw immigrant health as influenced by pre and post-migration social, political, and historical factors across the life course. Women in this study came from the Levant region and the majority arrived in Canada in the late sixties to early eighties. Many experienced similar macro political events, immigration policies and social norms despite variations in personal particulars. Life course theory captures the temporal and spatial dimensions of influences on immigrant health through the concepts of cohorts, trajectories, and transitions. Life course approaches also focus on the interaction between personal agency and broader structures and systems. I used life course theory to frame my interview guide and as an informing perspective during data analysis. I drew specifically from Elder's work on life course theory (Elder & Giele, 2009) and the work of other researchers concerned with life course influences on immigrant health (Gong, Xu, Fujishiro, & Takeuchi, 2011; Montes de Oca, García, Sáenz, & Guillén, 2011; Nicolau & Marcenes, 2012; Spallek, Zeeb, & Razum, 2011).

A critique of life course theory is that it lacks cultural relevance and reinforces a Western conceptualization of the life course (Elder & Giele, 2009; Holstein & Gubrium, 2007). Intersectional perspectives consider the influences of multiple social locations such as ethnicity, gender, and class on the progression of the individual life course. Transnational perspectives expand the notions of social locations across local, regional, and global spaces to address the ways immigrants construct their lives within these spaces. Chapter three addresses the social dimensions of health, identified in women's stories, across the life course within different

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migration contexts. Chapter four looks at the barriers and facilitators to stroke prevention from an intersectional perspective incorporating local, national, and global influences on health. In the final chapter of the dissertation, I draw from my experience of using these theoretical approaches in research with Arab immigrant women to present guiding concepts that can inform future nursing practice and scholarship that exists at the intersection of immigration, health, and ageing.

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## **Chapter Two**

**Title:** A Bicultural Researcher's Reflections on Ethical Research Practices with Muslim Immigrant Women: Merging Boundaries and Challenging Binaries.

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**Abstract:** Bicultural researchers are well positioned to identify tensions, disrupt binaries of positions, and reconcile differences across cultural contexts to ensure ethical research practices. This article focuses on a bicultural researcher's experiences of ethically important moments in research activities with Muslim immigrant women. Three ethical principles of respect, justice, and concern for welfare are highlighted, revealing the implications of binary constructions of identity, the value of situated knowledge in creating ethical research practices, and the need to recognize agency as a counterforce to oppressive narratives about Muslim women.

#### **Chapter Two**

# A Bicultural Researcher's Reflections on Ethical Research Practices with Muslim Immigrant Women: Merging Boundaries and Challenging Binaries.

Muslims living in the West experience racism and xenophobia as global politics and power struggles play out within local communities. Health literature on Muslims often emphasizes difference, reproduces colonial representations of the other, and fails to capture diversity within Muslim populations (Laird, Marrais, & Barnes, 2007). Muslim women have been particularly enmeshed in discourses of identity, power, and religion in the West and globally (Charad, 2011). These discourses often center on the idea of irreconcilable binaries of identities, positions, and values between Muslim and non-Muslim and between East and West. These discourses shape the ways researchers frame research questions, design research studies, and engage in ethical decision-making with Muslim communities (Laird, Marrais, & Barnes, 2007). As a bicultural Muslim researcher, such discourses influence my sense of self, color my interpretation of the world, and shape interactions with communities within which I live in ways that serve to both reinforce at times and disrupt in others existing binaries. I am a Muslim woman with Arab and European heritage pursuing a graduate degree at a Western university. I embody the tensions created by binaries of identities, values, and power positions and bring an awareness of them into my research activities.

In this paper, I focus on ethical decision-making during research activities with a group of immigrant women in a Muslim Arab community in Canada. The objective of the study was to better understand the facilitators and barriers to engaging in health promoting practices. Sixteen women participated in the study over a period of one year. The women formed a cohort that had immigrated to Canada in the 70s and 80s from the Levant region. I recruited women from both a Mosque and a Muslim community center, a pragmatic choice based on perceived community support for the research project. Researchers in cross-cultural settings can experience tensions due to competing expectations, loyalties, and interpretations within a research context (Bolak, 1996; Ganga & Scott, 2006; Manohar, 2013). When left unaddressed, these tensions jeopardize research quality and ethical commitments of a researcher to the participating community. I use my position as a bicultural Muslim woman to highlight the ways dominant discourses of binaries and difference serve to exacerbate ethical tensions and I look for an alternative lens from which to approach research within Muslim communities. My experience of reconciling ethical tensions involved processes of merging boundaries and challenging binaries.

Merging boundaries relates to a paradigmatic shift where Islam was placed at the center of Feminism when engaged in ethical decision-making. Challenging binaries relates to problematizing prevalent notions of identity, values, and power positions created by the social, historical, and political milieu within which I and the participating community exist. I provide concrete examples of reconciliation by highlighting ethically important moments in the research process, defined as instances where a decision or action has ethical ramifications and is a source of discomfort for the researcher (Guillemin & Gillam, 2004). The ethically important moments were often nuanced, open to interpretation, and at risk of fading in the backdrop of more ritualistic and normative ethical research standards. I reflect on the three ethical principles of respect, concern for welfare, and justice in ways that highlight implications of binary constructions of researcher and researched identity, the value of situated knowledge in creating ethical research practices, and the need to recognize agency as a counter-force to oppressive narratives about Muslim women.

#### Merging Boundaries: Islam at the Center of Feminism

#### Making Sense of the Many Shades of Feminism

As a woman engaging in research activities with other women, I utilized Feminist perspectives to help shape the research agenda, identify research methods, and guide interpretations of women's experiences. As a Muslim engaging in research activities with other Muslims, I was aware of historical and political narratives that describe Feminist and Islamic perspectives as incompatible. Central to Feminist orientation(s) is a commitment to social justice as a moral imperative (Hartsock, 1996) and an epistemology that defines knowledge production in terms of subjectivities and multiplicities stemming from the lived experiences of women (Harding, 1987; Haraway, 1988). In the early twentieth century Muslim women activists drew attention to gender equity and women's rights issues, in response to the dire condition of women's lives during and after colonialism (Seedat, 2013). This activism included a range of movements, from secular to religious, where the label of Feminism was adopted by some and rejected by others. Muslim women struggled with the inherited baggage of Feminism as a byproduct of European Enlightenment, a concern specific to white middle-class women, and a tool to reinforce the colonial notion of white men and women saving "brown women from brown men" (Mohanram, 1999). The rise of other Feminism(s)- Post-Colonial Feminism, Black Feminism, and Subaltern Feminism- expanded the Feminist lens to incorporate understandings of the interweaving systems of domination created by racial, gender, and class oppression (Anthias, 2002; Mohanram, 1999; Mohanty, 1991; Spivak, 1988). These Feminism(s) address the materialization of power within the production of knowledge and public discourses, the creation of social norms, practices, and institutions, and the lived experiences of women.

The conflation of a Western Feminism with other Feminism(s), however, still remains problematic in Muslim and Arab contexts with the rise of oppositional extremist narratives characterizing the West and East as a "clash of civilizations" (Cooke, 2001). I was engaged in a continuous process of locating differences, merging perspectives, and imagining possibilities when faced with potentially irreconcilable standpoints. I could see the merits of other Feminism(s), but also pitfalls when a Eurocentric Feminist lens is used to focus in on women's issues within Muslim communities. Although great strides have been made in the use of relational Feminist approaches to conduct health research with minoritized populations (Anderson, 2004; Kirkham, Baumbusch, Schultz, & Anderson, 2007; Racine & Petrucka, 2011), I would argue that the use of such approaches have been limited in health research within Muslim communities, resulting in essentializing of identities, reliance on overly culturalist narratives, and lack of attention to historical, political, and structural influences on Muslim women's health. I would also argue that a barrier to translating relational feminist perspectives into ethical research approaches with Muslim women continues to be the lack of conceptual tools that from inception incorporate the perspective of the Muslim Other.

# **Re-imagining Islamic and Feminist Convergence**

For researchers, a centering of Islam in Feminism can serve to guide research activities with Muslim women by providing a relational approach that privileges the point of view of the Other. Muslim women's work on gender equity and women's rights have begun to incorporate definitions that converge Islamic and Feminist ideals, creating new possibilities such as Tawhidic Paradigm (Wadud, 2008), Muslim Holistic Feminism (Badran, 2011), and Critical Faith Centered Feminism (Zine, 2004). These Muslim scholars/activists share the belief that Islam inherently includes a historical gender consciousness that precedes Western Feminism. This notion stands in opposition to Western metanarratives of Muslim women, stories tragically told, all calling for the liberation of Muslim women from the grasps of a patriarchal Islamic tradition. Feminism, as defined by Cooke (2001) in her introductory chapter is a "changing state of consciousness" that reflects women's understanding of themselves and their position in the world, making it neither culturally nor regionally bound. She defines Islam as a "spiritual and cultural nation" that creates a common space for resistance to the colonial intentions of the West. The term West does not signify a geographically bound region but rather refers to capitalist and neocolonial hegemonic structures of power that shape discourses, division of material and knowledge resources, representations of identity, and, hence, the lived reality of everyday experiences (Badran, 2011). Cooke (2011, p.113) argues that Islamic and Feminist perspectives can be utilized together in acts of "multiple critique" to expose corruption, create new possibilities, and build spaces for empowerment and agency. This is the approach I felt morally and ethically inclined to use when engaging in research activities with Muslim women.

Not all Feminists see Islam and Feminism as reconcilable nor do all Muslim women activists call themselves Feminists (Seedat, 2013). Despite a multiplicity of positions, Muslim women who take on gender equity and women's rights struggles cannot escape what Cooke sees as a double commitment to one's faith on one hand and to women's issues on another. This commitment entails resistance to both patriarchal nationalist agendas and capitalist hegemonic systems of power (Zine, 2004). In a local research context, this commitment interprets into awareness and resistance of the complex and inter-related structures of oppressions that materialize within women's lives. It also means acknowledging that personal religious practices, religious identities, and broader political, historical, and social processes are inter-twined and counter-influencing. The identity label of Muslim, when situated within broader social and

historical structures, impacts the daily lives of Muslim women irrespective of personal religiosity. Like gender and race, religion has multi-level and inter-related implications in shaping women's lives (Klassen, 2003; Reimer-Kirkham & Sharma, 2011). Subsequently as Muslims, who we say we are, how people see us, and how we interact within broader society influences our access to and participation in research activities. For researchers engaged in research activities with Muslim communities, becoming familiar with the perspectives of Muslim women who lead Feminist struggles, the discourses that support or hinder their efforts in the Muslim world, and the interweaving narratives that bridge cultural and religious divides can illuminate and facilitate research processes in local contexts.

# Moving towards an Islamic Feminist Ethics

A Feminist ethics is concerned with locating power and resisting oppression, in all its forms, for all women. Feminists have long argued for a relational ethics that gives privilege to the world-views of those they research (Anderson, 2002; Fisher, 1997). This partially means incorporating into the design and implementation of a research study the ethical and moral perspectives that guide research participants. Muslim Feminists describe a centering of Islam in Feminism where Islamic perspectives constitute the departure point for social, historical, and experiential understanding (Seedat, 2013). Feminism remains a tool for critique, dialogue, and political solidarity within Muslim communities and globally. Ethical research involves understanding Islamic principles that ethically and morally guide Muslims, deconstructing the ways these principles come into being, are interpreted, and implemented using gendered and racialized lens, and creating spaces of dialogue to share Muslim women's experiences. Ethical research privileges difference based on alternative historical, social, and political realities and recognizes the power structures across Western and Islamic contexts that serve to disempower

and silence women. Research activities morphed into a process of heightening awareness. I began to recognize the positionality of the women within their families, their community, and broader society. This positionality was structured around the negotiation of power horizontally and vertically in their lives, becoming evident in the particular experiences of recruitment, consent, and data collection.

Women questioned the objectives of the research project, recognizing the minoritized status of Muslim women in Canadian society, the misconceptions about them, and the need to create spaces for community engagement and dialogue. Women negotiated participation, involvement of family in the research process, and the level to which their private lives were to be made public. Implicit in giving consent was the condition that I, the researcher, avoid the essentialized and unitary objectification of the Muslim subject. Women constructed stories of themselves that revealed the particular within the collective, balancing individual narratives with acknowledgement of the disciplinary forces that governed their lives. Mohanram (1999, p.82) suggests women's bodies are coded racially, culturally, socially, sexually, and nationally, carrying within them the privileges and burdens of such embodiment. I came to realize that the women and I were engaged in the illusive quest for a disembodied self. In the following section, I describe the interplay of identity, values, and power positions that unfolded in the research context.

## **Challenging Binaries: Identities, Values, and Power Positions**

I defined myself from the onset of the study as a bicultural researcher. I am a Muslim woman in my early thirties. I was born in Canada to a mother of European heritage, lived in the Middle East and West Africa for 25 years, and was living in Canada with my family at the time of the study. Being a Muslim with Middle Eastern heritage on my father's side and having lived

in the Middle East created grounds for connection with participants. Having European heritage from my mother and an Arabic accent that hinted of a bilingual tongue were grounds for questioning origins and belonging. Being born in Canada also meant I could not personally identify with the immigrant experience fully. This was often acknowledged by community members who in describing a part of their immigration experience would end with: "It is different for you, you were born here." This comment was in juxtaposition with another frequent question by some Canadians: "Where are you *really* from?"

The binary distinction between Muslim and non-Muslim and between Western and non-Western are based on political and historical representations which are contested, forced, and exploited within various ideological agendas (Said, 1994). From the Colonial representations of the Muslim Arab Other to nationalist and religious representations of a unifying Muslim or Arab identity, history is rampant with examples of a watered down and bland Arab and Muslim identity construct (Said, 1994). Not so often recognized in health research is that using the term Muslim and Arab identities as a plurality reflects more accurately how people within these communities define themselves and relate to one another. The labels of Arab, Muslim, and female are often attributed to individuals in health research with little attention to influences of class, education, region of origin, life history, and personal attributes (Charad, 2011). The women in this study embodied complex and multilayered identities beyond being Arab and Muslim that shaped their life experiences, their values, their power positions, and, consequently, their interactions with the researcher over the course of this study.

I acknowledge the tension between emphasizing differences to de-objectify the Muslim Arab woman and isolating Muslim Arab women as a group cohesive enough to warrant focus in a research study. This tension is described by Cooke where feeling the tantalizing gaze of

outsiders Muslim communities emphasize their collective attributes in resistance to their disempowerment, but when unthreatened emphasize their multiple and multifaceted selves. She states: "Where we are and with whom changes how we speak; it may even change what we say." (Cooke, 2001, p.138). To belong to the same culture is to belong roughly to the same conceptual and linguistic universe, to know how concepts are referenced in different languages, and how language can be interpreted to reference the world (Hall, 1997). Culture, in this sense, is a process or a set of practices. Shifting from a definition of culture as a fixed group attribute to culture as a process that is continuously reinvented and redefined means that a person's cultural expressions and interpretations shift across the life span within different social spaces.

Muslim Arab women share a common linguistic heritage despite differences in regional dialects, share common experiences of struggle against patriarchal and colonial systems of domination despite variations in degree of oppression, and share Islam as a historical and socio-political influence in their lives despite varying degrees of religiosity. I am a Shia Muslim from the Southern region of Lebanon. Lebanese Southerners would want to know that my mother is Ajnabiyi -a Westerner- that my father comes from a specific area in Tyre, the Ally of Egyptians, that my family includes notable television personalities and upper class business men, and that I married into a Sunni family from the North of Lebanon. Only this level of detail would satisfy participants as sufficient to know where my loyalties are likely to lie, the level of trust I can be given, and which parts of my experiences mirror that of the collective. Although I identified with women in the community along ethnic, religious, and gender lines, the sense of belonging, reciprocity, and responsibility stemmed primarily from a common experience of being perceived in a Western context as the foreign Other.

### **Embracing Complexity in the Research Context**

My relationship with the community, similar to that of other researchers (Monohar, 2013; Weiner-Levy & Abu Rabai Queder, 2012; Zubair, 2015), could not be understood within discourses of binaries. I was trying to balance subjectivity and objectivity, belonging and not belonging, and investing the inner self with distancing the self. I felt a constant worry about the potential for partial belonging jeopardizing authenticity of research findings and partial outsiderness jeopardizing ethical sensitivity. As a bicultural researcher working within a Western university, Foucault's panopticon symbolizes well processes of self-monitoring where researchers internalize the disciplinary function of the research institution. A panoptican is a structure, often a prison that allows visibility of all who inhabit it at all times by a single guard. Inhabitants are unaware of when they are watched and are forced to govern their actions as if they always are. Foucault used a panoptican to symbolize the way power functions in society. As opposed to seeing power as a top down exertion of control over others, Foucault saw power functioning as a disciplinary force internalized in the self and resulting in self-monitoring by the individual at a sub-conscious level to ensure alignment of the self with the expectations of power elites and institutional structures (Mills, 2003). Bicultural researchers often remain unaware of their subjugation within institutional hegemonic discourses, yet I believe possibilities for awareness can arise from the shocking volts of moral tension in those ethically important moments of doing research. I have internalized other ways of knowing that color the way I see the world and regulate my reactions to it. These ways of knowing stem from growing up as a child in the care of an observant Muslim grandmother, participating in the worlds of two colonized continents, and speaking a language rich in alternative histories. The political becomes

personal for a bicultural researcher, as the multiplicities of disciplinary forces burden the body and shape subjectivities.

