Exploring the experiences of infertile Arab immigrant women: A qualitative study

Thesis

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Abstract

Background: Infertility rates in the Middle East and North Africa are among the highest worldwide. Despite its elevated prevalence among men and women, infertility is mainly blamed on women's reproductive health failures. Consequently, infertility threatens women's social and marital security, social power, and status in society. In Canada, the Arab population constitutes the second largest group of newcomers, but very little research has explored Arab immigrant women's experiences with and access to comprehensive reproductive health services.

Objectives: This project aimed to fill a gap in the literature on reproductive health in Ontario. This study explored: 1) Arab women's experiences with infertility and infertility-related services in Ontario; 2) the barriers these women face when seeking these services; and 3) possible ways infertility-related information and services could be improved.

Methods: This qualitative study consisted of in-depth interviews with Arab immigrant women and interviews with key informants. We used a multi-modal recruitment strategy including social media ads, flyers, advertisements through community organizations, and an Arabic-language radiobroadcast. We analyzed both components for content and themes using deductive and inductive techniques.

Results: Participants struggled with primary infertility, mainly due to polycystic ovarian syndrome or endometriosis. Women identified cost, socio-cultural dynamics, stigma, and embarrassment as barriers to seeking treatment. Women described existing services as lacking comprehensive information, cultural sensitivity, and emotional support.

Conclusions: Our findings suggest that Arab immigrants face barriers in accessing infertility care in Ontario. These services can be improved through engaging in education and awareness raising efforts, providing psychosocial support services, and building bridges between organizations and the community.

Résumé

Contexte: Les taux d'infertilité au Moyen-Orient et l'Afrique du Nord sont parmi les plus élevés dans le monde entier. Malgré la prévalence élevée de l'infertilité chez les hommes et les femmes, l'infertilité est principalement imputée à des défaillances de santé reproductive des femmes. Par conséquent, l'infertilité menace le role sociale des femmes, leur sécurité sociale, leur pouvoir et leur statut en société. Au Canada, la population arabe constitue le deuxième plus grand groupe de nouveaux arrivants, mais très peu de recherches ont exploré les expériences et les accès des femmes immigrantes arabes à des services de santé reproductive complètes.

Objectifs: Ce projet vise à combler l'écart dans la littérature sur la santé reproductive en Ontario. Cette étude a exploré: 1) les expériences des femmes arabes avec

l'infertilité et des services liés à l'infertilité en Ontario; 2) les obstacles auxquels ces femmes sont confrontées lorsqu'elles cherchent à obtenir ces services; et 3) les moyens possibles que l'informations et que les services liés à l'infertilité-pourraient être améliorées.

Méthodes: Cette étude qualitative consistaient de deux phases. La première phase consistait des entrevues en profondeur avec des femmes immigrantes arabes et la deuxième phase consistait des entrevues avec des informateurs clés. Nous avons utilisé une stratégie de recrutement multi-modale y compris les annonces de médias sociaux, des dépliants, des publicités par le biais des organismes communautaires, et une annonce à la radio. Nous avons analysé les deux composants pour le contenu et les thèmes en utilisant des techniques déductives et inductives.

Résultats: Les participants ont principalement souffert de l'infertilité primaire. Les causes de l'infertilité de les participants étaient en raison de syndrome des ovaires polykystiques ou de l'endométriose. Les femmes ont identifié, les coûts des services, la dynamique socio-culturelles, la stigmatisation, et l'embarras comme des obstacles à leur accès au traitement medicale. Les femmes ont décrit les services existants comme étant manquantes en informations disponibles, la sensibilité culturelle, et un soutien émotionnel.

Conclusions: Nos résultats montrent que les femmes immigrantes arabes font face à des barriers lors de leurs accès aux soins pour traiter l'infertilité en Ontario. Ces services peuvent être améliorés par l'engagement dans les efforts d'éducation et de

sensibilisation, la disponibilité de services de soutien psychosocial, et la liaison entre les organisations et la communauté.

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"A hopeless person sees difficulties in every chance, but a hopeful person sees chances in every difficulty" –Imam Ali (AS)

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List of Acronyms and Abbreviations

AI	Artificial insemination
ARTs	Assistive reproductive technologies
FP	Fertility preservation
GTA	Greater Toronto Area
ICSI	Intra-cytoplasmic sperm injection
IVF	In vitro fertilization
MENA	Middle East and North Africa
OHIP	Ontario Health Insurance Plan
PCOS	Polycystic ovary syndrome
PI	Principal investigator
REB	Research Ethics Board
STIs	Sexually transmitted infections

Chapter 1: Introduction

Background

The global rise of infertility in the past few decades is believed to affect more than 186 million women of reproductive age (World Health Organization, 2004). The reported international prevalence of infertility ranges from 4-14%, with an estimated average of 10% of married and cohabiting heterosexual couples (Nachtigall 2006). Among sexually active couples of reproductive age who are not contracepting, infertility is typically defined as the inability to establish pregnancy within a specified time period, usually one year (Sciarra 1994). Infertility is commonly classified as primary – occurring in the absence of a prior history of pregnancy – or secondary – occurring after a previous pregnancy (Inhorn, 2003a).

Some of the primary causes of infertility among women (female factor infertility) appear to vary by setting. In developing countries, possible leading underlying causes of infertility include sexually transmitted infections (STIs), unsafe abortion and postpartum complications, reproductive tract infections, unhygienic health care practices, and dietary and environmental toxins (Hamberger & Janson, 1997). In developed countries infertility is strongly influenced by overarching trends in relationships and patterns of family formation; social and economic factors have resulted in delays in marriage and childbearing that impact the overall ability of women to become pregnant and sustain a pregnancy (Nachtigall, 2006). STIs and exposure to environmental toxins are also major contributors and women in the Global North predominantly suffer from primary infertility (McAllister & Clark, 2000).

