Giving Voice to the Unheard: Perceptions, Practices & Beliefs About Breast Cancer and Screening Among Ethnic Minority Women From the MENA (Middle East & North Africa) Region in Edmonton, Alberta.

by

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Abstract

Breast cancer is one of the major causes of death among women in Canada and globally. In Canada, screening has been found to be successful in decreasing morbidity and mortality (Canadian Cancer Society, 2015). Use of breast cancer screening services by immigrant women however is limited (Bowser, Mrqusee, Kousa, & Auton, 2017). Cultural values and religion often shape health decisions, and failure to recognize this diversity results in breast cancer and screening disparities among ethnic minorities (Aziza, 2014). Studies on accessing breast cancer screening for particular cultural groups have been rare in Canada (Bowser et al., 2017). Using focused ethnography, this study examined how women from the MENA (Middle East and North Africa) region perceive and practise breast health, breast cancer risk and screening, and explored barriers to breast cancer screening. Six focus groups were conducted with six participants in each group, and the results were analyzed thematically. Three broad themes were identified: knowledge about breast health, cancer risk and screening services; barriers to maintaining breast health and screening; and potential solutions for overcoming barriers. The findings showed the participants have quite limited knowledge about breast cancer screening practices in Alberta and there remain multiple barriers to screening. The study contributes to the development of culturally appropriate interventions to overcome barriers and motivate MENA women to use breast cancer screening services.

Preface

This thesis is an original work by Dalia Eldol. This research work obtained research ethics approval from the University of Alberta Research Ethics Board, project name "Giving Voice to the Vulnerable: Perceptions, Practices & Beliefs about Breast Cancer and Screening among Ethnic Minority Women From the MENA (Middle East & North Africa) Region in Edmonton, Alberta", No. Pro00075586_REN2, 26 February 2018.

Dedication

I dedicate this thesis to my husband:

Tilal Abbasher

I would not be able to do this without him

He is my partner, my best friend, and my rock

He encourages and has supported me through all my desires and goals

He comforts me through all my fears and tears

I will forever be grateful for him for always being there for me

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Although I am thousands of miles away from them, I am grateful for my family. They have always stood by my side. Thank you to my parents. Their unconditional love, support, and prayers are the most precious gifts and blessings from God. Thank you to my brothers and sister. They hold a place in my heart that could be filled with no one else.

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Table of Contents

Abstract ii

Preface iii

Dedication........ iv

Acknowledgements v

Table of Contents vi

List of Figures ix

Chapter Page

1. Introduction........1
   - Breast Cancer Disease Burden and Screening........1
   - Breast Cancer and Screening Disparities........2
   - Immigration History........3
   - Unheard Voices........4
   - Research Objectives........6
   - Overview of the Thesis........ 6

2. Literature Review........8
   - Breast Cancer & Screening Experiences........8
     - Screening Practices........9
     - Breast Cancer Outcomes........14
   - The Role of Behavioural Theory in Understanding and Promoting Breast Cancer Screening........15
     - The Health Belief Model (HBM)........16
     - Health Action Model (HAM)........17
       - Beliefs and KAP (Knowledge, Attitude and Practice) System 19
       - Motivation........19
       - The Norm System........20
   - Historical Beliefs & Cultural Health Practices of the MENA Population........22
     - Cultural and Religious Influences on Attitudes About Breast Health........23
     - Adopting Preventative Oriented Health Care........26
     - Attitudes Toward Disease........27
   - Utilization of and Access to Healthcare by Immigrant Women........28
     - Health Literacy (HL)........29
     - Health Seeking Behaviour (HSB)........31

        Multiculturalism……………………………………………………………..33
    Previous Immigrant Research on Breast Cancer (Approaches & Issues)……………..35

3. Research Methodoogy...39
    Research Paradigm: The Interpretive Paradigm………………………………………39
        Ontology…………………………………………………………………40
        Epistemology……………………………………………………………40
    Theoretical Perspective…………………………………………………………40
        Constructivist Framework..…………………………………….................40
    Researcher positionality……………………………………………………......42
    Role of the Language Assistant……………………………………………………..45
    Research Methods…………………………………………………..………....47
        Research Design……………………………………………………………47
            Focus Ethnography………………………………………………….....47
        Participants…………………………………………………….................49
        Recruitment Process………………………………………………..........50
        Data Collection………………………………………………..………....52
            Socio-Demographic Characteristics of the Participants…………………....58
        Transcription……………………………………………………...........58
        Methods of Data Analysis…………………………………………….......60
            Thematic Analysis……………………………………………………..60
        Trustworthiness……………………………………………………….……63
            Credibility…………………………………………………….......63
            Transferability……………………………………………………......64
            Dependability…………………………………………………….......64
            Confirmability……………………………………………………......65
            Verification Strategies…………………………………………….…....65
        Ethical Issues……………………………………………..………………66
    Limitations in Data Collection………………………………………………………68

4. Results...69
    Knowledge About Breast Health, Cancer Risk and Screening Services……………….69
        Biomedical knowledge………………………………………………………....69
        How Breast Health Is Maintained…………………………………………...71
            Healthy lifestyle…………………………………………………………...71
            Breastfeeding…………………..…………………………………………..72
            Visits to the Doctor………………………………………………………...73
            Faith and Prayers…………………………………………………….….73
            Appropriately Fitting Undergarments……………………………………..74
        Knowledge of Breast Cancer Screening……………………………………..75
    Barriers to Maintaining Breast Health and Screening……………………………….76
        Language Barriers……………………………………………………………....77
        Healthcare Provider (Gender and Attitude)………………………………………78

        Gender Barriers……………………………………………………………………80
        Lack of Empowerment……………………………………………………………81
        Fear ……………………………………………………………………………..83
    Potential Solutions for Overcoming Barriers……………………………………………84
    Summary of Results……………………………………………………………………..87

5. Discussion……………………………………………………………………..…88
    Theoretical Framework: The Health Action Model (HAM)……………………………..88
    Lack of the Holistic Approach to Health ..…………………………………………...89
    Lack of the Screening Knowledge……………………………………………………90
    Barriers to Screening……………………………………………………………………..92
        Language Barriers and Functional Health Literacy…………………………...…..92
        Education and Empowerment and Its Implications for Health Literacy…………..95
            The Difference Between Knowledge and Practice……………………...…..96
        Healthcare Providers……………………………………………………………99
        Other Impacts of Immigration…………………………………………….……..100
    Cultural and Religious Concepts……………………………………………………103
        Normative Social Influences..……………………………………………………..103
        Islamic Values ……………………………………………………………………..106
    Culturally Sensitive Interventions……………………………...………………….…108
        Intersection Between Islam Faith and Health Promotion……………………….....110
    How was the Health Action Model (HAM) Useful as a Theoretical Framework in This Study?...111

6. Conclusion…………………………………………………………………………...113
    Strengths & Limitations…………………………………………………………...114
    Implications……………………………………………………………………… 116
    Recommendations for Future Research……………………..……………………119
    Knowledge Translation..……………………………………………………..…....121

    References ..……………….……………………………...………………………..…123

    Appendices……………………………………………………………………….……152
        Appendix A: Letter of Initial Contact …………………………………………152
        Appendix B: Letter of Initial Contact (Arabic Version)…………………….....154
        Appendix C: Socio-Demographic Questionnaire……………………………….156
        Appendix D Participant Consent Form……………………………………..….158
        Appendix E: Participant Consent Form (Arabic Version)……………………..162
        Appendix F: Focus Group Questions………………………………………..166
        Appendix G: Focus Group Questions (Arabic Version)………………………..167
        Appendix H: Confidentiality Agreement……………………………………… 168
        Appendix I: Focus Group Transcript Coding (Translated Sample)…………..169

List of Figures

Figure 1. The Health Action Model (HAM)……………………………………………………18

Figure 2. Social Influences on Individuals Health Actions……………………………………..21

Figure 3. Inter-relation between the Cornerstones of Research………………………………...41

Chapter 1

Introduction

Immigration is a unique and challenging experience that is usually characterized by a loss of social support and networks, a need to learn a new language, and the struggle to fit into a new cultural identity. These factors shape the health and welfare of individuals and communities, and they have an influential effect on disparities in health that are connected with being a member of a minority group (Weerasinghe1 & Mitchell, 2007). Newcomers to Canada face challenges in seeking health services and health information because they are unaware of how the Canadian health system works (Margareth, Zanchetta, & Poureslami, 2019; Amin, 2008). There is a lack of effective communication between health providers and healthcare seekers who are cultural minorities (Margareth, Zanchetta, & Poureslami, 2019). The available resources and educational policies are poorly designed for those with language and literacy barriers (Margareth, Zanchetta, & Poureslami, 2019). As a result, many ethnic minority groups lack access to quality healthcare services including cancer preventive services, and women from the Middle East and North Africa (MENA) region are no exception (Bowser et al., 2017).

Breast Cancer Disease Burden and Screening

Breast cancer is a major public health issue and one of the leading causes of mortality and morbidity among women in Canada and all over the globe (Bowser et al., 2017; Canadian Cancer Society, 2015). Annually, there are about 1.36 million new cases, representing a quarter of all cancers diagnosed in women, in addition to 456,000 deaths from breast cancer, accounting for 13.8% of the total cancer mortality rate among women worldwide (World Health

Organization, 2012). In Canada, breast cancer is the most common cancer among Canadian women and the second main cause of cancer deaths (Canadian Cancer Society, 2015). It was estimated in 2015 that "every day 68 Canadian women are expected to be diagnosed with breast cancer and 14 Canadian women will die from breast cancer" (Canadian Cancer Society, 2015).

Currently, regular screening mammography is highly recommended for early detection for women of average risk between 50 and 69 years of age (Canadian Cancer Society, 2015). In Canada, half of the new cases of breast cancer occur in women among this age group, and mammography has been found to be an effective method for early detection of breast cancer (Anthony, Miller, Teresa, Cornelia, Baines, & Wall, 2000). In fact, the breast cancer mortality rate has decreased by 44% among Canadian women since its peak in 1986, due to developments in screening technology and innovative treatments (Canadian Breast Cancer Foundation, 2015).

Breast Cancer and Screening Disparities

Women from ethnic minority groups in Canada have some of the lowest utilization rates of preventive services and are more likely to face many barriers in accessing screening (Vahabi, Lofters, Kumar & Glazier, 2016; Smith, Diana, Miglioretti, Nicole, Linn, Rachel, Jodi, Mark, William, Barlow, Cherry, Beasley, & Karla, 2006). More than half (57%) of recent immigrant women in 2008 were non-users of the screening facilities compared to 26% of Canadian-born women (Statistics Canada, 2009). Moreover, high mortality rates and high prevalence of advanced breast cancer as well as a poor five-year survival rate are reported amongst ethnic minority women (Statistics Canada, 2009). Cultural diversity influences decisions to uptake cancer screening and has a significant impact on breast cancer outcomes (Aziza, 2014).

Breast cancer is surrounded by fear, myths, and far-reaching implications (Rhodes, Song, Nam, Choi, & Choi, 2015; Remennick, 2006). Many women do not use the existing breast-screening facilities and present with progressive disease (Remennick, 2006). Multiple factors are involved in the etiology of breast cancer disparities among women from ethnic minority groups (Rhodes et al., 2015). It is well documented in the literature that barriers to preventive healthcare are experienced by women both in their original countries and as immigrants in multiracial Western societies (Rhodes et al., 2015). Understanding these barriers is important, not only to recognize patterns of late detection but also to produce effective programs and interventions (Margareth, Zanchetta & Poureslami, 2019).

Immigration History

According to the International Organization for Immigration (IOM), the Middle East and North Africa (MENA) region covers an area stretching from Morocco across Northern Africa to Southeast Asia through Iran, and down to Sudan in Africa. The area is quite diverse in terms of geographical history, climate, and natural resources (Barakat, 1993). However, consecutive occupations by different empires have formed the civilizations and led to similar social and political experiences and common themes in its traditions and culture today (Barakat, 1993). Over the preceding two decades, the immigrant population in Canada from the MENA region has increased considerably (Citizenship and Immigration Canada, 2014). A large number of immigrants have come to Canada from Middle East and North African (MENA) countries (e.g., Egypt, Iraq, Somalia, Syria, and Sudan), which are named collectively as the Arab world (Barakat, 1993). In Alberta, there is a large MENA population in comparison to other provinces (Statistics Canada, 2007). Several factors have been involved in this migration, such as natural disasters, wars, political and economic instabilities, and the voluntary seeking of different lifestyles and employment opportunities (Amin, 2008; Barakat, 1993). Immigration has potentially significant impacts (e.g., social, economic, and political) on both the host country and the country of origin (Barakat, 1993).

Unheard Voices

The diversity of ethno-cultural groups has shaped Canada's history and its national character (Statistics Canada, 2007). In Canada, there are certain ethnic minorities, such as Africans, Asians, Indians, and immigrants from the MENA countries, whose voices are not heard with respect to breast health and breast cancer risk (Weerasinghe & Mitchell, 2007). With regard to the female population from the MENA region, there are very few studies that have tackled their beliefs, knowledge, experiences, and access to breast cancer screening services in Canada (Bowser et al., 2017).

In Alberta, there is a rapidly growing immigrant population, especially from MENA countries, which contributes significantly to Canada's racial and cultural diversity (Citizenship and Immigration Canada, 2006). It is no secret that Canada (especially Alberta) has welcomed thousands of Syrian refugees, who indeed have added significantly to the body of the immigrant population from the MENA region. Compared to other provinces in Canada, immigration in Alberta has received limited research attention with regard to breast cancer, despite the fact that the province has seen a rise in immigration in the last two decades (Aziza, 2014).

Middle Eastern women's perception of health, including breast health, is deeply rooted in their religion and culture (Bowser et al., 2017). Hence, understanding the different factors that shape these women's health decisions and actions with regards to breast health is important in improving their health and providing appropriate preventive healthcare services (Amin, 2008).

There is a lack of qualitative research in Canada regarding MENA women's practices of breast health and barriers to cancer screening (Bowser et al., 2017; Gastaldo, Khanlou, Massaquoi, & Curling, 2002). In fact, most of the studies on breast cancer risk from a racial context have been dominated by quantitative studies that usually lack a comprehensive narrative of human insight (Gastaldo et al., 2002). Qualitative researchers dig deeper to understand people's perceptions, experiences, and how they make sense of the world (Sherman & Webb, 1988): "*Qualitative researchers attempt to interpret or make sense of the meaning people attach to their experiences or underlying a particular phenomenon*" (Mayan, 2016, p.11). Qualitative research provides in-depth description and rich information about MENA women's experiences and perspectives on breast cancer risk and prevention (Hwang, Donnelly, Ewashen, McKiel, Raffin, & Kinch, 2015). Comprehensive and rich information is needed to empower underserved populations (Electra, Paskett, Tatum, & D'Agostino, 1999). Only with this deep understanding of the culture can social changes be made to impact the rising inequalities in breast cancer (Hwang et al., 2015). In health promotion in Canada, it is important to view health and illness from the perspective of those from Arab and Islamic cultures, which could be different from the perspective of those from other ethnic groups (Walton, Akram, & Hossain, 2014; Azaiza & Cohen, 2006). Medical professionals' lack of understanding of Middle Eastern cultural perceptions may result in poor communication between with that community and, eventually, lead to ineffective preventive health services (Azaiza & Cohen, 2006). Qualitative research will provide insights into Arab Muslim women's cultural beliefs and practices with respect to breast health and screening that cannot be fully accomplished through quantification only. This deep understanding of MENA women's experiences will identify and decrease the gap in knowledge and overcome barriers to breast cancer screening (Bowser et al., 017; Amin, 2008).

Research Objectives

The purpose of this study is to explore perceptions, practices, and beliefs about breast cancer and screening among women in Alberta from the MENA (Middle East & North Africa) region. The objectives of this study are as follows:

1. to understand how immigrant women from the MENA region perceive breast health and breast cancer risk;
2. to understand their knowledge and practices of breast cancer screening;
3. to explore barriers to breast cancer screening services and factors that would facilitate their engagement in screening;
4. to identify culturally sensitive interventions that can be incorporated into the existing breast cancer prevention programs to motivate the uptake of screening practices among this group.

Overview of the Thesis

This thesis is presented in six chapters. The current chapter provides a general introduction to the subject, the rationale for conducting this study, an outline of the purpose of the study, and an overview of the structure of the thesis. Chapter 2 provides a wider and more thorough review of the available literature on breast cancer and screening disparities, determinants of utilization of and access to healthcare by immigrant women, and historical beliefs and cultural health practices of the MENA population. This chapter also identifies gaps in the current literature and underscores the importance of exploring breast cancer screening experiences of immigrant women from the MENA region within the Canadian context. Chapter 3 outlines the research paradigm and theoretical perspective I will be using as well as the qualitative research methods used in conducting this study, including research tools employed and the whole research process. Chapter 4 presents the data analysis and the outcomes of this study. Chapter 5 discusses the findings, with reference to theoretical perspectives and relevant literature. Chapter 6 provides conclusion to integrate the results including implications, recommendations for future research, and the strengths and limitations in this study. This chapter concludes by discussing the translation of knowledge of this study.

Chapter 2

Literature Review

In this review of the literature, I begin by discussing different studies that have examined breast cancer (BC) and screening from a cultural and ethnic perspective and disparities in screening and BC Outcomes. Second, I discuss information related to the history and culture of the Middle East and North Africa (MENA) population, what is already known about beliefs and practices related to health in MENA countries, and the effects of these beliefs on the perception of health. Third, I present the socio-cultural experiences of immigrant women living in Canada in relation to health and their utilization of and access to healthcare services. I also highlight the roles of health literacy, health-seeking behaviours, and multiculturalism as important determinants of the health inequalities among immigrant groups, and how these determinants influence the perceptions of health and illness from an immigrant health point of view. Last, I discuss some approaches and issues in previous immigrant research on breast cancer.

Breast Cancer and Screening Experiences

The statistics indicate that approximately 26% of all deaths of women in Canada are due to breast cancer (Government of Canada, 2017). The principal strategy of breast cancer prevention in Canada is cancer screening. Screening takes several forms, including breast self-exam, clinical breast examination, and regular mammography (Canadian Cancer Society, 2015). In fact, studies have shown that mammography reduces the risk of breast cancer death and improves survival rate (Gøtzsche & Nielsen, 2011; Schwartz et al., 2008; Madanat, 2002). For those reasons, breast cancer organizations created partnerships across the country to support and enhance screening and early detection policy (Canadian Cancer Society, 2015). These breast cancer organizations and their partners (e.g. research alliances, community foundations, public health organizations) focus on improving patient experiences and making evidence-based recommendations so that patients have access to better services, which will lead to controlling cancer (Cancer View, 2017).

Screening Practices. Variations in culture and ethnicity influence behaviours such as cancer screening participation and have a significant effect on rates of developing and dying from breast cancer (Aziza, 2014). In Canada, marginalized and immigrant women have some of the lowest consumption rates of screening services and are more likely to face significant obstacles in accessing preventive services (Vahabi, Lofters, Kumar, & Glazier, 2016; Smith, Miglioretti, Linn, Mark, William, Barlow, Beasley, 2006). This poor involvement places them at a higher risk of developing advanced stages of breast cancer and reduces their chances of survival (Vahabi et al., 2016; Smith et al., 2006). Vahabi et al. (2016) found that poor screening rates are associated with certain racial and immigrant groups in Canada. They also found that the screening participation level is low among immigrant women from Asia in comparison to those from Europe. Factors such as language, social isolation, and cultural differences were identified as barriers to involvement in screening services (Margareth, Zanchetta, & Poureslami, 2019; Bowser, Mrqusee, Kousa, & Auton, 2017; Vahabi, 2011; Shields & Wilkins, 2009).However, new immigrant women have a lower incidence of breast cancer than Canadian-born women, perhaps due to the process of the medical screening they undergo as part of the immigration process (Salman, 2012; Amin, 2008). Nonetheless, their risk goes up ultimately, probably due to changes in lifestyle, environmental risk factors, and other factors associated with a deterioration in their health condition (Salman. 2012). These other factors include smoking and drinking due to stress, low socioeconomic status, and unemployment (Salman, 2012; Amin, 2008).

Among the studies that explored the utilization of breast health services among immigrant women, only a small number looked at the association between acculturation and health behaviours related to breast health and screening (Gesinka, Filsingerb, Mihica, Norwooda, Raceya, Perezc, Antalb, Ritvoc, & Vernicha, 2016). The findings have been relatively inconsistent. Some showed that acculturation, specifically English proficiency, is associated with going for screening (e.g., mammography and Pap smear) (Margareth, Zanchetta, & Poureslami, 2019; Suarez, 1994). Schoueri, Campbell and Mai (2013) explored the length of stay and utilization of healthcare services among immigrant and minority women in Canada. They found that new immigrants had poor utilization of healthcare facilities compared to those who had lived in the country for a long time. Researchers also suggested that a longer stay in Canada had a significant impact on levels of screening among ethnic minority women; perhaps that longer time gave them the opportunity to know about the services and learn how they are operated (Margareth, Zanchetta, & Poureslami, 2019; Vahabi et al., 2016). With this knowledge, individuals who had lived in the country longer were capable of utilizing the services more efficiently (Vahabi et al., 2016; Remennick, 2006). In contrast, earlier studies indicated that acculturation is not a consistent predictor of seeking screening or participating in breast health promotion services (Lipson & Meleis, 1990). Acculturated or bicultural groups however were not found to be healthier or better educated about screening services (Lai, Tsang, Chappell, Lai, & Chau, 2007).

Previous researchers have not examined the perceptions, behaviours, and barriers to breast screening among Arab women in Alberta, nor looked at these women's health practice in relation to acculturation (e.g., length of stay in Canada and proficiency in English), education and knowledge, socioeconomic status, and other factors. Arab Muslim women in Canada are exposed to many disadvantages (Bowser et al., 2017; Gesinka et al., 2016). They are exposed to social and economic challenges, as mentioned above, and educational challenges that minimize their ability to learn about local breast health services (Bowser et al., 2017; Gesinka et al., 2016).

While the literature on racial groups' consumption of health services in Canada is limited, significant research exists in the United Kingdom (UK), United States (US), and Australia (Aziza, 2014). Research in those countries identified religious and socio-cultural factors, such as modesty and body covering, as impeding participation in screening programs among Asian Islamic immigrant women (Vahabi et al., 2016; Rajaram & Rashidi, 1999). In Australia, immigrant women from the Middle East are shown to have poorer screening practices than Western-born women (Azaiza & Cohen 2006). Studies of the determinants of mammogram screening behaviour among Arab women in Israel have shown similar results (Soskolne, Marie, & Manor, 2006). Factors such as low income, unemployment, low education, and religious beliefs are among the major barriers to participation in mammography and other screening services (Margareth, Zanchetta, & Poureslami, 2019; Bowser et al., 2017; Walton, Akram, & Hossain, 2014). However, similar to all cross-sectional studies, the outcomes in Soskolne et al.'s (2006) study do not establish causation. On the other hand, Ivanov, Hu and Leak (2010) found that immigrant women from regions such as the former Soviet Union (FSU) are attentive and committed to taking care of themselves to ensure good health. However, these women lack an understanding and awareness of good health (Ivanov, Hu, &Leak, 2010). These immigrant women from the former Soviet Union also describe health as the absence of disease, which perhaps explains their poor participation in health practices such as mammography and breast self-examination (Ivanov, Hu, &Leak, 2010).

In the United States, a telephone survey was conducted to study the prevalence of mammography screening as well as beliefs and practices regarding mammography screening among immigrant women from the Middle East (Schwartz et al., 2008). The prevalence of mammography screening among these women was 57.8% (Schwartz et al., 2008). Of the women whose ethnic groups were surveyed, Lebanese women who lived in the US for more than 10 years, were 50 years of age and older, and had health insurance were found to have the highest reporting rate, as they reported having a mammogram every 1–2 years (Schwartz et al., 2008). The above study evaluated Arab women who share similar ethnicities but did not take religious differences in consideration.

In other studies, factors affecting immigrant women's decisions to undergo screening included the lack of a doctor's recommendation, denial of personal risk, fear of diagnosis of BC, and fear of becoming a burden on family members (Bowser et al., 2017; Gesinka et al., 2016; Remennick, 2006). Additionally, in many traditional cultures, especially Islam, females' actions are controlled by males in the family (husband, father, brother), and sometimes men are unaware of the consequences of objecting to breast screening (Walton, Akram, & Hossain, 2014; Remennick, 2006). Hence, in these traditional communities it is recommended to involve men in efforts to address breast cancer screening disparities and also to include them in educational programs about cancer myths (Walton, Akram, & Hossain, 2014; Remennick, 2006).

According to recent studies, factors associated with increased participation in screening services include a high level of education, past history of BC, older age, and higher socioeconomic class (Bowser et al., 2017; Vahabi et al., 2016; Salman, 2012). A qualitative study using face-to-face interviews was conducted in Israel to determine the rate of mammography screening behaviour among Muslim Arab women (Soskolne et al., 2007). It was reported that the mammography screening rate was only 22% among Arab women ages 50–69 compared to 71% among Israeli women (Soskolne et al., 2007). The study also indicated that Arab women were most likely to undergo screening if they had a high level of education, had been advised to do so by a health professional, or were at risk of developing BC (e.g., had a family member with BC) (Soskolne et al., 2007).

However, we should recognize that even though Arab women have low levels of participation in BC screening programs, they are eager to learn more about breast cancer risk and preventive services (Amin, 2008). Studies have shown that Arab women are often reluctant to seek screening when they want it (Walton, Akram, & Hossain, 2014; Amin, 2008, Salman, 2012). By way of explaining this, Salman (2008) used self-esteem theory to argue that some Arab women in Western society are hesitant to seek BC preventive care because they are concerned that their peers may find it unacceptable and may criticize them, which will lead to low self-esteem. It is important that healthcare providers and policymakers understand the complex factors that influence Arab women's health decisions with respect to BC risks and outcomes, including structural, organizational, psychological, and sociocultural barriers (Margareth, Zanchetta, & Poureslami, 2019).

Breast Cancer Outcomes. A thorough body of evidence demonstrates that there are cultural and ethnic inequalities in breast cancer outcomes. Evidence from the US revealed that black women have a greater possibility of dying from BC than white women, indicating prominent racial inequalities for female BC (Salman, 2012; Rajaram & Rashidi, 1999). In the US, Hispanic and Asian Pacific American women with breast cancer have a poorer prognosis and lower survival rate than Caucasian women (Seiler, Murdock, & Garcini, 2017). Data from the UK found that ethnic minority women (Black, South Asians, Chinese and Arabs) have an increased risk of diagnosis of advanced-stage BC and higher death rates compared to women from dominant ethnicities (Aziza, 2014). Madanat (2002) indicated a high prevalence of advanced BC and high mortality rate in the MENA region because of the progression of malignant tumors and late detection of cancer at the time of diagnosis. Madanat concluded that Jordanian women have a limited understanding of BC risk. He said that Jordanian women, including nurses, who performed breast self-exams on a regular basis were less than 19% of the total women population. Similarly, evidence from Australia showed that high cancer risk and poor survival rates are prominent among Indigenous populations living in remote parts of Australia (Heathcote & Armstrong, 2007). A significant proportion of indigenous Australians are diagnosed at a later stage of cancer, have worse prognoses, and higher mortality rates (Heathcote & Armstrong, 2007). There is also evidence of treatment and medical care variations that could adversely affect the survival prospects of socio-economically disadvantaged patients living in rural and remote areas (Kricker, Haskill, & Armstrong, 2001). For example, in remote and rural areas of North South Wales, women with BC were more likely to undergo mastectomies and less likely to have breast conserving surgery (Kricker, Haskill, & Armstrong, 2001).

From a broader perspective, these inequalities in BC outcomes are shaped by variations in culture and ethnicity. Multiple factors including genetic, socio-behavioural, cultural, and ecological are likely involved in the etiology of these inequalities (Margareth, Zanchetta, & Poureslami, 2019; Heathcote & Armstrong, 2007; Todd & Hoffman, 2011). The health needs and outcomes of BC patients are greatly impacted by their diverse backgrounds including race, socioeconomic status, and disease pathophysiology (Tan & Li, 2016). However, Aziza (2014) has argued that the real disparities in BC prevalence and survival rates are concealed by overlooking the variations among the smaller groups and grouping them into larger categories. For example, the Middle Eastern region includes many smaller racial groups that are highly diverse in terms of demographics and social determinants of health (Aziza, 2014). These differences between the smaller ethnic communities are masked by the larger groups (Aziza, 2014). A complex and multidimensional approach is needed to reduce and eliminate these disparities, improve health outcomes, and enhance the quality of life among women from ethnic minorities (Margareth, Zanchetta, & Poureslami, 2019; Seiler, Murdock, & Garcini, 2017; Tan & Li, 2016; Kamimura, Christensen, Mo, & Reel, 2014).

The Role of Behavioural Theory in Understanding and Promoting Breast Cancer Screening

A large number of health behaviour theories and models help create an understanding about inconsistent ways immigrant groups use cancer screening services and how such inconsistency leads to inequality. Those same theories and models can be used to inform health promotion interventions (La Morte, 2018; Pasick & Burke, 2008). At first, researchers relied on the most common behavioural theory, the Health Belief Model (HBM) (La Morte, 2018). Then a combination of two or more theories was used to explain how individuals make health choices. Among these theories were the theory of planned behaviour, the social learning theory, and the protection motivation theory (Pasick & Burke, 2008). These theories and models have different terms and constructs, yet commonalities can be seen. Many are dominated by an individual-level approach devoid of a sociocultural context (Pasick & Burke, 2008). Other researchers have argued that the theory should involve more complex approaches, including psychological, cultural, and environmental perspectives, to generate an understanding of health action that is not separate from the cultural background of the users and to develop effective health promotion programs (Green et al., 2015). Breast cancer screening inequalities are typically due to barriers and a lack of promotion among ethnic minorities (Vahabi et al., 2016). The question remains: what is the best behavioural theory to understand screening disparities and inform successful health promotion interventions?