I came to realize that within ethically important moments in the research process tensions would manifest when ethical decisions potentially opposed the norms of the research institution. What if I had embraced from the onset the messiness and fluidity of my social location, made explicit my personal and political commitments unapologetically, and created space for shared construction of ethical perspectives? This would have meant recognizing that what is ethical was not my decision to make alone. This would also have required engaging in a reflexive process that sees methodology, epistemology, and ethical action as intertwined and interdependent (Haraway, 1988; Mohanram, 1999; Mohanty, 1991). This does not mean I advocate abandoning the ethics of academic institutions that ensure a basic foundation of ethical research activities. Like other Feminist and Post-Colonial researchers (Anderson, 2004; Reimer-Kirkham & Sharma, 2011; Racine & Petrucka, 2011), I argue for expanding and building on these principles in ways that address the concerns of communities with which we engage in research. In the following sections I focus on the reconciliation process that was needed to uphold the principles of respect, concern for welfare, and justice. I chose to focus on these three principles as being common terms used in research ethics policies in Western and Muslim contexts (Canadian Institutes for Health Research et al., 2014; Fadel, 2010).

#### **Reconciliation within Ethically Important Moments**

# **Navigating Identities to Ensure Respectful Interactions**

Navigating identities was part of ensuring respectful interactions with the Muslim community and the women who participated in the research study. When women agreed to participate in the study by giving verbal consent, they were agreeing to do me a favor and help

their community. Recruitment methods included using flyers and using community gatekeepers to advertise the study. In-person introductions through formal information sessions, community volunteering, and involvement in social events was the only successful method of recruitment. Many women admitted that I was allowed into their homes because I was one of them. I was perceived to be a good Muslim woman who was working hard to study and support her family and, thus, deserved support. Yet, in building trust, I had accentuated one aspect of my identity and downplayed another. I was a doctoral student who would take the collected data and place it in the public sphere. I was motivated by multiple world-views that might or might not have converged with the views of community members. Moving from the recruitment phase to the written consent process, the emphasis became on my position as a researcher. This experience has been reiterated by another Muslim researcher (Zubair & Victor, 2015), where the consent process shifts the interaction from friendly and relaxed to formal with institutional and governmental overtones. In response to this shift, women either showed hesitance to participate or trivialized the process by agreeing to sign the consent form without asking questions. The consent process had to move away from being an efficient and standardized formality. The process became one of understanding root causes of discomfort, illuminating the hidden processes of the research institution, and looking for common ground on which to move forward. Explaining the role of an ethics board, the need for confidentiality and anonymity, participants' right to withdraw or refuse questions, and purpose of data collection were all crucial elements in the consent process. I learnt to strike a balance between too little and too much information, define and translate terms in a simple and clear language, and overcome the barrier of illiteracy.

Some women spoke Arabic but were illiterate. I audio-recorded participants' verbal consent in such cases and, often, literate family members reviewed the consent form as well. In

the literature on Muslim populations verbal consent has been advocated as a legitimate cultural practice and, hence, necessary to ensure cultural sensitivity (Aroian, Katz, & Kulwicki, 2006; Mohammadi, Jones, & Evans, 2008). Potential participants might refuse written consent due to the perceived legal nature of signing a document, fear of negative implications of giving consent, or inability to read the consent form. I was concerned that verbal consent might be interpreted, wrongly, as less of a formal commitment or more likely to safeguard their concerns around data usage. I emphasized the role of the ethics board in monitoring my research activities as a doctoral researcher, including whether or not consent was free and informed. This approach seemed to put participants at ease, as the act of signing the consent form became one of holding the researcher accountable, not the participant. All women agreed to participate in the study after the initiation of the consent process. One woman asked me to write down the term "ethics" so she could research the comparative term in Arabic. Some women questioned access of government to interview data. Two women refused to be audio-recorded for interviews but allowed note taking.

Ethically important moments during the processes of recruitment and consent also emerged from the need to balance notions of personal autonomy and notions of community responsibility (Canadian Institutes for Health Research et al., 2014). Fostering community trust and building personal relationships with potential participants are important for recruitment success in Muslim communities (Aroian, Katz, & Kulwicki, 2006; Mohammadi, Jones, & Evans, 2008; Zubair & Victor, 2015; Weiner-Levy & Abu-Rubai-Queder, 2012). The most successful recruitment strategy involved face to face interactions with potential participants. I attended social and religious gatherings, publically presented my research project, and volunteered in a recreational senior's group. I was conscious about avoiding the implicit message that the good

Muslim thing to do would be to participate in the study, especially since recruitment was occurring in religious settings. Islamic teachings emphasize a collective consciousness regarding social justice issues where personal autonomy and interests of the community are always in need of balance (Atighetchi, 2009; Chamsi-Pasha & Albar, 2013). It would be difficult to separate the recruitment process in Muslim communities from beliefs around obligations towards furthering collective good. The potential for coercion in observant Muslim groups does not relate only to the material and social but to the spiritual as well. A potential participant's sense of obligation could stem from perceived obligations to the researcher, to community members, and to God. Phrases such as "Muslims need to help one another" and "we need to support our Muslim community" were common utterances by community members. Problematizing these comments means we simultaneously recognize the potential for agency and the potential for coercion. Emphasizing a community's need to participate in research and an individual's right to refuse can become conflicting messages. I often received positive feedback from participants, where the interview process was an opportunity to socialize or vent troubles to a sympathetic listener. The lower number of recruits in comparison to the number of potential participants might point to coercion not playing out in this context. Also, the few community women who helped with recruitment through advertising the study by word of mouth and gaining consent from women to be approached for participation were not in positions of power where coercion could manifest. Community leaders gave their approval of the study to increase legitimacy within the community but were not involved in recruitment activities.

### Valuing Situated Knowledge in the Pursuit of Justice

Justice refers to fairness and equitable treatment of others (Canadian Institutes of Health Research et al., 2014). Justice in this context largely involves just representation through a

rejection of a totalizing transcending objectification of Muslim women. Muslim Feminists continue to address the issue of justice in the context of the lived experiences of Muslim women and in the structural, political, and cultural discourses around Muslim societies (Cooke, 2001). My initial interest in researching Muslim Arab communities resulted from a sense of inequity in knowledge production where the rise of chronic disease is coupled with minimal research capacity to address the issue (Jabbour, 2014). Concepts such as "intersectionality" (Yuval-Davis, 2006) address the intermeshed and multilayered influences of multiple social positions on women's location within structures of power across temporally and spatially contingent contexts. Important in health research around Muslim Arab women is the need to avoid conflating identity constructs with locations of power that shape community and individual narratives. There is a strong focus on women in research related to Arab and Muslim populations, with a bias towards seeing them as vulnerable, voiceless, and in need of rescue from their Arab male counterparts (Beitin, Allen, & Bekheet, 2013). Conflating vulnerability with gender oppression can overshadow the complex ways oppression materializes in the lives of women (Mohanty, 1991). Also, equating identity categories with positions of vulnerability erases the multiplicity and fluidity of positions Muslim women occupy in any given time (Anthias, 2002; Yuval-Davis, 2006). Researchers affiliated with higher institutions of learning are part of the higher echelons of power, meshed into intersecting structures of power, and can be complicit in speaking for those they research. Without the recognition of women's "epistemic privilege", their unique position in understanding the conditions of their lives, projects of activism will lack relevant frames of reference to create strategies for resistance and to procure political momentum (Wadud, 2008). Justice can only materialize in research with Muslim women if political activism occurs simultaneously while attending to both the micropolitics of women's everyday lives and

the larger societal processes that recolonize cultures and identities (Haraway, 1988; Wadud, 2008).

Ethically important moments arose from family members' involvement in the data collection process. Informal participation of family members in the data collection process has been noted in non-Western cultures (Aroian, Katz, & Kulwicki, 2006; Killawi et al., 2014). The close role family members played in the women's health, the lack of research addressing the perspectives of Arab Muslims, and family members' expressed desire to add their voices to the study meant tensions arose in creating spaces for women to speak while acknowledging the valuable insights of family members. Participants were comfortable being interviewed at home but at times their homes were small with a single common family area. This meant family members often sat with us drinking coffee and offering their insights into my questions during the interviews. Obtaining consent was frequently a family affair where spouses and children listened to the explanation and clarified concerns. Family presence during the consent process was a display of support and concern for women's best interests. Some women chose not to have their family involved, stating that they were comfortable doing this independently. Family members were often curious and wished to provide their perspectives on health issues facing the Muslim Arab community. When family was present during an interview, I explained the study to family and welcomed their presence. The questions were still directed to the participant, but when family interjected, input was welcomed and further insights encouraged. Often family members discussed their personal health problems and sought advice. I questioned what to do with the information provided by family members. Often family would give verbal consent for their information to be used in the study but since the original study did not take into consideration family input and this possibility had not been presented to the ethics board, I made

the decision to exclude any of this information. When participants requested their family members explain or clarify information for the researcher the information was included as part of the data.

The insights and presence of family did influence the type of data collected and increased complexity of understanding of community and family health issues. I felt, however, that the concept of justice towards the community was compromised by excluding voices that seldom had a space to express concerns. It would be useful for researchers designing studies with similar populations to incorporate into the study a space for the voices of family members. It can be argued that family involvement hindered women's ability to tell their stories in an unconstrained manner and, hence, jeopardized data collection. Women who were interviewed alone were more prone to emphasize life stressors within family life and difficulties coping. These women approached the interview process as an opportunity to vent troubles they could not share elsewhere. Women who were interviewed with family members emphasized resilience when family difficulties were discussed and steered away from potentially sensitive topics. This difference was especially evident when children joined the interview process of two women midway, resulting in a dramatic shift in the tone and focus of their answers to interview questions. Women were revealing different truths about their lives to different audiences, meaning access to different types of data. The tension between family involvement and creating unconstrained spaces for sharing was ongoing in the data collection phase of this study.

# **Recognizing Agency in Concerns for Welfare**

Concern for welfare involves minimizing harm that can come from engaging in research and maximizing potential benefits (Canadian Institutes of Health Research et al., 2014). A danger of addressing welfare in research with Muslim women stems from identity constructs that

are culturally and historically bound, where women are viewed as unable to comprehend complexities of the research process, identify their best interests, or recognize the forces that shape their lives. Researchers then feel the need to think for, act for, and decide for research participants to safeguard their welfare. In the aim of protecting those they research, researchers unintentionally re-inscribe colonial discourses of the Other (Mohanram, 1999). Once I had gained access to the community, established a trusting relationship, and cemented my community membership, I began to ask myself what the community needed from me. Arab and Muslim researchers in other contexts have reflected on this need to ensure reciprocity beyond what would be expected of a Western researcher (Hawamdeh & Raigangar, 2014; Morsy 1988). I was entering spaces designated for religious and spiritual reflection, asking women to donate valuable time to my cause, and interrupting the flow of their lives to do research. Day to day interactions with the community revealed the need to engage, to feel with, and to act in tangible and continuous ways in support of seniors' health and social initiatives. This Muslim community had minimal access to material and knowledge health resources that were linguistically and culturally appropriate. The item on the consent form stating that no personal benefits were expected from study participation seemed irrelevant. It can be argued that a bicultural researcher who works to increase perceptions of belonging also increases community expectations of reciprocity and, hence, will struggle with the moral obligations to meet these expectations. A sense of ongoing obligation towards the community interpreted into decision-making that favored enhancing agency and supporting women in managing their health. This sense of obligation also resulted in tensions when attending to the welfare of the community meant I engage in non-research activities, muddying the boundaries between researcher, healthcare professional, and friend.

An alignment with Islamic Feminist ideals helps balance my sense of obligation as a Muslim, my role as a researcher in advocacy and empowerment, and the need to ensure quality research outcomes. One strategy implemented was volunteering in a non-essential position with a recreational senior's group. I was available to chat with seniors, provide information on community resources, and listen to community concerns. One contribution included locating an appropriate exercise video for seniors, which the group continues to use. I interviewed the majority of participants in their home, meaning I was more intimately aware of their living conditions and health practices. This increased the role conflict between researcher and nurse (Locher, Bronstein, Robinson, Williams, & Ritchie, 2006). Participants often requested information on snow removal services for seniors, English language classes, and health literacy resources. For participants with multiple vulnerabilities related to illiteracy, language and cultural barriers, financial restraints, and transportation barriers, it was rarely possible to find relevant community and health resources. I addressed knowledge gaps such as necessary lifestyle modifications and side effects of different medications. Education was provided at the end of interviews, as data collection partly involved identifying health literacy. I found myself musing over the need to strengthen my nursing competencies to better answer questions or provide teaching to participants.

Some participants saw us as developing a new friendship. When these participants were more vulnerable, their reference to friendship was stronger. Gestures of friendship included offering food, requesting future home visits, and asking to meet my family. I accepted the food, being the culturally respectful thing to do, but did not engage in social visits to participants' homes after the interviews. As I was involved in the community as a volunteer and attended social and religious events, social interactions with many participants continued after the

interviews. I was seen as a confidante, counselor, and professional where recruitment and data collection also included providing comfort and encouragement. However, the concern for welfare was reciprocated by the community. I often received advice about marriage, children, and religion as older community members shared words of wisdom.

Simultaneous recruitment, data collection, and socialization within the community increased the risk of compromising confidentiality and anonymity. Confidentiality refers to the need to keep collected data safe from unauthorized use, disclosure, loss, or alteration (Canadian Institute of Health Research et al., 2014). It is important in small communities, where social networks are extensive, to recognize the ease of identifiable information being traced back to participants. Due to a lack of experience with research, women did not initially grasp the concept of confidentiality. I was often asked if I had interviewed a specific person, how the interview went, and if they had told me about a specific event. Other times community members shared the information considered relevant to my research about participants, which participants had withheld from me. This information was never explicitly introduced into the study but could not help but influence my perceptions during data analysis. Confidentiality is emphasized in Islamic teachings as a practice that prevents malice in society (Alahmad, Al-Jumah, & Dierickx, 2012). I, also, explained the conditions of confidentiality set by research ethics boards and research policies. Using both Islamic and Institutional references, I justified not revealing who I had interviewed or details of the conversations. Participants sometimes told others that they had been interviewed to encourage participation. This occurred during the snowball method of recruitment, where one participant located another potential participant. Interestingly, this was almost never successful in increasing recruitment. One participant informed me, on arriving to her house, that she had just finished conversing with her friend whom I had interviewed an hour

ago and knew the questions I would be asking. Confidentiality could not be fully ensured during recruitment and data collection. This means attention to anonymity must be emphasized during data dissemination, especially in regards to unique personal stories and life events that might be common knowledge in the community.

### **Conclusion: Reflecting on Tensions and Imagining Possibilities**

This paper summarizes my reflections as a bicultural Muslim researcher engaging in ethically important moments with Muslim immigrant women. For researchers involved with Muslim communities, this paper highlights some of the ways ethical tensions can materialize when dominant narratives focusing on binaries of difference are unchallenged within particular research interactions. I see bringing Islam in from the margins using Feminist tools of engagement as a possible strategy to reconcile ethical tensions. Cooke (2001, p.184) describes Islamic Feminists as coming into "representation from the margins" in ways that disrupt dominant discourses and challenge metanarratives that define and limit Muslim women. This coming in from the margins involves building knowledge around ethical and moral perspectives of Muslims, as they continue to morph and re-morph within intersecting influences of culture, gender, class, and race. It also involves seeing Muslim women as a conduit for agency, while simultaneously recognizing the patriarchal and colonial powers that constrain us all, albeit in different ways and to different degrees. Lastly, it is necessary to disrupt the binaries of West versus non-Western, us versus them, and subject versus object to create participatory spaces of engagement and solidarity amongst women, while recognizing the horizontal and hegemonic power struggles that limit this process.

Ethical research with Muslim communities entails researchers develop a strong personal foundation of understanding around local and global influences in the lives of Muslim women,

reflect on personal identity, values, and power positions in the research dynamic, and ensure that Muslim women's needs, beliefs, and goals are incorporated into the research process. This paper focuses on my experiences and interpretations and, hence, fails to capture the full range and complexity of the community's experience. At best this paper adds my voice to a plethora of Muslim women who speak from varying standpoints. Some voices are heard more clearly than others, with some remaining whispers drowned out by the roaring hum of academic elitism, global capitalism, and nationalist extremism. Finding ways to create participatory spaces that engage Arab and Muslim communities in discussions about ethical research practices remains a future objective.

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# **Chapter Three**

**Title:** Social Dimensions of Health across the Life Course: Barriers and Facilitators to Engaging in Health-Promoting Practices in Middle-Aged and Older Arab Immigrant Women.

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**Abstract:** The increase in ethnically and linguistically diverse older adults in Canada calls for attention to healthy ageing in this population. This study presents the experiences of a sample of middle-aged and older Arab immigrant women engaging in health-promoting practices in the context of stroke prevention. Women describe their experiences of social connections, social roles, and social support constructed and maintained within transnational spaces across the life course. Five themes emerge that point to the relevance of social dimensions of health in creating barriers and facilitators to healthy ageing in this population: (a) the necessity of staying strong, (b) caring for self while caring for others, (c) double jeopardy of chronic illnesses and loneliness, (d) inadequate support within large social networks, and (e) triple ingredients of empowerment. These findings point to the need to incorporate an understanding of transnational connections and post-migration social support into initiatives that target health promotion with Arab immigrant women.

### **Chapter Three**

# Social Dimensions of Health across the Life Course: Barriers and Facilitators to Engaging in Health-Promoting Practices in Middle-Aged and Older Arab Immigrant Women.