Some of the primary causes of infertility among men (male factor infertility) generally involve low sperm count (oligospermia), defects in sperm morphology (teratospermia), poor sperm motility (asthenospermia) or total absence of sperm in the ejaculate (azoospermia) (Inhorn, 2004). Possible factors and trends influencing sperm count include lifestyle choices such as the use of cigarettes, drugs and alcohol (Close et al., 1990), health conditions, such as malnutrition or obesity (Hammoud et al., 2007), environmental influences such as pesticides (Wong et al., 2003) and overexposure to heavy metals (Sinclair, 2000), as well as trauma resulting from war (Kobeissi et al., 2008).

The underlying causes of male factor infertility are similar in the Global North and the Global South. However, in the Middle East, consanguinity is not uncommon and ranks highest in the world among Muslim Mediterranean populations (Inhorn, Kobeissi, Nassar et al., 2009). Consanguinity is usually defined as the intermarriage of two individuals who have at least one ancestor in common (Gunaid, Hummad & Tamim, 2004). Studies have shown that consanguinity influences male factor infertility and is highly correlated with rare genetic sperm-defect syndromes involving the sperm head or sperm tail (Baccetti et al., 2001). Hence, the high rates of male factor infertility in the Middle East may be related to the genetics of consanguinity (Birenbaum-Carmeli, 2005).

One of the main consequences of infertility, apart from childlessness, is the emotional distress and social stigma that many infertile couples face. Across many cultures, infertile couples are perceived as having “diminished status” and are associated with biological defectiveness and reduced competence (Valentine, 1986).

The stigma of being labeled as infertile often leaves couples feeling alone and isolated from the rest of society (Greil, 1997).

Despite the high prevalence of infertility among men and women, around the world involuntary childlessness is often considered to be a “woman’s problem” (Inhorn & Van Balen, 2002). Research indicates that, once diagnosed, women often experience high levels of depressive symptoms, anxiety, and hostility (Domar & Cousineau, 2007). Infertile women often describe having difficulty in social settings, such as dealing with feelings of jealousy or envy when learning of other women’s pregnancies or being in the presence of others who have infants (Domar & Sebeil, 1997). Many women will hide their distress from health care providers or family members because they are self-conscious, have low self-esteem, and fear being judged (Becker & Nachtigall, 1991). These reactions and emotions are tied to broader socialized gender dynamics that often place primacy on motherhood and caregiving and thus infertility can be perceived as a threat to core identity (Greil, 1991).

Infertility and infertility treatment in the Middle East and North Africa

The prevalence of primary infertility in the Middle East and North Africa (MENA) region among child-seeking women in 2010 was approximately 2.6% and the prevalence of secondary infertility in that same region was 7.2% (Mascarenhas, Flaxman, Boerma, Vanderpoel & Stevens, 2012). Strong pronatalist norms across much of the MENA region make children highly desired and parenthood culturally mandated. Infertility among couples not only presents emotional challenges, but also threatens social security, social power, and family lineage. Lack of pregnancy in this region is generally blamed on women’s reproductive failures even in cases of male factor

infertility. Consequently, childless women face various forms of community ridicule, social ostracism, alienation, self-doubt, and even harassment by family members and neighbours (Inhorn & Van Balen, 2002). Many are labeled as lacking femininity and are turned away from life-cycle rituals and events involving other women and their children, for fear that infertile women will cast an evil eye (Inhorn & Van Balen, 2002). In Muslim-dominated regions, childlessness may also threaten a woman's marriage; infertility can be used as grounds for divorce or, in countries where polygamy is permitted, taking an additional wife (Okonofua et al., 1997). These dynamics in the MENA region drive some couples to seek infertility treatment shortly after marriage (Inhorn, 1996).

The availability of assisted reproductive technologies (ARTs), such as in vitro fertilization (IVF), intra-cytoplasmic sperm injection (ICSI), and the use of gestational carriers, varies significantly across the globe. Legal, political, economic, socio-cultural, and religious factors shape not only the availability of different ARTs but also the accessibility of different treatments. Within the Middle East and North Africa there is wide variation in available services (Inhorn, 2010).

In 1980, just two years after the first IVF baby was born in Britain, the Grand Mufti of Al-Azhar University in Egypt issued the first *fatwa* (an authoritative religious ruling issued by a qualified theologian) on medically assisted reproduction (Inhorn & Gurtin, 2012). This foundational *fatwa* outlined the religious permissibility of different aspects of ARTs within Sunni Islam; subsequent medical advances were generally considered in light of this early ruling. In brief, within Sunni Islam, ARTs are only religiously permissible in the context of a legally recognized marriage and for the benefit of the married couple. Use of third party donors and gestational carriers is prohibited,

but most specific technologies (including IVF, ICSI, cryopreservation, and uterine transplantation) are religiously sanctioned (Inhorn & Gurtin, 2012).

The majority of the Sunni Muslim countries in the MENA follow these guidelines. In effect, this has meant that countries where laws and policies are heavily influenced by Sunni Islam, third party involvement in ARTs is banned. The theological argument against third party involvement centers around three primary issues: (1) the moral implications for marriage and a belief that these practices are akin to *zina* (illicit sex); (2) the potential for incest to occur among the half-siblings of anonymous donors; and (3) the destruction of *nasab*, or genealogical lineage to known parents, which has implications for kinship, inheritance, family life, and the psychological state of the child (Inhorn, 2003).

However, Shi'a religious leaders have interpreted third party involvement in ARTs differently. Indeed, the ban on third party ARTs was lifted in 1999 when the Supreme Leader of the Islamic Republic of Iran, Ayatollah Ali Hussein Al-Khamenei, issued a *fatwa* effectively permitting the use of donor technologies, including sperm donation, egg donation, embryo donation, and gestational surrogacy. This ruling was theologically justified as a way to preserve marriage among infertile couples (Inhorn, 2003).