The Health Belief Model (HBM)

As proposed by Champion (1993), there are four elements of the HBM that explain behaviours: 1) perceived risk, 2) perceived harms, 3) perceived welfare, and 4) perceived obstacles. For women, the perception that breast cancer at all times results in tangible illness may be a key factor in clarifying their low adherence to screening measures. However, the HBM does not tackle critical factors (e.g., environmental, economic, social, and religious issues) that shape health beliefs and practices (Glanz, Rımer & Vıswanath, 2008). Other critiques of the HBM include that habitual behaviours (e.g., smoking) and their impact on the decision-making process that involves accepting or rejecting a suggested action are not addressed (LaMorte, 2018). Also, the HBM lacks consideration of practices that are adopted for reasons other than health, for example social approval (LaMorte, 2018). The HBM expects that all individuals have equal access to knowledge on health and sickness (LaMorte, 2018). Critics have suggested that the HBM is lacking an instructive approach, and it does not recommend plans for changing actions (Glanz, Rımer & Vıswanath, 2008). In a review of the HBM, it was found that perceived benefits and harms are the main determinants of behavioural intention and action, yet "*based on the* *weakness of the predictive power of the HBM overall, the conclusion was that the continued use of the direct effects version of the HBM is not recommended*" (Green et al., 2015, p.122).

Thus, the HBM can be used more effectively if incorporated with other models that consider individual determinants that control whether a person rejects or accepts a health behaviour Glanz, Rımer & Vıswanath, 2008).

The Health Action Model (HAM)

Moving beyond the individual level, this model integrates several models and theories to identify multilevel determinants of health and illness-related decisions, including psychological, social, and ecological factors that are crucial in the process of health actions and the development of health promotion interventions (Green et al., 2015). The HAM (Figure 1) consists of two main components: the factors that determine the individual's willingness to act and adopt certain behaviours, including personal beliefs, motives, and norms; and the factors that facilitate the "intentions to act" into actual actions, for example knowledge, skills, and a supportive environment. As we can see in Figure 1, the two structures have many areas of interaction (section 1-7) that determine intentions and actions. Health actions are not necessarily limited to individual welfare but can also be beneficial to the community as a whole (Green et al., 2015).

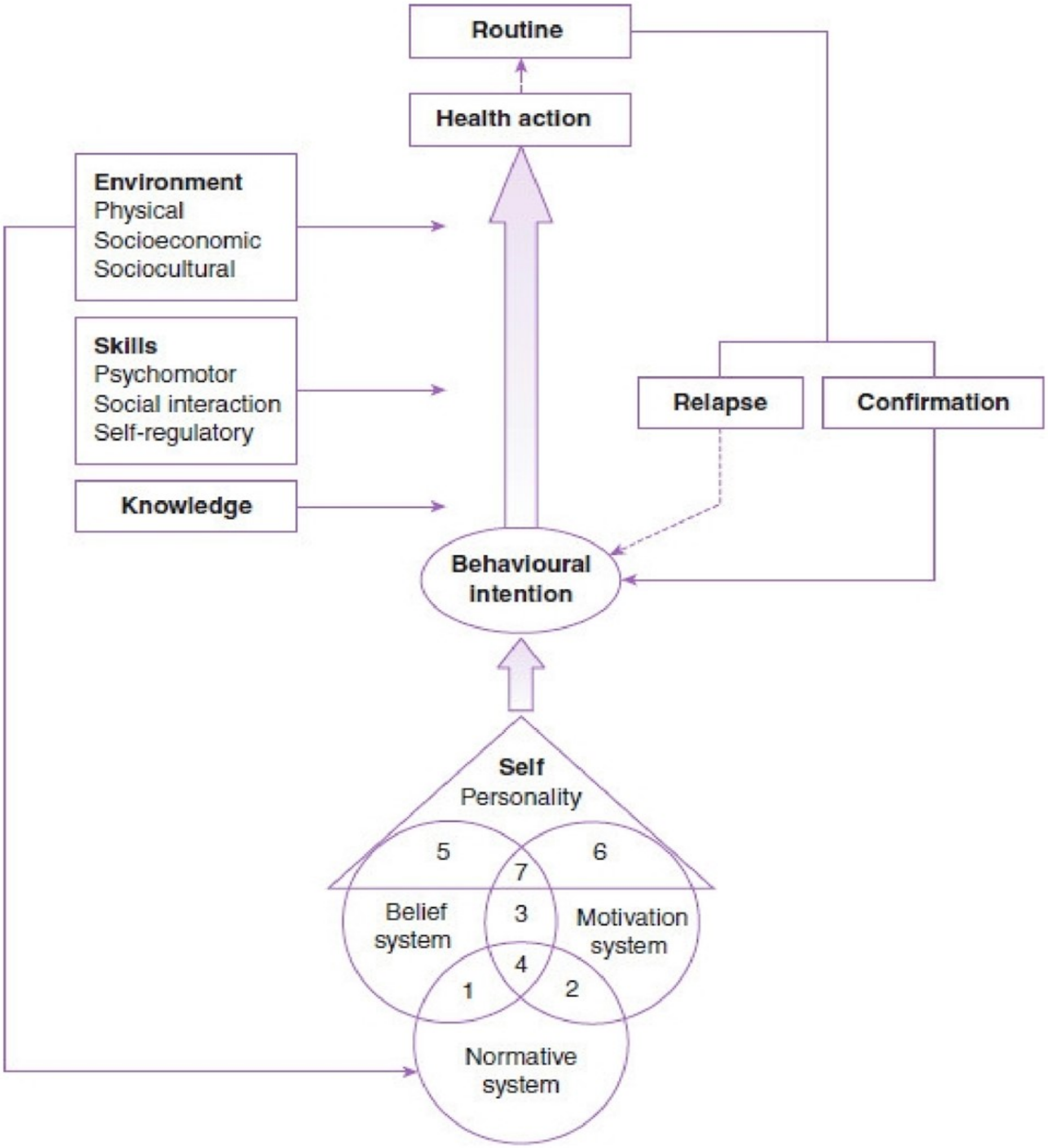


Figure 1. The Health Action Model (HAM) (Green et al., 2015, p.118)

Beliefs and KAP (Knowledge, Attitude & Practice) System. It has been argued that knowledge is inadequate in determining health actions, and therefore a KAP (knowledge, attitude and practice) system is needed (LaMorte, 2018). Knowledge has to result in a positive attitude to enable practice to take place (Al Rapaport. (2017). It is important to understand how beliefs and attitudes are conceptualized. Beliefs are mental constructs of how a person judges things (people, events, object), while attitudes are the emotions (positive or negative) that a person feels towards things (Green et al., 2015).

Motivation. This refers to "*goal-directed behaviour and its psychological underpinning. It defines the push and pull forces that impel individuals towards the achievement of pleasure and away from undesirable outcomes*" (Green et al., 2015, p.122). There are different types of motives that work on different levels, including values, attitudes, drives, and emotional status (Green et al., 2015). In general, there is an agreement in the literature that values vary across individuals and can change as people grow and acquire extra knowledge; culture also plays a key role in the construction of values (Al Rapaport, 2017; Green et al., 2015; Gany et al., 2006)). Values inspire and support attitudes due to values' mystical features (Shah, 2018; Green et al., 2015). Other dimensions of motivations include "drives" and "emotional states." Drives have a greater impact on decisions than values because drives are viewed as instinctive motivations, for example the drives for food, air, sex, and safety (Green et al., 2015). Emotional status also has a significant influence on an individual's decision-making process as well as on his or her acceptance of a health promotion message (Green et al., 2015). An example of an emotional state that affects health actions is mental distress as a result of possessing two or more contradicting beliefs (Shah, 2018). This is known as "cognitive dissonance." When cognitive dissonance occurs, an individual usually finds a way to relieve the distress, for example by avoiding, settling, or rejecting (Shah, 2018).

System of Norms. These are pressures that significantly impact individual health behaviours (Hassan, 2014). This “normative system” includes interpersonal influences, peer pressure, community norms, a lay referral system, stigma, and mass media pressures (Green et al., 2015; Hassan, 2014). As shown in Figure 2, the closest relationships place greater pressure on an individual to conform to or disagree with a practice. Due to socialization, community standards, and mass media, individuals are mostly likely to internalize norms that they are motivated to adopt (Shah, 2018; Green et al., 2015). In many societies, a “lay referral system” is an important concept in the process of seeking health knowledge or the use of health services (Green et al., 2015; Salman, 2012; Amin, 2008; Gany et al., 2006). A web of lay individuals including family, friends, community members, and other informal health personnel are the sources of knowledge that regulate individuals’ actions (Green et al., 2015; Salman, 2012; Amin, 2008; Gany et al., 2006). In the HAM, as shown in Figure 1, the interaction between the three systems (beliefs, motivations, norms) indicates beliefs about the norms and pressures, and the motivation to conform to these norms. This interaction contributes significantly to how people act. According to the social influences on individuals’ heath actions illustrated in Figure 2, it can be concluded that the motivational force of interpersonal norms is more likely to be stronger than that of national norms, given that interpersonal norms are meaningful to the individual (Green et al., 2015).

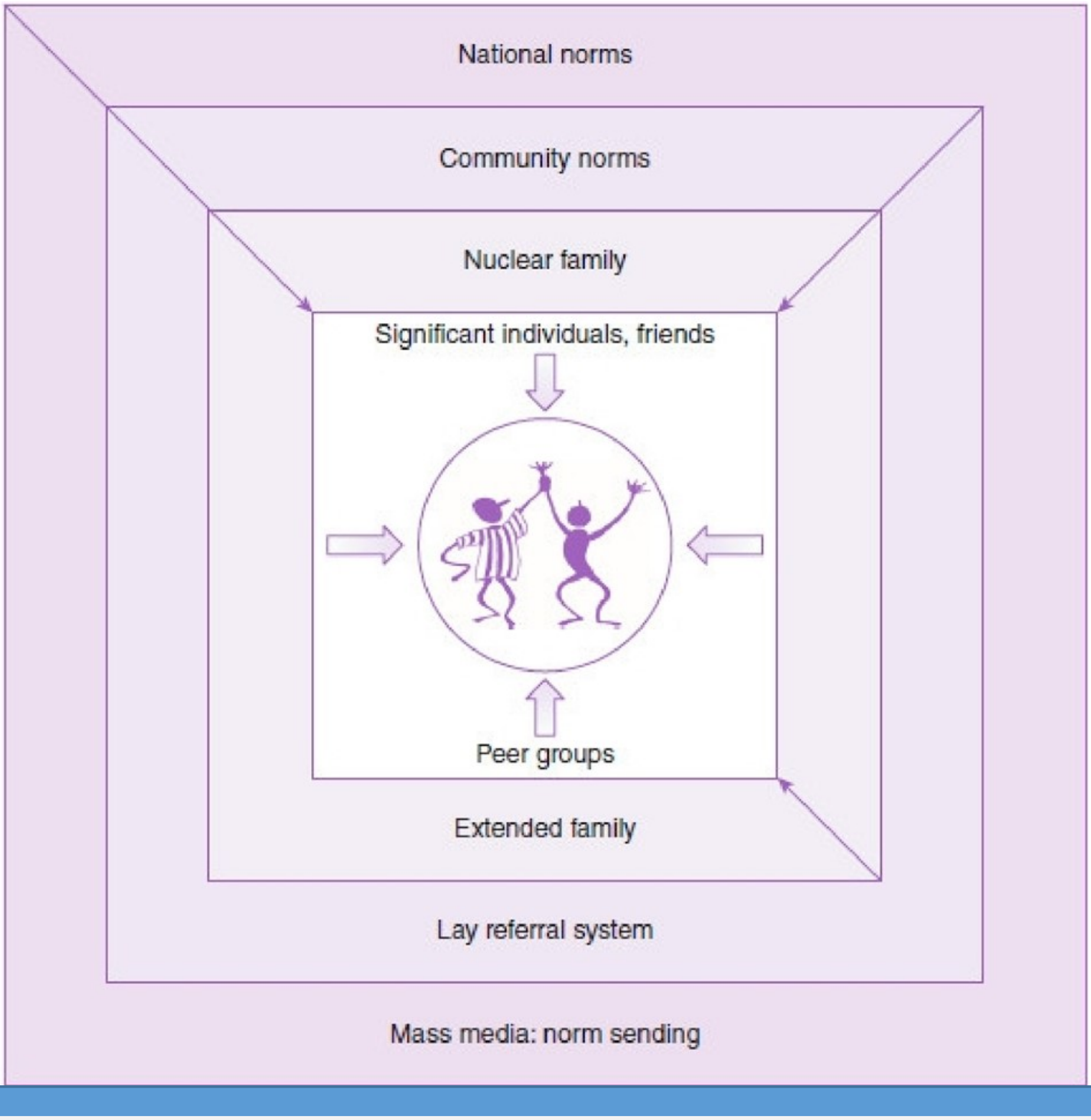


Figure 2. Social Influences on Individuals Health Actions

(Green et al., 2015, p.127)

Historical Beliefs and Cultural Health Practices of the MENA Population

In the 1980s and early 1990s, a substantial number of refugees came to Canada from Middle East and North African (MENA) countries. These regions are sometimes collectively referred to as the Arab world since Arabic is widely spoken in the majority of the regions' countries, including Lebanon, Egypt, Iraq, Yemen, Syria, Sudan, United Arab Emirates, Saudi Arabia, Libya, Tunisia, Morocco and Algeria (Barakat, 1993). The MENA countries are home to several world religions and are both ethnically and politically diverse (Lazar, 2008). These countries, however, have many unifying features and common characteristics, such as social behaviour and relations, culture in arts (music, poetry), traditional clothing (Abiah, Hijab), food (falafel, shawarma), and architecture. Nevertheless, there are also some dissimilarities in their socio demographics and cultural values. For example, traditions and customs related to marriage, birth, and funeral practices (Lazar, 2008).

The majority of people in the MENA countries follow Islam, although there are also Christian Arabs from different backgrounds (Barakat, 1993). Most Arab people practice Islam (Barakat, 1993; Amin; 2008; Salman, 2012). Some researchers have described Islam as a "binding force" that has significantly influenced Arab cultures (Barakat, 1993). Athar (1993) claims that ''*Islam is a way of life to live, a system to be followed, a code of ethics and a constitution to be applied in the daily life of every person''* (p. 94). Because of this perspective, there is a hazy distinction between Arab culture and Islamic culture in many MENA countries. Many people outside of the MENA countries are unaware that not all Arab people are Muslims and not all Muslims are Arabs (Salman, 2012). Worldwide, Arab Muslims represent only 18% of the total Muslim population (Salman, 2012). Other Muslims come from different countries with different racial and ethnic groups, countries such as Pakistan, India, Iran, Turkey, Nigeria, and

Indonesia (Anas, Alwi, Razali, Subki, & Abu Bakar, 2013). Islam is closely connected to the Arab identity because the original language of the Holy book of Islam (the Quran) was Arabic and also because Islam originated in the Arabian Peninsula (Williams, Mabiso, Todem, Hammad, Hill, Hamade, & Zambrana, 2011). There is a wide variation in culture among MENA countries; sharing a common geography, language, and religion does not mean sharing cultural and social practices (Barakat, 1993). Kabasakala, Dastmalchian, Karacay, and Bayraktar (2012) argued that Arabic is the language of the Quran, but it is not the dominant language in the area; other languages such as Persian and Turkish are also widely spoken. Kabasakala et al. also stated that local Arabic "dialects" spoken in Saudi Arabia, Jordan, Algeria, Oman, Lebanon, and Libya vary greatly from each other. Building upon the argument by Kabasakala et al., Bashkin (2010) wrote that Islam should not signify an individual's cultural identity; otherwise how could different spiritual groups such as Jews and Christians play effective roles in the same community? Cultural identities in the MENA region are complex and involve many conflicts. Amin (2008) wrote that more than religious and linguistic identities, a shared history links people to their land. Bashkin (2010) however criticized the notion that history links people to their land, claiming that such a notion is far too broad: "*what would this history be? Iraq with its Babylonian and Assyrian histories? Egypt and its Pharaonic past? Or Phoenician traditions of Lebanon, and the list goes on*" (p. 233)

Cultural and Religious Influences on Attitudes About Breast Health. As mentioned previously, the traditions that shape Arab women's health beliefs, practices, and values come from the intertwining of certain Middle Eastern social and religious restrictions, mainly Islamic. For example, Islam recommends that women wear a conservative garment, which is a long, nonrevealing dress with a head cover (hijab) (Walton, Akram, & Hossain, 2014). In North

America, this garment tends to be viewed as a symbol of female oppression (Walton, Akram, & Hossain, 2014). In some settings with extreme cultural restrictions women are required to cover their faces with a veil and are not allowed to have any sort of physical contact with males outside of their family (father, son, husband, brother) (Salman, 2012). Such beliefs and practices may affect a woman's decision to uncover her head or expose any part of her body for a medical examination, especially if the health provider is a male (Walton, Akram, & Hossain, 2014). In addition, a woman is expected to act in a manner consistent with Islamic and social traditions and to be modest in her appearance and behaviour (Walton, Akram, & Hossain, 2014). Modesty and shyness may impact discussions related to sensitive health concerns such as sexual relationships, family planning, and reproduction (Walton, Akram, & Hossain, 2014; Salman, 2012). In Arab cultures, men are usually not involved in women's health issues such as pregnancy, childbirth, breastfeeding, and family planning (Honein, 2007). For example, Arab husbands do not accompany their wives to any sort of obstetrical or gynaecological procedures, including childbirth (Honein, 2007). Since Islam prohibits women from having sexual relationships outside of marriage, unmarried females are not expected to have breast exams or obstetrical procedure (Amin, 2008). In Middle Eastern culture, the breast is viewed as a very private body part that should always be covered because its main functions are sexual (for a husband) and nourishment (for a child) (Amin, 2008). Some have argued, irrespective of religious beliefs, that Arab women's embodied understandings of their breast are various, complex, and multifaceted (Banning and Hafeez, 2010). There have been few contributions to the literature that examine Arab women's understanding of their breasts. Salman (2010) argued that Arab women's awareness of their breasts has a strong association with the Islamic religion.

Amin (2008) also concluded that perceptions about the breast in the Arab community are deeply rooted in the Islamic faith;

> And say to the believing women that they should lower their gaze and guard their modesty; that they should not display their beauty and ornaments except what (must ordinarily) appear thereof; that they should draw their khimar (Hijab) over their breasts and not display their beauty except to their husband, their fathers, their husband's fathers, their sons, their husbands' sons, their brothers or their brothers' sons, or their sisters' sons, or their women, or the slaves whom their right hands possess, or male servants free of physical needs, or small children who have no sense of the shame of sex; and that they should not strike their feet in order to draw attention to their hidden ornaments (Quran 24:31*)* (The English Commentary of the Holy Quran).

Researchers who have studied Islamic attitudes about breasts were bound by their own personal experiences. For example, Amin (2008) notes that her concern about exploring the link between perceptions of breasts in Arab cultures and Islam as a religion was embedded in her personal experiences growing up in rural Egypt. Amin states that it is very hard to distinguish between Islam and culture, especially when it comes to body concepts. She revealed that everything she was taught to do or not to do with regards to her body, including her breasts, was related to instructions from the Quran. After she had children, she writes, her husband asked her to breast feed for two full years because it is mentioned in Quran, not because it is recommended by the World Health Organization (WHO) (Amin, 2008).

Shireen, Rajaram and Rashidi (1999) explored the way that Islamic values affect behaviours related to breast health and screenings. They found that many Muslim women fail to follow the Islamic mandates that encourage health promotion and disease prevention. Prophet Mohammad said, ‘‘*an ounce of prevention is better than a ton of treatment*’’, and also “*a cure exists for every disease and individuals should use preventive measures to maintain good health*”

(Hadith). Shireen, Rajaram, and Rashidi (1999) also asked why Muslim women reported poor encounters with modern Western medicine while Islam encourages the use of knowledge and science for legitimate and ethical purposes. More recently, Banning and Hafeez (2010) note that understandings of breasts in the Muslim women's community are complex and should not be limited to discussions about Islam and women's breasts. Banning and Hafeez identified social and gender discrimination as barriers to breast health practices. Another barrier is wearing a veil, even in instances when a woman needs to expose her breasts for medical examination (Banning & Hafeez, 2010). These barriers, Banning and Hafeez say, are not encouraged in Islam. The Banning-Hafeez study focused on highly educated, employed, and urban Muslim women, a group not necessarily representative of all Muslim women. The findings may not be applicable to other Muslim women who live in remote and rural areas, and are uneducated, poorly educated, and unemployed. Indeed overall, there is little consensus about the meanings that Arab women assign to their bodies.

Adopting Preventative Oriented Healthcare. A closer examination of the health beliefs of MENA population shows that the perception among Arabs is that a lack of visible signs and symptoms of disease is equal to good health and that preventive care is an unnecessary luxury (Walton, Akram, & Hossain, 2014; Pollara & Meleis. 1995). Cancer screening in many Middle East countries is recommended for diagnostic purposes, and there is more emphasis on treatment than prevention (Walton, Akram, & Hossain, 2014; Pollara & Meleis. 1995). In 1990, Lipson and Meleis found that in the Arab world seeking healthcare was perceived as necessary only when someone was totally unable to function. They indicated that chronic conditions such as diabetes and cancer are asymptomatic at the beginning, so that by the time the disease is detected the chances of cure and survival have decreased. Although the Lipson and Meleis's paper was published more than 25 years ago, its evaluation of the cultural characteristics of Middle Eastern women and the impact of these characteristics on the way that these women interact with the western healthcare system are still relevant because more recent research revealed similar findings (Walton, Akram, & Hossain, 2014; Salman, 2012; Amin, 2008).

Attitudes Toward Disease. Building on the work that Pollara and Meleis and Lipson and Meleis did in exploring health beliefs of the MENA population, more recent studies have indicated that in Arab cultures mental health and chronic diseases such as cancer are viewed as shameful and signs of failure and should be hidden lest they destroy a family's social standing (Walton, Akram, & Hossain, 2014; Adnan, Rashid, Raja, Rosina, & Michael, 1999). A study evaluating health practices and barriers to cancer screening among Arab Muslim women in South Western Pennsylvania found that Arab women view cancer diagnoses as a "punishment from God" or a "test of their faith and patience" (Salman, 2012). Arab women often use the term "bad disease" instead of the word "cancer," especially when it involves a woman's reproductive organs (Salman, 2012). Another point Salman made is that many Arab women do not believe in Western healthcare and they use religious traditions such as prayers and natural herbs and remedies as alternatives to modern medicine. However, as only English-speaking women were part of Salman's study, there was not much (if any) representation from different racial and cultural groups. In addition, the findings were based on a questionnaire rather than interviews. Interviews would likely have yielded richer and more information. However, aligning with this study, Salman's paper recommended future research use qualitative methods to explore Middle Eastern women's beliefs with regards to cancer screening. Wu, LeBaron and Burke had similar findings in 2007, when they revealed that alternative medicine is prevalent and growing in the Arab world. Arab Muslims place great emphasis on their traditions and cultures, including health practices, and they pass these beliefs and behaviours from one generation to another (Salman, 2012; Amin, 2008; Azaiza & Cohen, 2006).

Utilization of and Access to Healthcare by Immigrant Women

Immigrant women have faced challenges in the process of integrating into the Canadian lifestyle and culture ((Margareth, Zanchetta, & Poureslami, 2019; Weerasinghe & Mitchell, 2007; Amin, 2008; Aziaza & Cohen, 2006). Cultural conflicts, social isolation (separation from family and friends), troubling interactions and relationships, limited language skills, male gender domination, lack of economic resources, and lack of knowledge about how to access healthcare impede these newcomers' ability to use healthcare and thus make it difficult for them to obtain quality healthcare (Margareth, Zanchetta, & Poureslami, 2019; Vahabi et al., 2016; Weerasinghe & Mitchell, 2007; MacKinnon & Howard, 2000). Physical and mental illness are more common among Arab women than Arab men in western society (Salman, 2012). Arab women play multiple roles as wives, mothers, and, sometimes, as students and workers outside the home (Honein, 2007). While fulfilling these different roles, immigrant women try to preserve their cultural and religious beliefs (Honein, 2007). This is especially true for women who immigrated when they were older, because they have stronger religious and cultural ties to their countries of origin (Aziza, 2014; Amin, 2008). Acculturation and adjustment may take years (Ivanov & Buck, 2002). The low acculturation level shapes immigrant women's perception of poor health, which consequently determines how they make health-related decisions (Ivanov & Buck, 2002). There is, however, some disagreement as to whether the low acculturation level is a determinant of immigrant women's consumption of healthcare services. For example, as discussed above, Wu, LeBaron and Burke (2007) argue that many immigrant women usually seek alternative healthcare options before pursuing healthcare services.

Racial oppression also plays a part in why immigrants have unequal or, in some cases, no access to healthcare (Weerasinghe & Mitchell, 2007; Anderson, 1987). Hasnain, Connell, Menon, and Tranmer (2011) found that negative behaviours of some healthcare workers towards consumers from certain ethnic groups could significantly affect immigrant women's access to quality care and reinforce inequalities in health.

There are important determinants of the health inequalities among immigrant groups that have been highlighted in the literature, for example health literacy, health-seeking behaviours, and multiculturalism (Margareth, Zanchetta, & Poureslami, 2019; Tsai & Lee, 2016; Mackian, Bedri, & Lovel, 2004; Flores; 2004). These determinants influence the perceptions of health and illness among immigrant groups and deter the utilization of and access to healthcare (Margareth, Zanchetta, & Poureslami, 2019; Tsai & Lee, 2016; Mackian, Bedri, & Lovel, 2004; Flores; 2004).

Health Literacy (HL). Health literacy is defined by the World Health Organization (1998) as "*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health*." This definition emphasizes that health literacy means not only being able to communicate (in writing or orally) health information but also to achieve knowledge and skill and take action to improve health on personal and community levels (Tsai & Lee, 2016). Nutbeam (2000) claims that although the widely held assumption is that health literacy is the ability to understand and use health information, it is really a narrow perspective. He developed a conceptual model of health literacy that comprises three levels: "functional literacy," "interactive literacy," and "critical literacy." The primary level, functional literacy, is present in everyday settings; at this level, individuals can successfully read and write (Nutbeam, 2000). The second level is interactive literacy, in which people acquire unconventional knowledge and skills and are able to apply both to different life conditions (Nutbeam, 2000). The third and the advanced level is the critical level. At this level, individuals can critically appraise information and have control over situations (Nutbeam, 2000). Nutbeam proposed that health literacy is a powerful tool that individuals can greatly benefit from to control their health (Nutbeam, 2008).

Research in the US, Canada, and Australia, has shown that healthcare consumers with limited language skills receive poor quality care compared to consumers who are native speakers (Margareth, Zanchetta, & Poureslami, 2019; Arora et al., 2012; Britigan, Murnan, Rojas, & Guyler, 2009). Inadequate health literacy has been identified as an important determinant of health inequalities in immigrant groups (Margareth, Zanchetta, & Poureslami, 2019). Most likely immigrants' ability to gain access to timely, proper, and quality health information and services is limited by inadequate health literacy (Gutierrez, Sarmiento, Marin, Castro, & Sanchez, 2018). Consequently, this may hinder immigrants' ability to make appropriate health decisions (Gutierrez et al., 2018). Health literacy issues of immigrants in non-English-speaking countries have received limited attention. Current research focuses mainly on health literacy matters of immigrant groups in native English-speaking countries, for example Canada, the US, the UK, and Australia (Bowser et al., 2017; Vahabi et al., 2016; Tsai & Lee, 2016). There is a need for research to explore the specific language and communication issues experienced by immigrant populations in countries where the first language is not English (Tsai & Lee, 2016). Interpreting services have been recognized as an important tool to provide safe and effective healthcare for immigrant populations (Bowser et al., 2017; Vahabi, 2011; Britigan et al., 2009). Studies have provided insights into the importance of professional interpreters to promote effective communication, patient comprehension, and satisfaction (Bowser et al., 2017; Vahabi, 2011; Karliner, Karliner, Jacobs, Chen, & Mutha., 2007). However, few studies have examined patients' insights into interpreter services (Karliner et al., 2007). While the aforementioned researchers found that the individual's role in literacy is crucial, other researchers have argued that health literacy is affected by other factors such as healthcare professionals and the nature of the disease and that these factors should be incorporated into the definition (Baker, 2006). Baker also emphasized that communication and collaboration in the health education process are necessary for consumers to achieve a high level of health literacy.

Health Seeking Behaviour (HSB). Jaramillo (1998) writes that health-seeking behaviour is a "multi-dimensional concept" that goes further than biomedical concerns and includes cultural, social, and organizational factors. Mackian, Bedri, and Lovel (2004) found that health-seeking models are critical for designing social interventions aimed at empowering individuals to adopt "healthy choices." Thus, in order to plan and deliver appropriate healthcare services, it is necessary to understand HSB (Chauhan et al., 2015). Health Seeking Behaviour (HSB) refers to a "*decision or an action taken by an individual to maintain, attain, or regain good health and to prevent illness*" (Chauhan et al., 2015, p.118). HSB is affected by multiple factors such as age, sex, type of illness, and affordability and availability of services (Chauhan et al., 2015).