Canada's ethnocultural diversity will increase in future ageing cohorts, due largely to increased immigration trends from non-European countries and decreased mortality rates (Carrière, Martel, Légaré & Picard, 2016). With the increase in number and diversity of older immigrants comes the need to attend to healthy aging in this population. Arab immigrants are one of the largest non-European ethnic groups in Canada and immigration from Arab countries continues to rise (Statistics Canada, 2007). Older immigrant women in Canada experience multiple health barriers, including barriers to managing chronic illnesses, with limited access to health-promoting resources (Guruge, Birpreet, & Samuels-Dennis, 2015). Arab immigrant women, in particular, have minimal access to and availability of supportive health resources that are culturally and linguistically appropriate (Aqtash & Servellen, 2013; Gholizadeh, DiGiacomo, Salamonson, & Davidson, 2011; Girgis et al., 2009; Qahoush, Stotts, Alawneh, & Froelicher, 2010). The purpose of this study was to better understand Arab immigrant women's experiences of engaging in health-promoting practices as they aged in Canada, with a focus on stroke prevention. The study used an interpretive descriptive methodology to look at the experiences of 16 middle-aged and older Arab immigrant women with making healthy lifestyle choices, managing chronic health conditions, and accessing health-promoting resources.

The study was framed around a life course perspective to conceptualize the multiplicity of environmental, societal, and individual factors that could influence Arab immigrant women's health. For this paper, we focus on findings that relate to the social dimensions of health identified in women's stories. Various social dimensions influence immigrant women's abilities to manage their health, such as size and quality of social networks, availability of social support, and social roles (Grace et al., 2016; Guruge, Thomson, George, & Chaze, 2015; Kokanovic & Manderson, 2006; Koch, Wakefield, & Wakefield, 2015; Stewart et al., 2008). We identify transnational connections and post-migration social support as relevant social dimensions of health influencing Arab immigrant women's participation in health- promoting practices.

### **Theoretical Approach**

The term 'life course' refers to a series of socially defined events and roles that an individual enacts over time (Elder & Giele, 2009). Transitions, from a life course perspective, mean the processes of moving into and out of roles and statuses across the life course (Elder & Giele, 2009). The migration process can be seen as a major life transition, where the reasons for migration, the context of migration, and the timing of migration impact the life course of an individual in ways that influence health (Leu et al., 2008; Montes de Oca, Garcia, Sáenz, & Guillén, 2011; Shishehgar, Gholizadeh, DiGiacomo, & Davidson, 2015; Spallek, Zeeb, & Razum, 2011; Vissandjee, Desmeules, Cao, Abdool, & Kazanjian, 2004). Theoretical approaches used to frame immigrant health issues need to reflect the ways immigrants live their lives in an increasingly connected world, propelled by advances in technology and communication. Evidence suggests immigrants structure their lives within transnational spaces, temporal and spatial contexts that transcend national borders and that are shaped by processes of globalization, capitalism, and colonialism (Calvasina, Muntaver, and Quino, 2015; Messias, 2002; Purkayashta, 2010; Gupta, 1997). A wider incorporation of transnationalism as it is shaped, disrupted, and reinvented across the life course and the resulting influences on health is needed in the context of migration.

The term "transnational spaces" is used in this paper to refer to immigrants' continuing ties to pre-migration contexts and the resulting impact on pre-migration and post-migration communities in which these connections are made. Pre and post-migration contexts, respectively, refer to the politically, historically, and socio-economically contingent realities of the countries of origin and destination as experienced by immigrants. Transnational theoretical approaches illuminate the complexity of macro and micro level factors across migration contexts that influence health, the ways immigrants navigate their interests within these spaces, and the sometimes conflicting social locations immigrants occupy across contexts (Mahler, Chaudri, & Patil, 2015; Sharma & Reimer-Kirkham, 2015; Wang, & Kwak, 2015). Social dimensions of health are often constructed within transnational spaces, revealing the fluidity, interrelatedness, and complexity of relationships migrants maintain across pre-migration and post-migration contexts (Carling, 2008; Viruell-Fuentes, & Schulz, 2009; Wong, 2006). We focus, in this paper, on women's subjective interpretations of social influences on health within different migration contexts across the life course.

# **Research Design**

Interpretive description, a non-categorical pragmatically-oriented qualitative methodology, was used to allow for a process of shared interpretation between researcher and participant, while bringing into the analysis the social, economic, and political contexts that shape life experiences (Thorne, 2016). Interpretive Description [ID] was a method that fit well with the theoretical approach used in this study, as it simultaneously focuses on the meanings of experiences to participants and situates these experiences in light of broader macro and micro level structures and processes.

# Sample

Recruitment posters in areas with high flows of Arab immigrants such as ethnic grocery stores, community and religious centers, and health clinics were initially used, but were unsuccessful as a recruitment strategy. Increasing researcher visibility through engagement in religious events and community activities over a period of one year and simultaneous use of community gatekeepers was a successful strategy. Convenience sampling was used initially, followed by purposive sampling later in the study. All participants were living in the community, with 16 participants recruited altogether. Participants were Arab Muslim immigrant women between the ages of 45 and 75, who emigrated from the Levant region of the Middle East between 1970 and 2000, and were currently living in a major Urban Canadian center in Alberta. Levels of education ranged from illiterate to completing junior high, with one participant having a university level degree. Income was low to middle range with those at retirement age receiving basic pensions. Five out of the 16 participants had a self-reported history of a health-altering event such as a stroke, transient ischemic attack [TIA], or myocardial infarction [MI]. Selfreported chronic disease profile included at least two cardiovascular chronic conditions and/or at least two cardiovascular risk factors, primarily diabetes, hypercholesteremia, hypertension, cardiac disease, obesity/overweight, and smoking. All participants were on at least two medications for their chronic illnesses. All participants saw their family physicians every three months to annually at a minimum. English language proficiency was mostly minimal, with all interviews completed in Arabic or a combination of Arabic and English.

# **Data Collection**

The Health Research Ethics Board of the University approved the research study before initiation of recruitment. All participants chose to be interviewed at home except for one

interview completed in a mosque. The interview process involved a socio-demographic and health questionnaire and a semi-structured interview. Interviews began with a broad question: 'Can you tell me about your health?' to allow participants initial control over the direction of the interview. Follow-up questions touched upon a broad array of health influences, from immigration experiences and re-settlement in Canada to recent experiences of aging with chronic illnesses. The aim was to identify across the life course major influences on the ability to engage in health-promoting practices. Data saturation was sought for the major themes that were elicited in the interviews with participants. Data saturation was interpreted as obtaining data that was both rich in the qualitative aspect of description and data that can convey commonalities and variations of participants' experiences. Objective health data were difficult to obtain as participants were often unaware of their current health profile, such as blood pressure readings, terminology of medical diagnoses, and rationale for certain prescriptions. All interviews were audio-taped and transcribed, by the primary researcher, using verbatim transcription. A second volunteer fluent in Arabic validated a random selection of the interview transcripts to ensure accuracy.

### **Data Analysis**

An ID methodology relies on constant comparative analysis processes, originating from grounded theory, to understand human phenomena (Thorne, 2016). Cross-language researchers have advocated for initial translation and coding to be done in the language of participants when a bilingual researcher is available, followed by translation to English during the categorization phase, so as not to lose cultural expressions and concepts (Temple, Edwards, & Alexander, 2006). A bilingual researcher participates in meaning construction when conducting crosslanguage research, therefore the assumptions and perspectives of the researcher need to be taken into account and made explicit (Temple et al., 2006).

The primary researcher was fluent bilingually in Arabic and English and had lived in the Levant region, resulting in familiarity with language and cultural expressions. However, the Levant region encompasses many dialects and participants were from a different generational cohort, meaning the researcher often asked for elaboration on colloquial expressions. Data collection, transcription, and analysis occurred simultaneously allowing for immersion into the data over a one year period. Preliminary data analysis was done in Arabic to ensure the original meanings of texts were not lost in translation, where initial codes and categories were located and organized thematically. The first few interviews and resulting data analysis were translated into English early on so that a second non-Arabic speaking researcher could identify areas needing further investigation or possible biases in the analysis processes. An audit trail was kept by the researcher to record details of interview contexts, changes in interviewing questions/approaches, and thoughts on emerging categories within participants' stories. Final themes and exemplars were translated into English by a certified translator.

### Social Dimensions of Health across the Life Course

Women in this study focused on social connections, social roles, and social support constructed and maintained within transnational spaces across the life course. Women's stories revealed the continuous, linked, and non-time sequenced influences of maintaining ties between countries of origin - the pre-migration context, and Canada - the post-migration context. Five themes were identified that highlight socially contingent barriers and facilitators of health in the lives of Arab immigrant women: (a) the necessity of staying strong, (b) caring for self while caring for others, (c) double jeopardy of chronic illnesses and loneliness, (d) inadequate support within large social networks, and (e) triple ingredients of empowerment. Some details have been slightly changed in women's stories to ensure anonymity within a small community.

# The Necessity of Staying Strong

Women in this study were living with one or more chronic illness and were managing their health in the face of multiple barriers stemming from immigration stressors, lack of social support, and caregiving responsibilities across the life course. Staying resilient and taking charge of their lives was a strong theme discussed by all women, who wove stories about the past to explain current health status and approaches to health management. Women saw the strength to be a good mother and wife in Canada as connected to positive life experiences in the premigration context that fostered resilience and self-sufficiency. They often described their happy childhood years in their countries of origin and compared it to the difficulties of migrating, often in the context of a new marriage, and adjusting to life in Canada with economic and cultural challenges: "...when we came here the most difficult thing was to get married and come here, meaning a husband and wife together....there was no car, nothing...we used to live in the lower level of my sister's house, spread the blankets on the floor to sit on, we didn't even own our own bed, someone bought one for us....I used to tell my husband I want to go back to Lebanon, I do not want to live here..." (Participant 12). Usually the adjustment phase was followed by finding economic stability, developing a sense of belonging in Canada, and focusing on their roles as mothers and wives, resulting in a sense of accomplishment and pride in older age: "...If we wanted wars and headaches we could have stayed home in Lebanon, we ran away from this to a decent life, right, to start and have a decent family, we came here, thank God, we worked so hard, we raised our kids and we raised beautiful kids..." (Participant 7) Positive stories were often connected to more positive attitudes towards health alterations and a stronger sense of control over health.

Other women experienced difficult childhoods due to war, economic disadvantage, and lack of education opportunities. These women constituted a cohort that grew up in a period when education was not readily available for girls and marriage in the teenage years was a norm. Traumatic life experiences such as witnessing violence, death of a parent, or poverty in childhood were connected in women's stories to negative perceptions of health and difficulty managing health concerns. The early death of one woman's mother and her subsequent mothering role for younger siblings was drawn upon to describe her perception of current mental and physical illnesses: "...I grew up without a mother, I came here and life was difficult...My husband was working at the grocery store then he would go out to party with friends...I was the man and the woman in the house...I suffered a lot." (Participant 8). Women who were most vulnerable as aging immigrants in Canada often told stories that reflected ongoing hardship and disempowerment across the life course, such as poverty in childhood, lack of education, war, and difficult marriages.

### **Caring for Self while Caring for Others**

Transnational connections were explained by women as ongoing social ties to premigration contexts. The majority of women in this study migrated in their late teens to early twenties. As the women became more economically and socially stable in Canada, usually in mid-life, they were more involved in supporting family in the pre-migration context and this support continued as they aged. Support was described as financial assistance to family, intermittent caregiving for elderly parents, and solidarity with Arab political struggles. Providing support often was a barrier to women's abilities to manage health, especially in times of family crises. Despite knowing that self-care was important, women often prioritized the needs of the family. Important here was that family responsibilities and loyalties extended across borders necessitating periodic travel and economic sustenance, plus precipitating an ongoing sense of worry towards global political, social, and economic realities that affect the well-being of family in other places.

These women came from a region marred by economic and political unrest that ebbed and flowed over their life course. At the time of the interviews, events such as the Arab Spring, the Palestinian Intifada, and the Syrian Uprising were ongoing concerns for the community: "The whole Arabic situation is tragic, after I watch the news my blood pressure increases...sometimes I watch about Palestine and I stop, I stop, my heart, my blood pressure increases." (Participant 4). One woman correlated her political activism with the onset of a cardiac event: "I went to a rally for Gaza, next day I had a heart attack, I feel the people's pain; it was a stressful summer." (Participant 3). Supporting family in the country of origin also entailed financial assistance: "You are not only supporting your family here, but your family back home too." (Participant 3). In further elaboration, this woman stated: "My brother has health issues in (home country) and we all feel guilty that he is alone...we help with money...I was worried that day about him."

Women's abilities to engage in health-promoting behaviors were also diminished due to caregiving role strains and lack of assistance with household responsibilities. Women's caregiving roles began at an early age as mothers and wives and continued in caring for ill spouses, ageing parents, and grandchildren. In discussing her spouse's illness and her role as a caregiver, one woman stated: "Things passed...but if I get a second stroke I will not be surprised, there was a lot of pressure." (Participant 12). A second woman reflected on her caregiving role: "what makes it difficult is when he gets sick, I stop taking care of myself, I worry about him and forget myself." (Participant 7). She later elaborates: "I was fine with my exercise, after my stent, I started with this senior program three days a week and I was doing good...until he had his heart

attack and then I was too busy with him, I was always scared to leave him and go…" In referring to the double stressors of caring for her father living in her home country during a terminal illness and her responsibilities towards her children a third woman said: "From that event...to now, is the period where my health was most affected...sometimes I do not get enough sleep...if a child speaks to me I do not have the desire to answer, I do not have the desire for anything…" (Participant 5). One woman described stopping her medication when she traveled to her country of origin to care for her father and attributed this as a potential cause for her stroke: "I lost half my body weight, I was not eating…I stopped taking my medication…I kept working and stayed beside my mother, may her soul rest in peace, I did not leave or go out or walk…at home…you see misery/sadness and staying at home all the time made it worse." (Participant 6)

# **Double Jeopardy of Chronic Illnesses and Loneliness**

Women coped effectively with chronic illnesses and/or the residual effects of a healthaltering event when strong social support was present in their lives. Women described social support as having close friends they could confide in, having social activities outside the home, receiving financial help and services from family, and being connected to community and religious organizations. When women experienced multiple vulnerabilities, such as decreased social support, caregiving role strains, family crises, and stressors from transnational connections, they reported experiencing more emotional and mental distress and, subsequently, decreased ability to manage health effectively.

Loneliness was a re-occurring term used by women with multiple vulnerabilities to describe their situation at the time of the interview. Two quotes that exemplified the feeling of loneliness well were: "For the person sitting quiet at home, do you speak to the walls, you listen to the television but you want to speak too." (Participant 13) and "Here (referring to Canada) is being in prison without having committed a crime...in Lebanon you can put the chair on the balcony and hear the cars go by...here is a place full of people but it is empty." (Participant 10). This last quote came from a woman who had significant physical limitations and minimal social support resulting in her being confined to the home the majority of the time. Loneliness was exacerbated in this group by a feeling that children were busy with their own lives, death and disability within peer cohorts in Canada, weakened ties to social networks in countries of origin, need to save face within the community by concealing problems, caregiving responsibilities, and chronic illnesses that limited mobility and stamina for social interactions. One woman whose spouse recently passed away stated: "I have a little bit kind of depression, I am alone....I have very nice children...they check on me, they call me, they have supper with me but not every day and they are busy too..." (Participant 10). Another woman said: "there are people who are disabled, who cannot drive...another person, if they can, should come every two weeks and say hello, how are you." (Participant 16)

## **Inadequate Support despite Large Social Networks**

Women consistently pointed to the lack of support in managing chronic illnesses and engaging in health-promoting practices as one of the biggest barriers to health. Lack of support was described as lack of information about ways to engage in health promotion, lack of emotional support in managing emotional and mental health consequences of their illnesses, and lack of access to community and health resources that are culturally and linguistically sensitive. Women's social networks were often consolidated within the same ethnic and linguistic community, making it difficult to access support within the wider Canadian context. Women described accessing different forms of social support in their lives from family, friends, neighbors, and community acquaintances to varying degrees of satisfaction. The majority of women did not want or felt they could not burden family members with their health concerns and attempted to hide their emotional and mental distress when present. Children were seen as having their own lives and being too busy to provide needed assistance: "I go to the mall and walk a bit and when I am tired I sit down, but to my children I say nothing, I say I am good...I don't want them to worry about me." (Participant 6). Women found their friends within the same age cohort as vital in countering the negative effects of life stressors: "what helped were my friends, my friends more than my kids, because my kids for example ask how dad is. 'How is dad doing?' Dad, dad, I tell them, I see you are asking about your father all the time but I am the one suffering." (Participant 12). Yet, at times, their mental/emotional state hindered socialization and in turn exacerbated expressions of frustration and anxiety. When asked about opportunities for socialization, one woman indicated: "I don't have (referring to social engagements)...I get bored...10 mins to half an hour and I say take me home again, I no longer have patience even with myself." (Participant 8) This same woman complained about frequent headaches attributed to staying home all the time and not being able to drive.

