University of Alberta

Immigrant Afghan Women and Breast Cancer Screening Practices

by

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Abstract

This thesis presents the results of a pilot study of immigrant Afghan women and their breast cancer screening practices. Literature was reviewed to identify factors that impact breast cancer screening and demonstrated in a conceptual framework. This was then used to guide the development of the data collection instrument. Immigrant Afghan women were surveyed using a closed questionnaire as well as open-ended interview questions. In addition, policy documents for Screen Test, the Alberta Program for the Early Detection of Breast Cancer were reviewed. After results of the study were obtained, the conceptual framework was revised. Due to the exploratory nature of this research, the findings are incapable of being generalized to the larger Afghan population. Possible policy options are offered. Avenues for future research are suggested.

Dedication

This thesis is dedicated to my family, whose support and encouragement guided me through this process. This thesis would not have been produced without the insight given to me by my thesis supervisor, Dr. Church, who devoted much time to providing constructive feedback. Many thanks to the Alberta Cancer Board who allowed me to review their policy documents. Finally, the interpreters/translators must be acknowledged for their hard work in collecting the data required for this study.

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Introduction and Literature Review

Significance of Studying Immigrant Women and Culture in Canada

In Canada, research on women's health has failed to thoroughly describe diverse population groups. As a result, there is currently a lack of knowledge about how best to approach health issues of immigrant and refugee women (Christensen, 2001). This is significant as one third of Canadians see their ethnic background as being other than British or French (MacKinnon, 1997). In major cities such as Toronto, over 40% of the population comprises visible minorities (The City of Toronto, 2003, Cultural diversity, para 2).

Many definitions have been proposed for the concept of culture. Culture is often defined as those parts of the environment that are human-made, including both its subjective and objective characteristics (Al-Issa, 1995). According to Al-Issa, the subjective subdivision consists of beliefs, values, norms, and tradition shared by the group. This subjective aspect of culture is passed down from generation to generation. Conversely, the objective aspect of culture refers to the physical environment which consists of roads, bridges, and buildings. The objective notion of culture is out of the scope of this research and will not be addressed. In multicultural societies, as Al-Issa points out, the concept of culture is defined in the ethnic sense where the nation is divided into ethnic groups defined on the basis of racial and physical characteristics, common language, collective historic origins, and shared customs. Acculturation is defined as the process in which individuals whose primary learning has been in one culture adopt attitudes, values, and behaviors from another culture (Suarez, 1994).

One sixth of the Canadian population is foreign born (Oxmann-Martinez, Abdool, & Loiselle-Leonard, 2000). As a result of the political situation in Afghanistan over the last decade, Canada began accepting more Afghan immigrants and refugees. This leaves the Canadian health care system with the additional challenge of providing this new group with culturally sensitive health care. According to Christensen (2001), the way in which culture influences illness prevention and the circumstances under which culture affects health are two areas where gaps in the literature exist. This thesis is a step towards addressing these gaps, as studies involving both culture and health remain the exception, rather than the norm. Since culture is an important variable in health, studying culture in relation to health is essential if we are to promote cultural pluralism in Canadian society.

Two thirds of immigrant women find Canada's health care system to be culturally insensitive (MacKinnon & Howard, 1999). Issues of health and wellness are important for everyone, regardless of cultural/ethnic backgrounds. Therefore, immigrants of different cultural backgrounds will inevitably come into contact with health care providers. The health care expectations of visible minorities do not necessarily vary from those belonging to the dominant culture, although many feel the services they do receive may be related to their cultural background. While visible minorities expect equal treatment according to recognized standards of practice, they feel that a minimum and maximum often exists in the standard of treatment received, which often is related to cultural background (Eddy, 2000). Some women feel they are not given the opportunity to participate in health care decision-making because of the way they look. According to MacKinnon and Howard, many reported that appearance, when combined with an accent, makes them seem less credible and not knowledgeable. Richard and Jagielski (1999)

explain that some providers have experienced resistance and hesitation by those in decision-making capacities to include the participation from minority populations in the process of health care decision-making. This poses a difficult challenge, as race and culture are inadequately dealt with in health care education and training programs (Eliason, 1999).

The lack of cultural awareness by health care providers, in general, makes health less accessible for culturally diverse individuals. In order to provide culturally sensitive services, health care providers must become aware of their own cultural perceptions and biases, as well as understand the effect that culture has on the interpretations of health, illness, and care giving (MacKinnon, 1997). MacKinnon points out that this is important because the way culture is understood as a probable barrier to health care determines how problems are defined, the resulting research conducted, and the way research findings are used to guide practice. If new Canadians are to be healthy and contribute to Canadian society to the fullest extent possible, then we must understand their beliefs about health and illness and provide the kind of health care that will support them in maintaining, promoting or returning to a healthy state. In addition to a lack of cultural awareness by health care practitioners, there is an unequal representation of visible minority health care professionals delivering front line health care. According to Eddy (2000) ethnically diverse health care providers expect that:

1. Composition of health care providers should reflect the ethnic diversity of the population at large, thus removing overt cultural barriers while accessing care, and
2. Implementation of policy should include educational material that echoes the various cultural groups within society including both providers and recipients of health care.

Another issue that affects the health of immigrant populations is insufficient health human resources. Inadequate health human resources results in two distinct barriers to accessing health: inadequate time spent with patients and the adherence to institutional policies that do not reflect the additional needs of multicultural groups (Eddy, 2000). Some of the current policies in place unintentionally cause inequitable distribution of health care services. For instance, according to Eddy, there is usually some flexibility within the execution of policies but the flexibility may not always be applied to the benefit of culturally diverse recipients.

Immigrant Women and Health

Immigrants, other than refugees, are generally healthier upon arrival to Canada than the Canadian-born population (Oxman-Martinez et al., 2000). This is due to the screening of unhealthy applicants and the fact that, in general, healthier people are more likely to immigrate. Health Canada (2003, Key determinants, para 5) identifies gender and culture as determinants of health. Once in Canada, immigrant women are hindered from maintaining their health, promoting their health, and preventing illness due to cultural, socio-political and economic situations. Factors affecting the health of immigrant women include language barriers, an increase in the number of roles they must take on, trying to understand and incorporate two different cultures in their lives (the mainstream culture and their own culture), the need to defend their values, dissimilarity in symbolic implications, the grief of losing everything that is familiar to them all at once, social isolation, a loss of pre-existing social support systems, abusive relationships, prejudice and discrimination (Oxman-Martinez et al., 2000; MacKinnon & Howard,

1999). Furthermore, in a study conducted by Mackey and Barron (1997/1998) newcomers experience the following stressors:

1. Insufficient skills of obtaining the bare necessities such as food, clothing and shelter,
2. Feelings of inadequacy caused by having to resort to the government for monetary assistance,
3. Feelings of embarrassment when asking how to do things they could do in their homeland, and
4. Adjusting to the changing roles within their families and communities.

In addition, these women are subject to excessive workloads and degradation within their home and work environments. As immigrant women are generally healthy upon arrival to Canada, including them in public health interventions is appropriate, as this would enable them to maintain or promote their health. Peragallo, Fox, and Alba (1998) note that immigrant women face barriers to accessing various illness prevention programs, including mammography. One such barrier is insufficient knowledge about how the health care system works (Richard & Jagielski, 1999).

Breast Cancer: Contemporary Significance

Five thousand years after its initial discovery, the incidence of breast cancer remains on the rise (Frykberg & Bland, 1998). Its representation in the earliest medical literature indicates that breast cancer has always been relatively common. Breast cancer is the most common cancer occurring in women, with 900,000 new cases occurring annually worldwide (Al-Lawati, Santhosh-Kumar, Mohammed, & Jaffer, 1999). Canada has the second highest incidence of breast cancer in the world surpassed only by the United States (Breast Cancer Society of Canada, 2003, Breast cancer history, para 14).

Breast cancer is the most common cancer in women in Canada (Health Canada, 2003 Breast cancer, para 1). It is predicted that 21,200 Canadian women will be diagnosed with breast cancer in 2003 (Canadian Cancer Society, 2003, Breast cancer stats, para 1). According to the Canadian Cancer Society, breast cancer will claim the lives of 5, 300 of these newly diagnosed women. One in 9 Canadian women is expected to develop breast cancer in her lifetime and 1 in 27 is expected to die from it (Health Canada, 2003, Breast cancer, para 1). The Canadian incidence rate for breast cancer for women over 50 has been on the rise - since 1988, breast cancer incidence rates have escalated by 10%. However, the Canadian Cancer Society reveals that in the same period mortality rates have also declined by 19%.

In Alberta, an estimated 1,850 new cases of breast cancer and 430 deaths are expected in 2003. (Canadian Cancer Society, 2003, Alberta/N.W.T. cancer statistics, para 4). While breast cancer remains the most common cancer diagnosed in Alberta women, mortality rates from this disease have declined progressively since 1986 (Canadian Cancer Society, 2003, Alberta/N.W.T. cancer statistics, para 4), consistent with that of the

national trend. This decline represents the success of various screening programs and advances in treatment options since the 1980's.

Significance of Studying Breast Cancer Screening Practices

The likelihood of a woman developing breast cancer increases dramatically with age, making age the most significant risk factor for breast cancer (Health Canada, 2003, Reducing the risk of breast cancer, para 4). A more detailed discussion of risk factors is presented in Appendix A. As prognosis for breast cancer survival is clearly gauged by the stage of disease at diagnosis, early detection is essential in order to increase survival rates (Catalano & Satariano, 1998). Currently, the only proven strategy to reduce breast cancer deaths is early detection through mammography in women over 50 (Ahmed, Fort, Micah, & Belay, 2001; Ernster, 1997). There is clear evidence from population-based trials that screening mammography can reduce mortality from breast cancer in women aged 50 – 69 and is supported by recent Canadian trends illustrating a decline in mortality rates over the last decade (Maxwell, Bancej, & Snider, 2001). According to Catalano and Satariano, the five-year survival rate for women aged 50 and older with localized cancer is 93%, although this may be partly attributed to improved treatment. Despite the evidence that regular screening can be beneficial in the early detection of breast cancer, some women nonetheless underuse mammography.

The Alberta Cancer Board Recommends that women aged 50 - 69 should have a screening mammogram every two years (Alberta Cancer Board, 2002). Mammograms are available through organized screening programs that have been implemented in 11 provinces/territories (P. Taschuk, personal communication, October 29, 2002). Some screening programs include a clinical breast exam and the teaching of breast self-

examination in the screening visit. Screening mammograms can also be obtained through a physician in hospitals or clinics under the general fee-for-service system (P. Taschuk, personal communication, October 29, 2002). Since mammography is accepted as the technology of choice for early detection of breast cancer, numerous studies have been undertaken to determine the effectiveness of interventions aimed at increasing participation of diverse groups in periodic screening (Zapka et al., 1996). Appendix B contains a discussion of breast cancer screening.

Minority Women and Breast Cancer Screening

Although Statistics Canada obtains information on the screening rates of the general female population, it is not known how many of these women are immigrants.

Minority women often demonstrate a higher risk of poor health (Oxmann-Martinez et al., 2000). Although breast cancer incidence is higher among White women than Black women, Black women have lower survival rates and higher rates of breast cancer mortality than Caucasian women (Chevarley & White, 1996). This may be explained by lower mammography use in Black women resulting in later stage at diagnosis. The question that arises, then, is why are the mammography screening rates lower among Black women? Women are more likely to regularly participate in breast cancer screening if a physician recommends it (O'Malley et al., 2001). In a study by O'Malley et al., twice as many White women reported physician recommendation for mammography than Black women. It is no surprise, then, that breast cancer, often at later stages when detected in Black women, contributes to shortened survival rates and increased morbidity. Hedeen, White, and Taylor (1999) obtained similar results as they discovered that Asian women had larger tumor sizes than White women at the time of

breast cancer diagnosis. Study findings suggest that women born in Asia are at considerable risk of never participating in mammography screening as cultural beliefs and attitudes about cancer risk and prevention continue to serve as significant barriers to screening (Maxwell et al., 2001). Although results from the studies provided above are alarming, it must be noted that these studies took place in the United States and transferal of the United States experience to Canada must be considered with caution due to the differences in health care systems of the two countries.