Chauhan et al. (2015) conducted a community-based descriptive study in a rural coastal area in India to evaluate HSB in a rural population. The study found that HSB was determined predominantly by people's perceptions about the quality of healthcare services. The study also identified factors that drove HSB among the rural population in the coastal area. These included income, type of illness, and accessibility of services (low-cost services were more frequently accessed). In other studies, HSB was found to be associated with various factors, for example gender of the person seeking care, area of residence, education, and the healthcare provider (Pillai, Polsky, Berlin, & Lowe, 2003).

In the US, poor access to healthcare and a lack of information may be associated with the deterioration of health among Latino immigrants (Garcés, Scarinci, & Harrison, 2006). Factors such as low income, low education, language barriers, and fear of deportation among undocumented groups have been found to keep people from seeking healthcare services and information (Garcés, Scarinci, & Harrison, 2006). Latino immigrants maintain their cultural health beliefs and practices when they arrive in the US (Garcés, Scarinci, & Harrison, 2006). The most commonly reported health practices among immigrants from Latin America were the use of herbs, chiropractic treatments, dietary supplements and home remedies (Garcés, Scarinci, & Harrison, 2006). The immigrant Arab population in the US also reported a significant use of alternative medicine (Salman, 2012; Lazar, 2008). However, there is limited information regarding HSB of the Arab community in North America (Lazar, 2008). In the context of this study, it appears that the HSB of Arab immigrant women is influenced by diverse factors such as cultural beliefs and the perception of diseases. For example, as seen earlier, in some Middle East communities, diseases such as cancer are seen as a form of a cultural curse (Salman, 2012; Adnan et al., 1999). If a woman contracts such a disease, it becomes difficult for her to seek medical care because of the fear of stigma, and she will also likely believe only traditional charms or alternative medicine can cure her (Salman, 2012; Adnan et al., 1999). To better understand someone's HSB, it is necessary to understand the culture that he or she comes from (Walton, Akram, & Hossain, 2014; Rought, Duaibis, & Hussain, 2010).

Multiculturalism. Culture plays a fundamental role in the perception of health and access to healthcare services (Margareth, Zanchetta, & Poureslami, 2019; Tan & Li, 2016). One of the ways in which culture can be defined is *"as a group of individuals who have similar attitudes, beliefs and values, both in the group and when on their own*" (Tan & Li, 2016, p. 112). Different background languages, social norms, religions, beliefs, and healthcare structures were found to be barriers to accessing health services for immigrants and ethnic minorities (Margareth, Zanchetta, & Poureslami, 2019; Tan & Li, 2016). Canada has a long history of welcoming immigrants from around the world. However, the challenge for new immigrants is transitioning from their previous cultural practices into the host country's culture (Vahabi et al., 2016; Adnan et al., 1999). According to Flores (2004), health issues touch on different human experiences and the migrants from diverse foreign cultures have many different experiences. In the UK, it is becoming more challenging for the National Health Service (NHS) to provide outstanding medical services because of the growing diversity of the population (Tan & Li, 2016). Many cultural issues complicate traditionally standardised healthcare, among them the religious beliefs of both practitioners and patients. For example, patient rejects treatment on cultural grounds (e.g. blood transfusion), and health provider refuse to conduct a medical procedure based on religious motives (e.g. abortion) (Tan & Li, 2016).

In a critique of multiculturalism in the NHS, Culley (1996) discussed the way in which healthcare is constructed and delivered to people from minority ethnic groups. Culley's paper highlighted the limitations of the cultural attitudes of health professionals and the impact of racism on access to quality health care. Culley pointed out large gaps in the awareness of health providers and their approaches towards the needs of people from ethnic minorities. These health workers claimed that they had not receive any training for working in multicultural settings

(Culley, 1996). Pearson (1986) argued that knowledge of culture is the most important component for enhancing quality health care. Pearson also stated that cultural variations are not disputed. What is contested, however, is the power imbalance between ethnic groups (Pearson, 1986). Fruitful communication can be hindered when providers and patients are ignorant about each other's differences (Margareth, Zanchetta, & Poureslami, 2019). Pearson (1986) described those perceptions of difference as "deviant, alien and stubborn." Black people, for example, are not only viewed as different but are seen as secondary and inferior, Asian-American girls are "caught between two cultures," and Muslim women in western societies often find themselves having to defend their choice to wear a veil (Pearson, 1986). Such cultural views are deeply rooted in societies and organizations and play a key role in access to quality healthcare by minority populations (Margareth, Zanchetta, & Poureslami, 2019; Pearson, 1986).

Multiculturalism affects patients and healthcare providers. For example, according to Nichols, Horner, and Fyfe (2015), if there is a language barrier or if the patient feels the physician is culturally insensitive, the patient may not continue seeking health care. It is important for healthcare professionals to recognize cultural diversity and that their patients may have different beliefs (Margareth, Zanchetta, & Poureslami, 2019;). Vahabi et al. (2016) highlighted the need of preparing and training healthcare providers to be able to see patients in a holistic way and focus on both biological and psychosocial aspects. A lack of understanding of cultural diversity influences not only the patient-physician relationship but also the relationship between healthcare professionals (Nichols, Horner, & Fyfe, 2015). Different experiences in the workplace were found. Some healthcare practitioners reported finding respect and satisfaction, whereas others reported finding negativity and discrimination (Nichols, Horner, & Fyfe, 2015).

Also, healthcare providers from ethnic minority groups were more likely to experience delays in their career paths (Nichols, Horner, & Fyfe, 2015).

There is a need for research that can address the complexity of different issues surrounding multiculturalism in healthcare from the perspective of patients and healthcare providers (Nichols, Horner, & Fyfe, 2015). Patients report different healthcare experiences. While some patients were happy and satisfied with their care, other reported discrimination and a lack of respect for their needs and beliefs (Nichols, Horner, & Fyfe, 2015). Generally, however, it is clear that it is important to build trust and have open discussions with patients and provide more information to ensure that "*the patient is viewed as a person, in a pluralistic society*" (Nichols, Horner, & Fyfe, 2015, p. 113).

Previous Immigrant Research on Breast Cancer (Approaches and Issues)

Qualitative methods have been widely used in the literature to address breast cancer and screening disparities among women from minority groups. An ethnographic approach has been adopted in many studies in Western countries. For example, Zhao et al. (2010) applied a focused ethnographic approach to explore Chinese-born immigrant women's beliefs about breast cancer screening and mammography in the US. They found that these women, who are highly influenced by their community, believe that the absence of signs and symptoms indicates health, which may perpetuate low screening rates. They suggested that a community-based culturally competent health education program may be beneficial in improving Chinese-born immigrant women's usage of healthcare services. However, a major weakness in this study was that the authors did not differentiate between Asian-born, Asian-American, and Asian immigrants, which creates confusion about the differences in cultural beliefs between these three groups. One of the issues in cross-cultural research is a lack of knowledge about the variations among subgroups

(Aziza, 2014). This ignorance may lead to misunderstanding and mistrust between the researcher and the study population (Aziza, 2014). It may also lead to inaccurate conclusions regarding the cultural beliefs of different groups (Zhao et al., 2010).

Research shows that Latino women with breast cancer underuse recommended follow-up chemotherapy, which reduces their survival rates (Kreling, 2008). A focused ethnography study was conducted in the US to explore how cultural beliefs and perceptions impact decision-making processes for Latino women regarding breast cancer treatment (Kreling, 2008). The amount and quality of data that have been obtained from this study allowed a comprehensive understanding of Latino women's perspectives and experiences with regard to breast cancer treatment. The outcomes from this study are expected to accelerate social change by shedding light on cultural diversity in health decision making (Kreling, 2008). However, one potential limitation of this study is the researcher's positionality. As a breast cancer survivor, Kreling's personal experience could have influenced her interpretation and analysis of the data. Different results might emerge if this study had been conducted by a researcher with no history of breast cancer. On the other hand, this personal experience might be beneficial as the researcher has a unique understanding of cancer patients which could positively affect the way she conducts interviews and potentially make discussions easier. It might also be easy for her to gain the study participants' trust (Dwyer & Buckle, 2009). In addressing insider-outsider issues, Ogilvie, Burgess, Pinto, and Caufield (2008) proposed that when exploring immigrant health, integrating different researchers from inside and outside can produce innovative thinking.

Focus group methodology was also conducted to study Emirati women's attitudes and beliefs about breast cancer and screening in United Arab Emirates (UAE) (Abdulbari, Honein, Carter, Da'ar, Miller, & Dunn, 2002). The study produced in-depth descriptions and rich data regarding determinants of participation in breast cancer programs, including factors that positively influence the screening practices as well as factors that discourage participation (Abdulbari et al., 2002). A critical ethnographic approach was also used to expose the social and cultural factors that affect breast cancer screening practices of Arab Muslim women in Qatar (Hwang et al., 2015). Beliefs about health and illness, religious practices and gender relations were the main themes identified (Hwang et al., 2015). The study demonstrated how Arab Muslim women's health attitudes cannot be recognized in isolation from their sociocultural context (Hwang et al., 2015) as suggested by the HAM model. In addition, interventions to address poor participation in breast cancer screening services must address the context and not be narrowed to the individual (Hwang et al., 2015). Abdulbari shares a language with the study population, which was not the case in the Hwang study. This brings us to issues of language differences in conducting cross-cultural health research. Research participants are usually more comfortable, more informative, and more accurate when using their native language, and sometimes researchers know little or nothing about their language (Ogilvie et al., 2008). Similarly, a researcher who is familiar with the participant's native language is more capable of building rapport (Dwyer & Buckle, 2009). Sometimes the researcher can be the translator if he/she is fluent in the language of the study participants (Ogilvie et al., 2008). Different methods have been suggested to overcome language differences in immigrant health research. Yang (2015) discussed in depth several methods that other researchers used to collect data. Among these methods were back-translating and hiring bilingual interviewers. Yang also examined the limitations of these methods and explained how to overcome them.

A community-based participatory approach has been adopted in many studies. For example, in Dallas, Texas, a community based-participatory study to reduce breast cancer inequalities among low-income African American women was conducted (Cardarelli1, Jackson, Martin, Linnear, Lopez, Senteio, & Weaver, 2011). This project was successful in enhancing knowledge, improving uptake of mammography and breast self-examination, and increasing the community's capacity for prevention and sustainability of the program (Cardarelli1 et al., 2011). Another community-based intervention in the US was conducted to improve the use of breast cancer screening among underserved African-American women (Electra et al., 1999). Results of this project showed that the percentage of women reporting regular use of mammography increased in the intervention city (Electra et al., 1999). Different approaches were applied in the intervention city, including clinic in-reach (e.g., in-service meetings and counselling) and community outreach strategies (e.g., lectures, media and events) (Electra et al., 1999). The outcomes from this study showed that screening rates in underserved groups can be enhanced by using multidimensional intervention (Electra et al., 1999).

In summary, the literature has revealed the significant gaps in existing research. Society views the meaning of health as subjective. Different groups and MENA, in particular, have different definitions of health. It is clear in this chapter that there is a significant relationship between healthcare services and HSB, multiculturalism, individual perceptions of the meaning of health, and the utilization of and access to quality healthcare. Much needs to be done in the province of Alberta as little research has been done in the communities where immigrants settle. Moreover, the cultural practices of immigrants are seen to highly impact HSB and the utilization of healthcare services. It is therefore of importance to understand these cultural practices to incorporate them or be able to understand the immigrants' points of view in regards to HSB.

Chapter 3

Research methodology

In this chapter, I start with outlining the research paradigm and my ontological, epistemological, and theoretical perspectives. Then, I outline the qualitative research methods, tools employed, and the whole research process.

Research Paradigm: The Interpretive Paradigm

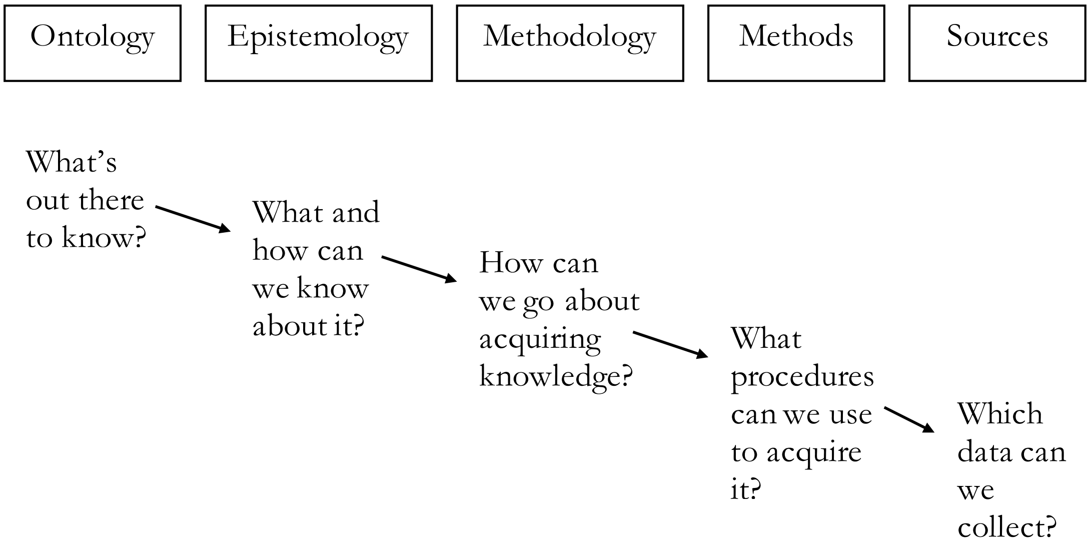
A research paradigm is a group of assumptions that direct the way we do research (Amatya, 2011; Cuba & Lincoln, 1998). Research paradigms can be categorised by their ontology, epistemology, methodology, and methods (Torti, 2017; Olusegun, 2015; Amatya, 2011) (see figure 3). Ontology is what exists and what can be known, while epistemology is concerned with the process of gathering and communicating the knowledge, and the relationship between the researcher and the research population (Mayan, 2009). These assumptions vary significantly according to the paradigmatic stance. For example, the positivism paradigm is based on uncovering knowledge about an objective truth, and the researcher and the researched are independent units (Torti, 2017). Conversely, the interpretivism paradigm is associated with subjective reality that varies from one individual to another; hence there are multiple interpretations (Guba & Lincoln, 1998; Crotty, 1989). In the interpretivism paradigm, meaning is not discovered; it is created and interpreted by individuals (Crotty, 1989). This study adopted the interpretivism paradigm that considers social and cultural contexts. This means that to understand how MENA women perceive and practise breast health and cancer screening we need to recognize that they experience and see the world differently because they have their own historical and cultural backgrounds (Mayan, 2009). Creswell (2013) pointed out that ontological and epistemological assumptions as well as the theoretical standpoint of the researcher shape and direct any interpretive paradigm.

Ontology. In correspondence with the interpretive paradigm, this research adopts a "relativist" ontology. This ontology rejects that there is a "single reality." It holds that the truth exists inseparably from our social communications and cultural experiences; therefore, there can be numerous realities (Guba & Lincoln, 1998).

Epistemology. In agreement also with the interpretive paradigm, this research adopts a "subjectivist" epistemology. This epistemology holds that knowledge production is a result of the interaction between the researcher and the research participants and rejects that "we just know things" (Olusegun, 2015; Amatya, 2011; Mayan, 2009). As a researcher, I am aware of how interactions with my research participants may shape the construction of knowledge in this study. I also recognize that there are multiple interpretations and ways of knowing, and I only present one way of understanding the phenomenon of interest.

Theoretical Perspective

Constructivist Framework. Guba and Lincoln (1998) pointed out that adopting a constructivist stance in research means to be "subjectivist" and "relativist." Hugly and Sayward (1987) highlighted the diversity of understanding experiences by saying that "*there is no objective truth to be known*" (p. 278). According to this approach, the reality is unknown and the role of the researcher is to present the world the way that the research participants perceive it (Ratner, 2008; Orlikowski & Baroudi, 1991). Holloway (1997) stated that constructivism is identical to interpretivism, in which behaviours cannot be isolated from their context (location, time, other people involved). In congruence with an interpretive paradigm, the development of knowledge in this study is also guided by a constructivist theoretical approach. Thus, as a researcher I am concerned with presenting participants' own meanings of their stories and experiences. These meanings are subjective and are shaped by the participants' cultural background and normative system (Mayan, 2009). I also recognize that my positioning as a researcher and my interpretations of the data will be shaped by my own background and personal experiences.



Adapted from Hay, 2002, pg. 64

Figure 3. Inter-relation between the Cornerstones of Research

(Hay, 2002. p. 64 in Amatya, 2011)

Researcher Positionality

Holloway (1997) has argued that the researchers need to consider how their views and values have impacted the research process and outcomes, and that they should stay reflexive throughout the process (Holloway, 1997). Aligning with this, the language assistant and I stayed open-minded and remained reflexive throughout to keep our own values and perspectives out of the process.

In the context of the MENA women's community, I am similar to the participants. I am an immigrant woman from the MENA region living in Edmonton. My religious, cultural, and social values are similar to those of the female participants, and so I identified myself as an insider. This assisted me greatly in building trust with this community, creating rapport, and encouraging the participants to feel more comfortable sharing their insights. It also helped me to better understand the participants' behaviours and responses. Participants usually tend to believe that they are familiar with and share perspectives with the researchers who have a similar race (Liamputtong, 2008). However, familiarity of the researcher with the participants' local culture may result in negligence of certain values and loss of objectivity (Liamputtong, 2008). For example, a researcher in a familiar setting may forget to describe what is obvious to him/her, and keeping a reflexive stance is one attempt to overcome this challenge (Liamputtong, 2008). To ensure that I remained reflexive, I wrote notes in a reflexive journal. I had regular meetings with my supervisor and the language assistant to discuss the thesis and revisions.

While I also consider myself as an insider because I share the Islamic faith with the study participants, I am aware that I may have widely different perspectives about many aspects of Islam. Diversity is one of the key features of Muslims (Salman, 2012; Huda, 2009; Lazar, 2008; Adnan et al., 1999). Core beliefs and religious practices unite Muslims, such as their faith in one

God and his Prophet Mohammed, the practice of prayers, pilgrimage to Mecca, and fasting during the month of Ramadan. However, Arab Muslims can be a highly diverse group in terms of what practices are acceptable in Islam and how the religion shapes their lives (Salman, 2012; Huda, 2009; Lazar, 2008; Adnan et al., 1999). This diversity depends on many factors including geographical, political, and social influences. For example, Sunnis and Shias are two main sub-groups in Islam, and there is a number of parties within such as Ibadi, Sufi, Mahdavia, Salafism, Wahhabism, and Druze. While Sunnis and Shias share core spiritual beliefs of Islam, chief differences between them are mainly political (Naik, 2000). Although the majority of Muslims worldwide are Sunnis, most Muslims, apart from the political leaders, like to identify themselves as just Muslim (Naik, 2000). When it comes to what extent religion influences Muslims' lives, Muslims are classified as conservatives, liberals, and moderates (Hassan, 2014; Huda, 2009). Although I identify myself as moderate, a middle position between conservative and liberal, I realize that the participants in this study can be highly diverse in terms of adherence to the religion. It might also be true that my self declared "moderate" status could be considered either liberal or conservative by others. This variation can be seen widely not only from country to country or from one organization to another but also from family to family or even among the same family (Hassan, 2014; Huda, 2009). There are no clear or universal factors behind this variation. Older women can be more open than younger women because of different experiences; similarly, some Arabs who were born and raised in Muslim countries can be more liberal than some born and raised in western societies (Huda, 2009). Nevertheless, a conservatism/liberalism clash can be seen among the Arab Muslims in the West. In the Sudanese community, for example, conflicting cultural values that shape gender attitude may be seen. For example, it can be acceptable that single Sudanese men in Canada have premarital sex, while single women are assumed to be virgin brides. This diversity was clear during the focus group discussions, and my understanding of this diversity has helped me in managing and moderating the focus groups as well as in interpreting and analyzing the data.

Furthermore, I considered myself as an outsider based on differences such as education level and professional experiences. In fact, as the research process continued, I realized that I was different in many ways from the participants. I have an education in general practice and public health, whereas the vast majority of the participants do not. In addition, I have some different religious and social practices and use a different Arabic dialect than many of the participants. Ogilvie et al. (2008) have indicated that differences in education level and social class can place the researcher as an outsider, even when the researcher shares cultural features and an ethnic background with the participants. I also have more of an understanding of the Canadian context in terms of health perceptions and practices. Thus, I viewed myself in a unique position between insider and outsider. This unique position helped me to understand the participants' views and cultural values and beliefs and gain their trust, as well guide and mediate their understanding of the research goals and implications. However, this unique position also came with responsibilities and drawbacks. Taking on such a responsibility occasionally put me in a state of uncertainty. The participants came from eight different countries in the MENA region. Even though there are main bonding themes, each country has a different dialect and social culture. When the participants were explaining complex situations, these differences made it difficult for me sometimes to understand exactly what they were talking about. For example, in the focus group discussions there were two participants from Saudi Arabia who used a local word (marah), which means "very" in their local dialect. In other MENA regions, such as Sudan, the same word means “few.” This created confusion during transcription. With help from the language assistant, however, I could clearly understand these situations.

Role of the Language Assistant

Language is the window of knowledge. We can learn a lot about culture through the words and expressions and the cultural references attached therein (Liamputtong, 2008; Temple & Edwards, 2002). Involving language assistants in the process of knowledge generation in cross-cultural research strengthens the rigour and reflects the validity of the research results (Liamputtong, 2008; Laverack & Brown, 2003; Temple & Edwards, 2002). This important contribution of language assistants in the creation of knowledge and in qualitative research should be acknowledged (Liamputtong, 2008; Laverack & Brown, 2003; Temple & Edwards, 2002). Such a role requires significant language and cultural knowledge. Researchers need to be aware of this when selecting a translator or cultural broker (Temple & Edwards, 2002; Liamputtong, 2008; Laverack & Brown, 2003). Failing to embrace a language assistant’s active contributions in the research process threatens the validity of research results (Liamputtong, 2008; Temple & Edwards, 2002).

My supervisor recommended that I use a language assistant because she does not speak or understand Arabic. Thus, she could offer only limited support regarding interpreting and developing the data. The language assistant in this study is a female member of the Arab community. I chose her based on her knowledge of the Arab women’s community in general, her education, and her bilingual (Arabic, English) competency. In fact, she has better knowledge and connections with the MENA community than myself due to her longer residency in Edmonton (>13 yrs.). She was also very interested in the research topic and goals. The amount of involvement of language assistants varies in research. In this study, the language assistant not only helped with translation tasks, she helped to culturally interpret the data and analyze and develop the final results. She also helped improved focus group discussions. For example, after she listened to the recording of the first focus group, she made valuable comments. She suggested that I was too serious, and that using jokes and humor would maintain solidarity and reduce the gap between me and the participants. This tip worked very well in the subsequent focus groups. This brought laughter and positive energy to the discussions. Using humor to steer coping in focus groups is supported in the literature (Wilkinson, Rees, & Knight, 2007). The language assistant also provided me with some interesting terms and nuances I was not aware of that MENA women develop during their time in Canada. For example, they develop certain unique terminologies for food, clothes, social activities, and even health and sickness issues. These phrases are a result of embedded Arab cultures within the Canadian society. These contributions and more from the language assistant therefore influenced how data was generated in ways that would not have been possible without her input. Interpretation of the participants' views and knowledge creation in this study was a collaborative process that required regular discussions and revisions with the language assistant.

I had interviewed the language assistant about her professional and social backgrounds and her perceptions of the research context. I had to do this in order to recognize the language assistant's role in and potential impact on the study (Laverack & Brown, 2003). The language assistant not only understood Arabic and local dialects but was also greatly aware of the research population's cultural and religious values. This made her well-suited to efficiently interpret the meaning of the data and assist in developing the final results.

Research Methods

Research Design

Ethnography is a qualitative research method specifically developed to investigate culture among a group of people (West & Turner, 2010; Patton, 2001; Germain, 2001). Ethnography is "*the art and science of describing a group or culture*" (Fetterman, 1998, p.1). Germain (2001) wrote that researchers from different disciplines have used ethnographic methods to explore and understand cultural perceptions among a particular race. Ethnography studies usually include long-term field studies; nonetheless, they had been altered into a more practical, narrower scope, a shorter timeframe and data intensive research method known as "focused ethnography" (Morse & Richards, 2002; Muecke, 1994).

Focused Ethnography. Ethnography expands the question, "*What is the culture of this group of people*?" (Patton, 1990, p. 67). In a similar way, focused ethnography asks, "*What is going on in this group about this issue or problem?*" (Morse & Field, 1995 p. 26). I used focused ethnography because it is an appropriate research design for a study about culture (Germain, 2001). Focused ethnography is largely applied by researchers from different disciplines to understand cultural phenomena among specific groups of people (Germain, 2001). Mayan (2009) has also pointed out that the ontology and epistemology that guide focused ethnography are constructivist. As argued earlier, constructivism argues that knowledge of the world is socially constructed (Crotty, 1998) and this study explores how the knowledge of breast health and the risk of breast cancer are perceived and constructed by immigrant women from the MENA region.

Morse and Field (1995) write that focused ethnography can be used to understand how health and disease are perceived by an ethnic group. Different from traditional ethnography make focus ethnography "*an important part of the ethnographic toolkit for social research*" (Stahlke, 2014, p.2). Mayan (2009) wrote that a focused ethnography design is directed by a specific research question, within a defined context, among a small group of people with similar values and experiences, with regard to a particular issue to inform the health policy. All these elements are found in this study. First, this study has a specific research question that focuses on MENA women's perspectives on breast health and breast cancer risk. The study explores their beliefs on screening services, so a focused ethnographic approach is more appropriate than a traditional ethnographic approach. Second, this study is conducted in a particular Canadian setting, focusing on women from the MENA region in Edmonton, in regards to breast health and breast cancer risk. The study is designed to inform decision-making about how to design appropriate preventive programs and services. Third, women from MENA share unique features that differentiate them from the general population; hence, they can be considered as a specific cultural group (Germain, 2001). These women are closely connected and their behaviours and perspectives about health and healthcare cannot be separated from the broader picture of their cultural context (Germain, 2001). Therefore, their health beliefs and behaviours are appropriate to be explored by a focus ethnographic approach (Germain, 2001).

I did not use a traditional ethnographic methodology because my study has a limited time frame in contradiction to classical ethnography (Mayan, 2009). As well, in traditional ethnography, usually the researcher is unaware of the cultural background being investigated and also has a goal that is both extensive and vague (Morse & Richard, 2002; Knobluck, 2005).

As a researcher, I have contextual knowledge of the cultural group and interest in a defined research question and there are no field visits in this study. Questions have been raised about the credibility of the information acquired using focused ethnography because of the methodology's short-term limited scope (Muecke, 1994). "*Only long-term field studies, it seems, epitomize what may rightly be called ethnography"* and ethnographic studies that vary from this "*appear to fall short or to be 'deficient*'" (Knoblauch, 2005, p.4). I agree, though, with Knoblauch's sociological description of the method and echo that ethnography is defined by the emphasis on the central purpose: to recognize and describe culture, rather than to focus on the form and volume of data being gathered (Knoblauch, 2005). Focused ethnography produces a massive amount of data in a limited period of time (Knoblauch, 2005). Data analysis in focus ethnography may require an intensive approach since it yields a large amount of data in a short duration in contrast to field notes which take long periods of time (Knoblauch, 2005). The intensity of data collection and analysis is often due to using different recording methods (Knoblauch, 2005). Beside what is recorded, focused ethnography also uses human reflection and narrative techniques (Kendon & Adam, 1990). Muecke (1994) and Holloway (1997) pointed out that recording can help the researcher to better perform his/her role as an observer because while the tape recorder is running, the observer is free to devote time and effort to moderating, observing, and questioning.

Participants

The participants in this study were immigrant women from the MENA region living in Edmonton. To ensure that women from different countries in the MENA region were represented, I recruited the participants from eight diverse geographical backgrounds. Also, I recruited MENA women of different ages with different socio-demographic backgrounds and levels of education to ensure that the study cohort would reflect diverse experiences and views.

According to the Canadian Cancer Society, a breast self-exam is recommended for women aged 20 and older, and mammography is recommended every two years for women aged 50 to 69. Based on these recommendations, I included immigrant women aged 20 to 69. The study also included women who were born in one of the MENA countries and had immigrated to Canada within the last five years and lived in Edmonton. Newcomers (≤5 years in Canada) tend to have less understanding of the Canadian society and a low level of acculturation (Ivanov & Buck, 2002). Female participants had to be able to read and speak Arabic and/or English. Women with a current diagnosis or a history of breast cancer were excluded. Women who had worked as healthcare professionals in Canada were also excluded as it was expected that they would have more knowledge of the Canadian health system than those who did not work in the health sector in Canada.