Some women identified external barriers to socialization. Extensive social networks when present, did not always interpret into emotional support and companionship: "I do not have a lot of friends, but I know everyone..." (Participant 2) and "I got to know a lot of people when I came to Canada, but only a few turned out to be my truest friends." (Participant 6). Many women felt they could not confide their personal troubles to people from the community as it was important to save face and avoid gossip or people were too busy with their own lives: "Nowadays everyone has their own problems…you cannot bother others, every day there is work, many worries, responsibilities of children, responsibilities of the home…" (Participant 16). Another woman's story reveals the complex ways lack of social support can materialize in the lives of immigrant women:

Once I stood on the sidewalk and waited for a lady from the community to pass and told her you have to come drink a cup of coffee...she came, maybe when she knew who I was and where I was from she didn't visit any more...everyday she goes walking with her friend or her neighbor, I never saw her at my place and she didn't invite me to hers. (Participant 4)

In an ethnically rich neighborhood the divide between different Arab groups on political, class, and religious lines hindered socialization and exacerbated loneliness for this woman. The sense of exclusion was exacerbated by being new to the neighborhood, having come from another province. Language barriers prevented her from getting to know her English-speaking neighbors: "My neighbor has children, non-Arabs, maybe because of language we don't talk, I don't say hello, how are you, they think I am different...If I could speak the language, I would talk to her...we have been here a year." (Participant 4)

# Triple Ingredients for Empowerment: Faith, Language, and Driving

Women referred to three ingredients: (a) faith, (b) speaking English, and (c) ability to drive as facilitators of health. Women who described themselves as healthy could drive and had a better command of the English language. They were more able to, independently, seek out opportunities to counterbalance loneliness and incorporate health-promoting activities into their daily routines through volunteering, working part time, going to malls for walks, gardening, and visiting with friends. Having a basic command of the English language and driving both increased opportunities for socialization with non-Arab neighbors and participation in wider community activities. When absent, a negative cycle ensued where, for example, women could not access English language lessons since they could not drive. They could not access avenues for social support within the wider English-speaking community due to language barriers that exacerbated a sense of difference and isolation.

English fluency and ability to drive were determined largely by re-settlement in the early post-migration context. Often work outside the home involved labor work or family businesses which offered little opportunity for socialization in English. For the majority of women access to English as an additional language [EAL] was hindered by childcare responsibilities, lack of support from family members, and transportation difficulties: "I said I want to learn (to become literate) and go to school. I would go 8 in the morning and finish at 2 pm and then return to work. I would finish work 6, 7, or 8 pm and come home. You have to cook, you have to clean, there are kids, and my husband is at home with an injured hand, anyway, what I could do. I learnt a little and felt I wasn't benefiting. Everyone else was advancing in class but I did not have time to study. I would come home and need help but there was no one to help me. So I said I am not going any more...I removed education from my plans..." (Participant 9) and "I studied at (name of immigrant women service organization). I went and bought books...my son was a baby, I got a babysitter, he kept crying, I would go home and find my four children unhappy...in the end I learnt a little from television, from life." (Participant 1). Driving, on the other hand, was often seen as a pressing necessity due to spouses working out of town and/or the need to take children to appointments and run errands: "I go visit people, friends, run errands, if my husband can't drive, he is sick, I take him to the doctor...driving is very helpful for a woman, especially in this country." (Participant 13) and "...the thing that helped me make life easy for both of us is he pushed me to drive...One time I had an appointment with the doctor and he forgot, so I called him at work and said we have to go to the doctor and he said that's it, you are going to drive." (Participant 7)

Women saw staying close to God using prayer, learning about their religion, and attending religious events as helping them build intrinsic coping abilities in the face of life stressors. In describing the experience of caring for a critically ill spouse, one woman shared her perspective: "They say if you have a problem you should confide to someone. Despite friends visiting I used to share very little....my problem I confided in God and complained to him and I ask why it is this way Oh God?" (Participant 12). Religious teachings provided women with fatalistic notions of illness and health altering events, where things were seen as being as God destined them to be. Yet, this perception was balanced with Islamic teachings that emphasized personal responsibility for one's health, not giving up hope, caring for the body, and seeking treatment. After a health-altering event or life crisis, women described their experiences of connecting to God to gain the strength to manage health effectively. Praying and reading the Quran were seen as effective stress management strategies. A woman described the impact of faith on overall wellness: "Faith helps you feel healthier, stronger, whatever happens to you, you say 'thank God' and if something happens to you, you don't cry over it…" (Participant 7)

#### Discussion

Women with multi-layered vulnerabilities described mental and emotional distress, loneliness, and unmanaged chronic illnesses such as diabetes and hypertension. Being an older Arab immigrant woman with chronic illnesses did not, however, consistently interpret into high levels of vulnerability. Some women in the study were able to navigate and access different levels of social support and foster personal resilience to manage their health effectively. Vulnerability here is used to reference women who experienced various barriers to engaging in health-promoting practices, minimal access to supportive resources that facilitate health, and who reported dissatisfaction with their health status at the time of the interview. We focus on transnational connections and post-migration social support as being key social dimensions of health influencing the ways vulnerability can manifest in the lives of Arab immigrant women.

## Maintaining Transnational Connections across the Life Course

The findings around 'the necessity of staying strong' and 'caring for self while caring for others' show the influences of social roles and caregiving responsibilities on women's abilities to care for self and manage health concerns effectively. For the women who had arrived as young adults and lived the majority of their lives in Canada, it might be expected that the postmigration context be most influential on health. The three migration contexts- pre-migration, migration, and post-migration- were not mutually exclusive in women's stories. Rather a fusion of spatial and temporal connections across contexts was the main insight gained from women's experiences. The 'there' and 'here', and the 'now' and 'then' were interconnected to create unique and tangible influences in women's lives, particularly in their abilities to manage health. Transnational connections were framed as women's emotional ties to loved ones in the home country, material assistance in the form of remittance, and intermittent caregiving for children and parents. The literature on transnational ties reveals that these connections across the life course can serve to either enhance well-being or increase stress depending on a variety of pre and post migration factors (Amoyaw & Abada, 2016; Sanon, Spigner, & McCullagh, 2016; Torres, Lee, González, Garcia & Haan, 2016). Women in this study often described the cumulative impact of ongoing caregiving roles transnationally and locally as resulting in physical and mental exhaustion and subsequent disregarding of personal health needs.

Despite strong transnational ties in this study, women often described feelings of loneliness as they aged in Canada, raising questions about reciprocity in continuing transnational ties in the post-migration context. Loneliness can be defined as a subjective sense of emptiness,

worthlessness, lack of control, and personal threat (Cacioppo, Hawkley, & Thisted, 2010, p.2). Immigration as a factor that influences loneliness continues to be an important area of study with some indication that timing of migration in an individual's life (Wu & Penning, 2015), the quality of social networks, (De Jong Gierveld, Keating, & Fast, 2015), and belonging to an ethnocultural minority ( De Jong Gierveld, Van der Pas, & Keating, 2015) influence the development of loneliness. Women in the study who had low income, mobility limitations, minimal English fluency, and who reported mental and/or physical health problems were more likely to report feeling lonely.

## Availability of Social Support in the Post-Migration Context

The findings around 'double jeopardy of chronic illnesses and loneliness' and 'inadequate support within large social networks' point to limited social support in the postmigration context in relation to engaging in health-promoting practices. Social relationships in the post-migration context were described as being part of a broad social network within the Arab community but, also, as having limited social support in managing health. Social support refers to the psychological and material resources a social network can provide to buffer life stressors (Cohen, 2004). Cohen defines three forms of social support: (a) instrumental, involving financial or task-oriented assistance, (b) informational, involving relevant information or advice, and (c) emotional, involving caring and empathetic behavior. Social support impacts health by constituting a stress buffer or what we term a facilitator of health, where perceived support helps facilitate positive cognitive processing of stressors and actual support facilitates successful coping strategies. These three forms of social support were addressed in conversations with the women. Having an extensive Arab social network or living in a neighborhood with a high percentage of Arabs did not necessarily interpret into social support due to possibilities for exclusion based on other categories of belonging, mobility issues that limit ability to interact with others, and need to save face when dealing with life stressors. Peers were seen as essential for companionship and emotional support, but family problems and personal issues were often concealed to save face and avoid gossip, meaning these women did not have ways to vent negative emotions. Women's families, especially their children, were the primary sources of informational and material support in the context of managing chronic illnesses and engaging in health promoting activities. Forms of support provided by family were often seen as inadequate due to lack of services specifically targeting the needs of Arab women, limited family financial resources, and unwillingness of women to burden family with their needs. Immigrant women might focus on co-ethnic social relationships for support due to limited fluency in English language, lack of workforce participation, or restricted opportunity for socialization within the wider community (Hynie, Crooks, & Barragan, 2011; Neufeld, Harrison, Stewart, Hughes, & Spitzer, 2012; Stewart et al., 2006; Wong, Yoo, & Stewart, 2005), despite this support not always meeting their needs. Also, immigrants from common ethnic backgrounds can differ in their historical and social positioning leading to a sense of difference, lack of solidarity, and loose social ties within social networks in the post-migration context (McMichael & Manderson, 2004). The findings in this study mirror those in the literature on other immigrant groups where social networks within the same ethnic group and proximity of family in the post-migration context do not necessarily interpret into the required quantity and quality of social support.

The literature shows that older adults migrating in later life tend to lack opportunities for social integration and face language and cultural barriers that influence health negatively (Chun et al., 2011; Emami & Torres, 2005; Tummala-Narra, Sathasivam-Rueckert, & Sundaram, 2013). This study also points to challenges when migration occurs early in life and women are aging in

Canada while experiencing multiple vulnerabilities. In the findings, women identified 'triple ingredients for empowerment', where English proficiency, ability to drive, and religiosity were factors highlighted by women as enhancing intrinsic coping and access to social support. Speaking English meant increased knowledge of and comfort accessing community and health services. Driving and owning a car were essential for socialization, access to health services, and for maintaining a sense of independence with increasing age. Religiosity enhanced intrinsic coping but also served to increase social connectedness and access to social support via mosques and religious activities. Providing English as an additional language [EAL] learning opportunities, facilitating access to transportation, and incorporating spiritual dimensions of health into health promotion initiatives are all important avenues for future exploration in supporting Arab immigrant women in managing health concerns.

# **Conclusion: Limitations and Implications**

Participants in this study chose to focus on aspects of their lives that they perceived as the most stressful and that hindered attempts to engage in health-promoting practices. Immigration to Canada is expected to increase, people are living longer, and the burden of chronic diseases is expanding. The margins between local and global will continue to dwindle necessitating new ways of conceptualizing immigrant health. A strength of this study is that it provides insight into the ways transnational connections create health barriers and facilitators across the life course. The need for expanding initiatives that provide opportunities for socialization to gain peer support, exchange knowledge, and access recreational activities and the positive impact such activities can have on health, especially in vulnerable isolated older adults from minority groups, has been addressed in the literature (DiGiacomo, Green, Rodrigues, Mulligan, & Davidson, 2015; Stewart et al., 2006). This study points to the need to incorporate into such initiatives an

understanding of stressors created by social connections locally and transnationally.

A limitation of this study was the small sample size and the restriction of recruitment to two urban community/religious centers. In speaking to community gatekeepers, we were told the most vulnerable women were difficult to access due to limited mobility and restricted opportunities for socialization within the community. This warrants further work on methods of accessing isolated older Arab immigrant women. Also, the open ended nature of the interview meant women chose to focus on aspects of their illness that were of most concern to them at the time, raising the question of other factors across the life course that were not shared in the interview process. Overall, this study points to the utility of framing immigrant health from a transnational life course perspective. Moving forward it is necessary to attend to life course influences on health across migration contexts within research initiatives, nursing practice, and policies that focus on immigrant women.

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#### **Chapter Four**

**Title:** An Intersectional Exploration: Experiences of Stroke Prevention in Middle-Aged and Older Arab Muslim Immigrant Women in Canada.

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**Abstract:** Arab immigrants living in the West have higher rates of stroke and uncontrolled stroke risk factors, more debilitating stroke events, and less knowledge and resources for stroke prevention in comparison to other immigrant and non-immigrant groups. Arab immigration to the West is increasing, yet there is a dearth of research addressing the experiences and needs of this population in the area of stroke prevention. This paper presents an interpretive descriptive study to understand experiences of practicing stroke prevention, with a focus on managing chronic illnesses that increased stroke risk, making healthy lifestyle choices, and navigating access to healthcare resources. Sixteen middle-aged and older Arab Muslim immigrant women were recruited between 2015 and 2016. Study themes relate to weaving a narrative to explain chronic illnesses, pursuing knowledge in the dark, negotiating medication and treatment options, making an effort to eat healthy and be active and navigating access to health resources. A transnational intersectional lens is used to highlight structural barriers to health and to address discourses that serve to reinforce barriers and hinder efforts to improve health.

#### **Chapter Four**

# An Intersectional Exploration: Experiences of Stroke Prevention in Middle-Aged and Older Arab Muslim Immigrant Women in Canada.

Stroke is a leading cause of death worldwide (World Health Organization, 2014), with the risk of stroke doubling every 10 years after the age of 55 (Public Health Agency of Canada, 2009). Women tend to have greater post-stroke disability and poorer recovery in comparison to men, which is partly explained by older age of stroke onset, poorer pre-stroke functional status, multi-morbidities, and poorer social support (Appelros, Stegmayr, &Terent, 2009; Persky, Turtzo, & McCullough, 2012). Arab populations and Arab immigrant groups living in Western nations have increasingly higher rates of uncontrolled stroke risk factors (Benamer & Grosset, 2009; Tran, Mirzaei, & Leeder, 2010), more debilitating stroke events (El-Sayed, Tracy, Scarborough, & Galea, 2011), and less knowledge and resources for stroke prevention (Ali, Baynouna, & Bernsen, 2010; Gholizadeh, DiGiacomo, Salamonson, & Davidson, 2011) in comparison to other immigrant and non-immigrant groups. Yet, there remains a dearth of research on stroke prevention and management approaches in Arab populations (El-Sayed & Galea, 2009; Musaiger & Al-Hazzaa, 2012).

Little is known about Arab immigrant women's experiences of managing health in the context of stroke prevention. In this paper, we discuss results of an interpretive descriptive study. Sixteen middle-aged and older Arab immigrant women were interviewed to understand experiences of engaging in health-promoting practices in the context of stroke prevention. The study addressed both primary and secondary stroke prevention practices involving managing chronic illnesses that increased stroke risk, making healthy lifestyle adjustments, and accessing supportive health resources. Results center on five themes: (a) weaving a narrative to explain

chronic illnesses, (b) pursuing knowledge in the dark, (c) negotiating medication and treatment options, (d) making an effort to eat healthy and be active, and (e) navigating access to health promoting resources. We use an intersectionality approach to analyze the results of the study with a focus on social structures and practices that influence women's abilities to manage health effectively.

# **Theoretical Approach**

Intersectionality, a term first used in the work of Patricia Hill Collins (1999) and Kimberle Crenshaw (1991), recognizes the influence of multiple social locations in creating patterns of privilege and oppression within spatially and temporally constructed realities. Intersectionality approaches incorporate other dimensions of social identity into the study of gender, by examining the inter-relatedness of social categories, the operation of power in the formation of social categories, and the resulting lived realities of those who inhabit multiple social locations (Dhamoon & Hankivsky, 2011; Vissandjee & Hyman, 2011; Shields, 2008). Intersectional approaches can be used in immigrant women's health research to illuminate micro and macro structures of power that operate in women's lives within the unique social spaces that they occupy (Doyal, 2009; Sen, Iyer, & Mukherjee, 2009; Veneestra, 2011). Social identities and positions are not seen as static, essential to a group or inherent qualities of a person but rather are emergent, fluid, and contingent on hegemonic and micro operations of power (Anthias, 2012).

Immigrant research can suffer from what is termed "domestic intersectionality" (Gupta, 1997; Patil, 2013), a failure to examine the interactions between international and regional forces and the resulting influences on local realities. Immigrants rarely live in the confines of the nation state to which they immigrate, but are more prone to structure their lives and see themselves

within spatial and temporal contexts that transcend national borders (Bustida, Browns, & Pagan, 2008; Calvasina, Muntaver, and Quino, 2015; Purkayashta, 2010). In immigrant health research, analyses of social, historical, and political processes within and across nation states are necessary to understand the factors that shape health outcomes and experiences. Data collection and analysis for this study were completed with the aim of illuminating influences on women's everyday lives but, also, with a pragmatic question of what could be done to effectively support women in managing their health. Here, we begin with describing the personal experiences of women and move to examining the ways these experiences were shaped by structures and processes that serve to limit or facilitate effective stroke prevention strategies.

# **Research Design**

# **Research Methodology**

Interpretive Description [ID] is a non-categorical qualitative methodology that is used to understand subjective experiences related to phenomena of interest to nursing practice (Thorne, 2016). Interpretive Description focuses on knowledge development using a combination of data collected in the practice field, prior knowledge in the area, and abstract theorization. The methodology involves inductive reasoning to move from a description of observed phenomena relating to human experiences to identifying patterns of experiences, to then searching for the meaning of these patterns within the context of their occurrence.

#### Sample

Recruitment involved increasing researcher visibility through engagement in religious events and community activities over a period of one year and simultaneous use of community gatekeepers to identify potential research participants. Recruitment posters increased community awareness of the study. Convenience sampling was used initially, followed by purposive

sampling to follow up on themes that required further investigation. Thorne (2008) argues that sample size depends on whether sufficient data have been collected to render the question answerable in a way that informs practice. Data saturation was interpreted as obtaining data that was both rich in the qualitative aspect of description and data that conveyed commonalities and variations of participants' experiences.

Sixteen community dwelling middle-aged and older Arab immigrant Muslim women from the Levant region were recruited altogether. Ages ranged from 45 to 75 years with immigration occurring in young adulthood for all except three who immigrated later in life. All participants saw their family physicians regularly, at least every three months or more. Tables 1 and 2 outline participants' health profiles and additional socio-demographic information. Seven out of the 15 women explicitly stated they were on low income government assistance, but yearly income was inaccessible for other women.