According to O'Malley, Earp, and Harris (1997), efforts to increase breast cancer screening should address, among many things, patient-physician interactions, particularly interactions involving minority and low-income women. However, promoting appropriate physician discussion is not always enough. After recommendations for screening were made by physicians, O'Malley et al. found that additional cultural, economic and other factors inhibited compliance, and complementary interventions, including messages tailored to these women's specific barriers and needs could increase mammography use. For example, brochures often use pictures of White women and may have a reading level too high for poorly educated people or people who do not speak English fluently. Research has shown that interventions to promote breast cancer screening increase actual screening rates when minority women were used as models, women of the same background were used to deliver the message of the importance of breast cancer screening, and the vocabulary of the target group was employed to deliver services (Sung et al., 1992). Using such methods to increase participation in breast cancer screening for ethnically diverse population groups is meaningful, as O'Malley et al. found that

screening Black and White women at equally intensive rates would reduce racial differences in breast cancer survival.

Another factor that may be associated with levels of breast cancer screening among immigrant women is acculturation. As previously stated, acculturation is defined as the process in which individuals whose primary learning has been in one culture adopt attitudes, values, and behaviors from another culture (Suarez, 1994). For immigrants from non-English speaking countries, one measure of acculturation is the choice of language to use in daily life (O'Malley, Kerner, Johnson, & Mandelblatt, 1999). In other words, those who have a higher level of acculturation in the West are more likely to choose to speak English in their every day lives. O'Malley et al. have linked having higher acculturation to having had a recent clinical breast examination and mammogram for screening purposes. Longman, Saint-Germain, and Modiano (1992) found that differences in use of and compliance with recommended screening guidelines among older Hispanic women were primarily caused by low literacy in English or Spanish, low income and education levels and little or no access to quality health care. In addition, Peragallo et al. (1998) discovered that short period of residence in the United States is related to inadequate breast care among Latino immigrant women. Interventions aimed at increasing breast cancer screening usage should then be aimed at first-generation immigrants.

Knowledge of the different meanings and interpretations of health beliefs and values is essential for those providing health care to different cultural groups. Although sensitivity to cultural beliefs and values about health, illness, and healing practices is increasing, consideration of cultural differences has largely been ignored in the field of cancer research (Longman et al., 1992).

Purpose of the Study

The purpose of the study is to examine the breast cancer screening practices of immigrant Afghan women in Calgary and Edmonton, Alberta.

Objectives of the Study

The objectives of the study are to develop a pilot survey to:

1. Understand the characteristics of immigrant Afghan women in two major cities in Alberta
2. Develop a conceptual framework that describes the factors that influence breast cancer screening practices in immigrant Afghan women
3. Determine if the identified influencing factors facilitate or impede the breast cancer screening practices of immigrant Afghan women
4. Identify additional factors that could be added to the conceptual framework
5. Research health policy options with respect to immigrant Afghan women and breast cancer screening in efforts to increase their screening rate

Research Questions

The research questions of the study are:

1. What factors influence the breast cancer screening practices of immigrant Afghan women?
2. Do the identified factors facilitate or impede breast cancer screening practices of immigrant Afghan women?
3. What types of policy options (with respect to Afghan women and breast cancer screening) could increase the screening rate of immigrant Afghan women from breast cancer?

Target Population & Inclusion Criteria

The target population consists of immigrant Muslim Afghan women. The inclusion criteria for this study are immigrant Afghan women 50 years of age and older, residing in either Calgary or Edmonton and who have been in Canada for 10 years or less.

Conceptual Framework

The conceptual framework used to guide this study was the "Breast Cancer Screening Practices and Immigrant Afghan Women" framework (Figure 1). The factors identified in the conceptual framework were derived from the literature review conducted and presented in the above sections. Four factors were identified from the literature. The first factor is culture. For the purposes of this study, this is defined as culture as retained from the participants' home country, Afghanistan. The second is the health care system. This includes participants' knowledge about the health care system in general, as well as the interactions the participants have with the health care system. The third factor identified in the research is socioeconomics. As socioeconomics is widely recognized as a determinant of health (Tulchinsky & Varavikova, 2000), it was only fitting to include this in the initial conceptual framework. The fourth influencing factor obtained from the research is acculturation. Again, acculturation is defined as the process in which individuals whose primary learning has been in one culture adopt attitudes, values, and behaviors from another culture (Suarez, 1994). For the purposes of the study, acculturation includes language, dress, and diet. As acculturation is thought to be related to the length of time immigrants spend in the countries they have immigrated to, time since immigration was another factor that was included in the conceptual framework. Religion was the final factor added to the conceptual framework. Religion was added

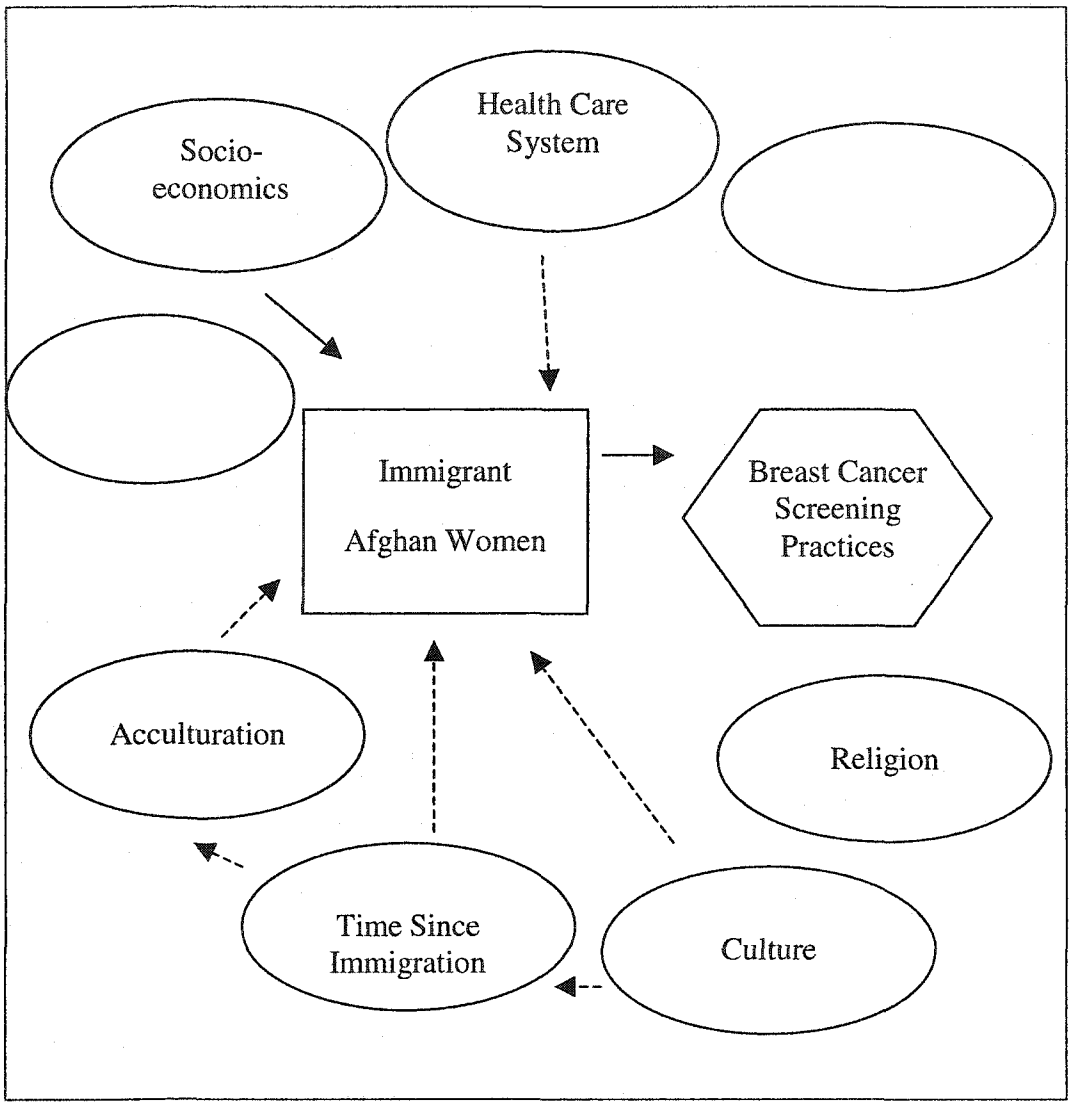
since no literature exists on Muslim Afghan women and breast cancer screening. Furthermore, a recent study by Bowen, Singal, Eng, Crystal, and Burke (2003), demonstrated that some relationship exists between Jewish women and intentions to follow physician recommendations for mammograms. Hence, in order to determine whether or not religion is an influencing factor for the breast cancer screening practices of this Muslim Afghan population group, religion was added to the conceptual framework.

The square represents the target population to be studied. The hexagon represents the public health issue that was studied in relation to the target population. The ovals surrounding the inner two shapes represent the factors that may impact the breast cancer screening practices of immigrant Afghan women. The ovals that are filled in represent the factors that this research addressed. The empty ovals suggest that the identified factors that impact breast cancer screening practices do not portray an exhaustive list. One aspect of the study was to identify other influencing factors that arose during the collection and analysis of data with the intent of adding more ovals.

At this point, the solid arrow pointing from the Afghan women to the breast cancer screening practices suggests the importance of breast cancer screening in this population group. As Health Canada (2003, Key determinants, para 5) lists socioeconomic status as a determinant of health, there is a solid arrow from socioeconomics to Afghan women. Although some studies suggest that culture, time since immigration, and the health care system itself affect the health of visible minorities, there is no clear evidence that these relationships hold true for Afghan immigrant women (Health Canada, 2003, Oxman-Martinez et al., 2000; Mackey & Barron, 1997/1998; MacKinnon & Howard, 1999; Eddy, 2000; Maxwell et al., 2001; Longman et al., 1992;

Peragallo et al., 1998). Therefore, dotted arrows represent the less clearly defined relationships between the immigrant Afghan women box and the ovals that represent these factors. All of the arrows are not shown in the conceptual framework diagram, as the directions of relationships are unknown, as well as the relationships, themselves. These arrows will be added towards the end of the study as relationships and their direction come to light.

Figure 1: Immigrant Afghan Women and Breast Cancer Screening Practices Framework



Organization of This Thesis

A broad selection of literature on breast cancer, breast cancer screening, and minority women is presented above. Chapter 2 contains the methods utilized for this study including the general research approach, sampling technique and the expected outcome. The results of this study are presented in chapter 3, followed by an in-depth analysis and discussion in chapter 4. Recommendations to improve health policy with respect to breast cancer screening are offered in chapter 4.

Chapter 2

Methods

General Research Approach

This project included the following activities: problem identification (refers to the activities that entail identifying, describing, and quantifying the magnitude of the public health problem, which is breast cancer screening practices), research and data gathering, data analysis and interpretation. A discussion of policy implications with respect to breast cancer screening was accomplished by using the available information to describe what factors need to be altered in order to improve the breast cancer screening practices of immigrant Afghan women.

Data were collected from two distinct cohorts of Afghan women in two Canadian cities, Edmonton and Calgary. The collection of data from Afghan women over 50 years of age, who have immigrated in the past 10 years, focused on attitudes and beliefs of breast cancer and breast cancer screening practices (mammography, clinical breast exam, and breast self exam). Various factors thought to impact breast cancer screening practices were also explored in the study. Since Zapka et al. (1996) found that women's self-reports of breast cancer screening practices can be used only as broad windows of accuracy, rather than reporting specific dates of past screening, the survey method is seen as an appropriate method of data collection for this study. Therefore, a standardized survey instrument and interview questions were employed for data collection (Appendix C).

The information letters (Appendix D) and consent forms (Appendix E) were translated into Farsi, and maintained at the same comprehension level, for those who are

unable to read, write and understand English. The accuracy of translation was confirmed by a Farsi-speaking individual. In addition, for those unable to read or write Farsi, a Farsi-speaking interpreter/translator was present to verbally aid with data collection. The interpreters/translators were trained to collect the data. They were trained to ask the survey and interview questions the same way with each participant in order to reduce the bias introduced to the study. In addition, they were asked to record the participants' responses exactly as they were conveyed. This was proposed in efforts to exclude the translators' interpretations of specific responses to the questions; this would reduce bias as well.