Recruitment Process

Before participants were recruited, news about the study had been spread in the community using social media and word of mouth in formal and informal women's gatherings. The first eight participants were purposively obtained. They were either my acquaintances or recommended by my language assistant. They came from eight countries in the MENA region and met the participation criteria. The goal of the initial purposeful sampling was to recruit female participants with the necessary criteria to understand the research goals and provide the best data possible (Mayan, 2009). They came from Sudan, Egypt, Lebanon, Somalia, Iraq, Saudi Arabia, Syria and Libya. According to the Canadian Arab Institute, these countries represent the majority of the immigrants from MENA countries in Alberta (Canadian Arab Institute, 2014). These women were approached using an information letter (Appendix A & B).

The letter included information about me as well as the research topic, goals, implications, and role of the participants. I followed up the letter with a phone call and/or meeting to further discuss the project. I then used snowball sampling to recruit the rest of the participants. Women from MENA are very conservative; snowball sampling provided them with more control over whether they would be contacted, and by whom (Bogdan & Bicklen, 1982). Initially the purposefully chosen women were given a contact phone number to pass along to other women from the same country of origin who met the study criteria and were willing to participate. When a potential participant phoned me, I first confirmed her eligibility by filling out a socio-demographic questionnaire (Appendix C). I also explained the study in detail and answered questions. I used the socio-demographic questionnaire also to categorize the participants in the focus groups by age, level of education, and socio-economic status in order to mitigate the power dynamics and ensure an open discussion. For example, I grouped women ages 20-39 and those from 40 to 69. My rationale was that young women might not feel comfortable sharing real "unacceptable" practices or behaviours in the presence of older women. The rationale behind choosing age 40 as a divider was that in Arab cultures, 40 is the age of maturity and wisdom for both men and women (Hassan, 2014): by age 40, men and women need to become wiser and more responsible (Hassan, 2014). Arab women in their forties tend to look more modest in appearance and behaviour (Hassan, 2014) than younger women. This perception is deeply rooted in Islam:

> We enjoined the human being to honor his parents. His mother bore him arduously, gave birth to him arduously, and took intimate care of him for thirty months. When he reaches maturity, and reaches the age of forty, * he should say, "My Lord, direct me to appreciate the blessings you have bestowed upon me and upon my parents, and to do the righteous works that please you. Let my children be righteous as well. I have repented to you; I am a submitter." [Quran 46:15]

The questions were based on similar studies that used a socio-demographic questionnaire and on Statistics Canada 2011 data about social classes in Canada according to household income (Statistics Canada, 2011; Amin, 2008). A pool of names of potential participants who fit the eligibility screens were generated. As expected, the pool provided more names than required. To minimize selection bias, random sampling procedures were implemented to recruit the final participants.

Data Collection

The focus group discussions took place over a series of six weeks. In focus groups, insights are usually developed by our interactions with other people and the environment (Webb & Kevern, 2001; Wiklund, Voog, & Kjellberg, 2014). Participants in focus group discussions do not necessarily come to an agreement but rather bring a diversity of experiences to the table. Interactions are also helpful as a way to identify subjects that people have trouble talking about (Wiklund, Voog, & Kjellberg, 2014; Webb & Kevern, 2001). Focus groups were selected as an appropriate data collection tool in this research because Arab women like talking in groups and gatherings. They can disclose sensitive information when they feel they are in a comfortable and safe place with like-minded women. In addition, some researchers like Strickland (1999) have found that a classic form of communication in focus groups resembles communication styles of some Middle Eastern communities, for example, “talking circle” and “storytelling” (Strickland, 1999).

Mayan (2009) reported that in focused ethnography, interviews and focus groups are often used to get a view of the participants’ perceptions and experiences and how they develop their insights within their culture. In the focus group discussions, I introduced the participants to different subjects in the form of 10 open-ended questions.

The women were then free to discuss whatever they felt related to these subjects. By encouraging this free form of discussion and not asking the participants directly for their views, this research has yielded valuable knowledge and an understanding of how the women perceived their experiences in relation to their culture (Wiklund, Voog, & Kjellberg, 2014). The free discussions were also helpful because they led the women in different directions; one participant's thought might trigger other thoughts, and sometimes there were misunderstandings and quarrels which generated in-depth information about the subjects and the interpretations of the data (Wiklund, Voog, & Kjellberg, 2014).

I conducted a pilot focus group a few months before the actual focus groups. This pilot focus group functioned as important mental preparation for the actual discussion and was a good opportunity for me to practice my techniques as a moderator and to understand how this process worked and what to expect. I made lots of notes and comments, which helped to improve my performance in the actual focus group discussions. It also allowed me to practise audio recording and decide which tools of audio recording to use in the real discussions. Furthermore, as a result of the pilot focus group, I modified, re-phrased, and changed the order of some questions in the actual discussions. This led me to a better approach to produce responses and fruitful discussions.

The data was generated by conducting six focus groups with six participants in each group (total: 36 participants), with detailed field notes and a researcher's journal for each group. The sample size was determined after data saturation was reached. Similar sample size was used in other cross-cultural research (Yang, 2015; Kawar, 2012; Flicker et al., 2008). Among qualitative researchers, there is little guidance and agreement as to how large a sample should be (Bryman 2012; Morse, 2000).

Baker and Edwards (2012) asked social scientists and researchers “How many is enough?” In a well-respected study (2012), they examined 19 responses, the majority replying, “it depends.” The responders listed many factors to consider when determining how large a group should be. Those factors include the scope of the research questions, research objectives, epistemological and theoretical underpinnings, type of analysis, resources, and the stage of the researcher’s career (Baker & Edwards, 2012). Unlike quantitative researchers, qualitative researchers intend to show the diversity of experiences and values instead of numerical representation (Gerson & Horowitz, 2002; Guest, Bunce, & Johnson, 2006). Data saturation is a beneficial criterion when determining qualitative sample sizes (Bryman 2012; Guest et al. 2006). In the deductive approach to quantitative research and prior to starting research, researchers usually have some ideas about the scope of their study (Onwuegbuzie & Leech, 2010). In the inductive paradigm, qualitative researchers work in the context of discovery, and it may not be feasible to identify the amount of data needed from the beginning (Onwuegbuzie & Leech, 2010). Therefore, data is usually gathered until no new themes emerge (Johnston, Robertson, Glidewell, Entwistle, Eccles, & Grimshaw, 2010). However, the meaning of saturation has become hazy since Glaser and Strauss (1967) first used the notion “theoretical saturation” (Guest et al. 2006; Mason 2010; Morse 1995). In “theoretical saturation,” researchers combined sampling, gathering, and analysis of one category of data until each category is saturated before moving on to a different category (Glaser & Strauss, 1967; Guest et al. 2006; Mason 2010). This approach of combining all three stages was found to be demanding in terms of data management and analysis (Mason, 2010). A different term, “*Saturation of knowledge*,” was proposed by Bertaux, and it has been widely accepted among qualitative researchers (Bertaux, 1981, p. 37).

Bertaux also outlined how the researcher generates a large amount of information from the initial few interviews; then, as the data generation continues, the researcher finds similar patterns and confirms what has already been recognised. The decision to stop data collection is influenced by different factors. For example, the more unstructured the interview, the more additional interviews are required (Guest et al. 2006). In this research, I used a semi-structured guide that provided clear instructions to follow relevant topics.

Heterogeneity of the study population is another factor in determining sample size, usually a more diverse group needs more interviews (Guest et al. 2006). Although the MENA women constitute a diverse group, their similarities cannot be denied in terms of gender, religion, cultural background, and place of residence. Onwuegbuzie and Leech (2010) found other factors that affect data collection such as the researcher's experience, fatigue, resources, and number of researchers. The sample size for this thesis was limited by time and resource constraints. A larger number of participants is more commonly recruited in certain conditions, for example in cases where the research is funded research (Murphy & Rosenbaum, 1998). That was not the case in this study. The style and theoretical underpinnings of the study also influence sample size. Studies in which "fine-grained analysis" is involved, such as in cases of interpretive phenomenological analysis and conversation analysis, are less likely to require a larger pool (Onwuegbuzie & Leech, 2010).

Gerson and Horowitz (2002) found that multiple factors affect how much qualitative data needs to be gathered. This is determined not only by the number of interviews, but also by the scope of the relationship established between the researcher and the study population. Reflective and deep relationship between the two parties can make up for a lack of diversity among the respondents (Gerson & Horowitz, 2002).

More than a decade before Gerson and Horowitz released their findings, Feagin, Orum and Sjoberg (1991) found that even if only a few participants contribute, those participants can offer valuable insights and represent sufficient numbers for qualitative research, especially when the target populations are hard to access, as in cases where the target population are political leaders or drug addicts.

Twinn (1998) suggested that it is not feasible to fix an ideal number of participants; the size depends on many factors, for example recruitment issues, the topic itself, and the depth of conversation needed. Gerson and Horowitz (2002) agreed with Twinn and proposed that while it may be frustrating to the readers, it is deceptive to offer numerical guidance. Yet, many other researchers proposed definite sample sizes (Baker & Edwards, 2012; Bryman 2012; Morse, 2000). These sample sizes vary significantly in qualitative research (Baker & Edwards, 2012; Bryman 2012; Morse, 2000; Onwuegbuzie & Leech, 2010). For example, a sample size of 30 is usually recommended for graduate students as a medium-sized pool as it exceeds a small number of people and at the same time saves the stress of limitless data collection, particularly when there is a time constraint (Guest et al., 2006). Mason (2010) examined interviews-based doctoral thesis papers in the United Kingdom and Ireland; he concluded that the sample size range was one to 96 (the median was 28) (Mason (2010). Another example of the variation in sample size in qualitative studies is that some researchers propose that for a qualitative study to be published, a minimum number between 20 and 30 interviews is needed (Warren's, 2002, Bryman 2012).

For a focus group's size, Fusch and Lawrence (2015) recommend that "*the size of the group comprise between six and 12 participants, so that the group is small enough for all members to talk and share their thoughts, and yet large enough to create a diverse group*" (p. 1410).

Bernard (1995) suggested that eight is the most typical group size. One or two people can dominate small groups (e.g., four), while large groups (more than 10) might be uncontrollable (Bernard, 1995).

The focus group discussions took place in July and August 2018. I took notes during and after each group discussion. To create a positive and trusting environment, all focus groups were conducted in community halls (Riverbend Community League and Eastwood Community Hall). Time varied according to the convenience of the participants, but we met mostly in the afternoon. The length of the focus group discussions varied between one to one and a half hours. I introduced different questions and then let the participants discuss their responses without interrupting or participating in the actual dialogue. Questions used in the focus groups (Appendix F & G) were similar across all focus groups. However, I tailored some clarifying and propping questions to explore and elaborate on issues that arose in each focus group. I constructed the questions and met several times with my supervisor to discuss how to use the questions in the focus groups. I digitally recorded all of the focus groups' discussions using two stereo recorders. I also took notes in each session. To honor the participants' preference, I conducted the focus groups in Arabic. I also stayed reflexive and neutral all along so that the focus would shift from my point of view to the participants' own perspectives.

For the purpose of member check to ensure trustworthiness of the data, four weeks following the focus groups I emailed/mailed the transcriptions back to the participants to check with them that the transcriptions accurately represented their ideas. Almost all of the participants provided positive feedback and agreed that the translations were accurate. Only two of the participants made minor changes, and another two never responded.

Data will be saved for a minimum of three years. Afterward, all identifiers will be erased from the records and discarded. Paper documents will be shredded and recycled. Data stored on a computer will be deleted using commercial software applications intended to remove all data from the storage device. Records on tapes, USB drives, and CDs will be physically destroyed. The participants' confidentiality will be protected throughout the process. I will also keep records stating the time, place, and mechanism of destruction.

Socio-Demographic Characteristics of the Participants. The participants, who ranged in age from 29 to 56, lived in Edmonton but were from eight countries in the MENA (Middle East & North Africa) region: Sudan (5), Egypt (5), Lebanon (4), Somalia (4), Iraq (4), Saudi Arabia (4), Syria (5) and Libya (5). Most were married (27). Nine were divorced, widowed, or single. Twenty-six had completed university (a bachelor's degree or higher) and 10 had a Grade 12 education or less. Almost half of the participants (17) were employed. All were Muslim and spoke Arabic as a first language. Roughly one-third rated their English proficiency as ‘‘poor.” The average household size of each participant was from three to five people. Of those who reported an income, five were classified as lower middle class, 14 as middle class, and five as upper middle class. This classification is based on Statistics Canada's 2011 data regarding the classification of social classes in Canada according to household income (Statistics Canada, 2012).

Transcription

As soon as the focus group discussions were conducted, I started transcribing the data from the tapes. Transcription is crucial to the process of analysis and the reliability of the study; thus, transcriptions should be created in the original language (Irvine, Roberts, Jones, Spencer, Baker, & Williams, 2006; Twinn, 1998). Likewise, Liamputtong pointed out that using the same languages of the research participants in transcription would enhance rigour (Liamputtong, 2008). The authentic meaning of the research participants' words may be lost if the interviews are translated into another language (Liamputtong, 2008). For example, in the MENA region the Arabic terms for “rich person” include “*gany*” (needs nothing), “*mortah*” (comfortable), and “*dafian*” (wearing warm cloth). Each term may have a different meaning that can be lost in translation. Also, there are phrases that refer to specific cultural concepts in the MENA region. For example, “*aar*” refers to the humiliation and shame that a girl can bring to her family by losing her virginity before marriage. By ignoring the cultural meaning, this term can be translated literally into a generic term that leads to a loss of important cultural references (Liamputtong, 2008). It is also important to consider contextual information such as jokes and the symbolic use of words, rather than just a literal translation (Liamputtong, 2008).

Furthermore, measures were applied to improve the rigour of transcription in this study. First, transcribing the data on the tapes into Arabic and having the language assistant review the tapes and transcripts to ensure accuracy. Second, member checking with the female participants to confirm the trustworthiness of the transcription.

I also took notes and recorded some observations during the focus group discussions, including nonverbal communications that were not reflected in the transcripts. Such behavioural responses were important in the interpretation of the data (Hennink, 2007). For example, the statement “you are horrific” can sometimes mean “you are extremely talented.” Such a statement can be interpreted differently according to the situation and the speaker’s facial expression and tone of voice (Hennink, 2007).

Methods of Data Analysis

Thematic Analysis. In this study, thematic analysis with focus on latent form was used. In latent thematic analysis, the contents of the transcript are broken into smaller units and undergo interpretative treatment in order to recognise the characteristics that contributed to that specific meaning (Sparker, 2005; Burr, 1995). Thematic analysis is a commonly-used method of analysis in qualitative research and can be applied to different theoretical and epistemological stances (Stewart, 2014; Mayan, 2009). It is accessible and not a complicated analytic method to learn, especially for researchers with limited experience of qualitative research such as myself (Stewart, 2014). Thematic analysis is suitable for addressing issues such as the insights of people regarding an experience and the motives of the people to use or not to use a facility or procedure (Alhojailan, 2012; Sparker, 2005). Thematic analysis that emphasizes latent themes has the ability to reveal, for example, variables that impact any subject produced by the participants. As a result, interpretations of the research data will yield the most accurate descriptions of the participants' beliefs and practices (Alhojailan, 2012; Hatch 2002). Latent thematic analysis also can reveal unexpected insights and provide in-depth yet complex data sets (Alhojailan, 2012; Hatch 2002). Thematic analysis is a flexible method that can be used within both essentialist and constructionist models; however, each will emphasize different concepts (Alhojailan, 2012; Hatch 2002). In a constructionist approach, thematic analysis focuses on the socio-cultural backgrounds that underpin individual's behaviours, rather than identify a direct link between the meaning and the event such as in an essentialist framework (Seale, Gobo, Gubrium, & Silverman, 2004; Burr, 1995). In this study, I used an inductive analysis to find meanings that are deep-rooted in the data and not shaped by my prejudices (Braun & Clarke, 2006).

I began the analysis by recording in my research journal any thoughts or assumptions I had after each focus group. Then I read each transcript carefully and repeatedly to understand and absorb the data (Morse & Field, 1995; Braun & Clarke, 2006). Using the line-by-line coding technique, I deduced keywords and phrases that appeared to capture the response (codes) (Appendix I) (Morse & Field, 1995; Braun & Clarke, 2006). This technique requires great attention to exact words and sections of the data in order to connect data to develop ideas and recognize the common notions (Brar, 2010). As I worked through the transcription, I tried to limit these emerging codes and then decided on initial analysis and preliminary codes. As this process continued, I added new codes whenever I came across new data that did not fit into the obtainable codes. The same process was repeated for each transcript, and I came up with a code book for each transcript. Then codes for all transcripts were compared and a main list of the developing codes was updated with each focus group (Brar, 2010). I did this until data saturation was reached (Morse & Field, 1995; Mayan, 2009). Next, I combined the codes into categories and subcategories based on how the codes were connected. I then manually tied together these evolving categories into a smaller number of expressive themes ((Braun & Clarke, 2006). During sorting the codes into themes, I linked together different categories and subcategories that had arisen in the previous steps (Braun & Clarke, 2006). For example, I had some codes that related to breast health and what female participants do or do not do to keep their breasts healthy. I gathered these into an initial theme called "breast health practices." Usually codes are linked to one theme; however, some are connected to more than one (Braun & Clarke, 2006). I then revised and modified the initial themes and grouped together all the data related to each theme. For this, I used the "cut and paste" tools in Microsoft word and also manually using scissors (Braun & Clarke, 2006).

During reviewing the themes, I re-read all the transcripts to confirm that the data support the themes and that there were no other themes within the data (Braun & Clarke, 2006). I also ensured that the themes were logical and coherent by checking that each theme was responsive to the research questions and that the themes were exhaustive (Merriam, 2009). I also identified sub-themes within themes. After the reviewing process, I defined each theme and what it expresses in relation to my research question. Direct quotations were integrated into the description of the themes. Finally, I came to conclusions, and I wrote a report of the findings.

The whole analysis process was conducted in Arabic, the original language of the participants in the focus group. My language assistant and I translated only the final outcomes and some of the quotes from the transcripts into English. Language has a fundamental role in the utility, validity, and quality of qualitative research (Larkin, 2007). In cross-cultural research, the impact of the language becomes even more complex and requires careful consideration in managing the methodological and analytic concerns (Larkin, 2007; Temple & Edwards, 2002). Lincoln and Guba (1985) proposed that researchers who share the language of the participants have an overall better understanding of the language and greater insight into the meaning of the participants' speech, therefore the data interpretations are more valid. Twinn (1998) also stated that in cross-cultural research, data should be analysed in the original language of the interview. Other researchers agreed with Twinn in circumstances where the investigator is bilingual, as in case of this study (Liamputtong, 2008; Irvine et al., 2006; Temple & Edwards, 2002). They recommended that researchers should preserve the language of choice of the participants throughout the study (Liamputtong, 2008; Irvine et al., 2006; Twinn, 1998; Temple & Edwards, 2002).

This means that all transcriptions, codes, and analysis should be in the original language to ensure that the findings are credible and sound (Liamputtong, 2008; Irvine et al., 2006; Temple & Edwards, 2002; Twinn, 1998).

In translating some of the quotes and the final findings into English, I adopted three steps to ensure the rigour of the study. First, the language assistant and I translated the final findings separately and then met and discussed inconsistencies until we reached an agreement. Second, after I translated the final findings into English, I back-translated into Arabic to make concept equivalence certain (Liamputtong, 2008). Third, I had an outside reviewer examine the translated copy of the final report.

Trustworthiness

This study used different approaches to demonstrate trustworthiness. Four criteria from Guba and Lincoln's ideas on trustworthiness were used, including credibility, transferability, dependability, and confirmability (Guba & Lincoln 1989). In addition, I used verification strategies suggested by Morse, Olson, and Spiers (2002) to establish trustworthiness.

Credibility. Credibility is evidenced by confirming the researcher has accurately presented the respondents' views (Mayan, 2009; Tobin & Begley, 2004; Lincoln & Guba, 1985). In this study, I applied multiple measures to establish credibility. As recommended in the literature, I generated and analysed the data in the original language of the participants (Lincoln & Guba, 1985; Twinn, 1998; Liamputtong, 2008; Temple & Edwards, 2002). I recruited a bilingual assistant to review the transcriptions and verify the translation (Liamputtong, 2008). I had regular meetings with the language assistant to continually discuss the thesis. I translated the final findings from Arabic into English and then back again into Arabic to ensure concept equivalence (Temple & Edwards, 2002; Liamputtong, 2008). The translated copy of the final report was also reviewed by an outsider reviewer.

In addition, I continually took notes during the focus group discussions as well as kept and used a reflective journal from the beginning of the research process to make my experiences, views, values, and emotions visible in order to create transparency. I followed a number of strategies to ensure that I understood the participants' responses and interpreted them correctly, for example member checks. I also had a prolonged engagement with the data through repeated listening to the recordings and repeated reviewing of the transcriptions and analysis.

Transferability. Transferability is shown by the ability to transfer the findings to other contexts (Lincoln & Guba, 1985). In this study, I provided a comprehensive description of the study context. As a result, the findings of this study can offer a logical explanation of breast cancer screening experiences of other immigrant groups who are in comparable positions. This view is supported by other researchers who have studied the issue of generalizability and argued that

> The aim is to make logical generalizations to a theoretical understanding of a similar class of phenomena rather than probabilistic generalizations to a population. Settings or case do not have to be typical for generalizations to be made. Indeed, the general relevant may derive from their typicality. (Popay, Rogers, & Williams, 1998, p. 348)

Dependability. Dependability is demonstrated by the degree to which the outcome could be replicated (Lincoln & Guba, 1985). It can be reached through a process of auditing (Tobin & Begley, 2004). In this study, I kept a self-critical account from the start of the research process until I had analysed all of my data. I clearly documented the research path and events, including emails and meetings with my supervisor as well as meetings and discussions with my language assistant. I kept records on how decisions and changes were made. For example, I modified the focus group questions after I conducted the pilot group, and I also kept personal notes.

Confirmability. Confirmability is achieved when the development of the outcomes is distinctly derived from the data and not a result of the researcher's perspective ((Lincoln & Guba, 1985; Tobin & Begley, 2004). For this reason, during the generation and analysis of the data I stayed reflexive to keep my own perspectives and feelings from interfering with the interpretation process. I had regular meetings and discussions with my language assistant to confirm meanings. Furthermore, confirmability is also reached by my supervisor's ongoing review of my writing process.

Verification Strategies. As proposed by Morse et al. (2002), I implemented verification strategies to establish trustworthiness in this study. I was attentive and had constant contact with my supervisor to ensure the methodological coherence of this inquiry. I worked hard to ensure sampling sufficiency, and this was evidenced by reaching data saturation (Morse et al., 2002). I was aware that the research process was not linear, as the research generated data that sometimes needed to be treated differently. Thus, I stayed open, flexible, and interactive. I stayed patient and continually checked and rechecked. I avoided making leaps. In this way, I was able to build solid ground for valid data to emerge (Morse et al., 2002). My focus on verification in this research was not without implications. It made me respond better to data and also reminded me to stay dynamic and be responsible for rigour throughout the research process.

Ethical Issues

This project was reviewed and approved by the Research Ethics Board at the University of Alberta. The language assistant signed a confidentiality agreement (Appendix H) promising that she would not share any information about the study with anyone other than me. Each participant signed an informed consent (Appendix D & E) form before data collection and after ensuring that they totally understood the objectives of the study and how the information they provided would be used. The written informed consent form was in English and Arabic. The initial sample of participants was approached through an information letter (Appendix A & B). The information letter, which was in English and Arabic, included information about the research topic, goals, implications, participant's role, and information about me, the researcher. It also included contact information for both myself and the supervisor so that the participants could contact us whenever they had questions and/or concerns or wanted to withdraw from the study.

At the start of every focus group discussion, I briefly presented the study topic and goals. I also reminded the participants that their participation was completely voluntary, the information they provided would be confidential, any identity information would be removed to ensure anonymity, and the conversation would be recorded. Also, I reminded them that they had the right not to respond to any question and could withdraw at any time from the project without giving reasons for doing so and without any consequences. I highlighted the importance of keeping the conversations confidential, and reminded them not to share any information outside the meetings. I also provided papers for the participants to write things they were not comfortable articulating in the group. I arranged to meet at community halls to ensure safety and accessibility for the participants. The participants selected the meeting times for their convenience.

It was expected that involvement in this study might cause emotional disturbances. Consequently, at the end of each focus group discussion, I provided the participants with information about resources for mental health and wellness including outpatient counselling services in Edmonton.

Some of the participants are my friends, hence I needed to be careful in attending to the researcher-participant relationship. To ensure that there was no pressure on them to agree to the study, I emphasized voluntary participation. I was also aware that my friends were motivated to contribute more likely to show me their support rather than because they were interested in the research subject. I treated my friends as participants during the research process. However, it was not possible or realistic for me to ignore these friendships, so I kept a balance between being formal and being casual. I ensured that my friends were well informed about their rights and responsibilities as research participants. I also emailed the consent form to them so they could take adequate time before signing. I stayed aware of this new relationship between researcher and participants. I never used group emails that would release each participant's contact information or any other personal data.

Regarding incentives for the participants, after consulting my research supervisor I provided each participant with a $15 Tim Horton's gift card. This was an appropriate incentive because MENA women are big fans of coffee. They usually gather around coffee tables to chat and exchange news. Previous researchers used a similar incentive (Flicker et al., 2008). According to the Research Ethics Board, the amount of the incentive should not be "large or attractive as to constitute coercion." Therefore, this amount was thought appropriate.

Limitations in Data Collection

In Arab cultures, breast related issues are seen as very private matters, and open discussion of these issues can make Arab women extremely uncomfortable. Using focus group discussions only to collect the data might not be the best approach. It was not surprising that I occasionally found it difficult to stimulate the discussion on emerging topics such as sexual relationships. Focus groups followed by individual interviews might have been more productive. In individual interviews, I could have explored further the issues that the participants were embarrassed to talk about in a group environment. However, as a moderator, I was well prepared. I carefully planned a safe and confidential environment for the participants to share their stories, and I explicitly told them that they would not be judged or evaluated.

Geographical backgrounds in this study were limited to eight MENA countries. It was difficult to get a representative sample. However, the aim was not to generate a representative sample or attempt generalizability, but rather to gather information that would offer insights into the specific contexts of the female participants from MENA. I intended to hear from marginalized immigrant women whose voices had not been heard.

Since every language has specific cultural contexts, researchers in cross-cultural qualitative research can encounter many problems when trying to interpret and make sense of participants' words or behaviours (Liamputtong, 2008; Temple and Edwards, 2002). I preserved the original language throughout the research process in order to not distort the cultural meaning. Also, I have carefully chosen the language assistant and outsider reviewer to ensure a high quality of translation and assistance.

Chapter 4

Results

In this chapter I present the outcomes of this study based on the focus groups. Overall, three main themes emerged from the analysis: knowledge about breast health, cancer risk, and screening services; barriers to maintaining breast health and screening; and potential solutions for overcoming barriers. During our discussions, some participants used quotes from the Quran. I cited these quotes from the Quran using the "The English Commentary of the Holy Quran," a five-volume Holy Quran with an English translation and commentary prepared and published in 1963 by the Ahmadiyya Muslim Community.

1. Knowledge About Breast Health, Cancer Risk and Screening Services

Overall, the results suggest that the respondents knew something about breast cancer; most could list some biomedical risk factors. But, crucially, they had minimal knowledge of mammograms. Some knew about breast exams; however, most of them said that they did not know how to do a proper breast exam.

1.1 Biomedical Knowledge

The majority of female participants had some knowledge about breast cancer, risk factors, and treatment options. The following was a typical statement:

> *I think it is a bad disease, the worst a woman can have. Men can get it too, though this is very rare. I think we as a woman should know everything about it. I know that it is a*

> *disease in which the breast tissues grow strangely, causing conditions like lumps and swellings.* (M. FG3)

A significant proportion of the participants demonstrated knowledge about the signs and symptoms of breast cancer (e.g., swelling, bloody nipple discharge, inverted nipple and changes in the skin of the breast), as summed up by this participant:

> *I also add that breast cancer is cells that grow out of control in the breast. I also know that it doesn't have to be a lump or any sort of growth: it can appear as a discharge, a bloody one or yellow in color or changes in the breast skin.* (J. FG2)

Many respondents had heard about risk factors and attempted to connect those factors to their own situations, even if the risk factors were not proven (Subhojit, 2014). They mentioned risk factors including exposure to radiation, exposure to certain chemicals in body care products, genetic factors, fat in the diet, obesity, tobacco smoke, night shift work, and personal hygiene:

> *I know that being overweight will increase my chances of getting breast cancer and also if other women in the family have it, especially a mother or sister.* (A, FG1)

> *I think I can decrease my chances of getting breast cancer by keeping my breasts healthy and clean. I never use any chemicals over my chest*. (AB, FG5)

When the participants described a healthy breast, they always did so using a negative term. In other words, for them, the overall indictors of breast health were based mainly on an absence of physical illness:

> *I think the breasts are healthy when nothing is wrong with them—I mean no soreness or bulges, and normal-looking skin over specially the dark area around the nipples*. (O, FG3)

Her statement was echoed by another participant:

> *For me, my breasts are healthy when I don't see or feel anything unusual such as bumps, cracks, blood or leaking from the nipples, and also if there is no discomfort during the breast exam or breastfeeding, and I can wear my bra comfortably*. (KL, FG6)

1.2 How Breast Health is Maintained?

1.2.1 Healthy Lifestyle. Practices such as eating healthy food, maintaining proper weight, and exercising were among the main healthy lifestyle choices that the majority of the participants adopted to initiate and maintain breast health. Summing up the philosophy shared by many of the women, one said,

> *Well, I go to the gym regularly, I eat lot of fruits and I stay away from fast food as much as I can.* (T, FG4)

However, the participants sometimes contradicted themselves. For example, one participant said,

> *In order to keep my breasts healthy, I always eat healthy and I exercise.* (CD, FG6)

Yet later she said, "*I don't really eat much vegetables and fruits"* Such inconsistencies may reflect pressure to follow desirable responses or dominant group members (Shah, 2018).