	Participant Data (total=16)		
One or more self-reported chronic	14/16		
illness*			
One or more self-reported stroke	16/16		
risk factors**			
Occurrence of health-altering	5/16		
event (stroke or transient ischemic			
attack, myocardial infarction)			
One or more medications to	14/16		
manage chronic diseases/risk			
factors			

\* Chronic health conditions: hypertension, diabetes, cardiac disease, arthritis

\*\* Stroke risk factors: sedentary lifestyle, smoking, obesity/overweight

	Participant Data (total=16)				
Marital status	Married		widowed		
	13		3		
Living arrangements	With family		Alone		
	15		1		
Occupational history	Housewife		Outside home employment, including running family businesses		
	10		5		
Education	None(illiterate)	elementar high	y to junior	Post-secondary	
	4	11		1	
English fluency	None	Minimal(f	functional)	fluent	
	9	6		1	
Income	Unable to gather due to difficulty obtaining disclosure				

# **Data Collection**

The health research ethics board of the university approved the research study before initiation of recruitment. All participants chose to be interviewed at home except one who was interviewed at a mosque. Interviews commenced mostly in Arabic. Health data collection was based on personal reporting and participants were often unaware of particular aspects of their health profile such as blood pressure readings, terminology of medical diagnoses, and rationale for certain prescriptions. All interviews were audio-taped and transcribed by the primary researcher, using verbatim transcription. A second volunteer fluent in Arabic validated a random selection of the interview transcripts to ensure accuracy.

## **Data Analysis**

An ID methodology relies on constant comparative analysis processes, originating from grounded theory, to understand human phenomena (Thorne, 2008). Preliminary data analysis was done in Arabic to ensure the original meanings of texts were not lost in translation, as Arabic words and expressions can have multi-layered conceptual meanings which are not easily translated into English. The first few interviews and preliminary data analysis were translated to English early on so that a second non-Arabic speaking researcher could identify areas needing further investigation or possible biases in the analysis processes. Final themes and exemplars were translated into English by a certified translator.

# **Experiences of Engaging in Stroke Prevention Strategies**

The study results center on five themes: (a) weaving a narrative to explain chronic illnesses, (b) pursuing knowledge in the dark, (c) negotiating medication and treatment options, (d) making an effort to eat healthy and be active, and (e) navigating access to health promoting resources.

# Weaving a Narrative to Explain Chronic Illnesses

Women's experiences of being diagnosed with a chronic illness or suffering a healthaltering event were connected to experiences of loss, sadness, or crisis. Often women identified significant life events as having a direct impact on their well-being, especially when those events related to the well-being of their children. One woman, in narrating a story of her son's divorce, stated, "From then on the problem developed, I got high blood pressure, high cholesterol, and I started from that time to take blood pressure medication. I was okay before that, after this too much stress."(Participant 13). When asked about the cause of her diabetes, a second woman replied, "It came from sadness, because I have no family history, it came from sadness. I was sad about my eldest daughter and I got diabetes from crying and being sad. I was dizzy, and they took me to the emergency. They didn't know it was diabetes and then they knew. Life's stressors are hard..." (Participant 2). While another woman who recently had a stroke and was grieving the recent death of an adult child stated, "I feel misery inside me, I feel tired always, tired. There is not one day I get up and my head is calm....the first year the boy died I lost lots of weight...from then on the high blood pressure started, it all started (referring to health alterations)...from that point I started to take medication for my blood pressure."(Participant 6).

These life stressors at times had psychological and emotional implications, where women described experiencing symptoms such as chronic headaches, insomnia, anxiety, and restlessness, as indicated in the following quotes, "This is life and I get very nervous, anxious, people used to say I speak shouting, but I don't think I do…" (Participant 8), and "I now go to sleep but I am not sleepy, all the troubles come to you when you have your head on the pillow…" (Participant 10). These symptoms were only reported to physicians when severe, but were not described by participants in terms of mental illness. Rather, women saw the stressors in their lives, their chronic illnesses, and their mental and emotional states as inter-related and counter-influencing.

#### **Pursuing Knowledge in the Dark**

The majority of women in this study who had stroke risk factors, such as diabetes and hypertension, were not aware of the signs and symptoms of a stroke, even when they knew about their high risk profile, "Strokes, I know nothing about it, but I hear people say this person had a stroke, that person died from a stroke....they say it relates to blood but I don't know." (Participant 2) Many women lacked knowledge in crucial aspects of managing their chronic conditions and preventing potential complications, "He (doctor) said your blood pressure is a bit high. What the symptoms are, what I should eat, what I should do, I don't know....I need more information about diabetes and high blood pressure."(Participant 4).

The five women who had experienced a health-altering event described themselves as being caught off guard, unaware of their risk profile. A woman stated, "I never imagined that a

heart attack can happen because I am walking, do not eat fatty foods or have high cholesterol... heart attack came from nowhere." (Participant 3). A second woman said:

I told all my doctors that I exercise and I am worried about if I should stay at home and stop exercising, why did this happen to me? I do all this exercise and I still got a stroke, so from now on I do not want to exercise. They (doctors) answered wait, wait, if it wasn't for the exercise you wouldn't be as good as you are now. (Participant 12)

Generally, women spoke positively about their experiences with family physicians and saw them as a supportive resource in managing their health. Women who had limited English proficiency looked for doctors who spoke Arabic or had family members accompany them to appointments. Lack of physician time and limited English proficiency were main factors hindering access to information, as exemplified in the following two quotes, "Doctors are not giving attention like before and they are all in a hurry..." (Participant 13), and "They are very good, they give attention and are calm....doctor is Libyan because we are not strong in English, meaning if I answer in English wrongly I would not benefit." (Participant 11). Family doctors were primary sources of health information. Often women were told about lifestyle changes needed, such as stopping smoking, more exercise, or diet changes by their family doctors but they were left to their own devices in discovering how to manage doing this. Arabic internet sites, for those who were computer literate, and television programs were sources of health knowledge as well. One woman who was an active community member stated, "I think they (women in the community) need someone to tell them, like lectures here, and tell them the cause for diseases, something like that." (Participant 12).

# **Negotiating Pill Taking and Treatment Options**

Women generally viewed taking medication negatively. They described attempts to stop their medication or decrease dosages, sometimes without consulting their physicians. Lack of symptoms was often interpreted as not needing to take medication. Women also had conflicting emotions when physicians prescribed medication they thought was unnecessary or when the medication failed to manage their symptoms effectively. This either led to conflict with physicians or led to women discreetly stopping medication or adjusting dosages. After experiencing a stroke at a young age one woman discussed her decision to stop prescribed preventive medication, "...when I got better I said I don't want to take it, I hate medicine, I don't want my body to get used to medication" (Participant 10). Another woman showed the interviewer a bottle of pills, "Medication for my bones. I have not taken it for three months. I want to give my body a rest from them....the white pill bothers me, you have to take it and not eat cheese and not eat yogurt while all my diet is made of cheeses..." (Participant 2). Reluctance to start medication newly prescribed was noted as well, "Sometimes I leave it (medication) for two months without buying it, sometimes I buy it and put it in the closet, I take it for a few days and stop taking it, why? What do I need it for?" (Participant 7)

Travel, financial pressures, and heightened caregiving strains were noted in some cases as a likely time for decreased medication adherence. Women felt taking medication was cumbersome, unnecessary, or thought that giving their bodies a rest would be beneficial:

It all costs money, expense on us, I told the doctor I want to stop some of the medication he said no, no, no you cannot stop medication. When I went to the hajj (Muslim pilgrimage to Mecca) I stayed three months without taking anything. Thank God I was okay. When I returned from the hajj I told the doctor I stopped the medication for three months. He said you are crazy He is Canadian...tomorrow you will have strokes or heart attacks or something so I started taking them again. (Participant 14)

Many women had limited health coverage beyond their public health insurance, which in Canada covers mostly acute and emergency healthcare needs. Even the small amount of money required to cover costs of medication and treatments in the community was a considerable financial strain. When asked about diabetic foot care one woman answered, "Sometimes I go and they take 65 dollars....I used to go to the doctor and don't go any more. He used to scrub them for me and fix them but I didn't go again. I do them at home." (Participant 2). One woman said, "Everything is expensive for us....They used to help pay for diabetic pills but they stopped...They don't pay for these anymore. A diabetic test strip costs a dollar..." (Participant 14). A third woman stated: "I think with old age pension they should give people a little more, what they give is not enough." (Participant 7) Women's stories pointed to the reality of access disparities within a public health system and this was exemplified in one woman's worry about taking a drug that requires frequent blood testing over a drug that was costly but more lifestyle friendly:

They prescribed a blood thinner and said your health insurance does not cover the costs of the blood thinner, so I asked what do you mean? They answered that there are two kinds of blood thinners; one requires a blood test weekly and one doesn't but the one that doesn't you have to pay for. I started to cry. My husband's income is not enough. I can ask for help from my children as they are in good financial situations but I don't want to ask them for help with everything... (Participant 15)

# Making an Effort to Eat Healthy and be Active

Lifestyle changes such as diet and exercise were the most discussed issues in the context of stroke prevention. Healthy eating was considered crucial in maintaining overall health and the women tried to focus on making healthy choices. Unhealthy diets were defined as eating too much and diets high in fat and animal protein, "I treat myself...my body gives me the information...I watch what I eat, if something bothers me I avoid it." (Participant 16), and "when I watch what I eat I feel there is a difference...this is what is protecting me from gaining a lot of weight." (Participant 8)

There was a lack of information for many women on specific restrictions and modifications related to chronic illnesses such as diabetes and hypertension, even after seeing dietitians. In referring to a visit from the dietician one woman stated, "...she knew all the dishes (Lebanese)....she told me I shouldn't eat these dishes. She said you can eat tabbouleh without oil or salt (laughs). What kind of tabbouli (Lebanese salad dish) that would be? I told her okay...I did not adhere to her recommendations but I decreased my salt intake." (Participant 12), and a second commented, " ...sometimes I eat potatoes and everything and my sugars are four (low) and sometimes I find my sugars are 15 (high), like yesterday, I don't know, something is wrong, something is wrong with my body..."(Participant 2)

Healthy eating was something the women reportedly managed better than physical activity. Most frequent physical activity described was walking and housework. The difficulty with maintaining adequate physical activity levels was related to chronic pain and mobility issues and lack of familiarity with ways to modify exercise appropriately, as exemplified in the following quotes, "I would like to walk, when I walk a little my back hurts…" (Participant 7), and "…I get up to the kitchen and do a thing or two, then my back hurts and I sit on the chair.

This is not movement. Housework is tiring. It is not exercise. What to do…" (Participant 1). Household obligations such as cleaning and cooking, and caregiving roles left women feeling they had little time for exercise. Transportation issues, weather, and difficulty finding culturally appropriate exercise facilities were other cited concerns, "I am not good at exercise. I exercise at home running here and there, I don't sit…I walk in the house a lot, go up and down the stairs…to exercise where they do exercise I find men there and such…" (Participant 5).

#### **Navigating Access to Health Resources**

Transnational ties to countries of origin facilitated access to traditional remedies and medical treatments in the countries of origin. This access relied heavily on social networks within countries of origin to learn about new treatment options, locate competent physicians, and procure medication not readily available in Canada. Women often used Arabic and Islamic traditional remedies, but this did not, in most cases, hinder the use of medical treatments prescribed by doctors in Canada. Many women commented on the practice of bringing herbs, spices, and remedies from the home country to use in Canada, "I do not buy herbs from here, never, we have (mashallah) in the home country a market where the herbalist will prescribe a remedy...when I came I brought the herbs with me..." (Participant 10). The use of traditional remedies, however, usually related to mild health concerns or symptoms that were not being managed well as shown in the following quotes, "If I tell you I have a sore throat, I go and boil some herbs, because if I go to the doctor he will say nothing wrong..." (Participant 13), and "...the Quran tells you that the (habit I barakah) and about honey and about vinegar is very useful...I believe these things...my information is from these sources..." (Participant 9).

Women navigated two healthcare systems when questions arose about treatments, symptoms were not managed, or health alterations occurred suddenly when they were visiting countries of origin. At times this leads to beneficial health outcomes where physicians cooperated transnationally to the best interest of their patients or when treatments not available in Canada were utilized successfully abroad. In describing successful treatment for managing a chronic health condition a woman stated, "...I couldn't find it in Lebanon and here they wouldn't give it to me so I ordered it from England....doctors here told me these injections are very very good but we can't order it for you because there isn't any here so I brought it from England..." (Participant 5). This woman's family bought the medication, prescribed by a physician in Lebanon, for her from Europe, to take in Canada. Other stories revealed that women were taken advantage of for financial gain by healthcare professionals abroad wanting to benefit from their perceived advantaged financial status as Canadians, "they tell me stop the Canadian medication so I would buy medication there. I started to buy the medication..." (Participant 14). This woman was later warned by a family member that the change was not needed but a way to get her to pay more money.

## Discussion

Stroke prevention involves managing chronic illnesses that increase stroke risk, making healthy lifestyle adjustments, and accessing health-promoting resources. Women actively navigated personal, social, and systemic barriers to engage in stroke prevention. These women share many of the barriers and facilitators to health experienced by the general Canadian population, but lack similar support mechanisms in the face of adversity. They, also, described unique health influences centered on the experience of migration. Intersectionality is a process of dissecting social structures and practices within different social spaces to draw attention to the resulting influences on people's lives (Anthias, 2009; Yuval- Davis, 2006). We discuss some of the ways women's social positioning served to limit or facilitate engagement in stroke prevention. We then move to address some of the discourses and modes of representation that can hinder progress towards better health outcomes for minority immigrant women ageing in the Canadian context.

# A Tug and Push Dynamic: Narratives of Exercising Personal Agency

Women's narratives illuminate the role of personal agency in mediating, negotiating, and re-structuring barriers to stroke prevention. Women were active in making decisions, weighing options, and searching for opportunities to enhance personal health using both local and transnational resources. Personal agency, however, is enacted within the constraints of one's social position (Anthias, 2009; Dhamoon & Hankivsky, 2011; Yuval- Davis, 2006). Women, in telling stories about managing their health, were also telling stories of their social locations in different social settings: their local communities, Canada, and country of origin. The tug and push dynamics between personal agency and social structures result in shifting social positions within different spatial and temporal locales for immigrant women (Chesla, Kwan, Chun, & Stryker, 2014; Lane, Tribe, & Hui, 2011). Women leveraged their social positions in these different settings to access supportive resources for health, such as seeking medical advice, obtaining health remedies, and gaining encouragement to enhance well-being.

Deteriorations in physical health resulted in mental distress for some women amplifying their positions of vulnerability as members of a linguistic and cultural minority group. During periods of stressful transition, such as being diagnosed with a new disease or experiencing a negative health event, women's positions shifted to amplify the disadvantages of low education

and minimal economic resources. On the other hand, women's positions as ageing adults in the Canadian context resulted in access to social, financial, and healthcare resources within Canada's social safety net. Women were grateful as similar supports were lacking for ageing peers in countries of origin. These women were socially positioned as advantaged in comparison to coethnic peers in countries of origin. An effect of this was that women were at risk of being targeted for financial gain when returning to countries of origin due to being perceived as well off Canadians. Some women told stories of being given medical treatments or undergoing procedures that were unnecessary. In conclusion, Arab immigrant women were not vulnerable all the time in all contexts which points to categories of identity, such as immigration status and ethnicity, as being erroneous indications of vulnerability.

# Fallacies of Representation: Moving from Narrative to Discourse

Focusing on women's capacity to negotiate positions that enhance power can result in overlooking the structures that limit agency (Anthias, 2012). Canada has a public healthcare system where stroke prevention, detection, and treatment are a priority at the health policy level (Public Health Agency of Canada, 2009). Theoretically, immigrants are able to access this system and utilize health-promoting resources. The literature points to Arab immigrants and other ethnic minorities experiencing challenges in accessing and utilizing healthcare services (Alzubaidi, Mc Narmara, Kilmartin, Kilmartin, & Marriott, 2015; Asanin, & Wilson, 2008; Hasnain, Connell, Menon, & Tranmer, 2011; Lai & Surood, 2010; Padela, Gunter, Killawi, & Heisler, 2012; Sanou et al., 2014;Vanstone, Giacomini, Smith, Brundisini, DeJean, & Winsor, 2013). All women in this study reported regular visits to family physicians and access to specialist medical care. Frequent contact, however, did not always address knowledge deficits, help manage disease symptoms, or support lifestyle adjustments for better health. Women described experiences of poor diabetes and blood pressure control, unmanaged chronic pain, emotional and mental distress, lack of knowledge regarding prescribed medication, and unfamiliarity with signs and symptoms of stroke.

Global inequalities in health service distribution are reflected in local immigrant communities, where immigrants bring to the host country experiences of healthcare interactions, exposures to health risks or benefits, and approaches to personal health. In this study, the healthcare realities of countries of origin remained influential in women's lives, persisting after spending decades in the Canada due to ongoing transnational ties. Engagement within a transnational context can be interpreted as a positive reaction to negative experiences of exclusion and othering (Portes, 1999; Salih, 2001). Transnational health utilization has been documented in the literature for other immigrant populations, where the use of formal healthcare services, procurement of medication and traditional treatments, and attainment of health information occurs across borders in both countries of origin and destination (Horton, 2012; Thomas, 2010; Wang & Kwak, 2015). Unmet local needs and the utilization of transnational healthcare services points to immigrant women navigating a labyrinth of inequality to improve the conditions of their lives. Re-presenting health inequalities to recognize marginalization processes that place Arab immigrant women at the periphery of conversations about healthcare is needed in Canada.