A convenience sample of Afghan women was identified by Farsi-speaking interpreters/translators during meetings with the Afghan community. As this population group does not speak English, women who met the inclusion criteria were informed of the study ahead of time by a Farsi-speaking translator/interpreter. This included providing them with an information letter and the consent form. The participants were given sufficient time (as requested by them) to review the information letter and the consent form. The objectives of the study were reviewed with the potential participants. The individuals were then invited to participate in the study. The women were asked to contact the translator/interpreter if they wanted to participate in the study. If the individual showed interest, the completed consent form was asked to be returned. After consent was obtained, the surveys were given to the participants.

The actual data gathering through the survey took place in a quiet area where confidentiality could be maintained. Where the collection of data at the meetings was not feasible, the translator met with the individuals in a different setting or completed the

survey and interview questions via telephone. After the individuals filled out the surveys, they were invited to respond to the interview questions. It took no more than 30 minutes to complete the survey and 30 minutes to complete the interview. The interpreter/translator was the best individual to complete telephone interviews since they were able to communicate effectively with study participants. A Farsi-speaking translator/interpreter was present at all times, to further explain the study if the potential participants had any questions regarding the study.

The survey instruments employed closed-ended questions structured on a 6-point Likert-type scale, with a grade 5.2 comprehension level. The questions were related to the main research questions and objectives of the study as well as to the broad areas depicted in the conceptual framework. The survey instruments collected background information on the perceptions of Afghan women on the following:

1. General knowledge about breast cancer screening
2. The process of acculturation by asking the women about the primary language spoken in and out of the home, their primary form of dress at home and in public, their diet at home and outside of the home
3. Cultural and religious norms with respect to breast cancer screening
4. Interactions with health care professionals
5. Breast cancer screening practices since they have been in Canada, as well as their screening practices in their country of origin
6. Socioeconomic status
7. Educational attainment

A pretest of the survey with one participant from Calgary was completed to assess the utility of the surveys. The purpose of the pretest was to identify words, phrases, terms, sentences, response categories and definitions that were ambiguous, unknown or irrelevant to the participants (Shi, 1997). As the interpreter/translator had no difficulties administering this initial questionnaire, no changes were made to the survey wording, order of questions, or format.

The interview questions were open ended in nature to complement the survey questions by allowing the participants to further explore the facilitators and barriers to accessing the health care system in general as well as breast cancer screening. Participants were also asked to provide suggestions for reducing the identified barriers. Lastly, they were asked why they do not participate in breast cancer screening initiatives if they do not.

To meet the final research objective, data were gathered through review of relevant regional and provincial policy and procedures documents. In the case of reviewing relevant policy documents, the principal investigator obtained permission from the relevant authorities prior to conducting the review.

Sampling Technique

Convenience sampling was selected as the most appropriate research approach because it would prove to be difficult to obtain random samples due to the nature of the population and the sensitivity of the issue. A convenience sample is a group of individuals who are readily available to participate in a study (Henry, 1990) and depends on subjects who are available at the time the study is taking place to be included in the sample (Shi, 1997). Convenience sampling allows the researcher to approach the

maximum number of people available from the study population, is useful for exploratory research, and is often used for pilot studies (Bernard, 2000, p.178). This was a pilot study undertaking exploratory research. The exploratory nature of this study is appropriate as no literature was found on Afghan women and their health. In addition, current literature reveals a lack of research reported in the area of Arab women (the closest cultural group found to the Afghan group) and breast cancer screening practices (Aghassi-Ippen, Green, & Shohat, 2002). There is no established number of subjects required for a pilot study. Factors such as time, cost, and availability of participants determine the size of the pilot group. A common number for participants in a pilot study is about 10 (Nielswiadomy, 1998). Therefore, 10 women were sampled from Edmonton and 15 from Calgary. The study was cross-sectional in nature, measuring variables at a single point in time.

Confidentiality

The following precautions were taken to ensure confidentiality: consent forms were kept separate from the completed surveys; participants were asked not to provide any names or identifying information during data collection activities (aside from filling out the consent form); no names or identifying information will be used in reports, presentation, or the final thesis document; and data will be stored in a locked filing cabinet for 5 years as per the requirement of the University of Alberta. However, the researcher acknowledges that anonymity may not be maintained due to the small sample size.

Ethics Approval

The University of Alberta's Health Research Ethics Board approved this study on January 20, 2003. The Health Research Ethics Board reviewed the protocol for this

research study and found it to be acceptable within the limitations of human experimentation. The Health Research Ethics Board also reviewed and approved all related research instruments and protocols.

Expected Outcome

This research was intended to provide insight for the study participants, health care professionals and decision makers working within breast cancer screening of Afghan women. The findings provide information on how the factors identified in the study are related to breast cancer screening practices. As well, it is hoped that this study will shed some light on the facilitators and barriers to accessing services from the current health care system. Current policies regarding breast cancer screening programs for immigrant women were analyzed and policy options were explored in order to identify methods to increase such screening practices by women of immigrant groups, Afghan women, specifically. The study will inform other researchers of the feasibility and the need to conduct larger scale studies in the future.

Chapter 3

Data Analysis and Pilot Study Results

The main objective of the pilot study was to determine the breast cancer screening practices of immigrant Afghan women in Calgary and Edmonton and identify what factors impact the screening practices of these women. This data was gathered through surveys and interview questions. The questionnaire was tested to ensure efficacy. One pretest survey was conducted in Calgary. As the pretest indicated that no changes to the survey were necessary, it was included in the results of the pilot study.

Quantitative Results: The Questionnaire

The survey response rate was 100%. In total, 25 responses (15 from Calgary and 10 from Edmonton) were obtained. The quantitative data were analyzed using SPSS 11.5 software. Descriptive statistical tests were run on this data set, including the mean, median, mode, standard deviation, standard error, minimum and maximum. The data were explored to determine how best to analyze them. For data analysis presentation purposes, questions were grouped together under broad categories: acculturation, culture, religion, knowledge of breast cancer screening, breast cancer screening in home country, breast cancer screening in Canada, health care system, socioeconomics, education, age, length of time in Canada and health status.

Qualitative Results: Interview Questions

In order to satisfy the third and fourth research objectives, (To determine if the identified influencing factors facilitate or impede the breast cancer screening practices of immigrant Afghan women and To identify additional factors that could be added to the conceptual framework) and the first and second research questions, (What factors

influence the breast cancer screening practices of immigrant Afghan women? and Do the identified factors facilitate or impede breast cancer screening practices of immigrant Afghan women?), a set of open-ended questions were asked at the end of the questionnaire. The interview response rate was 56%. Fourteen of the 25 individuals provided answers to the open-ended questions. Of these, some also provided multiple answers to individual questions. Due to the small sample size and overall low response rate for the open-ended questions, these were analyzed manually, without any statistical analysis software. Content analysis was performed on this data set and the data were also explored thematically. The results of the manual analysis will be incorporated into the presentation of the statistically analyzed quantitative data.

Results

The following is a representation of part of the descriptive statistics that were obtained using SPSS software. What is shown is a summary table of screening practices and sociodemographic factors, followed by the frequency of the responses obtained from the combined two sites of individual survey items. The qualitative results were paraphrased and are linked with the corresponding quantitative sections below.

Summary of screening practices and sociodemographic factors.

Table 1 shows that of those individuals who have not had a mammogram, approximately 75% (n = 14) are unemployed and uneducated, about 65% (n = 12) belong to the 50-59 age bracket and approximately 80% (n = 15) have lived in Canada for less than 4 years. One individual did not respond to the survey item pertaining to employment status.

Table 1

Summary of Screening Practices and Sociodemographic Factors

Screen	Employed	Unemployed	Educated	Uneducated	Age 50 – 59	Age 60 – 69	<4 years in Canada	>4 years in Canada
Yes	0	5	4	2	3	2	5	2
No	4	14	5	14	12	8	15	3

Questions regarding acculturation.

As shown above in Table 2, 100 % (n = 25) of the women surveyed speak their first language at home always or most times. Likewise, 64% (n = 16) of the women speak their first language either always or most times when in public places. In addition, 84% (n = 21) of the women surveyed testify that they wear their traditional clothes when at home always or most times, whereas only 40% (n = 10) do when in public. Of the women surveyed, 100% (n = 25) stated that they eat traditional foods always or most times when at home. Only 44% (n = 11) eat traditional foods always or most times when in public places. Finally, 88% (n = 22) of the women state that they socialize with people of their own culture always or most times, whereas 28% (n = 7) testified that they socialize with people from other cultures always or most times.

Table 2

Acculturation

Survey item	Never/rarely	Sometimes	Most times/always
I use my first language at home	0	0	25
I use my first language when I am in public places	2	7	16
I wear traditional clothes when I am at home	1	3	21
I wear traditional clothes when I am in public places	9	6	10
I eat traditional foods when I am at home	0	0	25
I eat traditional foods when I am in public places	8	6	11
I socialize with people of my own culture	1	2	22
I socialize with people from other cultures	6	12	7

Questions regarding culture.

Table 3 shows that 48% (n = 12) of the sample either strongly agreed or agreed that it is considered inappropriate for women of their culture to have a male doctor. About 70% (n = 17) of the women strongly agreed or agreed that they visit doctors only when ill. One participant did not provide a response to this statement. In addition, over 65% (n = 16) of the women strongly agreed or agreed that it is inappropriate for women in their culture to have their breasts checked for changes. One of the participants did not provide a response to this statement. In addition, almost 60% (n = 13) of the women strongly agreed or agreed that it was inappropriate for women in their culture to check their own breasts for changes. Three of the respondents did not provide responses to this statement. About 50% (n = 11) of the women strongly disagreed or disagreed that it is inappropriate for women belonging to their culture to have a mammogram. One of the participants did not provide and response to this statement.

Table 3

Culture

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
It is considered inappropriate for women in my culture to have a male doctor	7	6	12
In my culture, we go to a doctor only when we are sick	2	5	17
It is considered inappropriate for women in my culture to have their breasts checked for changes	6	2	16
It is considered inappropriate for women in my culture to check their own breasts for changes	5	4	13
It is considered inappropriate for women in my culture to have a mammogram (breast x-ray)	11	6	7

Questions regarding religion.

Table 4 demonstrates that of the women surveyed, almost 60% (n = 14) strongly disagree or disagree that according to their religion, it is inappropriate to have their breasts checked for changes by a doctor. Correspondingly, over 60% (n = 14) of the group strongly disagree or disagree that it is considered inappropriate, according to their religion, to check their own breasts for changes. Three participants from the study group did not provide a response to this section. Likewise, over 60% (n = 14) of the participants strongly disagree or disagree that, according to their religion, it is considered inappropriate for women to have mammograms. Three participants from the group did not provide a response to this section.

Table 4

Religion

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
According to my religion, it is inappropriate to have my breasts checked for changes by a doctor	14	4	6
According to my religion, it is inappropriate to check my own breasts for changes	14	1	7
According to my religion, it is inappropriate to have a mammogram (breast x-ray)	14	5	3

Questions regarding knowledge of breast cancer screening.

As demonstrated in Table 5, over 65% (n = 16) of the Afghan women strongly agree or agree with the statement "I know what a mammogram is". One participant from the group did not respond. Less than half, 49%, (n = 11) of these women surveyed strongly agree or agree that they know why they should have a mammogram. Two participants from the study group provided no response. Of the women who responded, over half, 54%, (n = 13) strongly agree or agree that they know why a doctor should check their breasts for changes, One participant did not respond to this survey item. Almost 60% (n = 13) of the women who responded to this item strongly agree or agree that they know why they should check their breasts for changes. Three individuals provided no response. Of all the women who participated in the study, 12% (n = 3) strongly agree or agree that a physician or a nurse has discussed breast cancer screening with them. Furthermore, less than half, 48%, (n = 11) of those who responded strongly agree or agree that they understand the significance of breast cancer screening after having come to Canada. Three participants did not respond.

Table 5

Knowledge of Breast Cancer Screening

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
I know what a mammogram is	6	2	16
I know why I should have a mammogram	10	2	11
I know why a doctor should check my breasts for changes	9	2	13
I know why I should check my breasts for changes	6	3	13
Since I have been in Canada a doctor or nurse has talked to me about breast cancer screening	22	0	3
Since coming to Canada I understand the importance of breast cancer screening	6	5	11

Table 6 shows that 84% (n = 21) of the Afghan women this study feel they do not know how often they need to have a mammogram.