More than a few participants said that they had not practiced a healthy lifestyle in their native countries; it was a relatively new practice:

> *I was not doing this back home; here in Canada I can go to the gym more easily and more frequently. There are more recreation centres, almost in every neighbourhood. Also, healthy food choices are more accessible here*. (Q, FG3)

N, another member of Focus Group 3, added:

> *I agree with you Q. I go for walks and sometimes to Zumba classes. I never did this back home. I've learned the importance of working out and walking here in Canada. Back home in Sudan you barely see women going to exercise classes or even walking in the streets.* (N, FG3)

1.2.2 Breastfeeding. Several women were aware of the protective role of breastfeeding. They knew that breastfeeding has many benefits for both mother and child:

> *I think breastfeeding is the best thing to do to keep our breasts healthy and free from cancer. I know two sisters whose mom passed away due to breast cancer. The eldest also developed breast cancer and she had surgery a few months ago. She has no children. The younger, who happened to be my friend, has three kids and breastfed them all. They are happy, healthy and smart. Now she is 55 and healthy. She goes for regular checkups and she is healthy as a horse.* (MN, FG5)

However, most of the participants who breastfed did so not because health professionals say to do so, but because Allah does:

> *I breastfeed my son. He is 10 months old and I will continue breastfeeding till he is 2. Allah in the holy Quran said this.* (E, FG1)

1.2.3 Visits to the Doctor. Some women maintain breast health by visiting medical clinics for checkups. These participants stated that they only go for checkups if they see or feel something wrong with their breasts. Again, this supports the negative concept of health among this group:

> *I go to see my family doctor if I feel there is something unusual with my breasts. Otherwise why I should bother?!* (KL, FG6)

1.2.4 Faith and Prayers. Some female participants said they believe in prayers and religious practices as a means to keep their body, including their breasts, healthy:

> *I also pray and ask Allah (God) to keep me safe and in good health. I try to stay happy and positive, because I believe that a healthy mind is important for a healthy body.* (W, FG4)

Islam's influence on attitudes toward breast health was clear during the focus group discussions. Some participants said they believe in the healing effects of listening and following rulings in the Holy Quran. The participants quoted the Quran during these discussions. One participant claimed that breast cancer may be "punishment from God" for committing sins:

> *I am also not drinking alcohol nor smoking, to keep my body healthy and to avoid upsetting Allah. God may punish us with cancer for the sins we commit like drinking alcohol. I also believe in the healing effect of the Quran on the body, mind and heart if we understand and follow its directions.* (H, FG2)

This woman faced strong disagreement from the other participants:

With all respect, I totally disagree with you. Cancer is not a punishment from Allah. It is abnormal biological changes that can happen for many reasons. (J, FG2)

Another participant added,

> *I agree with you J. We shouldn't think like that. It is not mentioned in the Quran that cancer or any bad disease is a punishment.* (L, FG2)

The participants who disagreed that cancer is a punishment stressed that many faithful Muslims get cancer, as do innocent children. They also pointed out that faith in God helps them to cope and feel less afraid when they or someone they love has cancer. For this reason, they adopt religious practices (e.g., prayers) as means to keep their bodies healthy. L from FG2 mentioned the following verse from the Quran:

> *O Mankind: There has come to you a direction from your Lord and a healing for the (disease) in your hearts - and for those who believe guidance and mercy*! (Quran 10:57) I recited the above verse here from The English Commentary of the Holy Quran (Ahmadiyya, 1963).

1.2.5 Appropriately Fitting Undergarments. A few participants suggested that wearing the right size bra can be protective as tight or badly fitted bras may cause breast cancer:

> *I keep my breasts healthy by wearing a bra that fits right. It should be comfortable, not too tight, not squishing my breasts, as this may cause something bad to happen to my breast. Definitely I don't sleep with a bra on at night*. (Y, FG5)

Only one participant claimed that a tight undergarment could jeopardize the blood and oxygen supply to the breast, which could harm the breasts. Not everyone agreed however; the other women indicated that they were not clear about how a tight undergarment could cause breast cancer.

1.3 **Lack of Knowledge of Breast Cancer Screening**

In general, the participants' knowledge about screening practices in Alberta was quite limited. A typical response to questions about screening was

> *I know there are services for cancer patients, but I don't know about cancer prevention services. Are there any?! Can this cancer really be prevented? How*? (Y, FG5)

Nearly half of the participants had no clue about mammograms, as evidenced by the following statements: "*To be honest, I have no idea*" (C, FG1) "*What is a mammogram*!?" (Y. FG5). The few participants who had heard about mammography said they were unaware of the specifics involved with the procedure. As one woman said,

> *I have heard about mammogram and I know it is only for older women, right? But I don't know when or how many times I should do it. (*V, FG4)

Some participants said they knew about clinical breast exams and self-exams but were not confident about either method used, and they were under the impression that breast exams are mainly for older women. A common response was a variation on

> *I usually check by myself after getting my monthly period. But it is better to have the checkup by the doctor. I mean, I don't know whether I'm doing it right, but the doctor is trained for this, right?* (IJ, FG6)

Many participants were unaware of the impact of regular breast cancer screening on disease outcome and were also uninformed about how or when to perform a breast self-exam, or what signs to look for.

> *I think my doctor talked about this if that what you mean. She talked to me about breast exams at home and at the hospital, but I don't know how to do a breast exam for myself.* (T, FG4)

Many participants said they found that being immigrants is an obstacle to screening due to language and cultural differences. However, some acknowledged that immigration has opened their eyes to new horizons in terms of preventive healthcare because they were not used to these practices back home:

> *I look at my breasts in the mirror for any abnormal skin changes. I also learned this here in Canada. Back home I don't remember somebody telling me I should go for breast checkups.* (Q, FG3)

Another participant in Focus Group 3 responded to Q's comment by saying,

> *I agree with you Q. It is a blessing to be in Canada. It is definitely a better way of living*. (N, FG3)

2. Barriers to Maintaining Breast Health and Screening

Female participants identified many obstacles that can hinder their screening and involvement in breast cancer preventive services. The majority of the female participants said they believe that the language difficulties as well as the gender and the attitude of the healthcare provider are key issues in their participation in screening.

2.1. Language Barriers

The main factor identified by the vast majority of the participants is language difficulties:

> *I'm still working on my English, so it would be helpful to hear health information in Arabic. I really don't understand well when they talk to me in English. That is why I switched to a family doctor that speaks Arabic. She is from Iraq, and she is great!* (C, FG1)

The group that was most affected by the language barrier—and saw it as a great obstacle to screening—was women who had lived in Canada for less than three years and/or those who had limited English/French skills. These participants explained that they could not fully describe their worries and health concerns in English or French. Health programs and services, information, pamphlets, and brochures are only provided in English. Many participants expressed hope that programs could be explained in Arabic, as this would improve health literacy and promote informed decision-making about health issues.

> *I will be motivated if I see information in Arabic and health providers speaking Arabic, in particular women providers. When I came to Canada few years ago it was very hard for me to communicate with the staff in the hospital or clinics because nobody was speaking or understanding Arabic. This makes me want to avoid visiting the hospital unless I really need to.* (AB, FG5)

While many say that programs in Arabic (e.g., public presentation, leaflets and posters, TV shows) are important to motivate them to get screening, only a few said that a lack of English language skills is not a challenge that it keeps them from accessing preventative services. Those who did not consider language an impediment to screening either had worked in health-related professions back home or were involved in higher education programs in Canada:

> *For me, although I prefer to see someone who talks and understands Arabic, t won't be a problem if I have to communicate in English.* (O, FG5)

2.2. Healthcare Provider (Gender & Attitude)

The presence of a health provider is an important determinant of whether these women participate in screening. Most of the participants said that the health provider's gender would influence their decision about whether or not to seek screening. They prefer to be seen and examined by a female practitioner. For modesty reasons, they feel extremely uncomfortable being exposed to a male practitioner. In addition, they said, their husbands would not approve them seeking health services staffed by male providers:

> *I'm more comfortable to see a women doctor. I would never let a male health provider examine my breasts. My husband also would not be happy if this happened.* (C, FG1)

Some women highlighted unpleasant experiences with health providers they described as being culturally insensitive. They pointed out that staff can be impatient or impolite with women whose first language is not English because they do not understand or respect the cultural differences. These negatives experiences caused the participants to avoid seeking health services unless absolutely necessary. When I asked them how healthcare services could be better provided to immigrants whose culture and language are different from those of Canada's two main language groups, they proposed that staff should be trained to be culturally sensitive to their religious and social traditions. Others said that they wished to see immigrant health providers from their own ethnic backgrounds working in health care.

*My daughter had heavy menstrual bleeding. It was too much: she was pale and tired all the time. In the emergency room there was a staff nurse. She asked my daughter if she was sexually active. My daughter was only 15 and it was not appropriate to ask such a question. We felt very uncomfortable. We are Muslims and wearing hijab (head cover): this was obvious. Muslim women don't have sex outside marriage as you all know. They should know that, too. (*AB, FG5)

Last year I had a pain in my hip. I went to a walk-in clinic. A male practitioner approached me and wanted to check me. I felt very uncomfortable and I asked him politely for a female nurse. He was nice, to be honest, but it took me more than 40 minutes waiting till a female staff [member] came and checked me. I think health providers should be trained about Muslim women and what makes them comfortable and what does not, because being nervous and unhappy would definitely discourage me from seeking any health services. (L, FG2)

I still feel like a stranger sometimes here, and some people don't respect where we come from. A few months ago, I visited the health clinic for high blood pressure and the nurse asked me about [my] current medication. I have mentioned karkadiah (herbal medicine) that we used to treat high blood pressure back home. Guess what? She rolled her eyes. I felt very bad and offended. I never went back to that clinic again. (Z, FG5)

2.3. Gender Barriers

Many female participants indicated that their choices are dictated by whether or not their husbands approve. One participant said,

> *I also want my husband to be involved, because if he is involved, it would be easier for me to talk to him about the issue.* (R, FG3)

When I asked her how her husband can be involved, she replied:

> *Well, he can be involved by, for example, targeting both men and women in the talks and events about breast cancer prevention. Also, if my doctor talks to him about this nasty disease and the importance of screening, he would probably take the doctor's words seriously more than my words and would support my decision to go for screening.* (R, FG3)

Other participants agreed with this woman, saying that physicians play a key role in facilitating women's health-care decisions. Many participants said that they would go for screening if the physician recommended it. They pointed out that the physician can be a trusted and well-accepted source of information and guidance for them and their spouses They suggested that their husbands could be convinced if they had been approached by the physician:

> *I would go for screening if it is recommended by my doctor. Otherwise, how I can convince my husband to do that? My husband is very difficult, but only the doctor can persuade him.* (F, FG1)

To sum up, most participants agreed that their husbands' endorsement played a significant role in their health-care choices.

2.4. Lack of Empowerment

Lack of information and skills is recognized by the participants. One example explored by the women was an insufficiency of information due to either poor language (English/French) proficiency and/or inadequate promotion of breast cancer screening. The participants called for information about breast cancer screening programs and campaigns to be promoted widely via the media, public seminars and lectures, newspapers, community events, and emails and posters:

> *I think there isn't enough information about these kinds of services. I hear about HIV prevention all the time, but I barely hear about breast health. I think Alberta Health Services should place more efforts to educate women about breast health*. (B, FG1)

> *Where do you guys hear about these services? I always watch TV and read newspapers. I don't really see news about breast cancer campaigns or services. I wish to receive, for example, emails regarding this. I check my email several time a day. There is no chance I am missing it.* (Y, FG5)

Many women reported they have limited knowledge and skills to perform breast self-exams or to make informed decisions about mammograms: "*I have no idea what to look for*" (T, FG4) and "*What is mammography?! I never heard of it*" (H, FG2) were typical responses to questions about the procedure. Many participants proposed that training and providing them with the necessary tools would help them to practice appropriate screening:

> *For me it would be very encouraging if I have been trained to do a breast exam and given enough information about how, when and where to go for screening. I prefer to learn about this in our community with familiar people. I guess I would be more comfortable.* (ST, FG5)

The participants said that this empowerment could be achieved by different means. For example, information could be made available via mail or emails and breast health education and training programs to be held, preferably, in their communities:

> *Of course I prefer at home; it is more convenient, but if not feasible it can be in the community halls or other community places. I don't prefer hospitals or clinics, to be honest. I don't like the smell or the environment of the hospital. And, of course, I would like to see female workers, not male.* (S, FG4)

Three female participants indicated that their empowerment would enable them to go beyond fear and take control over their breast health. The other participants supported this view:

> *I don't like being negative when it comes to my health. I want to learn how to help myself and my daughter. Before, I used to fear even talking about this issue, but when I knew about the subject of this meeting, I read a lot about this issue. Surprisingly, the more I know, the less the fear inside me.* (G, FG2)

Other factors that make it difficult for women to seek healthcare are inconvenient times and places for appointments and inaccessibility to child care. For many of these immigrant women, the loss of family, social, and financial support has led to busy lives and limited time to dedicate to their own health. Time and convenience seem to be important factors as to whether these women are willing to participate in screening, or only seek secondary and tertiary health care:

> *Location is the number one factor for me: if I have to travel more than 30 minutes by bus or train, I will definitely have a problem going. Also, time is a big issue for me. I'm working and it is hard for me to take time off. Second, English, English and English. I wish there were leaflets in Arabic or someone to talk to me in Arabic*. (OP, FG6)

> *Being a single mother with children in a new country gives me no balance to find time to visit healthcare services to perform screening or learn about women 's health services here. I also have no family or friends around to help me with the kids or take care of them if I become sick or need to see a doctor.* (S, FG4)

The inaccessibility of childcare is also a barrier keeping these women from seeking breast cancer screening. When they immigrated to Canada, they lost their trusted caregivers. Nineteen of the women agreed that integrating childcare services into the screening programs would make them more likely to seek screening. As one of them said,

> *I like the idea about child care in these services or at least a supervised playground. My husband is really busy and I have no family or close friends to trust with my kids.* (B, FG1)
>
> Another participant echoed that sentiment: *"I also would be happy if there is a child care services there, so I don't have to worry about my little one."* (P, FG3)
>
> *I think it is important to offer some help with our children in these services. I have three kids, one in Grade 2 and 18-month-old twins. I can't go anywhere if I don't have someone to trust with them. My husband works outside the city, so I'm by myself most of the time.* (D, FG1)

2.5. Fear

Eight women expressed concerns and nervousness due to the possibility of adverse screening outcomes, especially those who had observed close family or friends dying or suffering from breast cancer.

> *I'm scared to death to find that I have this bad disease in my breast. Who is going to take care of my family if I die? I don't want to live in fear and worry every time I go for screening. My friend passed away a few years ago because of this disease. I watched her dying. I still remember her every day. I can't forget how she suffered after her surgery and chemotherapy. She left behind small kids, a boy and a girl. My heart is still broken*. (EF, FG6)

Four of these eight women had a fatalistic attitude about breast cancer. Their attitude was that screening wouldn't change anything if they were meant to have breast cancer:

> *I don't really want to find something sinister. And it is not going to change my destiny anyway, right? If I have it, I have it. Nothing is going to change this* (I, FG2)

From the tone of the women's voices and their facial expressions, I could feel the great fear and worries that most likely caused them to avoid screening. "*No need to open the closed door*" (Y, FG5) was a common sentiment. Some participants had heard from other women that a mammogram is painful and uncomfortable and were reluctant to go because of that:

> *I don't think I can do that. It is painful as I heard. My friend did it last year and she was not happy. She said it was pretty painful and she thought the technician was not good enough. She took some pills for pain afterward. I really don't want to go through this. So I won't do it unless I feel something on the self-exam. (*U, FG4)

3. Potential Solutions for Overcoming Barriers

In the focus groups, female participants discussed several approaches to improve the ways that breast cancer prevention services are provided to their community. These culturally sensitive methods could be potentially incorporated into existing breast health services and guide future interventions and breast cancer research.

There is a general agreement on the need for bilingual (English/Arabic) programs to improve the uptake of screening services. The participants agreed that it is necessary to translate information so it can be provided in Arabic. The participants also stressed that screening programs and preventive care services should be available in both English and Arabic so that women who do not speak English are made aware of these programs and opportunities.

Many women expressed their hope that female health providers could be available for physical exams and check-ups in breast cancer screening services:

> *I would like to be approached by a woman like me, preferably wearing a hijab and talking Arabic. I also would like to see information available in Arabic, whether on the internet or in the hospital. I also would like to see health staff from my community, so they can understand our culture and values*. (K, FG2)

Other participants suggested that women from similar cultural and social background can be trained to educate women from the MENA community:

> *Some women from our community can be trained and receive special education about these services. Then they can educate the rest of us. Those women would be such a great help because they have the same religion and values*. (GH, FG5)

Many participants also brought up the idea of outreach programs: *"Instead of going to these services, why not have these services come to us*" (QR, FG6). They proposed events, such as presentations and seminars, be organized in their community and guided by Arabic-speaking or bilingual health workers. Other suggested approaches included online forums and apps to be specifically tailored, using symbols from Arab and Islamic cultures. For example, one woman suggested that:

> *If we could have an online forum for Arab women's health to discuss any health issue including breast cancer in Arabic, we could put pictures of Arab women and pictures of our countries and food.* (AC, FG4)

In advertisements about breast cancer prevention services, the women said they would like to see women with colored skin in the pictures instead of white women. They also proposed using quotes from the Holy Quran and Prophet Mohammed (Hadith) about the importance of protecting one's health. One woman also suggested an app similar to what the public-school system uses to keep parents informed about their children's education but it would be about breast cancer programs:

> *It would be great if they create an app to use on the phone, like the school zone for example, but about programs to prevent breast cancer in women from the Middle East. And I hope there will be pictures of women like us, I mean dark skin, curly hair, wearing abayas (long, loose body cover). And you know what I really wish for? I really like to see some quotes from the Quran. That would be encouraging*. (D, FG1)

Many women frequently said that in order for them to seek breast health services, the men in their lives would have to be involved. They suggested using separate spaces for men and women in public events and health education programs, because in some MENA countries, men and women who are not related by blood or marriage do not usually gather in the same area at formal events. Focus groups proposed multi-level interventions that target women and their husbands, the MENA community, healthcare providers and the healthcare system.

Summary of Results

The outcomes in this study revealed that women from MENA countries have diverse experiences and perceptions regarding breast health and breast cancer risks and screening. The results reinforced the reality that strongly held beliefs significantly impact whether and how immigrant women from MENA region will seek healthcare for breast cancer. The outcomes also emphasize the central role of religion even amongst educated women, indicating the potential for using this to engage women. Therefore, it is vital to consider the socio-cultural and religious values of this group in future interventions concerning breast health (Cohen & Azaiza, 2010).

This study identified many challenges to screening. Language and cultural differences were the main barriers. Contrary to existing studies, some participants viewed immigration as a positive factor in the promotion of a healthy lifestyle and acceptance of breast health practices including screening (Abdulbari et al., 2002; Anderson, 1987). Some women said that they had never experienced screening in their home countries and first practiced it in Canada.

It was clear that the female participants were highly motivated to improve their health literacy with regard to breast health and cancer screening. They proposed multi-level culturally sensitive interventions to help them improve their knowledge and screening behaviours. These interventions can guide healthcare policy-makers when designing screening programs for this ethnic minority group.

Chapter 5

Discussion

In this chapter, I broadly discuss the findings of this study in relation to both the research purpose and the current knowledge using the Health Action Model as a theoretical framework. I start with highlighting the value of the Health Action Model (HAM) in understanding and redressing breast cancer screening disparities across the MENA culture. I continue with discussing two main findings: lack of a holistic approach to health and lack of screening knowledge. Next, I discuss barriers to screening and their implications for health literacy. Then, I discuss the importance of cultural and religious values in shaping the screening practices among MENA women. I present culturally sensitive solutions for overcoming barriers proposed by the participants in this study. Lastly, I explain how was the Health Action Model (HAM) useful as a theoretical framework in this study.

Theoretical Framework: The Health Action Model (HAM)

The existing literature exploring the role of health behaviour theory in understanding and promoting breast cancer screening methods is inadequate because there are so many approaches and not all of them are suitable (Pasick & Burke, 2008). For example, as discussed in the literature review, commonly used theories (e.g. the Health Belief Model) focus on an individual-level approach and ignored the sociocultural context (Pasick & Burke, 2008). As a result, an approach is needed that covers psychological, cultural, and environmental factors.

As discussed in chapter two, the Health Action Model (HAM) combined a number of widely used theories such as the health belief model, the theory of reasoned action, and the social learning theory (Green et al., 2015). It emphasizes the importance of the intersections of culture and the different social and environmental factors. The HAM indicates a complex and ongoing interplay between the self, belief, motivations, and the social norms that result in an "intention to act" (Figure 1). However, facilitating factors are needed for the actions to occur. The HAM suggests that you cannot separate the design of targeted effective health promotion programs from the historical and cultural contexts of the participants for whom they are intended. This inclusiveness of the HAM results in understanding key sociocultural and ecological determinants of health-related actions beyond the level of individual health. Thus, instead of looking at the MENA women's experiences merely within a single analytic frame, the Health Action Model (HAM) has been chosen to provide a valuable basis for analysis of the present study's findings. It has the potential to facilitate a greater understanding of the study participants' experiences and the central roots of screening disparities.

Lack of a Holistic Approach to Health

A holistic approach to health as defined by the World Health Organization is "*a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity*" (World Health Organization, 1948. p. 100). The participants in this study are generally lacking a holistic approach to health. They articulated that absence of physical illness means that they are healthy and free of serious disease such as breast cancer. This finding is not surprising. As indicated before, women from the MENA (Middle East & North Africa) region view health mainly from the physical perspective (Salman, 2012; Amin, 2008; Adnan et al., 1999).

The women in this study are no exception. Multiple factors play a role in this limited understanding of health. There are gender disparities embodied in social norms and practices, for example shame and stigma when single women pursue sexual or reproductive health services (Hassan, 2014; Adnan et al., 1999). Islam forbids any sexual activities or conceiving of children outside of marriage; hence single women are not expected to adopt breast health measures in traditional Arab Muslim society (Walton, Akram & Hossain, 2014; Amin, 2008). Such cultural norms cause women and girls to avoid using available healthcare services (Hassan, 2014; Adnan et al., 1999). Laws and rules can also limit women's access to healthcare services. For example, with few exceptions, abortion is illegal in most MENA countries, and sometimes requires spousal consent (Shapiro, 2014). Lack of education and empowerment hinders women's understanding and awareness of health (Vahabi et al., 2016; Azaiza & Cohen, 2006). Political instabilities, wars, and weakness in health systems result in inadequate, inaccessible, and poor quality of healthcare, particularly for vulnerable groups including women and children (Salman, 2012). Poverty, poor sanitation, insecurity, and lack of other social determinants of health have dire health impacts for women and girls (Salman, 2012).

Lack of the Screening Knowledge

Overall, poor knowledge of screening practices is a common finding in this study. Many participants demonstrated poor participation in the screening services. For many of these women, screening itself is a new notion associated with their immigration to Canada. Mammography is still unknown to the majority of them, and those who know about mammograms believe they are for older women and exclude themselves.

This research confirms the existing literature by highlighting the overall poor awareness of newcomers to Canada from Arab countries about existing breast preventive measures in Alberta. Other studies indicate that Arab Muslim women in Canada have reported poor knowledge of breast cancer screening practices (Bowser et al., 2017; Aziza, 2014; Rajaram & Rashidi, 1999). Diversity in culture influences health behaviours such as uptake of cancer screening services and determines the morbidity and the mortality rate of the disease (Bowser et al., 2017; Aziza, 2014). There is a positive impact on participation in screening among ethnic minorities the longer their stay in Canada (Vahabi et al., 2016; Schoueri et al., 2006). However, these perspectives cannot be generalized across the wider Arab Muslim population. Arab Muslim women in Canada, including Alberta, are exposed to many limitations including social, economic, and institutional challenges that hinder their access to breast health knowledge and screening services (Bowser et al., 2017; Gesinka et al., 2016). Using self-esteem theory as a framework, Salman (2012) stated that some MENA women in Western settings are anxious about whether their peers would tolerate and accept their health behaviour. Since screening is not a normal practice in Middle Eastern culture, these women may deny screening services to avoid criticism and social isolation and to follow the norms in their culture (Amin, 2008).

In Canada, cancer screening involves several forms, including breast self-exam, clinical breast exam, and mammography (Canadian Cancer Society, 2015). As stated earlier, some of the participants in this study were aware of breast exams; however, the majority have little to no knowledge of mammography. The few participants that recognized mammograms as a breast cancer screening tool had a heated debate on mammogram risks and lack of efficacy. Mammogram may show abnormality while there is no cancer (false positives); second, mammogram may appear normal while cancer is present in the breast (false negatives)

(Canadian Breast Cancer Foundation, 2015). Those two weaknesses are behind the biggest fears some women have about breast cancer screening, and Arab women are no exception. There are ongoing debates among cancer experts regarding benefits and limitations of mammography, although some scientists believe that the disadvantages of the risks of mammogram are much less than the gains of saving lives through screening (Canadian Breast Cancer Foundation, 2015). Medical experts, like Dr. Martin Yaffe from the Canadian Cancer Society, have pointed out that the false positives estimates are probably due to the older, more primitive mammogram; nowadays, mammogram is more developed and hence more accurate (Canadian Breast Cancer Foundation, 2015). In fact, among cancer associations, many support that mammography is not ideal, and it has its advantages and disadvantages. Thus, breast cancer associations encourage women to learn about breast health and screening strategies in order to make an informed decision to lower cancer risk (Canadian Cancer Society, 2015).

Barriers to Screening

Language Barriers and Functional Health Literacy

Research in US, UK, and Canada found that the inability of health policy to accommodate the cultural and religious values of Muslim women impacts their uptake of cancer screening programs (Bowser, 2019; Schwartz et al., 2008; Aziza & Cohen, 2006). This is the case in this study. Similar to previous cross-cultural research, language difficulties are reported as one of the main challenges for accessing quality healthcare (Esposito, & Wang, 2010; Britigan et al., 2009; Zhao; Azaiza & Cohen, 2006). Nearly half of new immigrants to Canada do not have prior knowledge of English (Citizenship & Immigration Canada, 2009).

Language challenges can significantly hinder social integration (Cole, 1998). Failure to remove these barriers hinders an individual's abilities to transform his/her intentions into actions (Zanchetta & Poureslami, 2019; Vahabi et al., 2016; Green et al., 2015). In other words, the multiple aspects of vulnerability need to be addressed in order to develop empowering health promotion programs and services (Green et al., 2015; Kawar, 2012).

From the perspectives of the participants, bilingual programs (English/Arabic) are required to achieve an adequate level of health literacy. Similarly, other researchers have revealed bilingual services and events would increase knowledge of Canadian culture, bridge gaps with connecting newcomers to settlement services, and help with their adjustment (Bowser, 2017; Cohen & Azaiza, 2010). As reported in previous studies, health literacy impacts women's ability to communicate with their healthcare professionals, to read and understand cancer-screening directions and health information, and to take action to improve their health (Vahabi, 2016; Azaiza & Cohen, 2006; Davis, Evans, Jadad, Perrier, Rath, Ryan, & Zwarenstein, 2008). As discussed earlier in the literature review section, there are three dimensions of the health literacy (HL) model: "functional literacy, "interactive literacy," and "critical literacy" (Nutbeam, 2000). In a systemic review by Fernandez et al. (2018), few health literacy interventions for ethnic minority groups have been found. Fernandez et al. revealed that the studies were more successful in improving functional health literacy, while showing fewer effective changes in the second and third levels of health literacy. (Fernandez et al., 2018). It is well documented that healthcare seekers with inadequate language skills obtain poor quality healthcare in comparison to native language speakers (Margareth, Zanchetta & Poureslami, 2019; Britigan et al., 2009; Arora et al., 2012).

While the relevant literature describes the role of the individual as vital in health literacy, others argue about the significant impact of healthcare providers on the health literacy of service seekers (Padela et al., 2019; Baker, 2006). Institutional elements including healthcare services, programs, and providers were recognized as affecting newcomers' health decisions and actions (Ng & Omariba, 2013). A high level of health literacy can be achieved by effective communication and collaboration in the health education process (Margareth, Zanchetta & Poureslami, 2019; Baker, 2006). From this perspective, the results of this study emphasize the need for Arabic-speaking providers, translation, and interpretation services to achieve and maintain an adequate health literacy level among this group with regards to breast health and cancer screening. Other researchers found that interpreting services for immigrant groups are important tools to encourage safe and efficient communication and patient satisfaction (Margareth, Zanchetta & Poureslami, 2019; Vahabi et al., 2011; Karliner et al., 2007). Muhanga and Malunga (2017) pointed out that in spite of the huge amount of accessible information today, many people lack the necessary skills to be health literate because of multiple barriers and strains.

In the context of immigration, Health Literacy (HL) varies between immigrants and non-immigrants, as well as between immigrant groups by place of origin and time spent in Canada since their arrival (Ng & Omariba, 2010). In general, "*The levels among immigrants deserve particular attention; only 25% of immigrants have the requisite health literacy skills to maintain health*" (Ng & Omariba, 2010, p. 49). In order to improve health literacy of this population segment, we need to tackle cultural barriers and improve public health services and communication skills of health providers and educators (Muhanga & Malunga, 2017).