## **Conclusion: Limitations and Implications**

This study is the first, to our knowledge, to look at Arab immigrant women's experiences with stroke prevention. The study findings reveal Arab immigrant women navigate health resources locally and transnationally to increase access to health-supporting resources and diversify options for health management. Women experience to varying degrees barriers to exercising personal agency. Women who were more educated, had higher economic prosperity, and were more fluent in English were more comfortable navigating the healthcare system and utilizing health-promoting resources. Barriers were shaped by local and transnational processes, pointing to the utility of intersectional approaches that look beyond national borders to understand Arab immigrant women's health experiences. The relationships among age, culture, and gender and the resulting influences on shaping health experiences require further exploration in the literature (Koehn, Neysmith, Kobayashi, & Khamisa, 2013). Shifting discourses on immigrant health away from a focus on culture that stresses narratives of personal behaviors and group cultural norms to a focus on the intersecting influences of multiple social positions will better inform approaches to supporting healthy ageing in immigrant populations.

This was a small study targeting a group of Arab immigrant women in a single urban center in Canada. Due to challenges with recruitment, we believe the most vulnerable and isolated older women were not accessed. Community gatekeepers emphasized the increasing presence of vulnerable older Arab women in the community and the lack of resources to address their needs. The women interviewed and community gatekeepers put emphasis on the urgent need for community-based initiatives that target the needs of older adults with chronic illnesses, who are further isolated by low income, low levels of English fluency, and minimal social support. Navigating health services was left to the women and their families, with family members often attempting to fill in for health service gaps. Further efforts to increase research recruitment and participation to address health issues are needed in this community.

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#### **Chapter Five**

# **Emphasizing Strengths and Identifying Challenges**

I address in the dissertation two areas that relate to research with middle-aged and older Arab immigrant women: my experience of the research process and women's experiences of the phenomenon of interest. I reflect on my role as a bicultural and bilingual researcher in ensuring ethical and rigorous research processes (chapter two and appendix F). In the current political and social climate discussions about Arab and Muslim populations take on various shades of othering and difference. Chapter two shows that these conversations trickle down to impact the research process in a local community and refocuses on strategies to increase collaboration and understanding. One important consideration for enhancing understanding is working to critically reflect and advance methods to ensure rigouros research processes with Arab and Muslim populations (demonstrated through a work in progress in Appendix F). Working towards ethical and rigorous research processes was aimed at creating safe spaces for women to voice their experiences around health and ageing in the Canadian context. These experiences are summarized below and can serve to inform nursing activites in research, practice, and education that focus on supporting health in Arab immigrant populations.

The focus of women's stories was on major areas of concern that created significant stress in their lives, but these stories also revealed personal resourcefulness and resilience. Areas of concern identified were transnational stressors that could result in neglect of personal health, lack of social support to facilitate health management, a looming risk of loneliness and social isolation, deficiencies in health literacy about stroke and stroke risk factors, and difficulties with engaging in healthy lifestyle choices. Personal resourcefulness and resilience were demonstrated in women's use of local and transnational social networks to access healthcare resources,

balancing of traditional remedies with Western medicine to enhance personal health, the reliance on faith to cope with life stressors, and being a source of support for others. These findings are discussed in chapters three and four. Chapter three addresses social dimensions of health with a focus on transnational connections across the life course and availability of social support in the post-migration context. Chapter four highlights the structural and representational influences on health that stem from women's social positioning locally and transnationally. Areas for concern and identified strengths were contingent on women's social positioning within their local communites, Canadian society, and country of origin. Findings in this study at times mirror, contradict, or expand available knowledge in the literature. I present in the following section highlights of the findings that emphasize women's strengths but simultaneously point to continuing challenges with engaging in health-promoting practices in the context of stroke prevention.

A new diagnosis of diabetes or hypertension or the occurrence of a stroke or cardiac event was often understood by women as the result of stressful life events or the cumulative effect of multiple life stressors. Asking women the question of 'why do you think this happened to you' triggered telling of stories about personal life stressors. The connections between stress and manifestation of illness have their roots in cultural and religious interpretations of the holistic connection among body, mind, and spirit (Chaze, Thomson, George, & Guruge, 2015; Shah, Ayash, Pharaon, Gany, 2008; Tirodkar et al., 2011). A closer look at women's stories shows that life stressors, whether ongoing chronic stressors or one-time stressful events, resulted in negative perceptions of personal health. Women also reported neglecting personal health when life stressors increased by stopping medication, not exercising, not eating well, and not following up on health concerns. Loneliness was another concern experienced by many women in the study

and opportunities to connect with others were emphasized as growing needs for older adults in the community. Evidence continues to suggest associations of stress and loneliness with adverse health outcomes in minority and non-minority populations (Aroian, Uddin, & Blbas, 2017; Everson-Rose et al., 2014; Holt-Lunstand et al., 2015; Valtorta, Kanaan, Gilbody, Ronzi, & Hanratty, 2016). The evidence also suggests that these associations cannot be explained solely by the way stress and loneliness impact traditional risk factors such as lifestyle choices. This study presents a subjective account of the ways stress, loneliness, and negative perceptions of health manifest in the lives of Arab immigrant women.

Women reported not having adequate knowledge about their health conditions, stroke risk factors, or health management strategies. They found it difficult to address modifiable stroke risk factors such as physical activity, smoking, and diet; factors that account for high percentages of risk across all ethnic and age groups (O'Donnell et al., 2016). Absence of culturally and linguistically appropriate health literacy material and health management resources will likely continue to be a serious area of concern for Arab immigrant women in light of the minimal public health infrastructures in the Arab world (Jabbour, 2014). Arab women migrating to Western countries will continue to face a double jeopardy. Armed with little knowledge or previous exposure to health promotion about stroke prevention, they will then be exposed to an array of new health stressors. This double jeopardy is not expected to be uniform across subgroups of Arab immigrants but differs based on level of education, personal experiences with health promotion, economic status, and acculturation level. For example, being able to drive and having a stronger command of the English language enabled women to access and utilize more community and healthcare resources that would benefit their health. Arab immigrants who are well educated and enjoy upon immigration some level of economic prosperity might have the ability to effectively navigate the healthcare system and utilize resources for health promotion.

To summarize the above, the combination of decreased mobility, lack of social support, low income, cultural and linguistic differences, and personal life stressors pushed some of the women in the study into a downward spiral of vulnerability. Other women in the study were resourceful in using local and transnational connections to navigate access to resources that would help them effectively manage their health. Many of the challenges women experienced mirror those of the wider ageing Canadian population living with chronic illnesses and reflect a gap in community services that support healthy ageing (Public Health Agency of Canada, 2010). Other challenges were more specific to immigrant minority groups that have cultural and linguistic differences from the dominant society. Two barriers to health, being at the receiving end of discrimination and experiencing role conflict, identified in the literature on immigrant women did not surface as primary concerns in women's stories in this study. One out of four Arab Canadians reports experiencing discrimination based on race or religion (Statistics Canada, 2007). Experiences of discrimination are shown to differ based on religion, social class, acculturation levels, and country of origin (Abdulrahim, James, Yamout, & Baker, 2012; Derose, 2009). Women when asked explicitly and throughout the interviews often denied experiences of discrimination in relation to healthcare access and utilization. They did describe efforts to connect with non-Muslim neighbors and represent Arab Muslims positively to combat misconceptions. Women might have wanted to emphasize the positive aspects of the healthcare system as the interviewer was known to be a registered nurse. It might also be that women truly did not feel that discrimination was part of their experiences in utilizing and gaining access to the healthcare system.

The second area often addressed in the literature on immigrant women relates to changing social roles and role conflict with increasing age. Some studies emphasize ageing immigrant women's experiences of liberation from traditional gender roles (Charpentier & Quéniart, 2016; Chun, Chelsa, & Kwan, 2011), while other studies highlight the continuation of traditional caregiving roles for spouses, children, and grandchildren (Grewel, Bottorff, & Hilton, 2005; Lai & Surood, 2008). In this study women seemed to carry on the traditional gender roles of being homemakers and caregivers with pride and a sense of self-worth. These roles did not appear to be sources of conflict in their lives. Women acknowledged, however, that these roles became sources of stress and resulted in neglect of personal health during periods of disruption involving family strife, increase in familial obligations, or personal illnesses. Overall, study findings point to the need for approaching health management in Arab immigrant women from a holistic perspective addressing the contextual factors that can facilitate or limit their ability to engage in health-promoting practices across the life course.

### **Towards a Life Course Interpretive Framework: Guiding Concepts**

This study involved simultaneous immersion in the data and reflection on the wider processes and structures that shaped women's experiences around stroke prevention. In early phases of data analysis, I sensed that women were saying something different; women were contradicting my prior conceptualizations of temporality and spatiality in the life course paradigm. This process allowed for the use and refinement of three guiding concepts that shape a life course interpretive framework focused on immigrant women, health, and ageing.

• Three contexts are central in conceptualizing immigrant health from a life course perspective: (a) pre-migration, (b) migration, and (c) post-migration. Migration contexts refer to the politically, historically, and socio-economically contingent realities of the

countries of origin and destination as experienced by immigrants. Understanding life course influences on immigrant health necessitates considering migrants' pre-migration positioning and the resulting effects on migration and post-migration contexts (Abdulrahim, & Ajrouch, 2014; Castan<sup>~</sup> eda et al., 2014). Pre-migration contexts are always changing, where different cohorts of immigrants from the same country might have lived within very different socio-economic, environmental, and political contexts. The majority of women in this study had lived in Canada for decades and this meant the post-migration context was the most significant direct influence on health. The premigration context might be more relevant for new immigrants and the migration experience more relevant where trauma and disruption during the migration process are substantial.

• Immigration constitutes a major life transition and this transition impacts health through creating pathways of exposure to stressors or exposures to facilitators of health (Messias, 2010). Health stressors constitute factors that directly or indirectly result in negative health outcomes, while health facilitators constitute factors that directly or indirectly result in positive health outcomes or prevent negative outcomes. Women were telling stories of a spiral process involving moving back and forth across migration contexts within transnational spaces. This process of moving back and forth was at times physical, such as traveling to country of origin to be caregivers or seek healthcare services. This process could also be emotional, where social, economic, and political disruptions in the country of origin resulted in ongoing perceptions of a stressful life. It has long been documented that Arab women continue transnational connections in the post-migration

context (Meleis, 1991; Naber, 2009). Yet, I found minimal incorporation of this concept in research that lies at the intersection of immigration, ageing, and health.

A constructivist approach to life course theorization attends to the meanings ascribed to life course experiences and searches for subjective interpretations of time, place, and events (Holstein & Gubrium, 2007). Subjective interpretations are situated within temporal and spatial realities of immigrant's lives to create an understanding of contextual truths. These temporal and spatial realities shape and are shaped intersections of social locations women occupy, which requires attention to the workings of power. Women migrate under different circumstances than men and embody different premigration and post-migration realities. Women's health experiences and outcomes are influenced by the intersecting and counter-influencing spheres of social belonging across gender, ethnicity, and class (Anthias, 2009; Hankivsky & Christoffersen, 2008; Yuval-Davis, 2006).

#### **Implications for Future Practice, Policy, and Research**

## **Practice Considerations**

Concerns raised by women in this study can be useful to nurses engaged in health promotion activities around chronic disease management. Women unanimously discussed the risk for social isolation and loneliness, even when living in an Arab dense neighborhood and having family actively involved in their lives (addressed in paper 2). A second issue raised by women was the lack of access to health promotion resources and services in the Arabic language (addressed in paper 3). Nurses who work with Arab immigrant women should also consider the influences of transnational stressors on health and the potential access to transnational healthpromoting resources. For example, when Arab immigrant women discuss travel plans or nurses sense dissatisfaction with available treatment options in Canada, it is worth asking about goals of accessing transnational healthcare services and resources. The aim would be to provide information and foster collaboration when possible to ensure a cohesive and holistic approach to women's health. Another study finding that nurses might benefit from understanding is the central role of food in the lives of Arab immigrant women. Cooking, sharing food and hosting gatherings, and cultivating pride in personal culinary skills were essential components of women's lives. Nurses often take on the role of teaching about lifestyle modifications, such as dietary changes. Recognizing that food might not simply be a source of sensual pleasure but a source of identity, connection to the past, and a means for memory making ensures sensitivity to the impact, for example, of asking someone with diabetes to change their cooking habits and dietary intake.

## **Policy Considerations**

Immigrant visible minority women, even when highly educated, are more likely to be unemployed or underemployed in comparison to other Canadian women and immigrant men (Tastsoglou & Preston, 2005), which decreases opportunities for integration, economic security and language attainment. Such experiences are likely to influence women's abilities to manage health effectively as they age in the Canadian context. In a study of younger Arab immigrant women who were not in the workforce, had low levels of education, lacked social support from family and friends, and had poor language skills, there were reports of high levels of emotional distress and loneliness (Irfaeya, Maxwell, & Krämer, 2008). In our study, these findings were mirrored in middle-aged and older women with similar socio-demographic characteristics, which point to pathways of vulnerability that begin early on and progress as women age in the postmigration context. Barriers such as lack of language skills could be addressed in early phases of resettlement in the post-migration context by providing language services to increase integration. At the policy level, funding also needs to address the practical needs of women in their daily lives that influence the ability to learn and work, such as affordable childcare and transportation.

Canada is also accepting high numbers of refugees from Muslim and Arab countries. This population might need enhanced support for social and economic integration due to similar barriers experienced by women in this study in the early migration phase. Refugee populations experience additional stressors related to witnessing violence, forced displacement, death of loved ones, and family left behind (Freund, 2015). These factors disrupt the social dimensions of health discussed in this study as influential in women's abilities to engage in health-promoting practices. There continues to be a need for policy approaches and funding to focus on the long term health of refugees in the context of non-communicable diseases, such as cardiovascular health (Patil, Maripuu, Hadley, & Sellen, 2015; Yun, Graber, Sullivan, Chen, & Gup, 2012). This study points to some of the processes and structures that require attention to successfully promote health in populations from Arab contexts.

## **Research Considerations**

For the researcher who wants to engage in research with Arab immigrant women the first paper and appendix F point to important ethical and methodological considerations. Some main considerations for researchers embarking on research projects with Arab Muslim immigrant communities are the need to engage in self-reflexive processes, to ensure reciprocity, and to address translation and conceptual clarity issues. Engaging in a reflexive process requires researchers to understand their position in relation to the community of interest, be aware of personal biases, and recognize prevailing discourses and socio-historical narratives of a particular community. Reciprocity refers to the need to give back to the community in a way best

identified by that community; for this project giving back involved volunteering in a nonessential positon to help start a seniors' social and exercise group and providing community leaders with a summary of research findings. Potential problems with translation and conceptual clarity necessitate that researchers make explicit the processes used to ensure authenticity and trustworthiness of research findings. We found the resources sparse in the English language literature addressing these issues and encourage future bilingual researchers to make their processes explicit. It would be useful for a researcher, especially when a novice, to have a second researcher familiar with the language and culture to support the research process. Other pragmatic considerations were that face to face introductions to potential participants were essential for building trust, with snowballing methods not as effective as cited in the literature (see chapter 2). Another practical consideration is the timing of year when recruitment is most effective. Summer months were not a good time to recruit participants since this was when women traveled back to the Middle East or were busy visiting with children and family coming from other provinces or from abroad. Winter months were the most effective recruitment time; maybe because there was more free time for women to schedule interviews and the weather limited possibilities for leaving home.

## **Study Limitation and Strengths**

This study was conducted in a small Arab community in a major urban center. Contact with the community began in June of 2015 and the first participant was recruited in September of 2015. Between September 2015 and May 2016 a total of 16 women were recruited for the study. Time constraints meant termination of the study occurred while interest in the study was ongoing and potential participants were still coming forward. This study has increased the community's familiarity and comfort with participating in future research. The study also provided valuable

lessons regarding effective strategies for recruiting Arab communities to participate in research projects. The women in this study varied in terms of degrees of vulnerability, where some women were able to navigate barriers, draw from personal resources to maximize health, and express a sense of satisfaction with their lives. Other women were unable to overcome barriers in significant ways that would allow them to manage health in an effective manner. Community gatekeepers related that the most vulnerable women were hard to reach and would be difficult to recruit. This necessitates looking for ways to increase recruitment of Arab and Muslim vulnerable older adults. With the increase in negative political discourses around Muslim and Arab populations, engaging these communities in research to address health needs might continue to be a challenge. Participants in this study were Arab Muslim women from the Levant region. Claims for transferability of findings to other communities of Arab women who are not from the Levant region or to Arab women from other faith groups cannot be made. Women in this study cite marriage as a primary reason for migration, with pursuit of a better life, escape from political instability and violence, and desire to be with family already in Canada also influencing the decision. The study population was not highly educated or involved in the workforce (except for one of the women). Their experiences of migration probably do not mirror those of more educated or more recent economic migrants where social mobility and educational advancement can be driving factors (Killian, Olmsted, & Doyle, 2012).

This study emphasizes the multi-dimensional and inter-weaving systems and processes beyond culture and religion that shape vulnerability and impact health. The attempt to make these systems and processes identifiable and transparent allows for better use of research findings from a small study; consumers of this research project can decide for themselves whether the suggestions are relevant to their particular context. I emphasize the need for

building on this study to determine transferability of findings to other groups of Arab immigrant women. I also recognize that this study does not capture all that could be said about Arab women's experiences with stroke prevention.