Table 6

Knowledge of Mammograms

Survey item	Every 1-2 years	Every year	Don't Know
I need to have a mammogram (breast x-ray)	2	2	21

Table 7 demonstrates that 84% (n = 21) of the Afghan women in the sample feel they do not know how often they need to have clinical breast exam.

Table 7

Knowledge of Clinical Breast Exams

Survey item	Every 1-2 years	Every year	Every 3 months	Don't know
I need to have my breasts checked for changes by a doctor	2	1	1	21

Table 8 illustrates that 80% (n = 20) of the Afghan women surveyed feel they do not know how often they need to perform a breast self exam.

Table 8

Knowledge of Breast Self Exams

Survey item	Every year	Every month	Don't Know
I need to check my own breasts for changes	2	3	20

Questions regarding breast cancer screening practices in home country.

Less than 25% (n = 5) of the women surveyed strongly agree or agree that breast cancer screening is important in their home country, as shown in Table 9. Three participants from the study group provided no answer. According to all the women surveyed, only 8% (n = 2) strongly agree or agree that they used to perform breast self examinations while living in their country of origin. The same number of respondents also agree or strongly agree that their physicians performed clinical breast examinations while living in their country of origin.

Table 9

Breast Cancer Screening Practices in Home Country

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
In my home country, breast cancer screening is important	11	6	5
In my home country, I used to check my breasts for changes	21	2	2
In my home country, my doctor checked my breasts for changes	22	1	2

Questions regarding breast cancer screening practices in Canada.

As demonstrated in Table 10, about 20% (n = 5) of the Afghan women surveyed either strongly agree or agree that they have performed breast self examinations since having moved to Canada. One participant from the Calgary group provided no answer. Similarly, 20% (n = 5) of the women strongly agree or agree that their physician has performed a clinical breast examination on them since they have been in Canada. Less than 20% (n = 4) of these women strongly agree or agree that their physician has advised them to check their breasts for changes. Two participants from the group provided no answer.

Table 10

Breast Cancer Screening Practices in Canada

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
Since I have been in Canada I have checked my breasts for changes	18	1	5
Since I have been in Canada my doctor has checked my breasts for changes	20	0	5
Since I have been in Canada my doctor has advised me to check my breasts for changes	18	1	4

Table 11 demonstrates that only 8% (n = 2) of the Afghan women, regularly check their breasts for changes most times or always. One participant provided no answer.

Table 11

Breast Self Exam Practices

Survey item	Rarely/never	Sometimes	Most times/ always
I regularly check my breasts for changes	20	2	2

Table 12 shows that 25% (n = 6) of the women surveyed have had a mammogram.

Table 12

Mammography History

Survey item	Yes	No
Have you ever had a mammogram, that is, breast x-ray?	6	19

Although a total of 6 individuals responded to the question in Table 13, some checked off more than one box. The most common reason for having a mammogram was because it was part of a regular checkup or routine screening.

Table 13

Reasons for Mammography

Survey item	Previously detected lump	Age	On hormone replacement therapy	Regular check up
If yes (to previous question), why did you have it?	1	3	1	5

Table 14 demonstrates that of the women who have had a mammogram, 50% (n = 3) have had a mammogram in the time frame of 1 year to less than 2 years ago.

Table 14

Last Mammogram

Survey item	Less than 6 months	6 months- less than 1 year	1 year – less than 2 years
When was the last time (you had a mammogram)	1	2	3

As shown in Table 15, a recurrent theme in the answers to many of the questions is cost of health care services. Having coverage for health care services and having an open-minded family are facilitators in accessing health care services for this group of women. As well, many feel that no coverage for health care services is a barrier. In addition, language was also brought up as a barrier to accessing breast cancer screening services. Having translators in place was also a recurrent theme throughout the open-ended questions. The respondents believe that having translators will enable them to access breast cancer screening services.

Table 15

Open-Ended Questions on Breast Cancer Screening

Question	Answer
What things help you to access breast cancer screening?	Open-minded family (n = 3). Health care coverage (n = 3). Financial help from family. Help from family doctor. Translators. Do not know what breast cancer is.
What things hinder you when accessing breast cancer screening?	No health care coverage (n = 5). Inability to speak English (n = 3). Male doctors. No transportation
What do you think would get rid of the barriers to accessing breast cancer screening services?	Lowering the cost (n = 2). Having translators in place (n = 2). Health care coverage (n = 4). Respect for cultural differences.
What are the reasons other than the ones covered in the survey, that you do not undergo breast cancer screening?	Cost (n = 3). Risk factors (n = 3). Lack of effective translation. Lack of education.

Questions regarding the health care system.

According to Table 16, about 25% (n = 6) of the women either strongly agree or agree that they have visited their physician more than once every 3 months since having come to Canada. Two participants from the study group provided no answer. Less than 20% (n = 4) of the women strongly agree or agree that they visit health care professionals other than physicians. Two participants did not respond to this survey item. Almost 65% (n = 14) of the participants either strongly agree or agree that it is difficult for them to understand what health care professionals say. Three participants provided no answer. Of the women who provided an answer, 50% (n = 12) strongly agree or agree that they are active participants in their health care decision-making. One participant provided no answer. Less than half of the women, 48%, (n = 11) strongly disagree or disagree with the statement "it is hard for me to access health care services. Two participants from the study group did not respond. Over 75% (n = 19) of the women strongly agree or agree that they decide when they need to see a physician.

Table 16

Health Care System

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
Since I have been in Canada I visit my doctor more than once every three months	16	1	6
Since I have been in Canada I visit health care professionals other than doctors (like nurses, dietitians, and pharmacists)	19	0	4
It is hard for me to understand what health care professionals say	4	4	14
I am actively involved in discussions about my health with doctors and nurses	4	8	12
It is hard for me to access health care services	11	8	4
It is up to me when I think I need to see a doctor	1	5	19

As shown in Table 17, a recurrent theme in the answers to many of the questions is cost of health care services. Having coverage for health care services were thought to be the main facilitators in accessing health care services for this group of women. The perception that health care services in general need to be paid for was identified as a barrier for many women. In addition, language was also brought up as a barrier to accessing health care services. Having translators in place, as well as ensuring greater coverage for health care services will enable this group to access health care services.

Table 17

Open-Ended Questions on the Health Care System

Question	Answer
What things help you to access health care services?	Health care services are covered (n = 7). Easy access to health care services. Translators. Family doctor helps access services (n = 2).
What things hinder you from Accessing health care services?	No coverage for health services and medications (n = 6). Slow emergency access (n = 3). Waiting periods for specialists. Private hospitals.
What do you think would get rid of the barriers to accessing health care services in general?	More health care coverage (n = 3). More physicians and better Emergency services (n = 2). No privatization of health care. Having translators in place.

Questions regarding socioeconomics.

Table 18 demonstrates that over 80% (n = 19) of the women are not employed or self-employed. Two participants provided no answer to this survey item.

Table 12

Employment Status

Survey item	Yes	No
I am employed/self-employed	6	19

Table 19 shows that over 65% (n = 14) of the women strongly agree or agree that their family is well off financially. Four participants from the study group provided no response.

Table 19

Perception of Socioeconomic Status

Survey item	Strongly disagree/ disagree	Neutral	Strongly/agree agree
My family is well off financially	2	5	14

Question regarding education.

Table 20 shows that about 65% (n = 16) of the women have never received formal education, and about 30% (n = 1) of those who have been educated, have gone no farther than elementary school.

Table 20

Level of Education

Survey item	None	Elementary	Junior high
What is the highest level of education you have completed?	16	8	1

Question regarding length of time in Canada.

Table 21 demonstrates that over half of the women surveyed, 52%, (n = 13) have been in Canada for less than 2 years.

Table 21

Length of Time in Canada

Survey item	< 10 years	< 4 years	< 2 years
I have lived in Canada For	5	7	13

Question regarding health status.

Table 22 shows that almost 90% (n = 22) of the women say that their health is generally good, very good, or excellent.

Table 22

Health Status

Survey item	Poor/fair	Good	Very good/excellent
In general, compared with other people my age, my health is:	3	20	2

Chapter 4

Discussion

A number of factors that influence breast cancer screening practices have been identified in the data obtained. This chapter presents a discussion of the analysis of the results. First, the breast cancer screening practices of the sample studied will be discussed in relation to the screening practices of the general Canadian population. Second, the study findings of breast cancer screening practices will be discussed in relationship to acculturation, culture, knowledge and attitudes of breast cancer screening and religion. In addition a discussion of the possible associations detected in the analysis will be presented. The discussion will also incorporate the rationale for the revisions made to the conceptual framework.

Comparison with the General Population

Three questions from the 2000 Canadian Community Health Survey were utilized in this questionnaire in order to compare the sampled Afghan women with the women in the general population. These questions are:

1. Have you ever had a mammogram, that is, breast x-ray
2. Why did you have it?
3. When was the last time?

According to the national results of the Canadian Community Health Survey, 95.7% of the respondents eligible to answer the breast cancer screening questions have had a mammogram (Statistics Canada, 2003, Canadian community health survey results, Table 105-0043). According to Statistics Canada, of the same respondents, 69.5% had received a mammogram within the last 2 years. The number of responses to the question

"why did you have it?" was too small to report a meaningful result (S. Hebert, personal communication, September 2, 2003). The results of the pilot study of the immigrant Afghan women clearly indicate that their mammography screening rate is well below the national screening rate at a mere 25%.

Acculturation and Breast Cancer Screening Practices

As previously mentioned, acculturation is defined as the process in which individuals whose primary learning has been in one culture adopt attitudes, values, and behaviors from another culture (Suarez, 1994). Again, for the purposes of this study, acculturation includes language, dress, diet, and cultural norms. Differences found between language, diet and dress behaviors of these women while at home and in public places suggest that some level of acculturation has taken place.

O'Malley et al. (1999) have linked having higher acculturation to having had a recent clinical breast examination and mammogram for screening purposes. This may not be the case for this population group as those who have been in Canada for a shorter period of time seems to be more acculturated but have a lower rate of breast cancer screening than those who have been in Canada for a longer time period. For instance, more of the women who have been in Canada for longer than 4 years speak their first language when in public, wear traditional clothes when in public, and eat traditional foods when in public, and yet, have a higher breast cancer screening rate than the women who have been in Canada for less than 4 years. Further studies are needed to determine if these women actually speak English (and if they do to what extent) or simply not speak it at home as often as they would while in public places. The level of acculturation of the women who have lived in Canada for less than 4 years may be linked with the extent and

frequency of socialization with individuals from other cultures. More of the women who have been here for less than four years socialize with individuals from other cultures. One explanation may be that the women who have lived in Canada for less than four years may have had a transition period in the neighboring countries to Afghanistan before arriving in Canada. This would have exposed them to a different culture, as well as started the process of acculturation to some extent. The women who have been here for longer than four years may have arrived directly from Afghanistan during the period when Canada was accepting immigrants out of the sheer necessity to physically remove them immediately from war-torn Afghanistan. In addition, the level of acculturation may also be due to rural versus urban place of origin in Afghanistan. It may be that those from rural areas are having a more difficult time with internally negotiating a balance between Afghan culture and Canadian culture. The relationship between the extent and frequency of socialization of this cultural group with those from other cultural groups as well as level of acculturation needs to be studied further before any definite statements can be made.

It is important for future research to evaluate the cultural norms of this population group, as the current study did not address this in detail. For instance, is it frowned upon if members of this cultural group adopt the values, practices, and behaviors of the dominant culture? Questions such as whether or not it is acceptable for Afghan women to speak English or wear western clothes (at home or in public) need to be asked and explored further. How this affects acculturation (with respect to level of acculturation and the amount of time it takes for acculturation to occur) of the minority group should then be investigated.

No statistical significant linkages between acculturation and breast cancer screening practices were found during the data analysis of this study. This is mainly due to the pilot exploratory nature of this research, as well as the intrinsic difficulties in measuring levels of acculturation. However, this factor is kept in the revised framework, as further research is necessary in order to demonstrate any conclusive relationships.