Researchers have demonstrated the association between poor HL and socioeconomic characteristics, health actions, and health results (Muhanga & Malunga, 2017). Factors such as race, age, gender, employment, income, and level of education, as well as intellectual and physical skills, were found to influence HL (Muhanga & Malunga, 2017). How people view and practise health is greatly formed by their daily interactions with health knowledge and technology (e.g., at home, at work, at the market, in a clinical setting) (Muhanga & Malunga, 2017).

Education and Empowerment and Its Implications for Health Literacy

The Ottawa Charter has emphasized empowerment as a crucial component in health promotion (World Health Organization, 1986). This study shows how the female participants are highly motivated to improve their health. Education, training, and direction were common goals among the participants. Many female participants reported their inadequate knowledge and skills about screening practices, and they expressed a strong desire to be educated and trained in order to make an informed decision. They pointed out that empowerment would enable them to overcome their fear and take control of their breast health, one participant stated: "*the more I know the less the fear inside me.*" Fear is an emotion, and according to the HAM can be considered as a "drive," one of the dimensions of the motivation system (Green et al., 2015). This feeling is a factor in determining MENA women's responses to screening services. Despite the advertisements about breast cancer screening in Alberta, the usage of screening services among this group of women is still lacking (Shields & Wilkins, 2009). Participants in this study also identified a lack of direction from their healthcare practitioners about screening services. They stated that the present information made available is not attractive because it is either complicated or unclear.

According to them, empowerment can be attained by several means: through health education, training, and community outreach programs. Other studies have also highlighted how important it is to empower immigrant women about breast cancer screening (Kawar, 2012; Madanat, 2002). Scholars have pointed out that a high education level of an individual does not necessarily guarantee access to the healthcare and better health outcomes (Chinn, 2011; Minkler & Wallerstein, 2008). The concept of critical health literacy, involving the ability to critically engage with knowledge and take action to improve health, has received wide interest (Chinn, 2011). However, it has been criticized that this concept is ill-defined and has failed to better guide current intervention methods in health promotion research (Chinn, 2011). Gillis, Gray, and Murphy (2012) highlighted that critical health literacy can be obtained by both the educator and the learner working in a collaborative and sharing environment, benefiting from one another's skills and resources. Many have argued that the notion of critical HL is broad and includes not only the individuals but also types of sickness, healthcare professionals, and other health system resources (Baker, 2006). It was found that integration of critical HL into clinical practice can face many challenges, for example unsupportive or stressful environments and poor qualifications of health professionals (Gillis, Gray, & Murphy, 2012). There is some evidence supporting the notion that critical HL is a valuable tool for good health (Chinn, 2011), yet future research is needed to evaluate the usefulness of this concept as an asset to empower individuals for better health outcomes (Chinn, 2011).

The Difference Between Knowledge and Practice. As an empowerment tool, health education has been criticized in some studies, because a gap was found between “knowing what is healthy” and “doing what is healthy” (Yang, 2015, p. 122). This gap was also found in this study.While some participants demonstrated knowledge of how they can reduce breast cancer risk, such as through healthy eating and exercise, this knowledge did not necessarily lead to the best health decisions or actions. This gap, in fact, is not uncommon in health promotion research (Murimi & Harpel, 2010; Israel, Schulz, Parker, Becker, Allen, & Guzman, 2008). Today, an enormous amount of information can be accessible within a short time; however, too many options can be overwhelming (Al Rapaport, 2017). Such feelings from the over availability of knowledge can produce avoidance and be a barrier to implementation and practice (Al Rapaport, 2017). In the present study, these women have acted based on their own beliefs and not on the information that is provided to them. To successfully involve them in health promotion, an understanding of how actions or beliefs need to change should be accompanied with the given information (Green & Tones, 2010). Telling them they need to go for screening and providing them with information on health concerns such as advanced breast cancer is not health promotion. Health promoters should look further than individuals' behaviours in order to understand their health choices (Green & Tones, 2010). Different people from different cultural backgrounds can develop different perspectives on the same health problem (Ledwith & Springett, 2010). Understanding the cultural background of a group opens the door to efficient communication between individuals and their healthcare providers (Zanchetta & Poureslami, 2019; Hammoud, White, & Fetter, 2005). This eventually leads to adequate understanding of an individual's perceptions of health and illness (Hammoud, White, & Fetter, 2005). Context is a key factor that shapes how women from MENA countries perceive and practise breast health. Bridging their voices with those of decision makers could result in effective health promotion programs that enhance MENA women's access to quality healthcare with regard to breast cancer screening and prevention (Madanat, 2002).

Moreover, people do what is easy and available for them, and misinterpret or deny uncomfortable choices (Green et al., 2015). Collective efforts and shared responsibility are needed to make a change "*The empowering health education aims to strengthen capability to control individual health and work collectively to achieve supportive environments for health*" (Yang, 2015, p. 122). Knowledge is necessary for change to occur; however, in order for health education to be empowering, the emphasis should shift from individual to shared responsibility to direct learning toward action and change (Green & Tones, 2010). For example, some of the participants did not practise healthy eating or physical activities although they had the knowledge. Even though it may be necessary for them to learn how to cook healthy meals, it may also be important to make healthy food choices accessible and affordable for them. Safe neighbourhoods, maintained sidewalks, and availability of bike lanes may encourage these women to adopt physical activities. Therefore, building on the HAM model, in order to increase the likelihood of knowledge and intentions being converted into actions, certain elements that work on individual, community, and environmental levels are needed (Green et al., 2015). For example, on an individual level, personal skills and beliefs about oneself are key elements of empowerment (Green et al., 2015). Researchers have argued that self-perception is a collective concept resulting from different components that create personal identities such as self-impression, social, and academic presentation (Pasick & Burke, 2008). In terms of empowerment and health, individuals with high self-esteem will most likely adopt healthy choices with desirable health outcomes (Green et al., 2015; Kawar, 2012). Another element of empowerment is the role of the environment, including physical, socioeconomic, and cultural settings (Zanchetta & Poureslami, 2019; Green et al., 2015, Kawar, 2012). Actions on individual level are needed in health promotion. However, focusing on community and environmental modification is essential (Green et al., 2015). Individual, community, and environmental elements all contribute to the barriers to screening that newcomers face.

Healthcare Providers

Another major determinant of MENA women's participation in screening services is health providers themselves. The gender of a healthcare provider is a critical factor in attracting these participants to take part in breast cancer screening activities. The majority of the participants in this study indicated that they would agree to be seen and examined only by a female practitioner. The participants stressed the need for respecting their modesty in a clinical care setting. These findings are in agreement with the existing research literature. Institutional issues related to the modesty and privacy needs of Muslim women have been found to be sources of distress and failure to use healthcare services (Bowser et al., 2017; Salman, 2012; Amin, 2008). Valuing modesty and privacy for Muslim women patients is among the most important recommendations for appropriate healthcare for Arab and Muslim women (Bowser et al., 2017; Salman, 2012; Amin, 2008). It is considered to be extremely insensitive and a cruel violation of the Muslim woman and her family if the healthcare system offers a male health provider for a Muslim woman patient when performing intimate physical examinations such as breast and pelvic check-ups (Bowser et al. 2017; Rajaram & Rashidi, 1999). Amin (2008) also revealed that recent immigrant women living in Halifax considered having a female health provider from a similar social and religious background crucial in their acceptance of Canadian health culture.

The participants in this study also revealed negative experiences in healthcare settings that discouraged them from using the services. This emphasizes the necessity of eradicating discrimination and stereotyping in healthcare settings and providing cultural competency training. Immigrant women from the MENA region are a very diverse group and have cultural beliefs specific to their countries of origin (Bowser et al., 2017; Hassan, 2014; Barakat, 1993). Disrespecting alternative medicine or asking young single Arab Muslim women about sexuality (as happened to participants in this study), for example, is considered offensive and may cause extreme embarrassment for the women and their families (Amin, 2008). However, this is a good example of a matter on which to train health providers to offer culturally appropriate healthcare for Arab Muslim populations. Collaboration between the immigrant patients, health providers, and policy makers is important in the provision of effective healthcare that accommodates cultural values (Bowser et al., 2017; Hasnain et al., 2011). Immigrant groups cannot simply be expected to drop their values and adopt a new way of living (Margareth, Zanchetta, & Poureslami, 2019). However, they can, for example, be educated to better understand how sometimes their beliefs jeopardize their health (Salman, 2012). It is understandable that redesigning health programs to be culturally sensitive is a costly and challenging process for the healthcare system; however, it is achievable (Hasnain et al., 2011). Small changes can have big impacts. For example, in Oregon, it was found that many Muslim women were cancelling hospital bookings because they were too embarrassed to wear the hospital gown that they felt was revealing (Hasnain et al., 2011). As a result, hospital management used extra material to redesign the gown to provide extra coverage.

Other Impacts of Immigration

The participants in this study discussed the impact of their immigration experience on breast health practices including the notion of cancer screening. On one hand, issues related to immigration such as language barriers, cultural differences, loss of family, loss of social network, and financial struggles were identified as impediments to taking care of one’s health. On the other hand, female participants pointed out that immigration had opened a new horizon for them in terms of having a healthy lifestyle and accessing preventive healthcare including breast cancer screening. They stated that moving to Canada had promised them greater opportunities with regards to health. They reported that adoption of healthy eating, physical activity, and breast screening were not common practices in their countries of origins. Some of them pointed out that there are more recreation facilities and more accessible and healthier food options in Canada. This may reflect certain levels of acculturalization and integration into Canadian society since these findings are at odds with existing research which found that newcomers to Canada are more likely to suffer from poor health (Adnan et al., 1999; Azaiza & Cohen, 2006). These researchers based their analysis on the challenges faced by newcomers in general. However, in the context of migration, understanding gender is essential (Adnan et al., 1999) and there have been few attempts to integrate gender into migration theories (Boyd & Grieco, 2003). Reasons for immigration have always been the focus of migration theories rather than who immigrates, where, and for how long (Boyd & Grieco, 2003). As a result, little is known about women's migration (Boyd & Grieco, 2003), and some argue that in order to develop useful theories, different forms of migration (e.g., permanent, temporary, illegal, and war-induced) should be the vehicle for analysis. Decades ago, women were often unseen in the immigration process, and it was perceived that immigration was an outcome of men's decisions (De Jong, 2002). To a large extent, this is still the case for international immigration of the Middle Eastern population (Picot & Sweetman, 2012).

The traditional roles of men as breadwinners and women as housewives taking care of homes in MENA communities may explain why women are less likely to be involved in the migration decision (Picot & Sweetman, 2012). This presumed stay-home responsibility of women can be translated into inadequate time and space for immigrant women to seek healthcare services or invest in educational and occupational skills, thus precipitating low economic status (Salman, 2012). Although this domestic role may encourage immigrant women in North America to work in domestic services, they likely stay home to watch the children because childbearing is mainly a mother's responsibility (Salman, 2012; Honein, 2007; Boyd & Grieco, 2003; Adnan et al., 1999). Newcomers lost trusted acquaintances to look after their children when needed. In Arab cultures, children always have close family to look after them because extended family members including grandparents, brothers, and sisters are typically living under one roof (Adnan et al., 1999; Barakat, 1993). Grandparents are usually involved in raising children as much as their parents (Adnan et al., 1999; Barakat, 1993). Newcomers from the Arab world, especially parents, have worries about their children's safety and well-being (Adnan et al., 1999). The process of settlement into a new place involves separation of their offspring from their extended family and this imposes huge stress and uncertainties, in particular for mothers (Adnan et al., 1999). Likewise, in the present study, immigration has a negative effect in terms of child care. Therefore, from the perspective of participants in the present study, availability of child care at the screening services would encourage this group to undergo screening. It would also ease the financial stress of child care costs and promote trust and a positive relationship between these women and the Canadian healthcare system. In fact, a shortage of affordable child care is a big concern for women in general in Canada (Public Service Alliance of Canada, 2013). Except for Quebec, Canadian provinces lack universal, coherent, and well-developed child care systems (Public Service Alliance of Canada, 2013). For the last few decades, women's movements in Canada have been calling for an increase in federal funding to create quality yet low-cost public childcare (Public Service Alliance of Canada, 2013).

It has been argued that previous federal Conservative government did not support child care; instead, the government stopped federal-provincial budget allocations for child care in 2006 and substituted it with small monthly cash payments for each child under six years old (Public Service Alliance of Canada, 2013). Many argue that Canada is a wealthy country and has the ability to provide better care for children and families, though the political will to take action is absent (Public Service Alliance of Canada, 2013).

Cultural and Religious Concepts

Normative Social Influences. In the MENA cultures, woman and men have traditional duties that play a key role in the healthcare seeking process. For women, this role obliges them to obey their husbands, raise the children, manage the house, and consider all other family members' needs before their own desires (Hassan, 2014; Remmenick, 2006). Family is the central focus of the MENA culture (Hassan, 2014; Remmenick, 2006). In Western societies, family also is important but more emphasis is placed on individualism (Berry, 2005). This study found that women's fear of losing this traditional role impedes their screening practices and imposes silence. Traditional MENA communities demand a high level of adherence to this role with minimum deviation, while the Western host societies lack coherent norms due to multicultural settings (Shah, 2018). Some participants do not know which norms to follow with regards to participation in screening services—for example, whether to follow the norms of their community or those of Canadian society. This confusion felt by the participants calls for active communication between immigrant women and local society.

Clear and defined guidelines and frameworks in a number of domains (e.g., health, education, work, and housing) would guarantee balanced connection between women immigrants and the host society (Berry, Phinney, Sam, & Vedder, 2006).

One of the important factors that hinders an individual's decision to seek health services is the perception of the health condition and the expected social reaction to it (Walton, Akram, & Hossain, 2014). Social pressures on individuals can result in feelings of shame and stigma (Green et al., 2015). The fact that the breast is attached to the reproductive as well as sexual function may create the social stigma surrounding breast cancer in MENA communities (Azaiza & Cohen, 2006). The fear of disgrace and social stigma could also be reasons for worries about adverse outcomes of mammograms and other screening especially when those issues are related to sensitive body parts such as breasts (Hamid, Johansson, & Rubenson, 2010). As argued in chapter two, in Arab cultures disease such as cancer is viewed as a shame and something that should be hidden (Walton, Akram, & Hossain, 2014; Adnan et al., 1999). As argued by Brown (2006) shame can be triggered by many factors that differ between individuals and cultures (e.g., physical and mental health, body image, family, sexuality, and religion). When there is shame, people feel powerless and isolated (Brown, 2006).

In this study, the pressure to behave in an expected manner is sometimes reflected by participants contradicting themselves. For example, one participant said, "*There is nothing wrong with seeing a male health provider for breast exam*." Yet, later, the same participant said, "*I will only let a female nurse or a female doctor to touch my breast.*" Although this woman had first expressed acceptance of a new value (having a male health provider), she may have then felt a need to conform to the norms of her own culture. This attitude can be explained by the power of norms in Arab Muslim states to regulate behaviours and guide judgement (Shah, 2018).

It may also be a result of how an individual's public beliefs and practices tend to be more determined by norms than private acts, because public attitude is watched and noncompliance may result in punishment (Shah, 2018). The motivations that inspire individuals to remain part of the group would ensure their conformity to the groups' norms (Green et al., 2015).

The traditional role of women in MENA culture emphasizes the breast as a vehicle for providing milk for their offspring. Normal breastfeeding was viewed as an important determinant of breast health in this study. Few of the participants related their choice to breastfeed to the Islamic faith, while the majority pointed out that this choice was driven mainly by the recommendation of science and modern medicine. In fact, current science indicates breastfeeding is beneficial for both mother and child, as breastfeeding diminishes the likelihood of breast cancer (Ip, Chung, Raman, Trikalinos, & Lau, 2009). Salman (2012) and Amin (2008) have argued that perceptions about breastfeeding as an indicator of breast health in the Arab Muslim communities are deeply rooted in the Islamic faith. However, this is not the case here. Islamic faith was not a key factor in shaping this view perhaps due to the high rate of educational attainment among the study participants. This is not surprising, as newly arrived immigrants in Canada remain more likely to have earned a degree than others due to the highly selective immigration process (Citizenship & Immigration Canada, 2014).

In the MENA culture, men are the main providers and protectors of the family (Salman, 2012; Barakat, 1993). In the Islamic religion, men can have more than one wife. Although polygamy is illegal in Canada, some Muslim men practise it secretly (Hassan, 2019). A man can have one wife under civil law then marry another woman in a cultural or religious ritual away from the eyes of the law (Hassan, 2019). This can place more fear on women about being sick and scared by breast cancer outcomes and eventually losing their husbands (Abdulbari et al., 2002; Amin, 2008). Indeed, one participant revealed that her relative was being abandoned by her husband after a breast cancer diagnosis. Middle Eastern men consider breast health and screening the sole responsibility of the woman (Salman, 2012). For this reason, they do not accompany their wives to screening or get involved in their health decisions in order to avoid deviating from the cultural norms (Salman, 2012). However, conformity to these norms has been found to be variable among Arab men. As Shah (2018) explains, the varying degrees of following the norms and traditions depend on the individual's predisposition to social pressure. Perhaps this social pressure is reduced for many men in Western society and can make the integration of Arab husbands into breast cancer screening programs a possible and achievable mission. Other reasons for different conformity to norms that were clarified by Shah (2018) are that some norms do not apply equally to all groups in the same community or to all individuals in the same group. This could be due to different lifestyles, social status, and political and religious practices. As a consequence of the migration process, some norms allow a great level of individual interpretation, and some are weakly imposed (Shah, 2018).

Islamic Values. The theme of faith or destiny "al gada" and "al gader" is deeply imbedded in Islamic culture (Walton, Akram, & Hossain, 2014). Muslims believe that many events in life including sickness are meant to happen and are beyond one's control (Walton, Akram, & Hossain, 2014). Some participants in this study believed that if they are going to have breast cancer, then it is their destiny and nothing can be done to change it, even if they practise screening. They had faith in prayers to protect themselves from breast cancer. These findings are consistent with previous work that found immigrant women commonly practise alternative medicine such as prayers before seeking systematic healthcare services (Wu, LeBaron, & Burke, 2007).

The majority of the female participants who identified faith as an important health practice quoted from the Quran. However, this does not deny a spiritual component of health for others who did not quote from the Islamic holy book. The literature on Arabs and health indicates that spirituality with regards to health matters is not always related to the Islamic religion or any other religion, but rather for the purpose of practising peace of mind, relaxation, and hope (Aziza, 2014; Adnan et al., 1999). However, the findings of this particular study show that religious and cultural beliefs have a critical influence on MENA women's health decisions toward screening and preventive healthcare. Thus, a religious message could be carefully integrated into the health education programs and services targeting these women in order to motivate their practice of breast cancer screening (Padela et al., 2019; Aziza, 2014; Madanat, 2002).

For Muslims, knowledge arising from the holy book of Quran forms the central guidance for their lives (Shirazi, Shirazi, & Bloom, 2015). Since spirituality is not part of modern science, it can cause ambiguity and tension when Muslims attempt to integrate science and religious knowledge (Anas, Alwi, Razali, Subki, & Abu Bakar, 2013). One solution it is argued by some Islamic researchers is for devoted Muslims to interpret science from the Islamic point of view (Anas et al., 2013). Others argue that Muslims should prudently appreciate modern knowledge and strongly believe inside themselves that the truth exists only in the Quran (Anas et al., 2013). Some may argue it is hard to believe in books that have been there for thousands of years. Zakir Naik, an Islamic preacher, argued that many of us trust people's works and philosophies that are a few hundred years or few decades old; then why it is hard to put faith in a book written thousands of years ago and followed by millions of people (Naik, 2000)?

Tension between science and religion is a problem for all people who have trust and faith in old writings (Anas et al., 2013). Islamic and Christian leaders agree on there are no real conflict between what is in nature and what is written in the holy books and preached by different prophets throughout humankind's history (Collins, 2007; Naik, 2000). Religious leaders indicated that people understanding of religious texts needs human interpretation and that is imperfect because human’s insight and knowledge are significantly inferior to God’s (Collins, 2007; Naik, 2000). Muslims and Christians acknowledge that there are multiple interpretations of their religious books (Huda, 2009). Faulty interpretation of God’s revelations may cause the apparent tension between faith and science (Anas et al., 2013; Collins, 2007; Naik, 2000). Religious leaders also stated that some of the tension between religion and science can be resolved; however, we have to live with some of the conflict believing in God and his righteousness (Collins, 2007; Naik, 2000).

Culturally Sensitive Interventions

The participants in the present study identified multiple cultural concepts that fit well with their Arab identities and their Islamic perceptions on health. They also provided valuable strategies to placing cultural practices and religious symbols at the forefront of the planning process. They revealed their preferences for certain formats and how information should be displayed. For example, they wish to see Arab/Muslim health workers and bilingual (English/Arabic) health education programs using cultural materials and symbols (e.g., Hijab, Abaya) and quotations from the Quran and Prophet Mohammed (Hadith). Their vision on cultural issues should be integrated into the services that are intended for them. Many female participants suggested that these interventions would not only help overcome communication obstacles but also improve their capability to make appropriate health decisions. The participants stressed the need to respect the modesty and conservative nature of Arab cultures and to offer a female health provider to conduct sensitive body exams. Based on the HAM model, the likelihood of an action occurring depends on the strength of the positive interaction between beliefs and motivations (Green et al., 2015). Motivation in terms of how individuals evaluate their own worth plays a key role in health promotion practice (Green et al., 2015). Health promotion interventions usually work by influencing individuals' beliefs in order to inspire and motivate them to confirm actions (Hammoud, White, & Fetter, 2005).

In this study, participants indicated that their husbands' involvement in breast cancer education and screening programs provides them with the emotional support they need to overcome the anxiety and stress caused by the possibility of adverse screening outcomes. This view is consistent with the current literature. Women who have supportive spouses are almost two times more likely to participate in breast cancer screening services as well as more likely to be diagnosed at early stages of the disease (Dahlui, Gan, Taib & Lim, 2013; Abdulbari et al., 2002). As argued by the participants, husbands should be provided with the necessary education to support their wives (e.g., through family physicians). They proposed health education sessions targeting Arab men to present sensitive information about women's bodies would inspire male relatives to understand and support women's needs. This finding underlines the importance of involving both women and their husbands in the process of provision of screening and preventive healthcare. As discussed earlier, the HAM offers valuable perspectives to distinguish between individuals' interpretations of "normative pressures" and their motivation to comply (Green et al., 2015). Close relationships (e.g., spouse, father) usually have a major effect on an individual's plan to act or not to act. However, these influences are weak if the relationships are meaningless and vice versa (Green et al., 2015).

Intersection Between the Islamic Faith and Health Promotion. Many Islamic elements that can enhance positive screening behaviours among MENA women have been identified in this study. This emphasizes the role of faith and spirituality in the Arab Muslim communities. Islamic life is based on the concepts of belief, faith, and fellowship (Shirazi, Shirazi, & Bloom, 2015). Collaboration, or "*shura,*" another core value in Islam, refers to respect and the consideration of community members' different views on all matters (Shirazi, Shirazi, & Bloom, 2015). Another basic principle in the Islamic religion is education. The Qur'an says, "*Are those who have knowledge equal to those who do not have knowledge?!*" (39:9). Prophet Mohammed says, "*One who treads a path in search of knowledge has his path to Paradise made easy by God"* (Ryad-salehen, 245). Education and learning are highly valued in Islam. Knowledge in Islam is necessary for living in dignity, freedom, and justice (Shirazi, Shirazi, & Bloom, 2015). Islam also promotes health. Many Islamic observances and strategies are practised to enhance and maintain one's health and well-being, for example personal hygiene, avoidance of alcohol and drugs, fasting, and sexual boundaries (Shirazi, Shirazi, & Bloom, 2015). These values provide a framework for Arab Muslim individuals, families, and community members, and the integration of these values into breast health programs and policies can help this population move toward collaborative understanding and promotion of breast health and cancer screening. Faith-based interventions have been used in the literature to promote breast cancer screening among Muslim women. For example, Padela and colleagues have addressed challenges to mammography among American Muslim women in Chicago. They created a faith-based message and conducted mosque-based sessions. This intervention seemed to encourage a positive behaviour change among the participants (Padela et al., 2019). A considerable number of participants have been involved in mammography programs as a result of the study (Padela et al., 2019). Another study had been done earlier in Israel by Cohen and Azaiza (2010) to address barriers to breast cancer screening among Arab women. They conducted culturally sensitive educational programs about breast cancer in Arabic. The outcomes of this study also found that culturally based interventions are effective in encouraging participants to uptake breast cancer screening services (Cohen & Azaiza, 2010). The findings of these studies emphasize the importance of cultural and religious beliefs among Arab and Muslim women. Some of these beliefs may impose challenges for decision makers and healthcare professionals, in particular with regard to the provision of preventive healthcare including cancer screening (Cohen & Azaiza, 2010). Other researchers suggested that women's fear of stigma in their community by opposing such strong spiritual beliefs may cause them to avoid using health services (Donnelly & Hwang, 2013). Thus, it is important to involve key members of the community including religious leaders to distinguish health risks from religious views and enhance women's understanding and use of cancer preventive care services (Donnelly & Hwang, 2013).

How was the Health Action Model (HAM) Useful as a Theoretical Framework in This Study?

The Health Action Model (HAM) provided an inclusive framework of the key predictors (belief, motivation, and normative systems) of the choice and the intention of healthy behaviours with regards to breast cancer screening among women from the MENA region. The HAM model also gave an explanation of the main factors that determine whether women's intentions lead to action and likely inspire behaviour change. From the data analysis, it was clear that the participants' levels of knowledge and skills were inadequate to facilitate their involvement in screening services. Therefore, the participants suggested that any educational intervention should comprise two components. The first component was education and training about breast cancer screening options and techniques in order to make an informed health decision. The second component was culturally-sensitive interventions that would boost their motivation and facilitate conversion of behavioural intention into actions. As discussed, female participants in this study proposed integrating cultural and Islamic concepts into the health services that are intended for the Arab Muslim women to enable them to overcome communication barriers and improve their ability to make desirable health decisions. Taking a HAM-based perspective, these customized interventions would generate a strong positive interaction of belief and motivation systems that then translates intentions into practice (Green et al., 2015).

The HAM model was also beneficial in identifying different factors that can change the normative system and facilitate screening behaviour of this group. For example, the results underscore the importance of involving husbands in the process of provision of screening services. As discussed earlier in chapter two, it is a social norm among the Arab community that Arab men are usually not involved in women's health issues and therefore they do not accompany their spouses on their trips to health services (Honein, 2007).

Furthermore, the outcomes of this study emphasized that the HAM model can be used in health promotion as a guide to customize community interventions for improving the awareness and changing behaviours of women from minority groups in regards to the use of preventive healthcare services.

Chapter 6

Conclusion

The results of this study show that women from the MENA region are generally lacking knowledge about breast health screening strategies in Canada and a holistic approach to health. Yet, these women are highly motivated to improve their health. They are aware of their need to be educated, trained, and directed with regards to screening in order to make informed choices. They also communicate their own ideas about numerous interventions that fit well with their Arab cultures and the Islamic perceptions about health. Health beliefs and behaviours of Arab Muslim women are deeply rooted in historical and cultural contexts. To a great extent, culture and religion shape these women's perceptions and practices of breast health. These outcomes reinforce the importance of understanding the cultural context to improve the provision of healthcare to this ethnic minority with the goal of decreasing health inequalities. This study found a gap between knowledge and practice, indicating the need for multidisciplinary efforts to improve the health literacy of this population to accept recommended health actions (Zanchetta & Poureslami, 2019).

On the one hand, as a result of immigration, several barriers to screening were revealed: language barriers, social isolation, cultural differences, discrimination, and stereotyping in healthcare settings. On the other hand, for some women in this study, immigration offers opportunities for healthy practices that were uncommon in their original countries. These practices include healthy eating, exercise, and adopting preventive healthcare.

Strengths and Limitations

Strengths. Applying a constructivist approach is one of this study's strengths. Aligning with this framework, the outcomes are typically constructed as perceived by the study participants. This approach can encourage diversity of thought and allow participants to actively construct new knowledge during the course of a study (Abulnour, 2016). In this study, constructivism led to positive interactions between the participants and allowed them to open up and share their stories. It also encouraged the researcher and the participants to build rapport and collaboration (Abulnour, 2016). This was reflected by the participants showing their appreciation for the study and by their willingness to learn more about breast cancer risk and screening services. The findings of this study reveal that it is not possible to separate the understanding that immigrant women from the MENA region have about breast health beliefs and practices from the broader socio-cultural context. As happened in this study, adopting the constructivist approach can assist and inform policy makers in a particular context to further recognize what may improve the health of ethnic minority groups, and women from MENA are no exception (Britigan et al., 2009).

This study is the first qualitative research attempt to understand the breast health beliefs, experiences, and practices of MENA women in Alberta. It bridges the knowledge gap in the current literature. It also provides useful data to policy makers to help them improve breast healthcare access so that MENA women will seek that care.

Limitations. This study only relates to immigrant women from the MENA region who are residing in Edmonton, Alberta. The outcomes may not be generalized to corresponding populations in Canada without cautious investigation. Female participants in this study may have different demographic features and different living dynamics from those living in other contexts.