# **Areas for Future Research**

The objective of the study was to identify factors across the life course that facilitate or limit middle-aged and older Arab immigrant women's abilities to engage in stroke prevention practices and to identify gaps in resources that influence supporting women in managing stroke risk. The need to address health disparities by managing chronic health conditions and improving quality of life necessitates attending to the structural, social, and environmental contexts of people's lives (Quiñones, Talavera, Castañeda, & Saha, 2015; Rogers et al., 2015). This study was a first step towards addressing a broader research objective of identifying strategies to enhance stroke prevention practices in Arab immigrant populations across genders. There is evidence that Arab men continue to experience challenges with managing stroke risk factors ((Phillips, Monaem, & Newman, 2015; Tailakh et al., 2013; Tenkorang, 2017). I focused on women's health, but frequently during the study spouses and family members would comment on personal health struggles and perspectives on access to healthcare resources. Their stories were excluded from the final analysis because ethical approval had not been obtained to incorporate family perspectives. From the literature on continued barriers to health experienced by immigrant Arab men and from the interest expressed by spouses of women in this study, further attention is needed in research to experiences and support needs within Arab families across genders. The more collectivist nature of Arab families might mean that research approaches that incorporate families will see more success in recruitment.

Another area for future research is looking at the influence of transnational ties on immigrant health. For example, researchers could look at the experiences of healthcare professionals supporting immigrants in navigating transnational healthcare resources. Women shared stories of collaboration between physicians in Canada and country of origin with positive health outcomes. One woman's sister was diagnosed with a genetically linked form of breast cancer in the Palestinian territories and was told by her physician to inform siblings in Canada. The woman shared this information with her physician resulting in enhanced screening and identification of early breast cancer. A second woman spoke of consulting a specialist in country of origin for assistance with a prolonged gynecological problem and having her Canadian physician implement the specialist's recommendations. Delving into the experiences of healthcare professionals and their patients with accessing transnational healthcare resources was beyond the scope of this study, but constitutes an interesting area for future research.

Another area for future research relates to the way Arab immigrant women understand and participate in exercise in the presence of barriers such as chronic pain and physical limitations. Many women in the study recognized the need to engage in physical activity to decrease stroke risk, but lacked knowledge on effective strategies and exercise techniques. At the time of the study, weekly exercise sessions were being held at one of the recruitment locations. Older women took part in chair exercises by following an exercise video played on a projector screen. The women also participated in indoor group walking sessions. Informal discussions with women revealed satisfaction from these activities and an increase in exercise at home using techniques modelled in the video. The weekly exercise activity was spontaneously initiated based on women's requests, but opened my eyes to possibilities for initiatives that take a holistic approach to engaging women in health-promoting activities. The exercise activity

allowed for simultaneous attention to physical health, social connection, and spiritual development as activities were followed by prayers or short religious sermons. It would be useful to build on these findings and the literature (Barenfeld, Gustafsson, Wallin, & Dahlin-Ivanoff, 2015; Campbell et al., 2007; McCaffrey, 2008) that supports a multi-focus approach to health promotion initiatives targeting physical, spiritual, and mental health of immigrants. Further research is needed on what works to increase Arab immigrant women's quality of life and empower women with tools to effectively manage their health. These research approaches can expand to incorporate looking at cardiovascular conditions that share similar risk profiles with stroke.

#### **Study Dissemination Process**

There is little research on stroke prevention in Arab immigrant women. This study is, to my knowledge, the only study that looks specifically at stroke prevention in Arab immigrant women. Understanding stroke risk, prevention, and management is increasingly relevant as the number of immigrants from the Arab world continues to increase. Also, this study adds to available literature that highlight gaps in resources and call for increased attention to chronic disease management in Arab populations (Alzubaidi, Mc Namara, Browning, 2017; Hammad, Said, & Arfken; 2014; Levin-Zamir et al., 2015). Dissemination of the findings from this research project is ongoing and includes presentations at conferences and publications. Initial findings were presented at a national and a local conference. The first paper has been published in Advances in Nursing Science and hopefully will stimulate conversations around ethical research practices with Muslim Arab women. The goal is to submit the findings papers (chapter 3 and 4) and the methods paper (appendix F) for publication in peer-reviewed nursing journals.

Dissemination also included taking a summary of the findings to the community leaders who facilitated recruitment and are actively involved in addressing the needs of seniors in their community. The participating community identified knowledge deficits regarding managing chronic conditions such as diabetes and cardiovascular disease concerns. A second area highlighted was the need for more social and recreational activities for seniors in the community who have cultural and language barriers that limit access to wider community resources offered to seniors. In follow-up to this study, further conversations with the community will occur to identify possible strategies to address knowledge deficits and social isolation in community seniors. It is hoped that the findings of this study will support the community's activities to increase access to and development of initiatives that target the needs of seniors.

# **Final Thoughts**

One of my favorite memories is of an older woman who asked me to look out the window of the living room where we were sitting drinking tea. She pointed to a car parked out front, and said something to the effect of: 'I don't use it a lot but I like to look at it parked out there, ready for when I need it.' This memory stood in stark contrast to my memory of another older woman in the study. She also pointed outside her window while we were drinking tea. She pointed to a house across the street. A good friend lived there but it had been weeks without a visit. Mobility difficulties prevented her from walking across the road to her friend's home. Experiences like this heightened my awareness of the complexity of variables that influence immigrant women's experiences of aging in Canada. Arab immigrant women in this study share many of the strengths and challenges of their Canadian counterparts ageing in our Canadian urban centers. These women also experience unique strengths and challenges stemming from cultural and religious beliefs, transnational connections, and immigration experiences. I was

simultaneously inspired by their strength and pained by the difficulties narrated in their stories. This research project has been an intellectual and emotional journey with the outcome of better awareness of myself, the participating community, and the chosen research topic. This awareness involves recognition of the many questions that still need answers. In gaining consent for this study, women asked that I bring their voices forward with authenticity and truthfulness. This dissertation project reflects my attempt to meet their expectations and present my account of the journey.

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**Appendix A: Recruitment Posters** 



# Have you had a stroke or a transient ischemic attack?

We would like you to participate in a study. We want to understand the needs of the Arab immigrant community in caring for their health in the Canadian context.

If you are:

- an Arab Immigrant to Canada,
- 45 years of age or older, and
- you have previously had a stroke, we would like your input.

If you are interested in this study, please contact Jordana Salma (Registered Nurse, Doctoral Student at the University of Alberta):

Phone: (780) 263-8438 Email: sjordana@ualberta.ca

## Appendix B: Sociodemographic Questionnaire

- 1. Age:
- 2. Country of origin:
- 3. Nationality (please indicate if you have more than one):
- 4. Ethnicity:
- 5. Education:
- 6. Occupation:
- 7. Yearly personal income:
- 8. Yearly family/household income:
- 9. Year of immigration to Canada:
- 10. Number of years in Canada:
- 11. Year of stroke event(s):
- 12. Physical/cognitive deficits, if any, resulting from stroke:
- 13. Chronic illnesses/health problems:
- 14. Medication:
- 15. Alcohol/smoking consumption:
- 16. Weight: Height: (self-reported)

17. Access to family physician:

18. Last physician visit: total visits/year:

19. Use of other health services:

20. Frequency and type of physical activity:

21. Frequency and type of leisure activities:

22. Living arrangements: alone  $\Box$  with family  $\Box$  specify:

Date of completion: -----

Initials of Participant: -----

## **Appendix C: Interview Guide**

## **Opening Questions:**

- Describe your current health
- What do you think caused your stroke (or disease risk factor)? Do you think you could have prevented it?
- Describe the ways you currently maintain your health
- What are you doing to prevent another stroke (manage your risk factors)?
- Describe the factors that make taking care of your health easier? More difficult?
- What guidance were you given about preventing another stroke? Was that information helpful?

## Probes:

- Personal definition of health
- Current mental and physical health problems
- Comparison of current health to past health
- Stroke severity, timing, symptoms, post-stroke deficits, interaction with healthcare system
- Knowledge and access to secondary prevention resources
- *Knowledge/practices/challenges with diet, medication adherence, physical activity, smoking, weight, health monitoring*

• Tell me about your social life in Canada.

Probes: living arrangements, relationship with family in Canada/country of origin, social activities, availability and type of social support for health maintenance.

• Tell me about your journey to immigrate and settle in Canada.

Probes: pre-migration conditions, reason for migration, positive and negative aspects of immigrating, impact of immigration on health.

• Describe the factors you think can support or hinder engaging in stroke prevention practices.

Probes: healthcare system factors, social factors, gender, culture, environmental, personal factors, genetics.

## **Appendix D: Information Letter and Consent Form**

#### **Information Letter**

**Title of research study:** Stroke Prevention: Facilitators and Barriers in Middle-Aged and Older Adult Arab Immigrant Women.

Investigator: Jordana Salma, RN, PhD candidate	<b>Phone Number:</b> (780) 263-8438
Supervisor: Linda Ogilvie, RN, PhD	<b>Phone Number</b> : (780) 430-9221

<u>Purpose</u>: You are being asked to participate in a research study. The study will look at the facilitators and barriers Middle-aged and Older Adult Arab Immigrants experience in caring for their health after experiencing a stroke event or when living with stroke risk factors.

<u>Procedures</u>: If you agree to participate in this study, Jordana Salma will meet with you for an interview. The interview will take 1 to 2 hours. Jordana will ask you questions about your health and your health care practices. The questions will relate to your experience of having a stroke, the factors that facilitate or hinder your ability to maintain your health, and your health care experiences in Canada. Jordana will choose an interview location comfortable for you. The interviews can be done in Arabic or English. The interviews will be audiotaped.

<u>Possible benefits</u>: There are no direct benefits to taking part in this study. This study will help health care professionals understand the experiences of Arab immigrants who have had a stroke.

<u>Possible risks</u>: You might feel uncomfortable by some of the questions. These questions are about the difficulties you experience with your health. Otherwise, there are no known risks for taking part in this study.

<u>Privacy</u>: We will keep the information you provide strictly private. Jordana will use numbers to name you on the interview records. Any information made public will not identify you by name. Jordana Salma will lock the interview records in a safe place and destroy them after seven years.

<u>Additional contacts</u>: If you have any additional questions about this study feel free to contact Jordana Salma using the contact number provided above or email: <u>sjordana@ualberta.ca</u>. If you have any questions about your rights as a research participant or about the ethics of this study you can contact the Health Research Ethics Office: **308 Campus Tower**, **8625-112street**, **Edmonton**, **AB**, **T6G 1K8** 

reoffice@ualberta.ca

Phone: (780) 492-0459 Fax: (780) 492-7808

<u>Voluntary Participation</u>: You are free to withdraw from the research study at any time. You can withdraw before or during the interview process. You do not need to give any reasons for leaving the study.

<u>Payment of Expenses</u>: There will be no rewards for participating in this study. We will provide you with travel costs.

Signature of Research Participant:

Printed Name: \_\_\_\_\_\_Date: \_\_\_\_\_

Consent Form	
<b>Title of the research study</b> : Stroke prevention: Facilitators and Barriers in Middle-Aged and Older Arab Immigrant Women.	
Investigator: Jordana Salma, RN, PhD candidate Phone Number: (780) 263-8438	
Supervisor: Linda Ogilvie, RN, PhDPhone Number: (780) 430-9221	
<ul> <li>Do you understand that you have been asked to be in a research study?</li> <li>Have you read and received a copy of the attached Information Sheet?</li> <li>Do you understand the benefits and risks involved in taking part in this research study?</li> <li>Have you had an opportunity to ask questions and discuss this study?</li> <li>Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your employment?</li> <li>Has the issue of confidentiality been explained to you?</li> </ul>	
I agree to take part in this study: YES NO	
Signature of Research Participant:	
Printed Name:	
Date:	
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.	
Signature of Investigator: Date:	
THE INFORMATION SHEET WILL BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT	

## **Appendix E: Confidentiality Agreement**

Title of Study: Stroke Prevention: Facilitators and Barriers in Middle-Aged and Older Adult

Arab Immigrant Women.

\_\_\_\_\_, the\_\_\_\_\_\_(specific job I. description, e.g., interpreter/translator) have been hired to I agree to -1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*. 2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession. 3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks. 4. after consulting with the *Researcher(s)*, erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive). 5. other (specify). (Print Name) (Signature) (Date)

Researcher(s)

(Print Name)

(Signature)

(Date)

#### **Appendix F: Ensuring Rigor in the Research Process**

Nurse researchers continue to engage in research activities with ethically and linguistically diverse populations in the Western context to identify and address health inequities. This has drawn attention to the need for ethically driven and methodologically sound tools to ensure rigorous research processes and outcomes across linguistic and cultural mediums (MacKenzie, 2015; Ogilvie, Burgess-Pinto, & Caufield, 2008; O'Conner, 2004; Meleis, 1996). Interpretive Description [ID] is a methodological approach to qualitative research that is gaining momentum because of its pragmatic orientation towards enhancing disciplinary knowledge in nursing (Thorne, 2016). I used an interpretive descriptive approach to study the health experiences of Arab immigrant women. There has been an increase in the use of qualitative methods with Arab populations that brings attention to linguistic and cultural considerations for ensuring rigor (Ahammed, 2015; Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2016; Hawamdeh & Raigangar, 2014; Thomas, 2008). I draw from my experience as a novice doctoral researcher and from the broader literature on cross-cultural research practices to highlight considerations for data collection and analysis.

I positioned myself from the onset of the study as a bilingual bicultural researcher conducting the majority of data collection and analysis in the Arabic language. All languages are embedded within a cultural and historical conceptual universe; the use of a particular language in research influences the meaning making processes. In cross-language contexts the researcher must explicitly state the techniques and methods used to collect, analyze, and record data, such as translation processes, techniques to ensure conceptual equivalency, and rationale for language choices (Squires, 2009; Temple, Edwards, & Alexander, 2006). The Arabic language can be described as high-context versus English which is seen as low-context (Zaharna, 1995). Highcontext languages emphasize meaning making through the communicative process, where the burden of understanding falls on the listener who uses physical and emotional cues to grasp the underlying message. Low-context languages are more explicit and analytical with the expectation that the speaker convey a message in a way that is understandable to the listener. Differences in the function and expectations around language impact qualitative research processes that depend on interviews as a primary data source. The first focus of this paper is to elaborate on the meaning making processes that shaped data collection and analysis in the Arabic language. The second focus is to describe the challenges of learning the craft of qualitative research as a novice balancing considerations for methodological rigor. In the following sections, I outline the study, give a brief introduction to ID, and present considerations for data collection and analysis.

#### **Study Question and Process**

The research objective was to understand experiences around stroke prevention in a group of Arab immigrant women ageing in Canada. Approval was obtained from the University Ethics Board before commencement of the study. I recruited 16 women who emigrated from the Levant region of the Middle East and were currently living in a large Canadian urban center. Recruitment and data collection for this study occurred between June 2015 and May 2016. Women were recruited from a mosque and an Islamic community center. I conducted semi-structured interviews and administered socio-demographic and health questionnaires in the Arabic language. Interviews occurred mostly in participants' homes and lasted between 2 to 4 hours. I completed transcription and data analysis in Arabic, with final translation of themes and exemplars into English. The focus of this paper is on the data collection and analysis process; this involves considerations for the interview process, transcription and analysis of data, and

development of final themes. I outline my struggles and successes with enhancing rigor in using an ID approach to study the experiences of Arab immigrant women. In the following section, I present an overview of the ID methodology and outline relevant implications for data collection and analysis.

### **Interpretive Description**

Interpretive description is a method used to investigate a clinical phenomenon important to nursing, by extracting themes that are based on subjective interpretations of experiences, with the goal of generating findings useful to nursing practice (Thorne, Kirkham, & O'Flynn-Magee, 2004). Interpretive description focuses on knowledge development using a combination of data collected in the practice field, prior knowledge in the area, and abstract theorization (Thorne, 2016). The philosophical underpinnings of an ID methodology are that reality involves multiplicities that are subjectively and socially constructed, human commonalities and variations exist in every aspect of human experience, and the researcher is inseparable from the object of research. In approaching this research study, I was conscious of my shifting social position in relation to the research community as both an insider, based on my Arab and Islamic heritage, and an outsider, based on my status as a researcher and healthcare professional. I was aware that these multiple social locations shaped my approaches to engaging in research. I was also aware that despite identifying Arab women as a focus of study, women participating in the research process embodied multiple social locations which influenced the interview encounters and the narratives that emerged from these encounters. The fit between question and methodology seemed initially unproblematic. I discovered, however, in the process of data collection and analysis these varied social locations brought attention to cultural and linguistic nuances that added a dimension of complexity to the research process. I also experienced challenges related to being a novice researcher learning the craft of qualitative research. I describe below my experience and considerations for future research in the areas of interviewing, transcription and translation, and data analysis.

#### **Considerations for Data Collection and Analysis**

#### The Interview: Encouraging the Narrative Process

**Eliciting the senses.** The interview guide initially used semi-structured questions that were too rigid to elicit rich responses from women in the study. For example, such questions were responded to with short answers or met with silence. Some women would ask: 'what would you like me to answer?' Eliciting storytelling was more effective for engaging older Arab women; the dynamic switched to that of an elder transmitting knowledge, experiences, and life lessons to a member of the younger generation. Meaning making develops through reflection on behaviors, feelings, and thoughts to create a story of oneself in the world and can be facilitated through use of body awareness and sensory stimuli in the research process (Sharma, Reimer-Kirkham, & Cochrane, 2009; Stetler, 2010). To help women turn inward and reflect, I elicited the senses as a departure point in our discussions about health. Visual and tactile stimuli, like showing the interviewer pill bottles and medication, served to start a conversation about perceptions of health:

Interviewer: Can you show me your medication (pause to look at medication) When you look at this medication what thoughts do you have?