Culture and Breast Cancer Screening Practices

An appreciation of the need to focus on culture-specific models for delivering health care to diverse population groups is gaining momentum in the health care industry. Many theories, in the past, have ignored the important role of culture in explaining and understanding behavior of diverse groups (Baldwin, 1996). This is because the available literature on the Eastern world is limited (Arkoun, 1994). As well, the majority of this literature depends on Western scholars. However, more recently, studies are utilizing conceptual frameworks that incorporate culture as an important factor in obtaining particular outcomes. This is because ethnic culture is the medium through which an individual's beliefs, standards and norms for health and illness behaviors are learned, shared, practiced and judged (Drew, 1996). Cultural beliefs give meaning to health and illness experiences by providing the individual with acceptable causes of illness, rules for symptom expression, interactional norms with health care providers, help-seeking strategies, and determining desired outcomes.

Although no statistically significant linkages between culture and breast cancer screening were found, the results obtained provide practical significance. In general, the population group studied feel that breast cancer screening methods are unacceptable according to the conventions of their culture. About half of all the women studied feel

that having a male doctor is culturally inappropriate. Similarly, more than half of these women feel that it is considered culturally inappropriate to have a clinical breast exam or perform a breast self exam. However, less than half of the women feel it is culturally unacceptable to have a mammogram.

Modifying health care beliefs, as dictated by culture, is, of course, an enormous challenge. Some cultures place low value on early detection and screening of cancer, and this must be strategically addressed if we are to obtain positive health outcomes (Bailey, Bennett, Kicks, Kemp, & Warren, 1996). One way is by placing more emphasis on breast cancer screening through mammography, as this is not only the most effective method of screening to date, but also more culturally acceptable than the other screening methods in this population group.

Knowledge and Attitudes and Breast Cancer Screening Practices

Although information regarding knowledge, attitudes and behaviors was acquired in this study, it was not applied to any particular framework that would be useful in providing guidance as to how to positively influence behaviors that promote health. One framework that may prove to be useful when addressing the low breast cancer screening rates of immigrant Afghan women is the Health Belief Model.

The Health Belief Model provides a valuable framework for understanding health behavior, and could easily be extended to incorporating health behavior as it pertains to culture. According to this framework, susceptibility, seriousness, benefits, barriers, confidence, and general health motivation are related to health behaviors (Foxall, Barron, & Houfek, 1998). Within the Health Belief Model, women who believe that they are personally susceptible to breast cancer and that breast cancer is a serious disease are more

likely to engage in screening activities (Holm, Frank, & Curtin, 1999). In addition, women who perceive more benefits from participating in screening activities and fewer barriers are more likely to take part in screening activities (Champion & Menon, 1997).

However, in order for a population group to perceive benefits of a program, they must understand what the program is for. For instance, in response to the open-ended question: What things help you to access breast cancer screening?, one individual responded: "I think first we should know what breast cancer is". In addition, the majority of the women studied did not know why they should have mammograms or how often they should have mammograms. Almost all individuals who participated in the study do not feel they know how often they need to have clinical breast exams or perform breast self exams. This may be because only about 10% of the study group testify that a doctor or nurse has discussed breast cancer screening with them in Canada.

Similar results were found in the category of screening practices in their place of origin. Less than one quarter of the women studies strongly agree or agree that breast cancer screening is important in their home country. If emphasis on breast cancer screening was not placed in Afghanistan, it is not surprising that screening for breast cancer in Canada is at an alarmingly low rate. Thus, the importance of targeting specific cultural groups and framing education messages such that they impact the way these women think are becoming of great importance. A recent study found that presenting multicultural loss-framed messages (emphasizing the cost of not taking action) was effective for Latin American women (Schneider et al., 2001). Tailoring messages about breast cancer screening may increase the screening rate of immigrant Afghan women.

Motivating people to engage in behaviors that promote health is not as straightforward as merely providing relevant information.

Religion and Breast Cancer Screening Practices

Based on the pilot study results, no statistical significant association could be made between immigrant Afghan women's breast cancer screening practices and religious beliefs about breast cancer screening. As virtually no literature exists on this particular topic, the comparisons made in this section will be in relation to other minority groups. A recent study published by Bowen et al. (2003), demonstrated that Jewish women with a higher religious identity score were more likely to have intentions to follow physician recommendations for mammograms. This may be because religious institutions and organizations provide social regulation and social support that promotes compliance to societal rules, including behaviors that promote health. Similarly, the significance in Islamic religious law of health proposes another explanation for the association between religion and intention to abide by recommended breast cancer screening behaviors. According to Islamic law, health is of great importance. For instance, those who are ill or nursing mothers are not obligated to fast during the month of Ramadan (al-Uzma & al-Khui, 1989). Muslim women may comply with prescribed breast cancer screening out of a religious responsibility to lead healthy lives. Interestingly, practical significant differences were found between those women who have been in Canada for longer than four years and those who have been in Canada for less than four years. For instance, none of the study participants who have been in Canada for longer than four years and more than half of those who have been in Canada for less than four years strongly agree or agree that according to their religion, it is

considered inappropriate to have a clinical breast exam and perform a breast self exam. Although this provides no statistical significance, it is practically significant as it sheds some light on reasons behind the low screening rate. Yet another factor that must be considered here is many of these women may be coming from an area that may have had an extremely radical interpretation of Muslim law. This would, in essence, shape their behavior. If harsh consequences for certain behaviors were implemented, then out of being merely conscientiousness, these women may, in fact, be reluctant to engage in behaviors that promote health.

Less conflict was found between religion and mammography as a screening tool. Less than 15% of the women who responded to this question strongly agree or agree that it is considered inappropriate for women to have mammograms according to their religion. This raises questions about whether or not these women feel that breast cancer screening itself, or how the screening is done, or by whom it is done is in conflict with their religious beliefs. Siddiqi (1959), in his discussion of social restrictions that Islam places on both men and women, emphasizes the compulsory duty of keeping certain parts of the body covered. These body parts should not be exposed to any person, except spouses, or when medical or other pressing necessities require exposure. If this population group does not view routine screening as medically necessary then they may feel that screening contradicts their religious beliefs. On the other hand, if screening is seen as an acceptable practice, how the screening is conducted and by whom are issues that are worthy of further exploration. Mammography screening may be viewed as a more religiously acceptable form of screening because a certain amount of distance is

required to be kept between the health care professional and the client during the screening procedure.

Turning to the topic of health care professionals and religion, it would be interesting to see if these women would view screening by a male physician (versus a female physician) as contradicting their religious beliefs. If these Afghan women are coming from a society that does not place value on educating women, then the word doctor may be interpreted as meaning male doctor. It would be intriguing to uncover if these women would respond in a similar fashion if the words "female doctor" were used instead of "doctor" in the survey tools used in this study.

As expected, no statistical significant relationship was established between immigrant Afghan women's breast cancer screening practices and religion. This, again, is due to the limited sample size. Little research is available on breast cancer incidence rates or preventive health practices among Islamic women either in their homelands or as immigrants. A recent study published by Rashidi and Rajaram (2000) found that 85% of their study population had not heard of breast self examinations and 74% had not examined their breasts for changes. This is consistent with the pilot study results which indicate that about 75% of these women have never checked their own breasts for changes. Comparable with the pilot study, Rashidi and Rajaram found that the majority of their study participants had never had a clinical breast exam. The results of these two studies show that Islamic immigrant women may be a population overlooked by health care professionals in the area of breast cancer screening. This is demonstrated by the fact that, in this study, 12% of the women agree or strongly agree that doctors or nurses have

discussed breast cancer screening with them. Similarly, 20% of the participants strongly agree or agree that their physician has performed a clinical breast examination on them.

Religion was included in the revised conceptual framework. Many of those who have lived in Canada for less than four years believe that according to their religion, it is considered inappropriate to screen for breast cancer. None of those who have lived in Canada for more than four years believe that religion plays an influential role in their breast cancer screening practices. Interestingly, those who have been in Canada for more than four years have a higher breast cancer screening rate.

Possible Associations Detected in Analysis

A number of possible associations were discovered during the data analysis. One link worthy of discussion is that the majority of those women who had not had a mammogram at the same time had not had a mammogram recommended by their family doctor. This is consistent with the literature, as women are more likely to engage in mammography screening if recommended by a physician, as previously mentioned (O'Malley et al., 2001). As well, it was noted that the screening rates of those who have been in Canada for a longer time period were higher, and that these individuals also perceived that they understood the importance of breast cancer screening more than those participants who have been in Canada for a shorter time period. This could be been due to many reasons. For instance, it was noted that those who have lived in Canada for longer generally have interactions with health care professionals other than physicians, whereas those who have lived in Canada for a shorter time period do not. Similarly, the women who have lived in Canada for a longer time period have had discussions about breast cancer screening with doctors and nurses and those participants who have lived in

Canada for a shorter time period have not. Likewise, more of those participants who have lived in Canada for a longer time period felt that breast cancer screening was important in their home country and participated in screening initiatives there more than the women who have lived in Canada for a shorter time period. Furthermore, the participants who have lived in Canada for a longer time period frequented their family physicians more than those who have lived in Canada for a shorter time period. This could have provided more opportunity for physicians to discuss breast cancer screening. However, it must be noted that only 60% of the women who have lived in Canada for a shorter time period feel that they decided when they need to see a physician, whereas almost all of those women who have lived in Canada for a longer time period decide when they need to see a physician. Therefore, level of freedom about healthcare decision-making within the family is an issue that must also be kept in mind. The "health care system" influencing factor portrayed in the revised conceptual framework encompasses all of the factors described above.

Another connection discovered is that most of the women who participated in the study felt that breast cancer screening was not important in their country of origin, and did not regularly participate in breast cancer screening in their home country or in Canada after immigration. Therefore, breast cancer screening practices in country of origin was an influencing factor that was added in to the conceptual framework.

As education is a clear determinant of health (Tulchinsky & Varavikova, 2000), and hence linked with breast cancer screening practices, it is included in the conceptual framework as an influencing factor. It was noted that less than half of the participants have received no more than an elementary level education; and this, as well, could be

linked to the low rates of breast cancer screening practices. Having a low level of education could also provide a reason for experiencing difficulty understanding health care professionals. This alarmingly low level of education in this population group could be explained by the now well known punishment by the Taliban regime of women who were being educated.

One factor that is worthy of discussion is that "elementary" level of education could have also been misinterpreted as English as a second language training that some individuals may have received after arriving in Canada. More individuals who have lived in Canada for a longer time period found it difficult to understand health care professionals. This may be a function of the length of time since immigration, with those individuals being accommodated for their lack of skills in communicating in the English language. This may be because health providers may be making more of an effort to include translators during health visits of those who have arrived in the more recent past. Health care professionals may perceive those who have lived in Canada for a long time period to already have had some form of English language training. Since the length of time since immigration impacts so many factors, with respect to screening practices of the Afghan population group, it was kept in the revised conceptual framework.

In summary, the length of time since immigration is a significant influencing factor in the conceptual framework. Many of the participants who have been in Canada for a longer period screen for breast cancer at a higher rate, are more educated, perceive a better understanding of breast cancer screening, feel it is easier for them to access health care services, and are employed at a higher rate than the participants who have lived in Canada for a shorter time period. This could also influence their interactions with health

care professionals and the health care system in general. Although specific data on socioeconomics was not collected, it may be inferred that the participants who have lived in Canada for a longer time period are better off financially. Although the expected results in acculturation, as defined by language, diet, and dress were not found, the association between time since immigration and acculturation remains to be confirmed and is therefore left in the conceptual framework.

Rural or urban place of origin is an influencing factor that has been added to the revised conceptual framework. Although no linkages were found as this factor was not considered in this research study, it may be a factor that impacted their screening practices in their home country and may also impact screening practices in Canada. It is therefore a worthy inclusion in this framework.

Perceptions of individual health status may be another factor that impacts the breast cancer screening practices of this study group. Most of the individuals felt their health was good, very good, or excellent. This may contribute to the low screening rate since these women may be coming from an area or culture that generally associates sickness with health interventions. For instance, about 70% of the study participants agree or strongly agree that in their culture they visit doctors only when ill. Therefore, if these women view themselves as being healthy, then they may not see the need to seek out health care that is preventive. Again, because the results of this study are not conclusive, health status was added in as an additional factor that impacts the breast cancer screening practices of immigrant Afghan women and requires further study.