Although the participants have had a relatively short stay in Canada (≤5 years), their previous high levels of education (2/3 had completed university) might make a difference regarding knowledge and also influence their responses during the focus group discussions.

The participants in this study originated from eight countries in the MENA region. There are around 22 countries in the Middle East and North Africa (MENA) region (UNICEF, 2018). Thus, the outcomes in the study may not be accurate enough to represent the cultural health views and values of women from the MENA region in general in regards to their breast cancer screening practices. As well, married women make up the majority of the study participants, whereas only six of the participants are single. This reinforces the need for research in other geographic and demographic settings.

Using solely a focus group format to collect the data might not be the best approach. As mentioned before, an individual's public views tend to be more determined by norms than private views (Shah, 2018). Perhaps this motivated some participants to concur with the other participants in order to confirm to the group norms. This would have been avoided if personal interviews had been incorporated into the data collection plan. Personal interviews would have most likely yielded a deeper understanding of the validity of the responses.

Additionally, myself and the language assistant are both insiders. We also have many common features. For example, we originally come from one country (Sudan) in the MENA region, we both follow the Islamic faith, and we both have similar education levels. Our personal views and values may have influenced how we interpreted and analyzed the data. A different theory might have developed from the same study if it had been conducted by a different team. The language assistant and I, however, realized this limitation and stayed reflexive throughout the research process. We also had regular meetings and open discussions to interpret and translate the data in a consistent way. We recurrently listened to the recordings and repeatedly reviewed the transcriptions and data analysis. As stated earlier, I applied many strategies to ensure that participants' responses have been understood and interpreted correctly (e.g., member checks).

This study, therefore, sets the basis for future studies on the influences of culture and religion on health behaviours of the Arab and Muslim populations and the development of effective health promotion programs and services.

Implications

This study has implications for future research, practices, and policies with regards to MENA women's health in Alberta. There is a need to consider the sociocultural context using multilevel approaches. Thus, in order to reach an understanding of screening use that is not stripped from the cultural background, research must use theory that involves a more complex approach than merely a focus on individual cognition. Moreover, scholars can transfer the approach used in this study to future research among MENA immigrant women, or they can modify it for different contexts.

The implications for practice and policy emphasize the need to develop health promotion interventions that build on theories that have an inclusive lens. The existing interventions that have been established for the general populations do not benefit all communities (Pasick & Burke, 2008). These interventions should be carefully assessed for suitability for those who are targeted. The knowledge generated in this study can expand the policy makers' and practitioners' understanding of MENA women's perspectives on breast health, cancer risk, and screening practices. The outcomes of this study emphasized the vital role of religion in shaping women's perceptions of breast health. This importance of religion indicates that including cultural and Islamic concepts in current healthcare programs has the potential to help these women to better understand the purpose of the screening services and take responsibility for action and change. The potential solutions to overcome screening barriers proposed by the participants can be used to tailor appropriate preventive services for MENA women. For example, given that MENA women feel extremely uncomfortable with health services that require them to expose their bodies to male providers, it is important to ensure that female health providers are readily available. This would probably help MENA women to develop trust in the Canadian health system and encourage them to access services. In addition, some negative experiences in the healthcare system cause MENA women to avoid seeking services unless absolutely necessary. Healthcare providers should be trained to be non-judgemental and sensitive to religious and social traditions of ethnic minorities.

The main challenge to immigrants accessing the healthcare system remains the language barrier (Zanchetta & Poureslami, 2019; Zhao, Esposito, & Wang, 2010; Britigan et al., 2009; Azaiza & Cohen, 2006). There are language services and cultural brokers' groups in Edmonton such as the Edmonton Mennonite Centre for Newcomers (EMCN) and the Multicultural Health Brokers Co-op (MCHB) to support newcomers to thrive in the city and be actively involved in their communities. Through community education, outreach programs, peer support, and trusting relationships, these services focus on helping individuals and families access needed services and resources and tackle the wider social and economic determinants of health. Peer support is one of the important strategies in cultural brokers' groups. Green et al. (2015) argued that peers can bring a direct positive effect to individuals by supporting them to achieve desirable outcomes or indirectly by imposing a sense of belonging on those who feel they do not fit. While such programs and services have existed in Edmonton for many years, many of the participants in this study were not aware of them. The participants said there were no translators to help them navigate the Canadian healthcare system and suggested outreach programs steered by women workers from similar cultural and social backgrounds. Possible explanations for the gap in services are that the demand exceeds the need, and there is a lack of funding. Erick Ambtman, Executive director of the EMCN, told CBC News , "*As our wait lists were [sic] getting longer, we're having a hard time accessing the people who are asking us to help them…..They don't show up when they don't feel like their needs are going to be met quickly*" (Ambtman, 2019). Ambtman's comments emphasize the need to increase the investment and expand services to help more people. Poor advertising and inadequate education may also contribute to the lack of knowledge about the breast screening facilities. Efforts should be made to educate newcomers about how and where they can obtain support to bridge their move into Canadian society. For example, information should be available in airports, immigration offices, hospitals, and public schools.

As found in this study, Arab Muslim women's understanding of screening using mammography is limited compared to what they know about breast exams. This concurs with the literature on other immigrant groups, e.g. Chinese (Vahabi et al., 2016; Zhao, Esposito, & Wang, 2010). Only a few participants in this study could understand screening using a mammogram, which suggests that MENA women should properly be educated about the procedure.

Comparing the results of this study to previous studies on perceptions of health among immigrant women from Latin America and Asia shows that MENA women have some unique cultural values but also share perspectives with other immigrant groups. For example, herbal medicine used by Arabs as an alternative cure for certain health condition is also used widely among people from Latin America, Asia, and Africa (Salman, 2012; Zhao, Esposito, & Wang, 2010; Britigan et al., 2009). Conversely, Asians believe in exercise to promote health, while physical activities are less valued among Arabs and Latinos (Zhao, Esposito, & Wang, 2010; Britigan et al., 2009; Azaiza & Cohen, 2006). The similarities and differences between immigrant groups need to be recognized by stakeholders and policy makers to reduce health disparities.

Female participants desire the presence of their male partners during screening. For successful and sustainable interventions, planners of healthcare services should keep this in mind and target both women and men in their advertising for screening services. Pictures of men holding their women's hands, for example, can be used as an invitation to the men to support their women during these procedures. When scheduling an appointment with the woman, the health provider may encourage the male (husband, father, or brother) to be present, either by communicating directly with the woman or by sending invitations to both via Canada Post or emails. Moreover, the results of this study find that child care in screening facilities would improve the accessibility and effectiveness for MENA women. This should be acknowledged by health policy makers when they plan and implement proper screening services for this group.

Recommendations for Future Research

This research, which examined cultural beliefs about breast health, studied only Arab Muslim women who had been in Canada for less than five years. The length of stay in Canada makes a difference in the screening experiences of MENA women (Vahabi et al., 2016; Aziza, 2014). There is a call for future research to follow up and compare MENA women's breast health experiences at different times and in different settings (Aziza, 2014; Cohen & Azaiza, 2010) Because breast cancer is the number one cause of cancer deaths among Canadian women as well as globally (Canadian Cancer Society, 2015), there is a need to look at women from other immigrant groups as well as the Canadian population.

This study focuses only on the perceptions of breast health held by MENA women, and how these perceptions can influence the uptake of breast cancer screening services in Canada. Future research should further explore how these health beliefs and behaviours can impact health practices other than breast cancer screening.

While the ethnographic approach is still valuable, researchers may also use data from this study to conduct collaborative and participatory action research to apply intervention for community change, for example using religion-based interventions to promote the positive health behaviour of MENA women with regard to breast cancer screening. Padela and colleagues (2019) conducted a successful faith-based project in the United States. They integrated religious identity into the design of the intervention message to address challenges to mammography use among American Muslim women. Post-intervention, a significant number of the participants developed better awareness of breast cancer and increased their use of mammography (Padela et al., 2019). These results are encouraging for researchers in other settings to use "tailored message techniques" to create specific and meaningful intervention messages to modify health behaviour.

Knowledge Translation

Knowledge translation and exchange strategies are essential elements of any study. In knowledge translation, the academic results are put into practical use by community members, stakeholders, policy makers, and academics (Davis et al., 2003). According to the Canadian Institutes of Health Research, there are two major types of knowledge translation: integrated knowledge translation and end-of-grant knowledge translation. In the first, knowledge is translated throughout the research process, while in the second, knowledge is translated when the study is completed (Canadian Institutes of Health Research, 2013). In this study, I intend to apply the latter type.

For academics and policy makers (e.g., Alberta health services, Alberta Public Health Association, Breast Cancer foundations, University of Alberta), the results of this study are expected to be presented as oral and/or poster presentations at academic events that showcase the research work, for example at This is Public Health Week, an annual academic event within the School of Public Health at the University of Alberta.

I also intend to submit papers to journals such as the Canadian Journal of Public Health, Family Health Journal in Alberta, and Arab Publisher’s Representatives in Toronto. Arab Publisher’s Representatives is an independent community newspaper for discussing different views on topics of relevance to the Arab Canadian community.

For community members and community stakeholders, I may organize events to provide culturally appropriate bilingual seminars and talks to present and discuss the research results in order to increase awareness about breast health and screenings.

One such event could be held in collaboration with mosques in Edmonton. Every Friday, many Arab Muslim families attend prayers at their local mosque. Friday prayer is one of the important religious duties in Islam. With separate places for men and women, people usually gather after the prayers to greet and talk to each other. I believe it would be helpful to talk or provide leaflets to the women about my study, its results, and implications.

NGOs and groups such as the MCHB are looking to work with volunteers and supporters. This would be a great opportunity to discuss and present the findings of this study to them. The cultural brokers who work with the Arab Muslim community would have more and specific knowledge to how best support this community. The MCHB could use the results of this study to increase awareness about breast health and screening for health promotion programs for Arab Muslim families. For other community stakeholders such as Arab women's associations, the outcomes can be shared through workshops, meetings, and publications including fact sheets and reports on relevant websites (e.g., www.ciwa-online.com, www.assistcsc.org/en, etc.).

I hope these knowledge translation activities will eventually draw attention to the unique perceptions shared by women from the MENA region and will encourage them to participate in screening activities, thus initiating a positive change in health behaviours through the right interventions.

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Appendices

Appendix A
Letter of Initial Contact

Dear (participant's name),

Re: **Research Study**: Giving Voice to the Vulnerable: Perceptions, Practices & Beliefs About Breast Cancer and Screening Among Ethnic Minority Women From the MENA (Middle East & North Africa) Region in Edmonton, Alberta.

We are doing a study to learn about MENA women's understanding of breast health, breast cancer risk and screening. We also would like to know what would be the best type of breast health program for these women. Information from this study will be useful for decision-makers to tail specific prevention programs for women who share this background.

Participation in this study involve discussion in a group with other women called focus group discussion. If you don't want to speak during the discussion, no problem, you will be given papers to write down your responses if you want. I will use fake names for my final report, thesis and publications. Also quotes (using a pseudonym) may be used for public presentations and for teaching purposes. Confidentiality agreements will be signed by all research members (e.g. language assistant). If you choose to participate in a group discussion, what you say will be recorded. You are free to not take part in the discussion, or to not answer a question at any time. You are also free to remove yourself from the group at any time without giving a reason and without penalty. Due to the nature of a group discussion, even if you withdraw, we will be unable to remove your comments as it can be difficult to identify individual speakers from the recordings. For this reason, once you withdraw any contributions made up to that point will be included in the project. The researcher (Dalia Eldol) will be facilitating the group discussion and taking notes during the discussion. She can also provide translation when needed because she is a native Arabic speaker and proficient in English as well.

Later (approximately a couple of weeks), a transcription of your focus group responses will be sent (mail or email) to you. After reading your responses, you will be given a chance to change your answers if desired. You may communicate any desired changes to your own answers in writing or verbally to the researchers (email/phone). This round is expected to take less than an hour of your time, and you will be given several days to complete this stage at your convenience. Any revisions made to original answers will be changed to create a final compilation of all participants' answers, again with no identifying information.

We would love it if you would participate in the study. Before you make a decision, I will go over the attached form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of the form for your records.

The main researcher of this study, Dalia Eldol, is a master graduate in School of Public Health, University of Alberta. Dalia Eldol works under the supervision of Professor Jane Springett, School of Public Health, University of Alberta. Dalia Eldol is from Sudan and a native Arabic speaker.

For more information about the study or to arrange for your participation, contact **Dalia Eldol at [redacted] and/or P: [redacted]**. Participation in this study is completely voluntary. There are absolutely NO consequences if you choose not to participate or end your participation at any point. Dalia Eldol may contact you regarding your interest in this study in the next two weeks. If you do not want any further contact regarding this study, please contact [[redacted]]. **Supervisor:** Jane Springett, [redacted]
Email: [redacted]

Sincerely,

Dalia Eldol

Master of Science (MSc) candidate

School of Public Health

University of Alberta

Appendix B

Letter of Initial Contact (Arabic Version)

الموضوع : معلومات عن البحث

عزيزتي المشتركه: الاسم

عنوان الدراسة : دراسه مفاهيم وممارسات النساء من الشرق الاوسط و شمال افريقيا المقيمين في مدينه ادمنتون بالبيرتا عن صحه الثدي وخطر الاصابه بسرطان الثدي و خدمات الوقايه من سرطان الثدي

هذه الدراسة لمعرفة مفهوم نساء الشرق الاوسط و شمال افريقيا عن صحة الثدي و خطر الاصابة بسرطان الثدي و الكشف المبكر , وايضا نريد ان نعرف ما هي برامج الوقاسة المناسبة لهن . المعلومات الناتجة من هذه الدراسة سوف تفيد صانعي القرار لتصميم برامج الكشف المبكر لتكون مناسبة للنساء من هذه المنطقة .

المشاركة في هذه الدراسة تتطلب مشاركتك في حلقة للنقاش مع نساء اخريات اذا لم تريديالتحدث اثناء النقاش فلا مشكلة سوف يتم اعطائك ورقة و قلم للتعبير عن رايك .. سوف استخدم اسماء غير حقيقية لاغراض البحث , المنشورات , المحاضرات العامة والتدريس . جميع اعضاء هذا البحث سوف يقومون بامضاء اتفاقية سرية . اذا قررت الموافقة بالمشاركة في هذه الدراسة كل ما ستقولينه في جلسات النقاش سوف يتم تسجيله . لكي حرية التوقف عن المشاركة في اي وقت ومن دون اعطاء اي سبب و دون عواقب . و لكن لطبيعة هذة الجلسات حتى عند التوقف عن المشاركة لا نستطيع حذف ما قلتيه قبل التوقف لصعوبة التفريق بين ادا المشاركات في التسجيل . لهذا السبب عند خروجك جميع من الحلقة سوف يتم استخدام ما قلتيه سابقا في البحث. سوف تقوم الباحثة بتسهيل النقاش و اخذ مذكرات خلال اجاباتك النقاش. ايضا تستطيع الباحثة القيام بالترجمة لان العربية هي لغتها الام كما انها تتحدث الانجليزية بطلاقة. و لم اعضاء البحث سوف يوقعون اتفاقية سرية المعلومات. لاحقا حوالي عده اسابيع سوف نرسل اليك نسخة من بالبريد و تعليقاتك خلال النقاش بالبريد العادي او الالكتروني و ذلك لتتاكد منك ان اجاباتك كتبت صحيحة و دقيقة .يخطئ في نسخها. كما يمكنك تغيرها او تعديلها كما تريدي و التحدث بذلك للباحثة شفهيا بالتلفون او كتابة

سوف تمنحي الوقت الكافي لتقومي بذلك و يتوقع ان تحتاج هذه الخطوة اقل من ساعة.

نتمنى ان توافقي على المشاركة في هذا البحث. قبل اتخاذ اي قرار سوف اقوم بشرح كل شي في الورقة المصاحبة .. يمكنك السؤال او الاستفسار عن اي شئ غير واضح لديك و سوف يتم اعطائك نسخة من الاقرار ليكون معك

ان الباحث الرئيسي في هذه الدراسى هي داليا الدول طالبة دراسات عليا)ماجستير(في كلية الصحة العامة بجامعة البرتا . داليا الدول تعمل تحت اشراف بروفيسور جين سبرينقر , عميد بكلية الصحة العامة بجامعة البرتا . داليا

الدول من السودان و تتحدث العربية لمزيد من المعلومات عن الدراسة و كيفية المشاركة الرجاء الاتصال ب داليا الدول تلفون: [redacted]

ايميل [redacted]

ان المشاركة في هذه الدراسة اختياريا تماما و لا يوجد اي عواقب اذا قررت عدم المشاركة او التوقف عن . المشاركة لاحقا في اي وقت . قد يتم الاتصال بك من قبل داليا الدول في الاسابيع المقبلة للتحدث عن هذا البحث

للتوضيح [redacted]. اذا لم ترغبي في الاتصال بك الرجاء الاتصال على الرقم : [redacted] او ايميل

المشرف على البحث : جين سبرينقر

تلفون : [redacted] ايميل [redacted]

. داليا الدول

. طالبة ماجستير

. كلية الصحة العامة

. جامعة البرتا

Appendix C

Socio-Demographic Questionnaire

1. **Country of Origin:**

○ Libya
○ Somalia
○ Egypt
○ Iraq
○ Lebanon
○ Syria
○ Saudi Arabia
○ Sudan

2. **Marital status:**

○ Married
○ Single/divorced/widow

3. **Length of Stay in Canada:**

○ 5 years or less
○ >5 years

4. **Primary Language:**

○ Arabic
○ English
○ Other, Specify ………….

5. **English proficiency:**

○ Good
○ Poor

6. **Religion**
○ Islam
○ Christianity
○ Other, specify………….

7. Age:

- <20
- 20-39
- 40-69
- >69

8. Highest Level of Education:

- Less than elementary
- Elementary to high school
- Collage
- Higher than collage

9. Place of Residence:

- Edmonton
- Outside of Edmonton, specify…………….

10. Employment:

- Not Employed
- Employed, Occupation………………

11. History of breast cancer:

- Yes
- No

12. Family Size:

- **1-2**
- **3-5**
- **6-7**
- **>7**

13. Approximate Household Income:

- < $38,000/ YR
- $38,000-$61,900/YR
- $61,901-$88,074/YR
- $88,075-$125,010/YR
- >$125,011/YR

Appendix D

Participants Consent Form

Title of Study: Giving Voice to the Vulnerable: Perceptions, Practices & Beliefs About Breast Cancer and Screening Among Ethnic Minority Women From the MENA (Middle East & North Africa) Region in Edmonton, Alberta.

Principal Investigator: Dalia Eldol, **Phone:** [redacted], **Email**: [redacted]
Supervisor: Jane Springett, **Phone**: [redacted] **Email:** [redacted]

Why you are being asked to take part in this research study?
You are being asked to be in this study because you are a woman, aged between 20-69 years, your country of origin is located in the Middle East or North Africa (MENA), and you live in Edmonton and speak Arabic and/or English.

In Canada, women who come from the MENA region do not make use of the breast cancer screening services that are available to them and we want to know why. The best way of doing so is to ask women from the community themselves. Their voice will be useful for the people in decision-making positions to design appropriate programs for women from the MENA region.

Before you make a decision, I will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?
As part of doing my Master of Science course at the University of Alberta I would like to learn about MENA women's understanding of breast health and breast cancer prevention services. I also would like to learn about the factors that affect their use of screening services as well as what types of breast cancer prevention programs would be appropriate.

What will you be asked to do?
You will be asked to take part in a group discussion called a focus group. There will be 6 focus groups with 6 female participants from your community in each group. The group discussion will be at a community hall and at a time that convenient to you and the other participants. The

focus group discussion is likely to take between 1.5 to 2 hours. During the group discussion, you will be asked to talk about what you currently understand about breast health and how you can be best supported in maintaining it. There is no wrong or right answer and are not necessarily to come to an agreement but rather to share your story and experience. If you don't want to speak during the discussion, no problem, you will be given papers to write down your responses. All focus groups will be digitally recorded by two independent audio recorders. I will facilitate the focus group to ease the discussion and to answer your questions as well as to make sure that you are happy and comfortable. Since I'm a native Arabic speaker and proficient in English, I will provide translation if needed. Later (approximately a couple of weeks), a transcription of your focus group responses will be sent (mail or email) to you. After reading your responses, you will be given a chance to change your answers if desired. You may communicate any desired changes to your own answers in writing or verbally to the researcher. This round is expected to take less than an hour of your time, and you will be given several days to complete this stage at your convenience. Any revisions made to original answers will be changed to create a final compilation of all participants' answers, again with no identifying information.

What are the risks and discomforts?

Although I don't expect any emotional discomforts due to participation in this study, if this happens you will be directed privately to a proper counselling services. It is not possible to know all of the risks that may happen in a study, but I have taken all reasonable safeguards to reduce any known risks to the participants and to make sure that you have a safe and pleasant participation.

What are the benefits to you?

I expect your participation will be an interesting experience. You may not directly benefit from participating but being involved and sharing your story will help others from your community.

Do you have to take part in this study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time without giving a reason and without penalty. During the group discussion what you say will be recorded. You are free to not take part in the discussion, or to not answer a question at any time. You are also free to remove yourself from the group at any time. Due to the nature of a group discussion, even if you withdraw, we will be unable to remove your comments as it can be difficult to identify individual speakers from the recording. For this reason, once you withdraw any contributions made up to that point will be included in the project.

Will you be paid to be in the research?

Refreshment, free snacks will be offered during the group discussions. At the end of the group discussion you will receive Tim Horton's $15 gift card to thanks you for your time and efforts.

Will your information be kept private?

I will do everything I can to keep all information private. You do not need to use your real name. No real names of participants will be used in this research. I will use fake names for my final report, thesis and publications. Also quotes (using a pseudonym) may be used for public presentations and for teaching purposes. All information you provide will be confidential and all the audio tapes, notes, and transcripts will remain in a secure, locked location in my house, and will be transported securely to and from the community sites. On the computer, data will be stored with password to which only research members will have access. Also quotes (using a pseudonym) may be used for public presentations and for teaching purposes. Upon completion of this research, information will be saved for nearly 5 years, then I will destroy all audio tapes, notes, and transcripts. Confidentiality agreements will be signed by all research members. We will also ask the participants to keep the conversations confidential. While we will strive to protect the confidentiality of the information, we cannot guarantee that others from the group will do the same.

What if you have questions?

If you have any questions about the research now or later, please contact [Dalia Eldol, Email: [redacted] P: [redacted]]. The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers. Your participation is important to the success of this study. If you agree to participate, please read the attached consent form and sign your name.

CONSENT

Title of the Study: Giving Voice to the Vulnerable: Perceptions, Practices & Beliefs About Breast Cancer and Screening Among Ethnic Minority Women From the MENA (Middle East & North Africa) Region in Edmonton, Alberta.

Principal Investigator(s): Dalia Eldol **Phone Number(s):** [redacted]

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without penalty?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐

Who explained this study to you? ____

I agree to take part in this study:

Signature of Research Participant ____

(Printed Name) ____

Date: ______________________________

Signature of Witness ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _______ Date____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN

Appendix E

Participant Consent Form (Arabic Version)

ه   اقرار بالموافقه على المشاركه في الدراسه

عنوان الدراسه : اعطاء صوت للمستضعفين دراسه مفاهيم وممارسات النساء من الشرق الاوسط و شمال افريقيا المقيمين في مدينه ادمنتون بالبيرتا عن صحه الثدي وخطر الاصابه بسرطان الثدي و خدمات الوقايه من سرطان الثدي

الباحث الرئيسي : داليا الدول
تلفون : [redacted]
ايميل[redacted]

المشرف على البحث : جين سبرينقر
تلفون [redacted] : ايميل :
[redacted]

لماذا طلب منك المشاركه في هذه الدراسه ؟

لقد طلب منك المشاركه في هذه الدراسه لانك امراه عمرك ما بين (69-20) و موطنك الاصلي يقع في الشرق الاوسط او شمال افريقيا . وتعيشين في مدينه ادمنتون وتتحدثين العربيه و او الانجليزيه في كندا النساء اللواتي ياتين من الشرق الاوسط وشمال افريقيا لا يستخدمن خدمات الوقايه من سرطان الثدي ونريد ان نعرف السبب. افضل وسيله لذلك هو بسؤال النساء من تلك المنطقه انفسهن وذلك لان صوتهن سوف يكون مفيدا . لصانعو القرار ليقومو بتصميم برامج مناسبه للنساء من منطقه الشرق الاوسط و شمال افريقيا قبل ان تتخذي قرار بالمشاركه سوف اتفقد معك هذا الاقرار. يمكنك السؤال والاستفسار عن اي شى غير واضح في هذا الاقرار وسوف تحصلين ايضا على نسخه من هذا الاقرار ليكون معك ان المشاركه في هذه الدراسه اختياريا تماما ولا يوجد اي عواقب اذا قررت عدم المشاركه.

ما هو هدف هذه الدراسه ؟

ان هذه الدراسه هي جزء من رساله الماجستير في تعزيز الصحه التي اقوم بها في جامعه البيرتا اريد ان اتعلم عن مفهوم النساء في منطقه الشرق الاوسط وشمال افريقيا عن صحه الثدي ومدى ادراكهم عن خطر الاصابه بسرطان الثدي كما اريد ايضا التعلم عن العوامل التي تؤثر على استخدامهن لبرامج الكشف المبكر وماهي .البرامج المناسبه لهن.

ماهو المطلوب منك القيام به ؟

سوف يطلب منك المشاركه في حلقه نقاش. الحلقه مكونه من مجموعه من النساء من نفس المنطقه التي تنحدرين منها نساء وسوف تقام الحلقات في صاله الحي في زمن يناسبك 6 مجموعات للنقاش في كل 6 و سوف يكون هناك ويناسب الجميع وسوف تمتد تقريبا ما بين ساعه و نصف الى ساعتين. اثناء النقاش سوف يطلب منك التحدث عن مفهومك لصحه الثدي وكيف يتم مساندتك في تعزيز صحه الثدي. لا يوجد اجابه خاطئه او صحيحه ولا يزم التوافق في الاجابات ولكن الهدف مشاركه ارائك و خبرتك اذا كنت لا تريد التحدث اثناء النقاش فلا مشكله سوف يتم اعطئك ورقه وقلم للتعبير عن رايك. كل حلقات النقاش سيتم تسجيلها الكترونيا. سوف تقوم الباحثة بتسهيل النقاش و اخذ مذكرات خلال النقاش. ايضا تستطيع الباحثة القيام بالترجمة لان العربية هي لغتها الام كما انها تتحدث الانجليزية بطلاقة. جميع اعضاء البحثسوف يوقعون اتفاقية سرية المعلومات. لاحقا حوالي عده اسابيع سوف نرسل اليك نسخة من اجاباتك و تعليقاتك خلال النقاش بالبريد العادي او الالكتروني و ذلك لتتاكد منك ان اجاباتك كتبت صحيحة و دقيقة و لم يخطئ في نسخها. كما يمكنك تغيرها او تعديلها كما تريدي و التحدث بذلك للباحثة شفهيا بالتلفون او كتابة .بالبريد .سوف تمنحي الوقت الكافي لتقومي بذلك و يتوقع ان تحتاج هذه الخطوة اقل من ساعة

ماهي مخاطر المشاركه في الدراسه ؟

على الرغم من اني لا اتوقع حدوث مخاطر نفسيه نتيجه المشاركه في الدراسه الا انه سوف يتم توفير خدمه علاجيه عند الحوجه. كما انه من غير الممكن الالمام بكل المخاطر التي قد تحدث نتيجه المشاركه الا انني قد قمت باتخاذ الاحتياطات اللازمه لمنع المخاطر المتوقعه و للتاكد ان مشاركتك في هذه الدراسه .امنه و سعيده

ماهي فوائد المشاركه في هذه الدراسه ؟

اتوقع ان تكون مشاركتك تجربه فريده. قد لا تحصلين على فائده مباشره من المشاركه ولكن مشاركتك و .الادلاء بارائك سيكون مفيدا للنساء في مجتمعك

هل يجب عليكي المشاركه في هذه الدراسه ؟

المشاركه في هذه الدراسه هو اختيارك , اذا قررت المشاركه يمكنك ان تغيري رايك و توقفين مشاركتك في اي وقت و من غير اعطاء اي اسباب ومن دون عواقب . اثناء النقاش كل ما تقولينه سوف يسجل . انتي حره اذا لم تشاركي في النقاش او لم تريدي الاجابه عن اي سؤال في اي وقت. ايضا لكي الحريه اذا اردتي ترك حلقه النقاش في اي وقت ولكن طبيعه هذه الحلقات لا يمكننا حذف مشاركاتك لانه من الصعب التفريق بين المشاركات في التسجيل لهذا السبب عند توقفك سيتم الاحتفاظ بمشاركتك السابقه و .استخدامها في الدراسه

هل يتم الدفع لكي للمشاركه ؟

يوجد مشروبات ووجبات خفيفه اثناء الحلقه. وفي نهايه كل حلقه سوف تحصلين على بطاقه هديه بقيمه 15دولار مقدمه من تيم هورتون للتعبير عن شكري لمجهودك ووقتك.