This influential decision in Iran had an immediate impact in Lebanon where the Hezbollah party, a political party which follows the spiritual guidance of Ayatollah Khamenei, pressed for the sanctioning of third party donation (Clarke, 2009). This paved the way for the use of donor gametes among Lebanese couples; Catholic Maronites also supported this decision and argued that, similar to adoption, donation was an altruistic act (Inhorn, 2010).

As of 2014, Iran and Lebanon were the only countries in the Muslim Middle East that offered third party ARTs. This has resulted in increased intra-regional “reproductive tourism” in which couples from Sunni-majority countries cross international borders to avail themselves of a broader array of technologies (Inhorn, 2011).

Infertility and infertility treatment among Arab immigrant populations in North America

Challenges surrounding infertility may differentially impact members of the Arab diaspora living in North America. Arab immigrants and refugees who recently moved to Western societies may be exposed to new social norms, customs, and different belief systems. As a consequence, these dynamics may impact the experiences and challenges that the Arab populations face with respect to infertility and infertility-related treatment options.

Research on infertility with the Arab immigrant population in North America has mainly taken place in the United States. A study conducted by Inhorn & Fakih in 2006 looked at accessibility barriers among both African-American and Arab-American populations in Dearborn, Michigan. Although the social value placed on parenthood and having biological children was high in both populations, and interest in seeking treatment among infertile couples was present, actual help-seeking was low. Barriers to seeking infertility treatment included low levels of education, low socioeconomic status, the presence of racism and discrimination, linguistic barriers, mistrust of health care providers, and societal and religious factors.

Among these barriers, the high cost of infertility treatments was reported as the most significant. In the United States, infertility treatments are often extremely expensive and have infrequently been covered by insurance or the safety net programs

that serve low-income populations. For example, in Michigan the cost of an IVF cycle in 2002 ranged from USD10,000 to USD20,000 and insurance coverage for hormonal medications and ART procedures is not mandated by the state (Inhorn & Fakih, 2006).

Arab immigrants represent 12.4% of the total population migrating to Canada. In 2010, this population reached an all-time high in Canada with the arrival of 34,657 citizens of Arab countries. Although immigrants from Arab countries constitute the second largest group of newcomers to Canada, little research has explored their experiences with and access to comprehensive reproductive health services, including infertility (Canadian Arab Institute, 2013).

Immigrants are often identified as a vulnerable population that is a group at increased risk of poor physical, psychological and social health outcomes and inadequate health care (Aday, 2002). Some factors that influence immigrants' vulnerabilities include socioeconomic status, including education level, type of occupation, and earnings (Derose, Escarce & Lucie, 2007). Another factor that influences vulnerability is immigration status. In order to be considered for a provincial health insurance plan in Canada, newcomers must be deemed eligible through their immigration status, which includes but is not limited to being a Canadian citizen, a permanent resident, or a protected person under the Immigration and Refugee Protection Act. Each province and territory has its own health insurance plan and plans vary in what they cover. In Ontario, for example, newcomers are not covered through the provincial health insurance upon their arrival. Rather, immigrants must hold primary residence in the province, be in the province for at least 153 days of the first 183 days immediately following the date they established residency in Ontario (or not being

absent for more than 30 days during the first 6 months of residence), or they must be in Ontario for at least 153 days in any 12-month period (Ministry of Health And Long Term Care, 2016a).

Further, the vulnerability of immigrants may be influenced by language proficiency, particularly those with limited knowledge of either English or French, and the stigma and marginalization associated with being a newcomer. A variety of factors can contribute to this last issue, including differences in appearance (wearing traditional dress), cultural and religious practices, sociolinguistic barriers, speaking with an accent, and skin tone (Derose, Escarce & Lucie, 2007). Stigmatization of immigrant populations can make them reluctant to seek care and as a consequence exacerbate health problems and conditions (Lauderdale et al., 2006). The results of the National Population Health Survey indicate that immigrants are in relatively good health when they arrive in Canada, partly because of the selection criteria imposed by the immigration process, but their health begins to deteriorate to some extent due to the increase of adoption of North American habits and some inadequacies in the North American health care system and approaches (Vissandjée et al., 2001).

Infertility treatment in Ontario

In the Global North, financial resources and health insurance coverage are the two most crucial factors in decision-making around ARTs (White et al., 2006). In Ontario, a full range of diagnostic tests is covered through the Ontario Health Insurance Plan (OHIP). The most common ARTs offered in the province are intrauterine insemination (IUI), IVF, ICSI, and cryopreservation. In 2009, an IVF cycle cost CAD6000 and increased to CAD8000 if ICSI was also required. Of course, these costs

do not include travel, accommodations, lost wages, or additional medications. Cost continues to be a major barrier to residents of Ontario who desire to build a family with ARTs (Ministry of Children and Youth Services, 2010).

Before December 2015, treatment for infertility through ARTs, with the exception of IUI, was not covered by OHIP. There was no public funding for ARTs in the province, which meant that most Ontarians (with the exception of women treated for blocked fallopian tubes) needed to pay for infertility services out-of-pocket (Ministry of Children and Youth Services, 2010). In December 2015, the province of Ontario announced that it would be investing CAD50 million a year into expanding access to IVF treatments, in addition to the CAD20 million per year they would spend on other assisted reproductive services under OHIP. Dr. Eric Hoskins, Minister of Health and Long-Term Care stated that expanding access to fertility services was part of the government's plan to build a better Ontario through its *Patients First: Action Plan for Health Care*, which would provide patients with faster access to the right care, better home and community care, the information they need to stay healthy, and a health care system that is sustainable for generations to come (Ministry of Health and Long-Term Care, 2015).