Open-Ended Questions

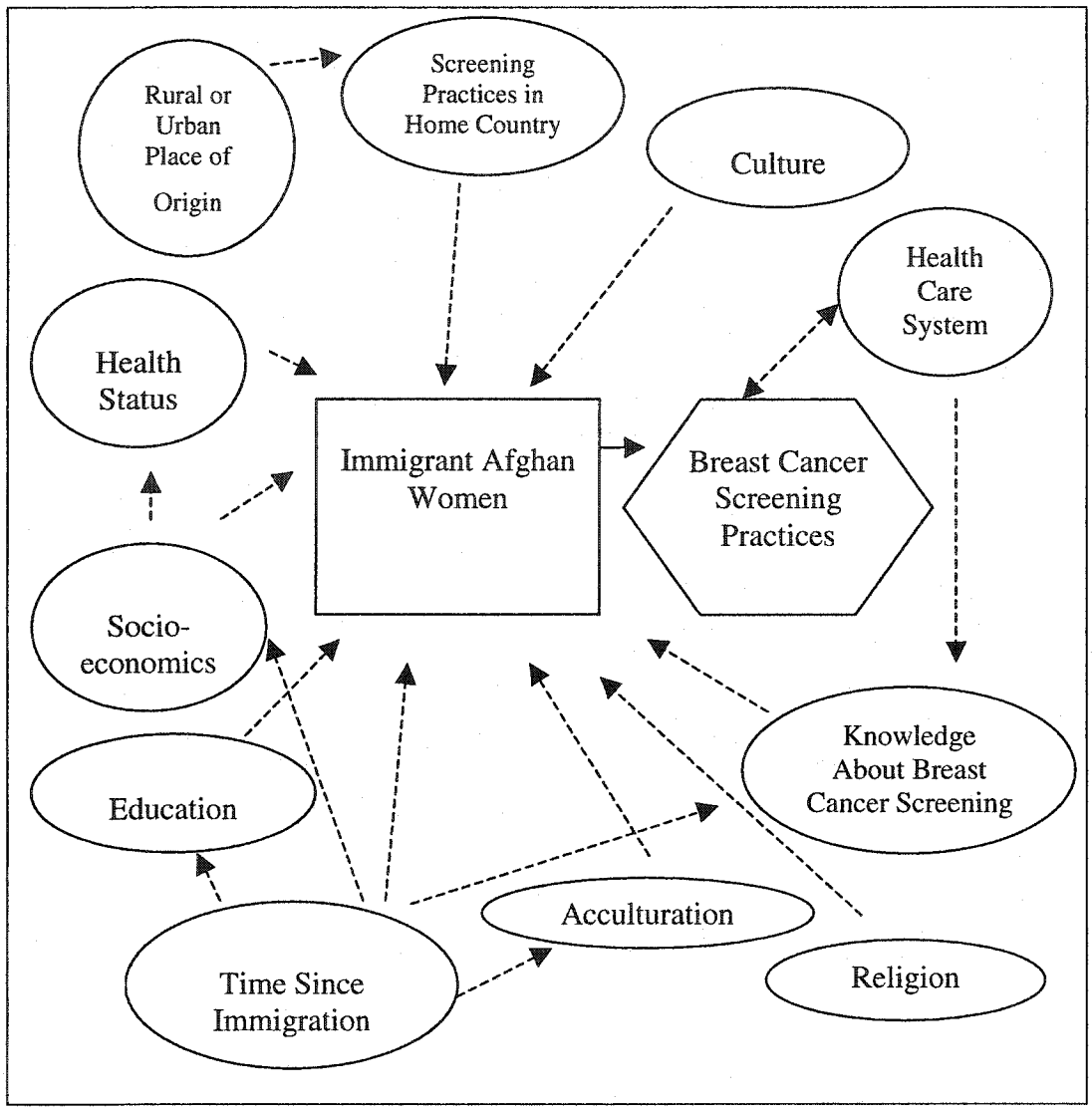
The cost of health care was a recurrent theme in the open-ended questions. Although many of the respondents believed that health care coverage was an enabling factor when accessing health care services and breast cancer screening services, almost an equal number of respondents noted that the lack of health care coverage and the resulting perceived cost of services is a barrier when accessing health care services and breast cancer screening services. In response to the open-ended question: What things hinder you when accessing breast cancer screening?, the responses included: "no coverage plan", "costs", "the high cost might not be covered by my insurance", and "it is not covered by my work insurance plan". This demonstrates a lack of knowledge about the health care system in general. This is consistent with the literature as Richard and Jegielski (1999) found that one barrier to accessing illness prevention programs is insufficient knowledge of how the health care system works. As a result, it is important to educate this population group about the Canadian Health Care System, with the hopes that their perception of cost barriers will not deter them from accessing services that are covered under the Canada Health Act.

Revised Conceptual Framework

The revised conceptual framework is shown in Figure 2. All of the ovals surrounding the inner two shapes represent the factors that may impact the breast cancer screening practices of Afghan women. The empty ovals were filled and represent other factors that may also impact breast cancer screening practices. Again, these ovals do not portray an exhaustive list. The arrows remain dotted, as this research did not provide any conclusive evidence that the factors listed do, in fact, influence the breast cancer

screening practices of immigrant Afghan women or how they influence screening practices. The dotted arrows represent the fact that these relationships are not clear and require further investigation.

Figure 2: Immigrant Afghan Women and Breast Cancer Screening Practices Framework - Revised



Study Limitations

The main limitation of this study is the small sample size. For this reason, the results obtained in this analysis cannot be generalized to the larger Afghan population.

Initially, the plan was to obtain two responses from the piloting of the study instruments: one from Calgary and one from Edmonton. Unfortunately, due to initial data collection difficulties in Edmonton, the instruments were piloted only in Calgary.

After descriptive statistics were run on the data set, the data were subsequently analyzed using the cross-tabulations function in SPSS software. This was done in order to satisfy the third and fourth research objectives, (To determine if the identified influencing factors facilitate or impede the breast cancer screening practices of immigrant Afghan women and To identify additional factors that could be added to the conceptual framework) and the first and second research questions, (What factors influence the breast cancer screening practices of immigrant Afghan women? and Do the identified factors facilitate or impede breast cancer screening practices of immigrant Afghan women?). This was accomplished by cross tabulating the individual breast cancer screening practices, with all of the other variables. In order to accomplish this, the data was re-coded into SPSS, into broad categories. As expected for a pilot study, due to the small sample sizes, no statistical significance was found.

The two interpreter/translators at the Edmonton site provided insightful information about accessing health services for this population. They mentioned that due to the language barrier, as well as cultural traditions, other family members most often make health decisions for the elders in the family. It is often the children or grandchildren who not only tell the elders what types of services they need, but also make the

appointments for them. Hence, exploring these open-ended questions with this specific age group would not have yielded the best results. For future studies, including family members may be beneficial because they would have more information about facilitators and barriers to accessing health services in the community at large.

Another interesting point is that the translator/interpreter in Calgary has lived in Calgary for over 10 years, whereas the translators/interpreters in Edmonton have lived in Edmonton for less than 2 years. It is noteworthy that of the Immigrant Afghan women who participated in the study in Edmonton, the majority of them have lived in Canada for less than 2 years, and of the Calgary women, the majority of them have lived in Calgary for at least 4 years. This may demonstrate a bias on the part of the interpreters/translators in that they may have contacted those individuals with whom they are familiar. This demonstrates that the study population is not representative of the greater Afghan population.

Similarly, as the time since immigration for the interpreters/translators is considerably different between the two sites, the validity of the responses of the Edmonton site in particular is questionable. For example, the way in which participants' questions were answered in Edmonton may have differed than how they were answered in Calgary, although training on data collection was provided to all interpreters/translators. The interpreter/translator at the Calgary site has lived in Canada for more than a decade and may be better versed in answering questions about the health care system and may also be better at translating as she has been schooled in Canada.

A final limitation is that the population profiles of the individuals in the sample were not obtained. It is unknown whether or not the individuals actually have similar

backgrounds. For instance, it would have been useful to know if the individuals came from urban or rural locations in Afghanistan, and if they came from different regions in Afghanistan. This would have added insight into the interpretation of the results.

Policy Implications

The way care is delivered has remarkable impact on the patient-provider interaction and the outcomes experienced by the patient. Interventions to improve the rates of mammography have varying degrees of success. Many interventions are unsuccessful because they fail to address the real need of target groups, especially underserved populations.

Physicians play a major role in people's health and well-being through recommending prevention and curative activities. The physician's referral was mentioned as a strong influence on screening mammography (Ahmed et al., 2001). In this pilot study, 17% of the women agree or strongly agree that their physician has advised them of breast cancer screening. This implies a need to educate physicians to discuss not only emergent health issues with minority population groups, but to also include them in health promotion activities. Furthermore, it may prove to be beneficial to rely on other health care professionals, such as public health nurses to engage themselves in this health promotion/illness prevention role.

Inadequate communication skills are an obstacle of great magnitude for many minority groups when trying to access health care services. Of the population studied, 64% of the women agreed or strongly agreed that it is difficult for them to understand what health care professionals say. This could be caused by two factors: the inability of the women to speak English fluently and the lack of culturally sensitive care provided by

health care professionals. Therefore, educating health care professionals about addressing issues of breast cancer screening in a tactful way that takes cultural sensitivities into consideration could possibly be a policy option. As well, implementing English language classes for this group of women would also prove to be beneficial. Both of these interventions would open the lines of communication between the health care professional and the client. Lastly, having interpreters/translators that are readily accessible may prove to remove the language barriers often experienced by this population group when accessing health care services, and breast cancer screening services specifically.

A good quality physician-patient relationship and having a woman as primary care physician have shown to increase knowledge about breast cancer as well as participate in screening mammography for Islamic women (Ahmed, Fort, Micah, & Belay, 2001). However, physician recommendation may not be enough. As previously mentioned, O'Malley et al. (1997) found that it could be useful to implement interventions aimed at this specific ethnic group including commercials aired on ethnic channels as well as information pamphlets with illustrations that depict women of varying cultural backgrounds.

Although Screen Test already tracks the ethnic background of the population it surveys, successes to date with respect to diverse cultural groups includes Chinese, Vietnamese, Filipino, East Indian, and Aboriginal (Alberta Cancer Board, 2002; P. Taschuk, personal communication, October 29, 2002). No specific interventions toward the immigrant Afghan group have been initiated. Please refer to Appendix F for a description of Screen Test. The Afghan population seems to be underserved with respect

to breast cancer screening services. The health care system must reexamine its policies, processes and procedures in order to determine whether the successes to date can be sustained and enhanced in light of the national commitment to abolish racial and ethnic inequalities in cancer screening and therapeutic management (Ahmed et al., 2001).

Future Research

Future research on immigrant Afghan women and breast cancer screening practices should focus on:

1. Determining whether or not health care professionals are aware of the low rates of participation in breast cancer screening programs by Afghan women.
2. Gathering baseline data on knowledge, attitudes, and beliefs related to breast cancer screening through a larger-scale study.
3. Determining what factors would empower these women to participate in screening programs.
4. Applying the baseline data gathered to a conceptual framework, such as the Health Belief Model in efforts to positively influence screening practices of this population group.
5. Determining whether or not health care practitioners are well-versed in pertinent religious and cultural values and beliefs of this particular group of women and taking appropriate measures to implement education programs for health care professionals, if required.

Increased attention to these main areas will help sensitize practitioners in providing culturally competent care to immigrant Afghan women, thereby reducing the emotional and physical costs related to breast cancer screening.

Conclusion

When compared with national statistics, the immigrant Afghan women surveyed in this study screen for breast cancer at an alarmingly low rate. Many diverse factors may influence the breast cancer screening practices of immigrant Afghan women. These factors include: acculturation, culture, urban/rural place of origin, screening practices in home country, knowledge about breast cancer screening, interactions with the health care system, religion, socioeconomics, health status, education and time since immigration. The factors, themselves, and the extent and direction of influence has yet to be determined, though this research project allowed for a glimpse into some potential factors. Once validated these factors as well as other potential influences must be included in research, education and practice if improvement in breast health care for immigrant Afghan women is to become a reality. The current research is a first step in this important journey.

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Appendix A

Common Risk Factors Affecting Breast Cancer

It must be noted that this section is by no means comprehensive, and is intended to provide the reader with an overview of some of the more common risk factors, both non-modifiable and modifiable. As well, due to the nature of this thesis, confounding effects, as well as additive effects of risk factors are minimally discussed, but must be kept in mind nonetheless.