Participant: I don't like to think about it.

Interviewer: Why is that?

Participant: Because in my entire life I never took medication. I started in the last two years. Moving forward what is going to happen? My husband does not know the

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medication I am on. I mean what if I die. He doesn't know anything about me. I came from [city in other province] not on any medication. I might have taken Aspirin and Tylenol. I would take these pills and they would put me to sleep because my body was not used to medication.

Interviewer: You said you are worried about what could happen, you are worried about the future?

Participant: Yes.

Interviewer: In what way?

Participants: That my health will get worse. (Participant 4)

Hawamdeh & Raigangar (2014), in one of the few discussions in the literature on interviewing Arab populations, describe participants' struggles to narrate, where they questioned the worth of their narratives or focused on giving perceived correct answers. The interviews in Hawamdeh & Raigagner's study occurred in an institutional setting with employee nurses which might have contributed to interview anxiety. I identified, however, a similar pattern with the women in this study where women needed encouragement in telling their stories and frequent assertions that their narratives were valuable to the researcher.

**Managing intense emotions.** Strong emotions of sadness, anger, and worry emerged in the interview process. This did not relate necessarily to women being vulnerable or in crisis, rather the women perceived the interview as an opportunity to share the stressors in their lives with a sympathetic listener, without losing face as might occur when these stressors are discussed within their social networks. In re-reading the first few manuscripts it was evident that I was uncomfortable with these experiences of intense emotions; I would change the topic or jump into

a consoling mode. This resulted in loss of opportunity for further insights or superficial understandings of the sources of these strong emotions:

Participant: ...I am scared, he has not been feeling well and I am worried about him...he has many health problems, he has diabetes and he takes medication for his heart, and cholesterol, and his thyroid and he has an appointment tomorrow with a specialist. Now he has dizziness and tremors (starts to cry)....they told him this is the beginning of it and referred him to a specialist.

Interviewer: Beginning of what?

Participant: I don't know what they call it. We still don't know. We will see the physician tomorrow (continues crying).

Interviewer: You are bothered by this...

Participant: All we have is God in this country

Interviewer: You feel that all you have is each other?

Participant: That's it (seconds of silence)

Interviewer: Tell me about other ways that you care for your health? (participant16)

As the study progressed, the use of silence and the reference to food were the most effective strategies in dealing with strong emotions, allowing for opening up to discuss difficult topics. Food was the soul of this research project; sharing food, swapping recipes, and boasting about culinary skills created safe spaces and normalized the interview encounter. With strong emotions in an interview and when second interviews are not scheduled, knowing when to end the interview was important to avoid unresolved feelings or experiences left untold. Probing into painful memories was avoided when unrelated to the research question. I always asked myself: 'is going there necessary for the data?' This question ensured that curiosity did not lead to asking unnecessary questions that women might later regret answering or that would force reliving painful memories. Wegraf (2001) advises letting the participant guide us to when the interview is over by watching for statements that indicate comfort with terminating the interview. The interviews ended when women made statement such as: 'I told you everything I have to say.' or 'You know my life story now.' Women were asked if mental health support was needed and were offered information on resources on two occasions when I sensed possible emotional distress or mental health issues.

**Embracing multiple agendas and expectations.** At various points in the interview process it was apparent that the agenda of the interviewer and that of the interviewee were at odds. Increasing the understanding of stroke prevention in immigrant women meant engaging in a process of always returning to the question. Socialising, giving advice, and venting emotions to a sympathetic ear were alternate agendas that were brought by participants to the interview context. These interactions were valued as authentic expressions of self-identify and personal beliefs shared with the interviewer whose insider status allowed for relating to participants' experiences:

Interviewer: Are there needs that you have that are not met here?

Participant: Like food for the house?

Interviewer: Could be anything in your life, not only food.

Participant: To tell you the truth I have a lot of needs not met. Am I in need of this isolation? I am not happy and being away from home I find it very hard. When I feel

overwhelmed from thinking I open the window and take a deep breath. To tell you I am happy, no, I am not happy. This country has a lot of good and it is safe and there is honesty and it has everything you could want, like living in heaven. When I think I left my country and my family, being away becomes difficult.....do you have girls or boys?

Interviewer: One girl and two boys.

Participant: God keep them protected for you. Listen, stay in this country and work hard and create a future for yourself and your children...then return to your country. It is enough they do not hear the Athan [Muslim call for prayer from mosque minarets] here and if they enter a mosque they do not understand what the imam is saying. You are at work and their father is at work...school starts at home with the mother... [Continues with detailed description of how she raised her children in Syria as a single mother, working as a housekeeper, and the respect she received in her community] (Participant 10)

Reminiscing about her social life in Lebanon, the support she had in her community, and the wide network of friends, created the opportunity for further questions about her social networks and support in Canada. Koven (2014) describes the interview as an 'ideologically mediated speech event', which requires that the researcher understand and accommodate the communicative norms in the interview process to ensure comfort of both parties. I was familiar with the expectations of communication with Arab elders that centered on respect, listening to stories, receiving advice, and avoiding being perceived as too intrusive.

Some women in the study expected a rigid 'I ask- you answer' type of interaction because using the word research and interview conveyed the idea of a serious, institutional,

constrained communicative event. It often took the first half hour of the interview to re-set mutual expectations on the interview style, which always yielded more in-depth and reflective narrations. The use of humor, analogies, and metaphors is part of Arab language communication (Zaharna, 1995) and conveyed important messages about women's experiences with stroke prevention. Comprehending these messages required an understanding of the Arab culture, life in the Levant region, and Islamic norms. Comprehending these messages also required situating culture, past experiences, and religious norms within the specific context of women's lives at the times of the interviews. It could be argued that if qualitative researchers are expected to engage in an interpretive process, then qualitative researchers working in the Arabic language cannot avoid engaging in this interpretive process; high level interpretation being a function of interpersonal communication in the Arabic language. In the interview context, I found that more open-ended forms of questioning that elicited the senses, followed by more structured questions, was a successful strategy to gain in-depth and reflective responses. This form of interviewing can be useful within all qualitative interview contexts and requires practice for novice interviewers. Using multiple interview encounters might allow for increased participant comfort and more time for reflection in Arab older adult populations.

## Transcription and Translation: Accommodating Linguistic and Cultural Nuances

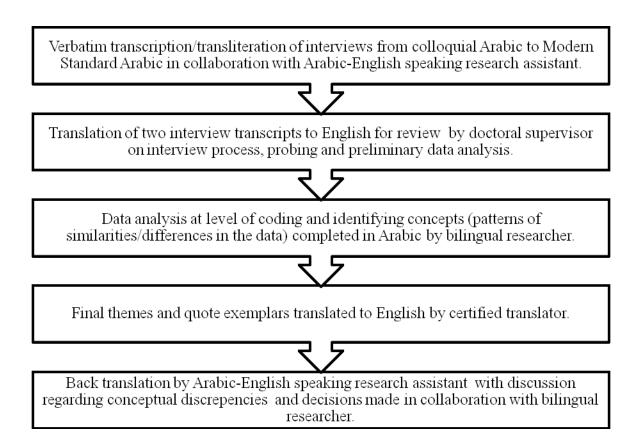
**Moving between spoken dialects and written Arabic.** Arabic has both a spoken form, colloquial Arabic, and a written form, Modern Standard Arabic [MSA] (Haeri, 2000). Colloquial Arabic is spoken in multiple dialects that differ by country and region. Levantine Arabic relates to the Arabic spoken in the Levant region but still includes variations across urban and rural contexts and across national borders in the region. Modern Standard Arabic is taught in schools across the Arab world and is used mostly in formal conversations amongst the educated class.

Rigor in qualitative interviews includes attention to accuracy in transcribing the spoken word of participants to written texts (Hammersley, 2010). Transcription, however, has interpretive and constructive elements where the transcriber influences how and what is transmitted to written form (Lapadat & Lindsay, 1999; Tilley, 2003). In listening to spoken dialects of Arabic and transcribing what I heard women say, I found it difficult to write some words in dialect form and when written I could not re-read the words after a period of time. In these instances, I used transliteration, which involves substituting the dialect form of a word with a MSA word of conceptually equivalent meaning (Regmi, Naidoo, & Piklington, 2010). Accuracy of transcription was enhanced in that both I and a research assistant helping with transcription were from the Levant region and understood many of the cultural expressions, metaphors, and speech connotations. Being both the interviewer and transcriber also allowed for better understanding of the mood, context, and connotation behind a speech segment. Here, understanding involved an interpretive element which meant the process of transcription was not only a technical activity. In larger studies where the interviewer, researcher, and transcriber are different individuals, close collaboration to ensure conceptual equivalence between spoken forms and written Arabic is essential (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2016).

**Translating to preserve original voices.** Following recommendations of other bilingual researchers (Chen & Boore, 2009; Larkin, Dierckx de Casterlé, & Schotsmans, 2007; Nurjannah, Mills, Park, & Usher, 2014; Santos, Black, & Sandelowski, 2015; Temple, 2006), I completed the process of transcribing and preliminary data analysis in Arabic. My doctoral supervisor checked two translated transcripts from early interviews to comment on the interview process, use of probes, and initial concepts visible in the data. Themes and exemplars were translated by a certified translator familiar with Arabic Levant dialects. The last step was blind back-translation

of exemplar quotes into Arabic by an Arabic-English speaking research assistant to check for equivalence of terminology and conceptual meaning (Figure 1).

Figure 1: Transcription and Translation Process.



Cross-language researchers have advocated for initial translation and coding to be done in the original language of participants when a bilingual researcher is available, followed by translation to the target language during the categorization phase, so as not to lose cultural expressions and concepts. Chatti (2016) describes the differences between Arabic and English using metaphors of colors, where the meaning of a phrase can be distorted or seem illogical without defining a conceptual equivalence of meaning. The women in the study often used terms that were difficult to translate into English due to varied conceptual meanings the words held in different conversational contexts. For example, the word Al-ḥamdu lillāh (ألحَمُدُ شُلَ stated throughout the interviews was often eliminated from final quote exemplars due to difficulty explaining the varied meanings of the term. Al-hamdu lillāh translates to Praise be to God: it serves as a personal reminder to be grateful, comforts a person in time of difficulty, shows others the admired quality of patience, and is believed to elevate a Muslim's spiritual status when said often. The word can be used to show thankfulness for a good occurrence and it can be used to convey a person's patience and acceptance of God's will around a negative occurrence, or as a transition in a conversation to re-focus on the positive aspects of a difficulty:

Example 1: Now these evenings I sit alone....I have a little bit kind of depression. I am alone. It is a little difficult. This is my life now, al-hamdu lillāh, I have very nice children... (Participant 13)

Example 2: I said to him how many stents did you put. He said 'three' I said 'really, how blocked was it [referring to coronary arteries]' He said '90% and the scan said between 60 and 70%, all the doctors are shocked that the first scan missed it'. Thank God it was not for me to have a heart attack, so I always say al-hamdu lillāh God loves me and he does. (Participant 7)

Example 3: I told you when I was sleeping at night I couldn't breathe. So he [the doctor] sent me to a cardiac specialist and a respiratory specialist, al-ḥamdu lillāh, I hope I am not sick though. (Participant 1)

Transcription and analysis in Arabic meant avoiding problems of misinterpretation that might occur with moving within various linguistic forms: colloquial Arabic, standard Arabic, and English. The insider/outsider lens brought by my bilingual and bicultural status added a dimension of complexity, where enhanced effort was needed to avoid making assumptions in the interpretive process. The study was small and I was engaged in both interviewing and conducting data analysis which supported a more cohesive and reflective process. This approach, however, would be time consuming and impractical for large data sets. This approach can also impact negatively the collaborative process when members of a research team are not familiar with the target language. To my knowledge there is no qualitative data analysis software that can accommodate variations in Arabic dialects. This means in larger studies translation of transcripts to English will be necessary to allow for management of large data sets. It might be useful to select a sample of transcripts and conduct analysis in the original language, translate the same transcripts to English and conduct analysis by a second independent researcher and then compare analysis results across languages (Chen & Boore, 2009; Nurjannah, Mills, Park, & Usher, 2014). This requires a collaborative effort in analysis and a discussion of discrepancies, but is a possible way to trial enhancing rigor. This approach would also allow for better collaboration when some members of the research team are not familiar with the original language (Santos, Black, & Sandelowski, 2015).

## Moving to Themes: Answering the Final Interpretive Question

**Identifying patterns within context.** An ID methodology relies on constant comparative analysis processes, originating from grounded theory, to understand human phenomena (Thorne, 2016). In analyzing interview data, I became aware of the risk of misinterpreting contradictory data, making erroneous inferences, and missing important data patterns. Attention to these risks evolved from viewing myself and the women in the study as social actors bringing our beliefs, assumptions, and agendas to the research encounter (Clandinn & Connelly, 2000; Yanos & Hopper, 2008). This meant that data collected from the interview could not be viewed in isolation of the inter-personal context of the interview encounter. Data contradictions relate to

differences within the data that are hard to explain. For example, the women in the study did not criticize the healthcare system when directly asked for feedback but described a lack of access to and utilization of health-promoting resources. I wondered if women were being respectful of my registered nurse status or if the women were following the narrative of what 'good immigrants' would say' or whether they were truly grateful despite not having all their needs met. In reflecting, I believe all three positions were true and the contradictions related to my perception of the need for a single cohesive narrative. Making erroneous inferences relates to attributing variations or similarities of data patterns to unrelated or secondary causes. Some women were experiencing a life transition due to an unexpected alteration in health. Other women had lived many years with personal health struggles. Women who had the time to emotionally and mentally process the alteration in health were more likely to weave a positive storyline of triumphs despite adversity. Women in transition struggled more with processing the impact of the change and showed a lack of confidence about personal ability to manage health. It was important to recognize that some variations in women's experiences related to where women were situated in their health journeys, versus differences in personal coping styles or external socio-cultural influences. Missing important data patterns refers to an insider overlooking data patterns that relate to shared experiences within the researched community. I was initially not attuned to the relevance of transnational connections in shaping women's lives until my doctoral supervisor, a cultural outsider, drew my attention to this pattern in the data. As a bicultural woman my life was built within transnational spaces, but I could not distance myself as a researcher to identify the relevance to the phenomenon under study.

Attending to non-conforming data. Negative cases or exceptions that do not fit the data patterns can allow for a more in-depth and complex understanding of study findings when the

lack of fit is explored closely (McPherson & Thorne, 2006). The dangers of thematic saturation claims are higher with small studies where there might not be enough cases to generate a range of variability in experiences (Morse, 1991). This study cannot claim to have reached thematic saturation around the phenomenon of stroke prevention experiences in Arab immigrant women, as evidenced by the emergence of experiences that suggest there is more out there to know about the phenomenon of interest. For example, the woman in the sample with a university degree and a career discussed difficulties with returning to work, and balancing career, family, and health within a cultural context that values traditional female roles:

The event did happen [heart attack]. I had a hard time accepting it. It is like you let everybody down. You feel guilt, like you did something wrong. People judge you because you kill yourself working. They say you are running after money... It is not about the money but satisfaction from work...it is hard for people to understand. (Participant 3)

The identification of role tension was not present in the accounts of other women who were less educated and described themselves primarily as homemakers, wives, and mothers. Although this woman shared many of the experiences of other women in the study, her experience of role disruption might emerge as a thematic pattern with a larger sample of educated Arab women.

Another example relates to participation in physical activity. One of the women in the study was actively engaged in exercise, going consistently to a female-only gym before and after her stroke event. Her experiences helped elaborate the challenges women face with staying physically active by demonstrating the prerequisites for successful engagement. She provided a counter narrative of other women's experiences with physical activity:

Participant: I know many ladies from the Arab community who stay at home, watch television, and refuse when their children ask them to go to an exercise facility...I meet

more than one of their children, I meet them and they say I wish our mom was like you, I wish she would go. I tell them to bring their moms. I swear if it wasn't for my daughter who signed me up for the gym I wouldn't persist.

Interviewer: Tell me more about your persistence with exercise, not all people are like you, it isn't easy to keep at it.

Participant: Honestly, I am scared for myself, scared. If I have a headache when I go to bed, I get worried about dying (laughs). Exercise keeps me in good shape.

Interviewer: You know it is good for your health so you continue with it.

Participant: Yes, I do not want to die because my sister, like I said before, had a stroke and I do not want a stroke. (Participant12)

Non-conforming data, or data that does not fit the overall patterns of experience identified in the study, can highlight areas that need further study or help enhance understanding of study themes. The inability to always follow up on experiences that did not fit the overall data patterns was a limitation of this study and resulted from difficulties with recruitment and time constraints.

## Conclusion

For cross-cultural research to demonstrate rigor research processes must be culturally relevant by serving the interests of the study population, contextual where the conditions of the research process are factored into analysis, appropriate and flexible by attending to language and communication processes, and respectful towards the cultures and traditions of research participants (Im, Page, Lin, Tsai, & Cheng, 2004). I used interview strategies that balanced the need to answer the research question with the needs of women to tell stories, express emotions, and give advice. Translation and transcription were approached as interpretive processes that were facilitated by being positioned as a bilingual and bicultural researcher. Finally, data

analysis required flexible and open approaches to attend to patterns in the data and interpret these patterns within a broader social and cultural context. Ensuring rigor in cross-cultural research was complicated by being a novice researcher who needed to learn the craft of doing good qualitative research.

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