Ontario's fertility program

Ontario's new fertility program provides funding to help eligible Ontarians build their families at 52 clinics across the province. The program is available to eligible Ontario residents of any sex, gender, sexual orientation, or family status, who hold a valid OHIP card. Female patients are eligible for the one-time per lifetime IVF cycle if they are under the age of 43 and if their health care provider has determined IVF as being the most appropriate family-building option for them. Patients interested in the

government-funded fertility preservation program (i.e., freezing of eggs) must have a valid medical reason such as risk of infertility due to treatment of illness.

The treatment options offered by the program include artificial insemination (AI), IUI, IVF and fertility preservation (FP). The program provides over 10,000 patients per year with AI and IUI services, as well as over 5,000 IVF and FP services. The program does not cover costs associated with fertility drugs, so patients still need to cover the CAD1,000 per AI cycle and CAD5,000 per IVF cycle out-of-pocket. Additionally, the program does not cover costs associated with other services such as genetic testing and the storing of sperm, eggs, and embryos, which means that these services would either be covered by private health plans or paid for out-of-pocket (Ministry of Health and Long-Term Care, 2016b).

Description of infertility treatments

As previously stated, the most common infertility treatments in Ontario include artificial insemination, IUI, IVF, ICSI and cryopreservation. Below is a brief description of these procedures:

1. Artificial insemination (AI) is a medical procedure used to transfer sperm into the vagina or cervix (Ministry of Health and Long-Term Care, 2016b).
2. Intra-uterine insemination (IUI) is a type of artificial insemination that involves placing sperm inside a woman's uterus to facilitate fertilization. The goal of the IUI is to increase the number of sperm that reach the fallopian tubes and subsequently increase the chance of fertilization (American Pregnancy Association, 2016).

3. In vitro fertilization (IVF) is a type of ART, which consists of manually combining an egg and sperm in a laboratory dish, and then transferring the blastocyst to the uterus (American Pregnancy Association, 2016).
4. Intracytoplasmic sperm injection (ICSI) is a procedure that involves the direct injection of sperm into eggs obtained from IVF (American Pregnancy Association, 2016).
5. Cryopreservation is a type of fertility preservation that consists of freezing sperm or egg samples to be used later with AI or IVF patients, who are preparing to undergo treatment that may lead to infertility (Ministry of Health and Long-Term Care, 2016b).

Rationale

Although there has been a significant body of research dedicated to infertility and the accessibility of treatment options in the Middle East, little is known about Arab women's experiences with infertility and their access to information and treatment in Canada after immigration. However, research on immigrant populations in Canada more generally has found that cost, language, location, transportation, community awareness, and cultural insensitivity of providers create barriers to accessing health care (Asanin & Kilson, 2008). In addition to all these factors, the three-month waiting period for immigrants and new residents to gain OHIP coverage as well as the long waiting times to find a family physician in Ontario may present additional challenges for those seeking care for infertility (Ministry of Health and Long-Term Care, 2012).

This project aimed to help fill a gap in the literature on reproductive health in Ontario. Findings from this project give voice to Arab immigrant women's experiences and have the potential to help identify strategies for improving access to culturally- and linguistically-appropriate care in the province.

Specific Objectives

My project focuses on the experiences of infertile Arab immigrant women living in Ontario. My specific research questions are:

1) What are Arab women's experiences with infertility and infertility services in Ontario?
2) What barriers, if any, do Arab immigrants face when seeking infertility services in the province?
3) In what ways, if any, could infertility-related information and services be improved for Arab immigrant women in Ontario?

Outline of Thesis

The first chapter provides an introduction to infertility in the MENA region, infertility in the Arab community in North America and the situation of infertility related treatments in the province of Ontario. Chapter one also provides the study rationale, specific objectives, and the outline of the thesis. Chapter two describes the methodology of the study including the recruitment strategy, interview process, details about the analytic approach, ethics, and an explanation of the conceptual framework. Chapter three presents the results from the key informant interviews and chapter four presents the results of the in-depth interviews with women. Chapter five discusses the

findings, policy implications, and limitations and includes a section on reflexivity in the context of this thesis, a statement of contribution for the overall study, and the final conclusions. The bibliography and appendix can be found at the end of this document.

Chapter 2: Methods

Following an extensive review of the existing, but limited, literature we determined that a qualitative approach was the most appropriate method to investigate our research questions. In order to investigate the experiences and perspectives of those working with infertile Arab women in Ontario and the experiences of Arab women experiencing fertility struggles, we utilized a multi-method qualitative approach that includes interviews with both key informants and self-identified infertile women.

Participants

Key informants

The first component of the study included key informant interviews. We intended to interview individuals working with/encountering infertile Arab immigrant women such as clinicians, representatives of community-based organizations that provide information and support for infertile women and couples, and religious and community leaders. We identified key informants through publically available information and early participant referral. We first approached key informants through an invitation email that we pre-developed and adjusted accordingly, and by calls made to their clinics and services.

Infertile Arab immigrant women

The second component of this project included interviews with Arab immigrant women living in the province of Ontario and who self-identified as being infertile. The self-identification factor is important, as infertility is not simply biological but also social and we wanted to include women who may have sought treatment in their

home countries shortly after marriage. We recruited participants by reaching out to the community through social media (Kijiji, Facebook, Twitter, etc.), community organizations that service infertile woman, churches and mosques, community-specific venues, such as grocery stores, Arabic-language newsletters, and through an ad on the CHIN multicultural/multilingual radio station. Women were eligible to participate if they:

1) Were between the ages of 18-45 and self-identified as being infertile;
2) Lived in the province of Ontario;
3) Immigrated to Canada from the Arab world; and
4) Were sufficiently fluent in English, French or Arabic to complete the interview.

Interview process

Key informants

I developed the interview guide before the commencement of recruitment and, upon refinement of these questions by my supervisor, I was able to start the interview process. Prior to each interview, I sent a consent form outlining detailed information about the research project and the goals of the study to the key informants. I began each interview by reading the consent form to the key informant and upon their informed and verbal consent, I commenced the interview. I audio-recorded and conducted all interviews by either telephone or Skype in a quiet and private location. The interviews varied in length between 30 minutes and 45 minutes each.