هل سوف يتم الحفاظ على سريه معلوماتك ؟

سوف افعل كل شي للحفاظ على سريه و خصوصيه المعلومات. لا يجب عليك استخدام اسمك الحقيقي. لن يستخدم اي اسم حقيقي في هذه الدراسه. سوف استخدم اسماء غير حقيقيه لكتابه هذا البحث او اي مشورات. ايضا سوف استخدم اقوال من المشاركات تحت اسم غير حقيقي لاغراض التدريس والمحاضرات العامه. كل المعلومات سوف تكون سريه وكل اشرطه التسجيل والمذكرات سوف يتم الاحتفاظ بها في مكان امن في منزلي من والى صاله الحي. في جهاز الكمبيوتر يتم حفظ المعلومات باستخدام كلمه للسر تكون فقط مع اعضاء البحث. سوف يتم اباده كل التسجيلات و المذكرات بعد انتهاء 5سنوات . وكل المشاركين سوف يقومون بامضاء اتفاقيه للسريه. سوف يتم تامين بيئه البحث بعد حاضنه و مسانده لكي حتى تكوني مرتاحه في مشاركاتك والادلاء بارائك. سوف يطلب من جميع المشاركات الحفاظ على سريه المعلومات. على الرغم من اننا سوف نبذل ما وسعنا للحفاظ عاى سريه و .خصوصيه جلسات النقاش الا اننا من غير الممكن ان نضمن بان باقي المشتركات سوف يقمن بالمثل

ماذا اذا يوجد لديكي سؤال ؟

اذا كانت لديكي اي اسئله عن هذه الدراسه الان او لاحقا الرجاء الاتصال ب داليا الدول
على الرقم [redacted] او ايميل [redacted]

ان خطه هذه الدراسه تم مراجعتها عن طريق لجنه اخلاقيات البحث ب جامعه البيرتا. اذا لديك اي اسئلهعن هذا البحث الرجاء الاتصال بالرقم 7804922615 ,هذا المكتب منفصل عن الباحثين في هذه الدراسه. ان مشاركتك مهمه لنجاح هذه الدراسه .

اذا وافقت على المشاركه الرجاء قراءه الاقرار ادناه

Consent
اقرار بالموافقة

عنوان الدراسة: اعطاء صوت للمستضعفين : دراسة مفاهيم و ممارسات النساء من منطقة الشرق الاوسط و شمال . افريقيا المقيمين في ادمنتون بالبرتا عن صحة الثدي و خطر الاصابة بسرطان الثدي و خدمات الوقايه من سرطان الثدي

الباحث الرئيسي : داليا الدول تلفون : [redacted]

	نعم	لا
هل فهمت انك طلب منك المشاركة في هذه الدراسة ؟	---	---
هل قرات و حصلت على نسخة من ورقة المعلومات المصاحبة لهذا الاقرار ؟	---	---
هل فهمت المخاطر و الفوائد الناتجة عن المشاركة في هذا البحث ؟	---	---
هل اتيحت لكي فرصة للاسئلة و مناقشة هذه الدراسة ؟	---	---
هل فهمت انك حرة في التوقف عن المشاركة في اي وقت و من دون اعطاء سبب او عواقب ؟	---	---
هل تم لك شرح سرية المعلومات ؟	---	---

من قام بشرح هذا البحث لكي ....

اقر بالموافقة على المشاركة في هذه الدراسة

الامضاء :--------------------------------------

الاسم : ---

التاريخ :---

امضاء الشاهد ---------------------------------------

ان الشخص الذي قام بالتوقيع على هذا الاقرار قد فهم محتوى الدراسة ووافق طوعا :

امضاء الباحث :-------------------------------------

التاريخ---

يجب ان تكون ورقة المعلومات اعلاه مصاحبة لهذا الاقرار ويجب اعطاء نسخة منها للمشاركة .

Appendix F

Focus Group Questions

"Please keep all the information produced during the focus group confidential and not discuss what happened during the focus group outside the meeting. What happens in the focus group stays in the focus group"

Please introduce yourself, and tell us what Western dishes do you like to eat?

(A warm up question)

1. What does "healthy breast" mean to you?
2. How do you keep your breasts healthy?
3. What do you know about breast cancer?
4. How do you think you can minimize your chances of getting breast cancer?
5. In your opinion, what are the factors that increase your chances of getting breast cancer?
6. What do you know about the existing breast cancer prevention and screening services in Alberta?
7. What are the factors that would facilitate your participation in the breast cancer prevention or screening services?
8. What are the challenges that hold you back from practising screening or using breast cancer prevention programs?
9. If you have the decision to design breast cancer screening programs for your community, what interventions relevant to your community you would use to encourage women from your community to use screening?

10. Is there anything else you would like to add to this discussion? (Exit question)

Appendix G

Focus Group Questions (Arabic Version)

اسئلة حلقة النقاش

الرجاء الحفاظ على سرية المعلومات في هذه الجلسة و عدم مناقشة ما طرح خلال هذا النقاش خارج هذا الاجتماع . ما يحدث داخل الاجتماع يبقى داخله

الرجاء التعريف بنفسك و ما هو الطبق الغربي المفضل لديك ؟ (سؤال للترفيه

.١
ماذا تعني "صحة الثدي" بالنسبه اليك؟
.٢
كيف تحافظين على صحة ثديك؟
.٣
ماذا تعرفين عن سرطان الثدي ؟
.٤
كيف تقللين من خطر الاصابة بسرطان الثدي.؟
.٥
في رايك , ما هي العوامل التي تزيد من خطر الاصابة بسرطان الثدي؟
.٦
ماذا تعرفين عن برامج موجودة للوقاية من سرطان الثدي .؟
.٧
ما هي المعوقات التي تعوقك عن استخدام برامج الكشف المبكر و طرق الوقاية الاخرى.؟
.٨
ما هي العوامل التي تسهل من مشاركتك في برامج الوقاية و الكشف المبكر عن سرطان الثدي ؟
.٩
إذا كنت في موقع تصميم برامج للوقايه من سرطان الثدي كيف ترين برامج الوقاية المناسبة لك ، او ما هي المواد التي تحبين رؤيتها في هذه البرامج وتحفز مشاركتك ؟

.١٠
هل تريدين اضافة اي شئ لهذا النقاش ؟ (سؤال خروج)

Appendix H

Confidentiality Agreement

This form may be used for individuals hired to conduct specific research tasks, e.g., recording or editing image or sound data, transcribing, interpreting, translating, entering data, destroying data.

Project title:
Giving Voice to the Vulnerable: Perceptions, Practices & Beliefs About Breast Cancer and Screening Among Ethnic Minority Women From the MENA (Middle East & North Africa) Region in Edmonton, Alberta.

I, ____________________________ the ________________________________ (specific job 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).

____________________________ ____________________________ ____________________________

(Print Name) (Signature)
(Date)

Researcher(s)

Dalia Eldol ____________________________ ____________________________

(Print Name) (Signature)
(Date: ------------------)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Research Ethics Board at the University of Alberta.

Appendix I

Focus Group Transcript Coding
(Translated Sample)

Focus Group 5, Friday 27/07/2018

Me (researcher), MN (participant), Y (participant), AB (participant), O (participant), Z (participant), ST (participant).

Start 10:05 AM

Me Asalam Alykom (means Hello) every one and thank you all for coming. I truly appreciate your participation in this research. As you can see, I've got a number of questions I'd like you to talk about among yourselves. I believe you're all aware of the purpose of this gathering. I'd like remind everyone kindly that all the information produce during this meeting should be kept confidential and please do not share what will happen here outside this meeting. What happens in the focus group stays in the focus group. I'm here to make this discussion easy. I'll also record this session and I'll take notes during this conversation so I won't forget important information.

What I would like to do is to ask you a question and then ask each of you perhaps to comment. I mean you don't have to answer any question if you don't want to, however I'm hoping you will. There are no right and wrong answers, as I am interested in the differences of opinions. Also, if you don't want to speak during this discussion, please let me know so I can give you papers to write down your responses if it is ok with you. You are also free to remove yourself from the group at any time without giving a reason and without penalty. Feel free to ask any question any time.

Is anyone would like to comment or ask a question before we begin?

First, please introduce yourself, and as a warm up tell us what Western dishes do you like to eat?

MN Salam (means Hi), my name is -----. My favorite western food is Lasagna with meat balls.

Y Hi I'm ----. I like to eat Spaghetti.

ST I'm happy to be here, thank you. My name is ----. I love Pizza.

Z Salam. My name is -----, nice to meet you all. I like BBQ & grilled beef steak.

O Hi. I'm ----. I like to eat cheese ravioli and chicken scaloppini.

AB Nice to see you all today. My name is -----. My favorite dish is Fajitas.

Me Well, Sounds delicious (smile). I can see most of you like Italian food (laughter) Thanks for sharing this.

First question; what does "healthy breast" mean to you?

ST (For me healthy breast means good looking skin over my breasts.) (1) (I'm able to breastfeed well and my child is happy with breastfeeding.) (2) (And of course, no lumps) (3), (no aching) (4) (and no bleeding) (5).

Z (Yeah! For me breasts are healthy when they are not hurting) (4) (or oozing or bleeding) (5). (Both breasts of equal size and shape.) (6) Also, the nipple is not upturned. (I also think my breasts are healthy when I don't feel hurt or discomfort when I exercise or play sport.) (4)

MN I agree with what Z and ST have said, but I think it is ok if my breasts hurt during my monthly period, because this is normal right?

Z I don't know. My breasts never hurt during my periods!

MN (They do, mine usually hurt all day during my cycle) (4). (But I think it depends. I mean if they are hurting and there are unusual things such as cracks or lumps, then it might be something wrong) (3). (I don't think only pain is a sign of a disease. My breasts also hurt me when I breastfed my child, and my nurse said it is ok especially in the first few days of starting breastfeeding) (4). The nurse also said I can just take a pain killer such as Panadol.

AB I agree with you MN. (Healthy breasts also mean that I can wear my bra comfortably) (4). (No swellings and no bleeding from the nipples) (5). (And the dark skin around the nipple has no cracks or any funny looking) (1)

O You guys said it all! (I agree with what you have said that healthy breast means normal looking shape) (6) (and skin) (1) (No soreness) (4), (no lumps) (3) (and of course no cancer) (7). (And no problem with breastfeeding as well) (2)

Y Mmmmm. (For me healthy breast means I can wear my cloth comfortably) (4). (I look and feel good about myself) (8). And it is all good when it comes to my intimate relationship with my husband.

Me Second question: How do you keep your breast healthy?

Z (I don't do anything in particular for my breast, I try to keep my whole body healthy by eating healthy) (1) (and reduce my weight) (2). (I also talk to my family doctor if any changes happen to my breasts or any part of my body) (3)

O (I work out, I go to the Gym twice a week and do yoga as well) (2). (I don't smoke) (4) (or drink alcohol) (5). (I also go to the clinic for regular checkups including breast exam) (3). (I also use sunscreen when I wear summer tops. I don't wear revealing cloth, but since I don't wear hijab, my neck and the upper area of my body are exposed to the sun rays, so I take precautions) (6). (I also try to practice good posture and sitting up straight in my office, because my doctor told me that poor posture can cause breasts to sag and droop) (7).

MN (I think breastfeeding is the best thing to do to keep our breast healthy and free from cancer. I know two sisters who their mom passed away due to breast cancer. The eldest also developed breast cancer and she had surgery few months ago, she has no children. The younger who happened to be my friend has three kids and breastfed them all. They are happy, healthy and smart. Now she is 55 and healthy. She goes for regular checkups and she is healthy as a horse!) (8)

Y (I keep my breasts healthy by wearing comfortable and right size bra. The bra should not be too tight squishing my breasts or has underwire) (9), (and definitely I don't sleep with a bra on at night) (10). (I try also to reduce my intake of sugar because sugar cause wrinkles everywhere in my body and cause my breasts to be saggy, and I want to keep young appearance as long as possible (laugh). I also eat more fruits that have anti-cancer effect such as watermelon and avocado.) (1)

ST (For me breastfeeding is good because I heard it is kind of protective from breast Cancer) (8) and also because Allah (God) recommended in the Holy Quran. (I also go to see my family doctor if I notice anything unusual about my breast or if my husband comments about anything looks weird about them, you know, he and my son share this property too (pointing to her breasts and laugh). One time I felt like a small lump in my left breast and when my doctor checked me it was not there. It simply disappeared. She said this could happened especially with breastfeeding as accumulation of milk can do that. I was relieved! It scared me at the beginning.) (3)

MN Oh, I'm glad it was nothing to worry about, breast lumps are kind of scary!

ST Yeah!

AB (I keep my breasts healthy in the same way I keep the rest of my body healthy. I exercise regularly) (2). (I don't smoke) (4). (I eat healthy, like more veggies and fruits and watch my body weight) (1). (I also try to get enough sleep) (11). (I also use natural oils like organic coconut oil and olive oil to moisturize my breast skin) (12). I don't use any chemicals over them. (I also look at my breasts in the mirror to see if there are any funny things.) (13)

Me Thanks everyone, now the third question; what do you know about breast cancer?

Y My information about breast cancer is very limited. (I know that it is very bad disease) ⁽¹⁾ (and if a woman gets it, the doctors will remove her breasts completely) ⁽⁶⁾, otherwise she will die.) ⁽²⁾ (I also know that it runs in families) ⁽³⁾ (and wearing too tight bras can cause it.) ⁽⁴⁾

AB (I know that Women over the age of 50 are more likely to have it.) ⁽⁵⁾ (I also know that it could be inherited.) ⁽³⁾ (I heard that if you have a strong family history like your mom or sister, it is better to remove your breast, which I find scary and extreme.) ⁽⁶⁾

Y That is scary!

Z Who can do that?! There must be other things that can be done to save a women life rather than this.

AB I don't know I heard about it. I think this is very extreme.

Z (I know that lots of women in the US and Canada are developing breast cancer.) ⁽⁷⁾

In my home country I barely hear about this disease. (I think as the woman grows older, she has more chances of getting it) ⁽⁵⁾. (It can show as lumps) ⁽⁸⁾ (or bleeding.) ⁽⁹⁾

O This cancer happens when the breast cells grow out of control for many reasons. (For example, air pollution) ⁽¹⁰⁾ (or radioactivity.) ⁽¹¹⁾ (Some women get swelling) ⁽¹²⁾, (some get skin changes) ⁽¹³⁾. (It can affect men too) ⁽¹⁴⁾. (I know it can be deadly.) ⁽²⁾ (It is curable if noticed earlier though.) ⁽¹⁵⁾

ST (I usually see on TV little pink bow people wear when they talk about breast cancer prevention. They usually talk about breast exam and the changes that can happen to the breasts if get cancer.) ⁽¹⁶⁾

MN (I had a friend who died few years ago after a long battle with breast cancer. I was devastated. Her mother and one of her cousins also died from this bad disease. She has two daughters and I'm really worry about them; I hope they will never get this disease. I think we as a woman should know everything about it.) ⁽²⁾

ST Sorry about your friend MN

O I'm very sorry about your friend MN, And I agree with you that we need to know better than that so we can protect ourselves.

Me I'm sorry too about your friend MN. Question NO 4. How do you think you can minimize your chance of getting breast cancer?

ST (Self-exams) $^{(13)}$ (and maintain a healthy weight.) $^{(1)}$ But it is better for the exam to be done by the doctor, because the doctor is trained to do this right?

MN (I agree with you ST, sometimes I get confused when I touch my breast trying to find if there is a lump or anything weird.) $^{(13)}$ (So, it is better to be done by a doctor or a nurse. I also heard women over 50th 0r 60th should do some kind of special test.) $^{(3)}$

O I can minimize my chance by (getting regular checkups) $^{(3)}$, (eat healthy) $^{(1)}$ (and exercise.) $^{(2)}$ I believe this could minimize my chances of getting any cancer or a bad disease, right? (This special test called mammogram MN if that what you mean. It is for women over 60th. This mammogram can find out breast cancer when it is in a very early stage. I also think the earlier the finding of this disease the better options for treatment.) $^{(3)}$ (And…. yea stay away from radioactivity.) $^{(16)}$

AB (I think I can decrease my chances of getting breast cancer by keep my breast healthy and clean.) $^{(14)}$ (I never use any chemicals over my chest) $^{(15)}$. But how can we stay away from radioactivity O?

O For example, avoid unnecessary x-rays.

ST But how can we avoid it if the doctor order it?!

MN Yeah, that is a good question!

O If you have done many of x-rays, talk to your doctor about it and explain your worry. The doctors are knowledgeable and well trained.

AB Actually when my daughter was 9 years old, she had many chest infections and needed to have multiple chest x-rays to find out what caused these infections. Do you think this may harm her in the future?

O To be honest I don’t know, but I hope not. I think the best thing to do is to talk to your family doctor about your worries.

AB Yeah, I will. Thanks.

Y I don’t think as a woman we can do much to reduce our

Chances. (However, I immediately visit my doctor if I feel sick.) $^{(3)}$ (I also pray to God

to keep me healthy. Although I believe that if God want you to have it, you cannot

escape it!) $^{(17)}$

Z I disagree with you Y. God also says in Quran that take precautions to keep yourself safe and sound. (So, I think we can to some extend reduce our chance of getting this disease by stay healthy) $^{(1)}$ (and positive) $^{(18)}$. It is important first to have all the knowledge from legitimate sources about this cancer and how can we protect ourselves and our daughters.

Y Talking about knowledge, where can I have legitimate information? There are tons of information out there especially on the internet, so how would I know that what I'm reading is legitimate?

AB Good point Y.

O I see what you mean Y. There are trustful web sites such as Canadian breast cancer group or American cancer group I guess, not quite sure about the name, but you can google it. Also, you can always ask Alberta health line on 811.

Y Thanks O.

O You are welcome.

Me 5. In your opinion, what are the factors that increase your chances of getting breast cancer?

Z (Bad genes I guess.) (1) (Overweight) (2) (and unhealthy eating.) (3) (I also heard that the hormones pill that women take in menopause can cause breast cancer.) (4)

AB I know many women who are taking this pills for many years but they didn't get breast cancer.

Z I said they might cause it because these pills disturb women's hormones.

AB (I think being a women will automatically increase my chances.) (5) (And of course, family history. I you have a first degree relative with breast cancer, this will definitely increase your chances of getting the disease.) (1) But sometimes there is no obvious reason for getting this disease.

Y (Alcohol) (6) (and smoking) (7) are also bad for our health and they can cause cancer. That is why Allah (God) prohibited them. (Stress can also be a factor. I heard that women who works long hours at night are more likely to get it. For example, nurses and doctors.) (8)

AB Yeah! That is why I take enough sleep.

ST I agree with you AB that we sometimes can't tell what would have cause this disease. I mean there are many healthy-looking women who still getting it. (But I guess it is all in the genes.) (1)

MN (Maybe…ummmm being overweight) (2), (eat fast food) (3), (not checking with the doctor as soon as feel or see something funny in the breasts.) (9)

O (I totally agree with you MN that we should ignore alarming signs such as lumps or fissures in the breast skin and to see the doctor as soon as possible. Sadly, it can be no signs at all.) (9)

Z Yeah, and this is the worst part, because you won't go for a checkup if you don't Feel or see anything and then the cancer would spread without knowing.

Y What should we do in this case?

O Unfortunately we can do nothing, but at least we should do our part and have a checkup regularly.

Me Well-done everyone. Now question six: What do you know about the existing breast cancer prevention and screening services in Alberta?

Y I know there are services for cancer patients, but I don't know about cancer prevention services, are there any?! Is this cancer can really be prevented? How?

O (I know that women over 60th should go for a mammogram every 1 or 2 years.) (1)

Y What is mammogram!?

O It is a special test that takes picture of the breast to see if there is strange growth inside women breasts. And if it sinister or not.

Y Where do you guys hear about these services? I always watch TV and read newspapers, I don't really see news about breast cancer campaigns or services. I wish to receive for examples emails regarding this. I check my email several time a day, there is no chance I miss it.

MN (My doctor actually talked to me about this test, but I forget all about it. I just heard about breast self-exam and breast exam by the doctor at the clinic if that what you mean.) (1)

ST (Yeah I hear about breast exam all the time, but I don't know how to do it the right way for myself.) (1)

AB (For me, when I need any health advice I just call Alberta Health line on 811. I think this is a good service, convenient and always available.) (2)

Z Actually I don't know about these services.

Me Question 7. What are the factors that would facilitate your participation in the breast cancer prevention or screening services?

ST (I would love to participate. But I don't know how, when or where to go.) (1) (I mean I love to see ads in the TV) (2), (or flyers coming in the mail for example to explain how and where we can get these services) (3). (Emails are also great ways to educate us about these services.) (4) (I also wish if my doctor train me on how to do breast exam for myself.) (5)

Z (For me, it would be much easier to understand if someone explain to me in Arabic. I don't understand many of the English medical terms.) (6) (I'm also busy with my kids and the household. I have no close family or friends here to help, so it would help if I can have some sort of child care in these services to take care of my kids for the time am having the checkups.) (7)

AB (I will be motivated if I see information in Arabic and health providers speaking Arabic, in particularly women providers. When I came to Canada few years ago it was very hard for me to communicate with the staff in the hospital or clinics because nobody was speaking or understanding Arabic. This makes me want to avoid visiting the hospital unless I really need to.) (6)

MN I agree with you guys. (I will also be encouraged if I have been reminded by Alberta health and by my family doctor through emails) (4) (or regular mail to book my next appointment for the checkups.) (3) (I also want to be seen and checked by female health provider.) (8) (I also appreciate if there are special events in the community to educate us about such issues using our own culture.) (1)

Me Can you explain more about "using our own culture", what do you mean by that MN?

MN (I mean using our own Arabic language so everyone can understand.) (6) And also, the lecturer can be women from our community and in our community. We have lots of educated and smart Arab women, right?

O (For me, although I prefer to see someone talks and understands Arabic) (6), but it won't be a problem if I have to communicate in English.

ST I agree with you MN. I prefer to learn about this in our community with familiar people, I guess I would be more comfortable. (It would also be very encouraging if I have been trained to do breast exam) (5) (and given enough information about how, when and where to go for screening.) (1)

Y Yes, me too guys. (My English is not very good, so I would love to see services in Arabic.) (6) (I also want to be approached by a women nurse or a doctor. I'm not comfortable to expose my breast in front of a male doctor. My husband also will be very mad if this happens.) (8)

O (I'm also busy with my work and family, so it would be great if screening services are available at walk-in clinics, because waiting time in clinics and hospital is too long.) (9)

Me Most of you have shown their preference of a female health provider, it this because you personally prefer a female health provider or because your husband want this and he may be unhappy if you see a male health provider?

ST I would rather see a female doctor when given the choice. It is not because my husband dislike it. Because I'm more comfortable with women like me.

MN To be honest with you it doesn't matter to me, but it matters a lot to my husband. He always tells me to ask for a female nurse, if she is not available then he can accept a male provider. But I have to do my part and ask first.

Y My husband can get really mad about this. So, I just try to avoid any fights with him. This is eastern men thinking, we all know that.

AB NO, I'm more comfortable with women health provider, even if my husband wouldn't mind.

O It does matter to me or to my husband.

Me Question 8; what are the challenges that hold you back from practising screening or using breast cancer prevention programs?

AB (The most thing I hate to see is rude nurses. My daughter had a heavy menstrual bleeding. It was too much that she was pale and tired all the time. In the emergency room there was a staff nurse, she asked my daughter if she is sexually active. My daughter was only 15 and it was not appropriate to ask such question. We felt very uncomfortable. We are Muslims and wearing Hijab, this was obvious. Muslims women don't have sex outside marriage as you all know, they should know that too") (1)

Z (I'm sorry about your experience AB. You know I still feel like a stranger sometimes here, and some people don't respect where we come from. Few months ago, I visited the health clinic for high blood pressure and the nurse asked me about current medication. I have mentioned karkadiah (herbal medicine) that we used to treat high blood pressure back home, guess what? She rolled her eyes. I felt very bad and offended. I never went back to that clinic Again.) (1)

ST Yea, that is bad guys. I'm sorry. (I hear sometimes from my friends how the people in the hospital can be cruel) (1). I never experience something like that thanks God and I hope I will not. (For me what is holding me from screening is that I don't know about these services and I hope I will learn about them.) (2)

Y I haven't tried these services yet, so I am not sure about the challenges. (Although I believe if they provide these services in Arabic or at least offer some sort of translation services, it would be enlightening.) (3) Usually if I don't feel sick I don't go to the hospital or the clinic. I also don't like to think about this nasty disease too much. So, no need to dig for it if there is no obvious signs. No need to open the closed door, right?

O For me, (timing) (4) (and location are issues. It is hard for me to take time off work or drive for long distances.) (5) With my busy life, I also don't remember when to go for my breast exam, so I hope there will be some kind of reminder from the system every now and then.

MN (I believe number one challenge for me is the language. I don't really understand many of the medical terms, and it is hard sometimes for me to read the medical instructions. I always ask my husband to translate for me. But he cannot be always with me. I always wonder why there are no Arabic interpreters in the hospitals. I think there are many Arab families here in Edmonton. They should at least offer translation services as Y said.) (3)

AB (I totally agree with you MN. Translation services are the least they can do for us.) (3)

Me Question 9; If you have the decision to design breast cancer screening programs for your community, what interventions relevant to your community you would use to motivate women from your community to uptake screening? HA

ST What a great idea HA, (I also add that it would be great if this app can be in Arabic with pictures of women wearing Hijab (head covering) or Abaya (long, loose dress).) (1)

MN (I will definitely use bilingual programs in both English and Arabic.) (1) (I will also hire more female health providers in these services.) (2)

AB (I will first train the health staff to be sensitive and aware of our culture and traditions.) (3) (I will also make sure these services reach women in their communities) (4)

Me Can you elaborate more on this AB or anyone, I mean how can these services reach you?

AB (I mean like planning events in our community. For example; public presentations, talks and gathering to be designed especially for women of our community.) (5)

ST (I also would like to add we can ask for health trainers from our community. I mean some women from our community can be trained and received special education about these services. Then they educate the rest of us. Those women would be such a great help because they have the same religious and values.) (7)

Z This is a great idea. Women from our culture and religion. I like that. And also, if I have a say on designing these services, (I will send information letters or brochures) (6) (by email) (8) (or regular mail) (6) to educate and remind women from our community about screening.

O (An online forum for all Arab and Muslim women would be great. We can talk about these issues and help each other to know where and when we can use these services and also encourage one another.) (9)

Z I like your idea O. But I prefer to meet in person and talk.

O But it is hard to meet everyone right? People have different schedules. The online forum will include all Arab women from other provinces as well, so we can have wider connections a bigger source of information.

ST I thought every province has its different health system and different programs. How can we help women from other provinces or get help from them?

Z Yeah! Good point ST.

O Yes you are right ST. Although every province has its own regulations, but I think there are also commonalities. For example; all Canadian provinces use mammogram to screen old women.

Y You know what guys, I still don’t understand what mammogram is. Do we just visit the clinic and ask for it? Or what to do? My doctor never talked to me about it!

O Yeah, this one of the problems, I guess. Your doctor should have talked to you about it. I suggest book an appointment I go talked to your doctor about this.

Y Yes. I will. Thank you.

Me MN have said earlier that events about breast cancer screening can be designed for women of your community. Can you MN or anybody elaborate on this?

How these events can be designed for women of your community?

MN (Arabic language to be the language of the presentations or the public talks.) (1) (Also hire women from the Middle East to talk to us, I mean immigrant Muslim providers, as it is easier to talk to them and understand them.) (2)

Y (I would also suggest using materials from our Arab and Islamic culture in these events. This will definitely attract my attention.) (3)

Me What kind of cultural materials can be used to encourage you to use these services?

Y Ummmm. For example (pictures or videos of Arab women wearing hijab or niqab (veil). This makes me feel I belong.) (4)

Z Yeah, I agree with you Y. I also like to say that I like to see these Arab symbols in other health services not only breast cancer screening services. If I see these in other clinics and hospitals, I would definitely feel more comfortable to use the services.

AB Totally agree Z. And I also believe it is all about how we have been approached in these health services.

Me How would you like to be approach by the breast cancer prevention programs?

AB (I would like to be approached by a nice and respectful health provider) (1) (preferably a woman.) (2)

Z I would like to be approached by my family doctor. I like her to talk to me about any information or programs regarding my health. I don't like to see many doctors, so I prefer one source of information, it is more convenient for me. (I also want to see more respectful health providers not like that nurse who rolled her eyes at me.) (1)

AB Me too. I would like to see my family doctor more often; I like her to talk to me about any information or programs regarding my health.

ST (I like home visits, like when you give birth to your child, a nurse usually visits you for checkup and teaching about the baby. In this case I don't have to go out, especially in extreme cold weather.) (3)

O (I am comfortable being approached in any professional and decent way.) (1)

Y (I would like to be approached by a woman like me. It is embarrassing to talk to a man about breast issues. Beside my husband won't accept any man talking or touching my breast. He can get a heart attack (laugh).) (2)

Me Q. 10. Is there anything else you would like to add to this discussion?

Y (No.) (1)

AB (Nothing to add, thanks.) (1)

MN (No. Thank you.) (1)

ST (I just want to say that I'm hoping this gathering could be a start in helping each other regarding health issues in general and breast cancer screening and prevention in particular.) (2) (I wish to see many health educated women in our community such as yourself (pointing to the researcher) help and guide other women in terms of the language challenges and understanding the Canadian health system.) (3)

Z I totally agree with you ST.

O Well said ST.

ST Nice to meet you all, hope we will keep in touch outside this meeting.

Me This is the end of this discussion. Thanks a lot everyone for your input. As an appreciation for your time and efforts, you will be given $15 Tim Horton gift card shortly. Please help yourself to some snacks over there. Thanks!

END 11: 18 AM