Non-Modifiable Risk Factors

Risk factors are factors such as habits, characteristics, or environmental conditions that are associated with an increased rate of a subsequently occurring disease or conditions. Non-modifiable risk factors are those factors that an individual has no control over and cannot change.

Gender and age.

Gender is the primary non-modifiable risk factor for breast cancer, with the ratio of women to men with breast cancer being approximately 135 to 1, respectively (Bilimoria & Morrow, 1995). Age is another non-modifiable risk factor for breast cancer. Bilimoria and Morrow assert that as age progresses from 35 to 65 years, there is a six fold increase in the risk for acquiring breast cancer. Similarly, for women younger than 65 years of age compared with women aged 65 or older, the risk of acquiring breast cancer for the women in the older age bracket is 6 fold higher (Singletary, 2003).

Reproductive factors.

Reproductive function is an important factor in breast cancer. In essence, breast cancer is a hormone-dependent disease. Women lacking functioning ovaries who never

receive estrogen replacement therapy do not develop breast cancer (Lippman, 2003). Estrogen regulates growth and differentiation of breast epithelium and is thought to be a major contributor to the pathogenesis of breast cancer (Krisnamurthy & Sneige, 2002). However, hormones produced and released by the female reproductive organs are difficult to study on a population scale because of their complex cyclical patterns in pre-menopausal women (Windham et al., 2002).

Reproductive risk factors for breast carcinoma are all believed to operate through alterations in the intensity of exposure to estrogen (Krisnamurthy & Sneige, 2002). The three dates in a woman's life that significantly influence breast cancer incidence are age at menarche, age at first pregnancy, and age at menopause. Women who experienced menarche at the age of 12 have a higher chance of developing breast cancer, with a relative risk of 1.3, when compared to women who began menstruating after the age of 15 (Singletary, 2003). Women who deliver their first full-term pregnancy by the age of 18 have a reduced (30 to 40%) risk of developing breast cancer when compared with women of the same age who have never given birth to viable offspring (Lippman, 2003). As Singletary discovered, at the other end of the reproductive spectrum, women who did not experience menopause until age 55 or after demonstrated a relative risk of 1.22 compared with women who experienced menopause before the age of 45. No discussion about female hormones would be complete without reference to oral contraceptives and hormone replacement therapy. Lippman indicates that studies of oral contraceptive use indicate that these sources of exogenous hormones cause little if any increased risk of breast cancer. Contrary to the many well-documented protective effects of hormone

replacement therapy, according to Lippman, studies demonstrate a small increase in breast cancer incidence, particularly with high dosages and a long duration of treatment.

Family history.

With family history as a risk factor for breast cancer, the degree of risk is a function of the type of relative affected (first or second degree), the age at which the relative developed cancer, and the number of relatives affected. Compared to individuals with no family history of breast cancer, studies have predicted a relative risk of 1.8 linked with a first-degree relative who developed breast cancer at 50 years of age or older, while the relative risk for a first-degree relative who developed breast cancer at an age less than 50 years is 3.3 (Singletary, 2003). In other words, relative risk for having a first-degree relative who developed breast cancer younger than 50 years of age increased by approximately 2-fold when compared with the relative risk off having a first-degree relative who developed breast cancer older than 50 years of age. According to Singletary, the relative risk associated with having a second-degree relative with breast cancer is 1.5. Approximately 10–15% of affected women have a mother and/or a sister with breast cancer (Aghassi-Ippen et al., 2002). Singletary found that if two first-degree relatives (e.g., mother and daughter) are affected, the relative risk is 3.6. In other words, if an individual has two first-degree relatives with breast cancer, this individual's risk for developing breast cancer is increased almost 4 fold when compared to an individual who has no first-degree relatives with breast cancer. If a first-degree relative was diagnosed before menopause and both breasts were affected, this increases the woman's risk even further (Gross, 1998).

Genetic predisposition.

Recent developments in genetics have advanced the understanding of the risk of hereditary breast cancer. In 1994 the BRCA1 gene was discovered, followed in 1995 by the discovery of the BRCA2 gene (Zimmerman, 2002). Both BRCA1 and BRCA2 are tumor suppressor genes, localized to chromosomes 17 and 13, respectively (Chabner, 2001). Humans have two copies (alleles) of almost every gene including these two genes. An individual who inherits one mutated allele of the gene and one allele that has a normal sequence is considered a mutation carrier (De Prince, 2000). Women who inherit a mutated allele of this gene from either parent have an approximately 60 to 80% lifetime chance of developing breast cancer (Lippman, 2003). Similarly, a woman with a mutation in BRCA1 or BRCA2 has a 33–50% likelihood of developing breast cancer before age 50 compared with a woman with no mutation of these particular genes (Frank & Critchfield, 2002). Zimmerman asserts that over half of the women with a mutation of either gene develop breast cancer by age 70. As Zimmerman discusses, in May 2002 researchers in Britain announced the discovery of another genetic mutation, of the CHEK-2 (or CHK2) gene, that heightens the risk of the development of breast cancer in both women and men. Although germline mutations in BRCA1, BRCA2 and CHEK-2 present a high risk of breast cancer, these two genes account for only a fraction of inherited susceptibility to breast cancer (Domchek & Weber, 2002). Specifically, BRCA1 and BRCA2 account for only 5% of all invasive breast cancers (Hindle, 2002). Nonetheless, identification of BRCA1 and BRCA2 mutation carriers is an important focus in early detection of breast cancer risk.

Modifiable Risk Factors: Primary Prevention

There appears to be an interest by the general public in risk factors that are under the direct control of the individual, for example cigarette smoking and lung cancer. This may also relate to breast cancer, since lifestyle and environmental factors are believed to be responsible for about 85% of cases (Walker, 2000). Consequently, through alterations in lifestyle and environmental factors there could, theoretically, be significant control over the occurrence and the development of breast cancer. The factors discussed below are already included in some of the present-day attempts to combat the occurrences of degenerative diseases, such as cardiovascular disease, in general, by means of alterations in lifestyle. Walker suggests that interventions made in the potentially modifiable risk factors including physical activity, diet and alcohol consumption, could help in the avoidance of nearly a third of breast cancer cases annually.

Diet.

There is considerable awareness of the association between diet and the risk of breast cancer. Because diet is modifiable, for the most part, it represents an opportunity for preventive efforts. Low dietary fat intake is presumed to reduce estrogen levels by decreasing the overall energy intake and consequently reducing adipose tissue production and storage of estrogen (Yardley, 2000). The effect of diet on endogenous hormones and breast cancer risk has been considered in various studies, but with inconsistent or inconclusive results (Bosetti, Altieri, & La Vecchia, 2002; Walker, 2000). Similarly, Bosetti et al.argue that the protective effect of a diet rich in vegetables and fruit and breast cancer risk remains unconfirmed. In contrast, in a study of dietary fiber, yardley suggests that increases in fiber result in decreased serum estrogens levels. Furthermore, a

recent study found that women who regularly consumed a multivitamin or B-complex supplement, were at lower risk of breast cancer than women who did not take supplements (Sellers et al., 2001). According to Sellers et al., Vitamin B is believed to decrease breast cancer risk by increasing DNA repair capacity.

Exercise.

In addition to its well-established cardiovascular disease and other chronic disease health benefits, physical activity, is one potential preventive measure that has recently received significant attention in relation to breast cancer risk. The interest in the association between physical activity and cancer is a relatively recent phenomenon. It is mainly in the past decade that well over 100 epidemiological studies have linked work, leisure and household physical activities to cancer risk. Physical activity is known to exert striking effects on the human body that may have some bearing on cancer risk, such as endogenous hormone levels, immune function, antioxidant defense and DNA repair (Vainio & Bianchini, 2001). Furthermore, Physical activity may also reduce the risk of cancer through its normalizing effect on body weight (Dorn, Vena, Brasure, Freudenheim, & Graham, 2003). One recent study found that occupational and household activity, both of moderate-intensity, contributed to a reduction in breast cancer risk; recreational activity of any intensity had no visible effects on breast cancer risk reduction (Friedenreich, Courney, & Bryant, 2001). In contrast, another recent study conducted by Dorn et al. demonstrated that strenuous recreational activity is associated with a reduced risk of breast cancer risk in both premenopausal and postmenopausal women. As findings from numerous studies accumulate, it is hoped that the effect of exercise on breast cancer risk will present with more consistent and conclusive results.

Alcohol consumption.

The documented effect of alcohol intake on the incidence of breast cancer appears to be modest, at best. There is, nonetheless, a positive association between alcohol consumption and breast cancer risk (Yardley, 2000). Studies indicate that consuming one drink per day or less does not significantly increase the risk of breast cancer (Singletary, 2003). Even at very high doses of alcohol (seven or eight drinks per day) Singletary found that the relative risk of acquiring breast cancer does not increase more than 2-fold, when compared to an individual who does not consume alcohol. The exact mechanism of the effect of alcohol remains unclear, however, a few theories have been postulated. Yardley presents that alcohol may possibly influence membrane permeability to carcinogens, hinder the detoxification of carcinogens, or act as a carcinogen itself and thus affect breast cancer risk. Furthermore, Yardley found that higher estrogen levels are noted in women with alcoholism than in women who are moderate consumers of alcohol. Although alcohol consumption increases breast cancer risk only slightly, there are documented preventive measures that individuals can take. For instance, in addition to ceasing alcohol consumption completely, Sellers et al. (2001) and Yardley indicate that increasing folate intake reduces the effect of alcohol consumption on breast cancer risk.

Appendix B

Breast Cancer Screening

Screening

Various research trials are under way internationally to evaluate prevention interventions such as low fat diets, and exercise therapy, as described above. However, the value of these measures is not yet known. With no widely acknowledged primary prevention, early detection through screening measures remains the main hope of decreasing mortality from breast cancer. Early detection generally means more effective treatment. In addition to saving lives, it can also contribute to a better quality of life by reducing the need for radical treatments, including extensive surgery, chemotherapy and radiation therapy. Current screening practices for breast cancer include mammography and clinical breast exams (Chalmers & Liker, 1996). To date, early detection through secondary screening measures offers the best defense against the disease. In the United States, ninety percent of women diagnosed with breast cancer in a localized stage survive at least 5 years after diagnosis (Vietri, Poskitt, & Slaninka, 1997).

Breast self-examination and breast awareness.

Despite controversy surrounding the effectiveness of breast self-examination in reducing mortality, health departments and voluntary cancer organizations do not oppose breast self-examination practices. Although no randomized study of breast self-examination has demonstrated an improvement in survival, its chief advantage seems to be detecting tumors that are suitable for conservative local treatment (Lippman, 2003).

More recently, recommendations for "breast awareness" are replacing breast self-examinations. Women are urged to become more aware of their usual or normal breast texture and appearance through routine daily practices such as showering or dressing (P. Taschuck, personal communication, October 29, 2002). In addition to becoming aware of breast texture and appearance, familiarizing oneself with changes in breast sensation and nipple changes, including nipple retraction or discharge, may indicate a need for further investigation (Cooper, 1999). However, there has been little research to determine if this recommendation results in earlier detection of breast abnormality.

Mammography.

There is general agreement that mammography is beneficial for women aged 50 or older but less agreement on its benefit for younger women. Given that the efficacy of screening mammography is well documented for women in the 50 – 69 age group, screening mammography is recommended every 2 years for this age group (Health Canada, 2003, Mammography and women's health, para 12). The time interval between mammography screenings may be adjusted based on the history of the individual, at the discretion of the family physician.

Mammography is an imaging procedure that uses X-rays to generate an image of the internal breast structure (Health Canada, 2003, Mammography, para 3). Mammograms can identify abnormalities that are 5 mm in diameter, whereas humans often cannot feel lumps less than 1.0 cm in diameter (Weaver, 2002). Mammograms are capable of demonstrating abnormal growths or changes in breast tissue before they can be detected by any other method. According to Health Canada, studies indicate that

mammograms have the potential to reduce breast cancer mortality for women between the ages of 50-69 by up to 40%. However, mammography does have certain limitations. The value of mammography is limited in women who have dense breasts, women with breast implants or women who have had breast surgery or radiation therapy, all of which make breast visualization difficult (Khalkhali & Itti, 2002).