During the interview, I asked the participant to discuss his/her education and professional background and the organization he/she represents. I then asked the participant to report on his/her experiences related to infertility information, support, and/or services, in general, as well as with Arab immigrants, in particular. I then moved on

to a discussion of the factors that influence Arab immigrant women's access to infertility services and any barriers they may experience. I concluded the interview with a discussion of the ways in which services could be improved for immigrant populations in the province. During the interview, I took notes and wrote formal memos shortly thereafter.

Infertile Arab immigrant women

I developed the interview guide before commencement of recruitment and my thesis supervisor redefined it. I began the interview process with a verbal review of the consent form and objectives of the study to ensure that participants understood the purpose of the project. I assured participants that the study was completely voluntary and that their answers would not impact the care they receive. I made clear to participants that they were free to decline to answer any question or withdraw from the study at any point without penalty. The interviews averaged about 60 minutes and I conducted them in a private and comfortable location either by telephone or Skype, depending on the participant's preference.

During the interview, I engaged in active listening and was mindful and sensitive to the participant's stories and concerns. I began the interview with a series of demographic questions (such as name, age, country of origin, religion, religiosity, types of social support, etc.) before moving to questions about the participant's immigration experiences and her overall reproductive health. I then turned to the issue of infertility and asked the participant questions about her infertility experiences with diagnosis, disclosure, and treatments. I then asked women about the types of care, if any, that they received in Ontario and their perspectives on treatment options and quality. I concluded the interview with a discussion as to the ways, if any, information, support, and services could be

improved in Ontario. With the participants' permission, I audio-recorded all interviews and as a thank you for participating in the study, I sent participants an online $20 gift certificate to www.amazon.ca.

During the interview, I took notes on the participant's infertility experiences, opinions, and suggestions on improvement of services in the province. After the interview, I engaged in memoing to reflect on the experiences of participants and my own experience as an interviewer.

Analytic approach

The data collection and multi-phased analysis process was designed to be iterative, which is why I began to review data as they were collected. Upon completion of the initial interviews, my thesis supervisor listened to the interviews, reviewed the memos and read transcripts to provide me with feedback and thoughts about participants' answers and my skills as an interviewer. After both the key informant interviews and the in-depth interviews, I engaged in formal memoing, which allowed me to capture reflections and insights as well as observations of my own role in the interview process. This allowed me to be iterative in the analysis process, giving me a refined understanding of the data being gathered from interviews that had recently taken place (Srivastava, P., & Hopwood, N. (2009)). Memoing also helped me reflect on my personal perspectives, feelings, and opinions about each participant's experience and story. Additionally, memoing gave me the ability to reflect on my skills as an interviewer and gave me the ability to improve the flow of the questions I asked through the interview guide. I was also able to note common themes that emerged through the interviews to see if I had reached thematic saturation where new ideas and themes stop emerging from the data (Marshall, 1996).

As a first phase, I transcribed all interviews, analyzed the data for content and themes, and used ATLAS.ti to manage the data. In phase two, I developed an initial codebook that focused on *a priori* (pre-determined) codes and categories based on the interview guide, notes, and memos. The research study aims and my research questions informed the initial codes and categories. Then, I derived insights from my memos, and these acted as supporting documentation (Birk et al., 2008). I then recreated initial codes to generate the initial codebook using the content of the interviews and the discussion with my thesis supervisor. I then defined and described each code and added new codes as the analysis phase progressed. Once I coded the transcripts, I worked within each code to identify principal sub-themes that reflected more suitable distinctions in the data. The third phase focused on interpretation and drawing connections between ideas, and a combination of results. The final phase comprised looking at both the key informant and participant components paying close attention to convergence and divergence.

To prepare me for the analytical and interpretive process, I attended regular group meetings held by my thesis supervisor as well as individual meetings with my supervisor. Furthermore, the feedback that I received on my abstracts, posters, and write-ups assisted me in improving my ability to communicate the findings.

Ethics

This study received ethics approval in March 2015 from the Social Sciences and Humanities Research Ethics Board (REB) at the University of Ottawa (File#02-15-10). The letter of approval from the University of Ottawa REB's can be found in Appendix A. Throughout this thesis, I have used narrative vignettes to provide a picture of the women

we interviewed and we quote participants to showcase central themes. I have masked or redacted all personally identifying information and use pseudonyms throughout.

Chapter 3: Key informant results

This phase of the study consisted of four key informant interviews with a Health and Wellness coach, a naturopathic doctor, a fertility specialist, and a fertility support group representative.

Participant characteristics

The first key informant that I interviewed is a female Health and Wellness coach and a fertility support group representative. This key informant is located in the Mississauga area and obtained a bachelor's degree from a university based in Toronto. She is of a South Asian background and has been working as a holistic coach for a number of years and part of her role as a Health and Wellness coach is to empower women and improve their overall health and well-being. Her role in the fertility group is mainly to moderate the sessions and create a safe place for women to share their experiences and network with others in the infertility community. People that seek this key informant's services are mainly women who have been struggling to reproduce due to female and/or male factor infertility.

A second key informant that I interviewed is a female naturopathic doctor based in the Greater Toronto Area (GTA) and is a graduate of the Canadian College of Naturopathic Medicine. As a naturopathic doctor, this key informant specializes in treatment of infertility and other aspects of women's health. Her role at the women's health centre is mainly to offer treatment and care to patients with a clinical focus on acupuncture, botanical medicine and homeopathy. The patients that seek her services

mainly consist of women and, in some cases, their male partners, who have tried services at fertility clinics, but did not see success and opted to try natural therapies.

The third key informant that I interviewed is a male fertility specialist based in Ottawa who is completing an infertility fellowship. This key informant has been practicing for five years and worked at a fertility centre. His main role at the centre is to provide care to patients at all stages of the care process starting from clinical consultations, then workup of first tests, treatments, and medical procedures regarding IVF. The people that seek his services are patients looking for assistance in achieving a pregnancy. His patients include mixed sex couples and same sex couples both under and over the ages of 35, those suffering from recurring pregnancy loss, and patients seeking third party reproductive technologies that include donor sperm or eggs.

The final key informant that I interviewed is a cofounder of a fertility support group in the GTA. This key informant is completing a graduate degree in a university based in Toronto and cofounded the infertility support group because throughout her infertility struggles, she felt a lack of support from her community. She is a South Asian Muslim woman who was a teacher for a number of years and whose main role in the support group is to organize educational events, and create a safe space for women to come and talk about their struggles and issues, receive advice and connect with others. The support group is for women only and is a Muslim focused group, but welcomes all women within the GTA community.

Experiences with immigrants and Arab immigrant populations

> Creating a space and creating an environment where women are welcome…where they feel safe in that their voices will be heard, so this is what our focus is, primarily I guess this is the service that we provide is to have that environment for women. So that is key, that is important to keep in mind, just because we know, we are not looking to give them answers for their infertility but we are encouraging them to seek it and to work with their doctors and to work with their fertility clinics but also to have that support and to have that perspective. (Fertility support group representative, GTA)

Our key informants had different experiences with immigrant and Arab immigrant populations. They offered immigrant women a wide range of information upon their first meetings with them. Information mainly surrounded support and treatment options as well as setting a plan for the women or couple to attain their goals. The founder of the Muslim women's support group noted that both immigrant and Arab immigrant women had difficulty talking about their struggles and experiences due to a wide range of factors. She explained that it was important for her to create a safe environment where members can openly talk about their fertility struggles, treatment experiences, and overall personal lives.

The Health and Wellness coach spoke of similar experiences and further emphasized the importance of mental health during the infertility journey. Both these key informants emphasized that a great part of any woman's infertility experience is the emotional and social aspect of it, and so being part of a support group helps women connect with others who understand them and who are experiencing similar struggles.

When asked about their experiences working with Arab immigrants specifically, these two informants mentioned that there were no real differences between working with the general immigrant population and working with the Arab population in particular, but mentioned that there are differences that emerge revolving around religious beliefs and

their influence in decision-making surrounding the types of fertility services that are sought and the possible threat to a couple's marriage.

> Some other kind of stories I hear are...you know, my husband's family, they want...they've been thinking about or they've been talking about having him get married again because of the infertility that we have been experiencing but he's been resisting, and that is heart breaking...um because it's like being punished twice...so that is really difficult to hear. (Health and Wellness coach, Mississauga)

Two of the key informants we interviewed described their experiences offering women infertility-related treatment options and explained that their first interaction with patients is through a consultation. Both the naturopathic doctor and fertility specialist explained that during their consultations with patients they start off by understanding their medical history and where they are in their fertility journey.

> I basically discuss the treatment options with them at the first visit and, you know, especially within the world of fertility and within the world of naturopathic medicine, I specialize in Chinese medicine so acupuncture is my go-to hands down, I do not leave a single patient without doing acupuncture. So that is definitely discussed, there are some limitations that are discussed, like maybe waiting a little bit for supplementation because I will have to request their blood work, their ultrasound, their other, you know, tests that have been performed, so without the results, seeing the hormone panels, like I need to see all of those to see if there is hormone imbalance, so we discuss it and then I have to wait to get the results to then get them started. (Naturopathic doctor, GTA)

Similarly, both the naturopathic doctor and fertility specialist mentioned working closely with women and couples in creating a partnership, in order for them to work together to attain the couple's goals. Both key informants emphasized the importance of the health care professional and patient partnership as a necessity in assisting the creation of a sensitive and culturally appropriate environment for Arab immigrant women and their partners. They further elaborate that through this partnership they can better

understand where their patients are stemming from culturally and better understand their decision-making and level of willingness to try certain treatments versus not try others.

> [I] think that the most important thing is to try and get a sense, as I mentioned, kind of like on a case by case basis where a couples comfort zone is, for example, some may find that IVF is too far of a departure from quote unquote natural conception, you know for some people they wouldn't tolerate going that far… if obviously they're not open and don't feel comfortable to be given a treatment course...you know we try to explore what it is about it that they don't feel comfortable with, and if its still something that they don't want to do then obviously we are not going to push it...but I think that the important thing is to get a sense because the availability varies from patient to patient and couple to couple. (Fertility specialist, Ottawa)

All key informants we interviewed offered some kind of counseling services. The fertility group representative and Health and Wellness coach's main focus is to offer support and counselling to women. Similarly, the naturopathic doctor and fertility specialist offer counselling services through their centres and emphasize its importance for mental and emotional health of their patients. As the naturopathic doctor stated, "[T]he mental and emotional, you know which is huge in the world of fertility so we talk about the different, you know, ways that we should be arguing that as well." At the centres, counselling serves are not mandatory for patients, but the fertility specialist explains that they oblige patients to go through counselling services when seeking third party assisted reproductive technologies.