Mammography is not without risks. The X-rays used in mammography can cause damage to the cells, which can cause cancer (Health Canada, 2003, Mammography, para 3). However, if mammograms are conducted correctly, the radiation dose delivered is typically low. After a low dose of radiation, the body can generally repair the few cells damaged by the X-rays. An association between low-dose diagnostic X-ray exposure or therapeutic radiation treatment and breast cancer risk has not been established (Zheng et al., 2002).

Several newly emerging techniques have been proposed to improve the specificity of conventional mammography. These include, but are not limited to, positron emission tomography and single photon scintimammography (Khalkhali & Itti, 2002). Fiberoptic ductoscopy is a new technique where a physician can visualize a patient's breast mammary ducts directly with a 0.9mm scope (Sparks, 2002). Ultrasounds are most often used to distinguishing fluid-filled cysts from solid lesions; they are used as screening tools for women with dense breasts or pregnant women (Weber, 1997). An ideal screening tool would distinguish benign from malignant tumors, be cost-effective, and diagnose breast cancer without using radiation. According to Weber, one such imaging technique that may have this aptitude for screening is the magnetic resonance imaging.

Currently, as Weber recognizes, magnetic resonance imaging can guide treatment by characterizing the extent of invasive cancer and may be particularly beneficial in evaluating recurrence of breast cancer. In addition to being an effective screening tool for younger women with dense breasts, it images tissue close to the chest wall, where according to Weber and Weaver (2002), mammography may be less effective. Researchers continue to investigate the effectiveness of these promising techniques. Improved mammographic technology, including digitized mammography and advanced skill in mammographic interpretation, combined with newer diagnostic technology may make it possible to detect breast cancers earlier and with greater certainty (Lippman, 2003).

Clinical breast examination.

The public debate on early breast cancer detection is mainly centered on mammograms. However, clinical breast examinations are of comparable importance. A recent study, which analyzed breast cancer data from several screening trials that the Canadian Breast Cancer Study Group conducted, found that the sensitivity of mammography alone in women aged 50-59 was 0.66 (Shen & Zelen, 2001). In other words, in this particular group of women, mammography successfully identified an abnormality 66% of the time (Hennekens & Buring, 1987). However, Shen, and Zelen found that when mammography was combined with clinical breast exams, the sensitivity increased to 82%. Comparably, Khalkhali, and Itti (2002) found that mammography and physical examination when taken together have a sensitivity of 85%. Thus, it is evident that clinical breast examinations complement mammography screening and these screening techniques, when combined, are more likely to detect breast abnormality

Appendix C

Questionnaire

(Instructions: Please read the statements and check the most appropriate box)

	Always	Most Times	Sometimes	Rarely	Never	No Opinion
I use my first language at home	☐	☐	☐	☐	☐	☐
I use my first language when I am in public places	☐	☐	☐	☐	☐	☐
I wear traditional clothes when I am at home	☐	☐	☐	☐	☐	☐
I wear traditional clothes when I am in public places	☐	☐	☐	☐	☐	☐
I eat traditional foods when I am at home	☐	☐	☐	☐	☐	☐
I eat traditional foods when I am in public places	☐	☐	☐	☐	☐	☐
I socialize with people of my own culture	☐	☐	☐	☐	☐	☐
I socialize with people from other cultures	☐	☐	☐	☐	☐	☐

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	No Opinion
It is considered inappropriate for a women in my culture to have a male doctor	☐	☐	☐	☐	☐	☐
It is up to me when I think I need to see a doctor	☐	☐	☐	☐	☐	☐
In my culture, we go to a doctor only when we are ill	☐	☐	☐	☐	☐	☐

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	No Opinion
It is considered inappropriate for women in my culture to have their breasts checked for lumps	☐	☐	☐	☐	☐	☐
It is considered inappropriate for women in my culture to check their own breasts for lumps	☐	☐	☐	☐	☐	☐
It is considered inappropriate for women in my culture to have a mammogram	☐	☐	☐	☐	☐	☐
According to my religion, it is inappropriate to have my breasts checked for lumps by a doctor	☐	☐	☐	☐	☐	☐
According to my religion, it is inappropriate to check my own breasts for lumps	☐	☐	☐	☐	☐	☐
According to my religion, it is inappropriate to have a mammogram	☐	☐	☐	☐	☐	☐
Since I have been in Canada I have checked my breasts for lumps	☐	☐	☐	☐	☐	☐
Since I have been in Canada my doctor has checked my breasts for lumps	☐	☐	☐	☐	☐	☐
Since I have been in Canada I have had a mammogram	☐	☐	☐	☐	☐	☐
Since I have been in Canada a doctor or nurse has discussed the importance of breast cancer screening with me	☐	☐	☐	☐	☐	☐
Since coming to Canada I understand the importance of breast cancer screening	☐	☐	☐	☐	☐	☐

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	No Opinion
Breast cancer screening is important in my home country	☐	☐	☐	☐	☐	☐
In my home country, I used to check my breasts for lumps	☐	☐	☐	☐	☐	☐
My doctor examined my breasts for lumps in my home country	☐	☐	☐	☐	☐	☐
In my home country, I have had a mammogram	☐	☐	☐	☐	☐	☐

I came to Canada as a:

☐ Landed immigrant

☐ Refugee

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	No Opinion
Since I have been in Canada my doctor has advised me to check my breasts for lumps	☐	☐	☐	☐	☐	☐
Since I have been in Canada I visit my doctor frequently	☐	☐	☐	☐	☐	☐
Since I have been in Canada I visit health care professionals other than doctors	☐	☐	☐	☐	☐	☐
It is hard for me to understand health care professionals	☐	☐	☐	☐	☐	☐
I am actively involved in discussions about my health with doctors and nurses	☐	☐	☐	☐	☐	☐
It is hard for me to access health care services	☐	☐	☐	☐	☐	☐

	Yes	No
I am employed/ self-employed	☐	☐

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	No Opinion
I look after and financially support my family	☐	☐	☐	☐	☐	☐
I stay at home and take care of my family all the time	☐	☐	☐	☐	☐	☐
I am aware of how much money is brought home every month	☐	☐	☐	☐	☐	☐
I look after and support myself	☐	☐	☐	☐	☐	☐
My family looks after and supports me	☐	☐	☐	☐	☐	☐
I am aware of how much money is brought home every month	☐	☐	☐	☐	☐	☐
My family is well off financially	☐	☐	☐	☐	☐	☐

What is the highest level of education you have completed?

- ☐ None
- ☐ Elementary school
- ☐ Junior High school
- ☐ High school
- ☐ College
- ☐ University

	Always	Most Times	Sometimes	Rarely	Never	No Opinion
I regularly check my breasts for lumps	☐	☐	☐	☐	☐	☐

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	No Opinion
I know what a mammogram is	☐	☐	☐	☐	☐	☐
I know why I should have a mammogram	☐	☐	☐	☐	☐	☐
I know why a doctor should check my breasts for lumps	☐	☐	☐	☐	☐	☐
I know why I should check my breast for lumps	☐	☐	☐	☐	☐	☐

	Every Month	Every 3 Months	Every 6 Months	Every Year	Every 1-2 Years	Don't Know
I need to have a mammogram	☐	☐	☐	☐	☐	☐
I need to have my breasts checked for lumps by a doctor	☐	☐	☐	☐	☐	☐
I need to check my own breasts for lumps	☐	☐	☐	☐	☐	☐

	This Year	Last Year	2 Years Ago	3 years Ago	Don't Remember	Never
The last time I had a mammogram was	☐	☐	☐	☐	☐	☐
The last time I had my breast checked for lumps by a doctor was	☐	☐	☐	☐	☐	☐
The last time I checked my own breasts for lumps was	☐	☐	☐	☐	☐	☐

	50-59	60-69	70-79	80-89	90-99
My age is	☐	☐	☐	☐	☐

	Less than 1 year	Less than 2 years	Less than 4 years	Less than 6 years	Less than 8 years	Less than 10 years
I have lived in Canad	☐	☐	☐	☐	☐	☐

	Excellent	Very Good	Good	Fair	Poor	No Opinion
In general, compared with other people my age, my health is:	☐	☐	☐	☐	☐	☐

Interview Questions

1. What things help you to access health care services?

2. What things hinder you from accessing health care services?

3. What things help you to access breast cancer screening?

4. What things hinder you when accessing breast cancer screening?

5. What do you think would get rid of the barriers to accessing health care services in general?

6. What do you think would get rid of the barriers to accessing breast cancer screening services?

7. What are the reasons other than the one's covered in the survey, that you do not undergo breast cancer screening?

Appendix D

Information letter

September 10, 2002

Aliyah Mawji, Principal Investigator
Masters of Public Health Student
Department of Public Health Sciences
University of Alberta, Edmonton
Office Phone Number: (780) 492-4647

Dr. John Church, Co-Investigator and Supervisor
Assistant Professor
Department of Public Health Sciences
University of Alberta, Edmonton
Office Phone Number: (780) 492-8604

Re: Afghan Women and Breast Cancer Screening Practices Study

Study purpose: We are doing a study of Afghan women and their breast cancer screening practices. This will help us to see what changes are needed to current breast health programs.

What is involved: If you agree to be in the study, you will be asked to fill out a survey. The survey will ask questions about your breast health and general information about you. Help in filling out the survey will be provided if needed. The survey will take about 30 minutes to complete. After the survey, you will be asked 4 short questions. This should take about 30 minutes.

Risks and Benefits: If you are in the study, you may learn new things about breast cancer screening. There are no known risks from participating in the study. If you have any concerns about the study please contact your family doctor.

Confidentiality: All of the information will be kept confidential. Due to the small sample of people in this study, we cannot promise that the information you give us will be kept anonymous. Your name will not be in this study. The researchers and translator are the only ones who will see the information collected today. We would like to tape record the interview so that we do not miss any important points. We will only tape-record if you feel comfortable with it. The researchers will be the only ones who will have access to the tapes. All information will be locked in a drawer for five years. It will then be destroyed. Consent forms will be kept in another locked drawer for five years and will then be destroyed. The findings from this study may be published or presented at a conference. If this occurs, your name will not be used.

Freedom to withdraw: You do not have to be in this study if you do not want to be. If you agree, you can withdraw at anytime by telling the researcher. You do not have to answer any question that you do not want to. Your connection with your community will not be affected in any way if you decide not to be in the study.

Questions or concerns: If you have any questions about this study, you can call the Principal Investigator in Edmonton at (780) 492-4647, or Dr. John Church, the Study Supervisor at (780) 492-8604.

Appendix E

Consent Form

Part 1: Researcher Information		
Name of Principal Investigator: Aliyah Mawji, MPH Student Affiliation: University of Alberta Contact Information: (780) 492-4647		
Name of Co-Investigator/Supervisor: Dr. John Church Affiliation: University of Alberta Contact Information: (780) 492-8604-		
Part 2: Consent of Subject		
	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 been able to ask questions and discuss the study?		
Do you understand that you are free to refuse to be in or withdraw from the study at any time? You do not have to give a reason.		
Do you understand who will have access to your records/information?		
Do you agree to allow the researcher to audio-record your responses?		
Part 3: Signatures		
This study was explained to me by: _____ Date: _____		
I agree to take part in this study. Signature of Research Participant: _____ Printed Name: _____		
Witness (if available): _____ Printed Name: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. Researcher: _____ Printed Name: _____		
* The information letter must be attached to this consent form and a copy provided to the research subject.		

Appendix F

Screen Test: Alberta Program for the Early Detection of Breast Cancer

Screen Test: Alberta Program for the Early Detection of Breast Cancer is a province-wide breast cancer screening program directed by the Alberta Cancer Board. (Alberta Cancer Board, 2000). It was established in 1990 as part of a national effort to reduce the number of breast cancer deaths (P. Taschuck, personal communication, October 29, 2002).

Screen Test has 4 main goals (Alberta Cancer Board, 2000):

1. To decrease the mortality rate of women aged 50-69 years by 30% within 15 years of full implementation of the program
2. To have 80% of the women aged 50-69 years old aware of the program one year after implementation of the screening program in a particular community
3. To have 50% of the women aged 50-69 years be aware of the appropriate screening procedures for their age group after 3 years of implementation of the program, regardless of which community they belong to
4. To have 80% of all women aged 50-69 years screened at least once, with no less than 70% of any particular subgroup, within 5 years of implementation into a regional area