> [T]he only case where it's mandatory as far as clinic policy goes is if the couple or patient is looking to use third party reproduction, so whether that is donor eggs or donor sperm or gestational carriers, just in terms of exploring, you know, she [clinical psychologist] is very good at being able to explore the implications for offspring and kind of go through that aspect of things with the patient (Fertility specialist, Ottawa)

Facilitators and barriers to accessing care

> There is a stigma within the community and there is underreporting at the expense of...I think there's this idea of, you know, you kind of keep your problems to yourself and you don't necessarily share this personal stuff with others and then, so that sense of isolation I think is a big part of the problem, so I think that if more women felt comfortable voicing it um...I think that would make a big difference, like we have so many women who have said, you know, I didn't even want to like the Facebook page because I don't want people to know…I didn't want to attend the adoption seminar because what if I saw somebody I knew, so things like that are really big barriers that we have to overcome first, it's that you need to normalize this within the community and not make women feel like there is something wrong with them or their spouse um...you know, because they haven't been able to have children yet. (Health and Wellness coach, Mississauga)

A first barrier to accessing care that was mentioned by all of the key informants we interviewed was the stigma and embarrassment that many immigrant women, including Arab immigrant women, feel within their respective communities. Informants mentioned that stigma exists within the general community of Ontario, but it is even more prevalent among certain immigrant populations, particularly among Arab immigrants. The stigma and feelings of embarrassment experienced by several of their clients and patients influenced women's access and the timing around access to infertility related services in Ontario.

Three of our key informants also mentioned that due to the stigma and feelings of embarrassment, many women feel isolated in their infertility and, in consequence, they may not openly speak about their infertility journey with their family and friends. Support from family and friends can facilitate access to services and care for women in the general community, but even more so for immigrant women in the population of Ontario. Lack of support can act as a barrier for immigrants, including Arab immigrants, by

preventing these women from engaging in health-seeking behaviours that may aid them with their struggles.

One of the key informants goes on to explain that the topic of infertility as whole is a sensitive, and sometimes taboo, subject, which her patients do not always share with others for fear of being judged or not receiving support after disclosure.

> I think the whole subject of fertility is so sensitive, right? Nobody talks to another person about it, if they're going through it…It's like, you know, how do you talk about wealth, again, it's a very hard subject, and it's a very sensitive subject, so I feel like people often lock themselves up within their own little cocoon…then sort of bury themselves in it and I see that a lot of times because patients come in and tell me, I have not shared this with my parents, I have not shared this with my family, nobody knows that me and my partner have been struggling for the past 5 years per se, so support, social support…I guess people are afraid that if they say they are experiencing infertility issues and they kind of don't receive any support, or what would the reaction be, you know, if they were to discuss it with family members...the anticipation...um so I think those are big ones that really hold them back….from accessing other things openly. (Naturopathic doctor, GTA)

Support from family and friends as a whole is essential for the overall mental and emotional health of Arab immigrant and other immigrant communities in Ontario. What is even more crucial in regards to the overall well-being of the women is the support that they receive from their spouses and partners. Two of our key informants mentioned that the presence or absence of support from Arab immigrant women's partners could act as a facilitator or barrier when accessing care for infertility and influence the process of decision-making around treatment options.

> [T]he support that a woman gets from her partner can also be a big factor...maybe let's say she has done her research and she really wants to come seek fertility treatment and her spouse may not be supporting, or may be supportive of her going to the treatment but if there is a male factor, he may be like 'meh' all good...so that factor can also be a big thing. (Naturopathic doctor, GTA)

One key informant added that lack of support from women's spouses or partners can exacerbate their feelings of loneliness in their fertility journey and impact the dynamic of their relationship by creating disagreements regarding health-seeking behaviours within the couple.

> Like the stigma was definitely one that people thought or felt hesitant to kind of go out and seek help because, first of all, that takes you admitting that there is a problem and there's also, some of the women mention in terms of like spousal support or family support was not necessarily always ideal, so sometimes, you know, getting the husband on board was a bit of an uphill battle because you know, it's one thing for the woman to kind of make peace with it and again there's the okay, this is what we have to do and sometimes with that, they are not necessarily on the same page as their spouse. (Fertility support group representative, GTA)

The Health and Wellness coach we interviewed goes further to elaborate that lack of support from male partners in case of male factor infertility could really place a strain on the relationship of the couple and negatively influence decision-making around health seeking options.

> [I]t comes down to a man and his ego where he feels like he is going to lose a part of his manhood, if it is discovered that he is the infertile one. So um....So it's a whole new can of worms…And that makes it a lot more difficult for women, a lot more difficult for women because, whether something is wrong with them or not…It doesn't matter, if the man is the one with the issue so...this is why it's really important to get men involved in the conversation and have them be made to feel that what they are experiencing is normal and they are okay…Your manhood is not at stake because you are the contributor to infertility. (Health and Wellness coach, Mississauga)

As this key informant points out, in order to prevent barriers of treatment in cases of male factor infertility, it is important to include men when speaking about infertility as it does not only affect women. Including men in the conversation about infertility and educating men on diagnosis, treatment and services, can act as a facilitator to treatment for both men and women.

Additionally, two of the key informants I interviewed mentioned treatment option limitations among the Arab immigrants, but more particularly, the Muslim immigrant population due to cultural or religious beliefs. Their experiences with the Muslim immigrant population showed that religious beliefs mainly limited the possibility of utilizing third party ARTs as treatment options.

> [Y]eah, so again depending on religion and you know the extent to which the person, you know, feels about getting a donor egg or getting an embryo or, you know, because sometimes they have to go for both, a donor egg and a donor sperm…And then, so now you have a donor embryo, or some people are told you know you may need to seek a surrogate, so that may not be an option for them because of religious beliefs. (Naturopathic doctor, GTA)

One of these key informants further elaborated noting that limitations surrounding third party ARTs among the Muslim immigrant population can influence a couple's treatment options in cases where the infertility of the couples is due to both female and male factor infertility. This, in consequence, impacts their overall success rate when trying other forms of assistive reproductive technologies.

> [I]t tends to play a role potentially more in…when we start talking about more invasive procedures or things that may end up being a little bit more from a departure of what couples are comfortable with...you know form typical conception to fertility so, and I mentioned that tends to be for some, the whole concept of IVF of taking the eggs from a woman's body and then the sperm from the male and combining it in the lab and then...For some who tolerate that are tolerant of donation...donor egg or donor sperm and for others cryopreservation, you know, your own produced embryos between the couple, for some they do not feel comfortable freezing the embryos and just placing it in storage and not using it right away...so its variable like…But I would say of the situations, it does tend to play a role sometimes. (Fertility specialist, Ottawa)

Furthermore, informants also touched on the issues of cost as a potential barrier for immigrant couples seeking infertility related services. As stated by the Health and Wellness coach, “Well, money is a big issue for people, cost is definitely a big issue.”

One informant pointed out that when couples first approach her centre and seek her services, she is very straightforward with them regarding the cost of services and treatments. This informant further elaborates that when seeking infertility treatments, cost can definitely be an issue, but it should not be the main focus of the couple or woman seeking services.

> You know, people end up paying out of their pockets um...it only takes you, like if someone has $500, and my initial consultation is $400, then you're left with maybe one acupuncture after that, so yeah that’s what I try to sort of teach them, don’t lock yourself with this X amount of dollars. (Naturopathic doctor, GTA)

Related to cost as being a potential barrier for immigrant and Arab immigrant populations when seeking infertility treatments, some of the key informants mentioned the new fertility program implemented by the province. One key informant further stated that the new program is definitely much needed and is a turn in the right direction for the province, but cost still remains an issue for those couples or women of lower socioeconomic status.

> In December they announced an IVF program for women under the age of 43...per lifetime it’s one cycle not including medication which is probably a bit [financially straining]...or you know 75% of insurance plans do cover a great portion of it, so there is financial relief that way but you know, if they do not have the drug plan and they do not have [insurance]...Or if they’ve used their first cycle of the funding from the government, then cost can reach as high as CAD14,000 a cycle. (Fertility specialist, Ottawa)

Avenues for improving the availability and accessibility of services

Key informants highlighted a number of ways in which information and services could be improved for immigrant populations, but particularly Arab immigrant populations within the province. In order to reduce the stigma attached to infertility, many mentioned that it was important to normalize talking about infertility and educating the community on its prevalence. One key informant emphasizes that for Muslim immigrants specifically, there needs to be more religious-community involvement in educating Muslim Canadians on infertility, its prevalence and the struggles that many couples face in isolation.

> So I think that the community centres and the mosques need to be addressing this and addressing these topics, whether it be through sermons, whether it be through events or community events...they have to be talking about these issues, these are how people are feeling in their day-to-day and they need, like I think ...You know if you hear a sermon whether it's at a church or a mosque, and this is being talked about, I think that would be a big step to normalizing it within the community. (Fertility support group representative, GTA)

Additionally, all of the key informants mentioned that raising awareness and reducing the stigma is an essential part of improving information and services for immigrant and Arab immigrant populations particularly. One of the informants further suggested that the first step in raising awareness and reducing the stigma needs to include more involvement of the Arab community as well as the medical community.

> I definitely think that this has to be dealt the help of different organizations such as the Infertility Association of Canada or the Adoption Council of Ontario, I think [there needs to be] bridges between the Arab/Muslim community and they need to be fostered and you know I think through that they will have a better sense of what our community's needs are and we will have a better sense of, you know, how to get appropriate resources that are needed. (Fertility support group representative, GTA)

Key informants equally mentioned that an increase in outreach on behalf of the medical community would be beneficial to offering more information and appropriate services to the immigrant population in Ontario and would demonstrate a sense of partnership within this population.

> I think, you know, it can be something just as simple as communication to primary care physicians, particularly, you know, if we are talking about immigrant health particularly...Among those clinics that do provide a lot of services to the immigrant population, just again to remind them a bit of the potential of, or a piece of the clinical picture that may be overlooked because of more general health greeting and treatment so...That may be all it takes to be honest, because sometimes it's just a little reminder....It could become more formal as far as potential rounds, presentations or actual outreach from specialists so that the community would hear it from primary care providers um....but yeah, I think covering the spectrum of education would be good use. (Fertility specialist, Ottawa)

Along the same lines of this idea of further outreach from the medical community, one key informant pointed out that there needs to be bridges built between the infertile immigrant population and the medical community, as well as a the implementation of an integrative approach when offering information and services to patients. One key informant pointed out that seeing as though not all patients seek services at fertility clinics and many opt for a more holistic approach, there should be a link between both these services in order to offer the best care possible for patients, all while presenting them with a number of different options.

> Make the services integrative, so rather than me having my clinic separately operating in a fertility clinic, we should be working under the same roof because you know, being a naturopathic doctor, sometimes my hands are tied, like I cannot send a patient for an ultrasound, then they have to go back to their fertility doctor and do all this, so there is a lot of back and forth, you know, between me and the doctors, for me...put us all under the same roof, you know, there are areas that I am really good at, and then there are areas that they are really good at, and then at the end of the day, its patients that actually benefit, so I think that's the best model Ontario can have. (Naturopathic doctor, GTA)

Additionally, one improvement mentioned by some of the key informants was to shift the focus of infertility away from the woman and concentrate it on both genders. The Health and Wellness coach that we interviewed emphasizes that it is very important for fertility clinics and all fertility related services to include men in the conversation of infertility so that they can act as supporters to women, but so that they are not stigmatized in the situations where they are contributors to the couple's fertility struggles.

> I think, first of all, maybe if there is cultural issues, those need to be addressed specifically, people need to...at the fertility clinics, if you have Arab immigrant women, they need to understand or have some training in the culture, have some training into the stigma that is involved, have some training into the...I'm sure they already know this but try to include the men in the conversation because they may not...they may feel like it's a woman's issue and women might end up going to the appointments by themselves, so make it a priority to have the males at the appointment, um....and have the men be a part of the conversations, especially for immigrant women because, you know, and some men might accompany the woman because the woman might be the one who doesn't speak English or whatever have you, and they may need someone to translate or whatnot, but um....definitely, a lot of the you know, patriarchal societies, those are the societies that they come from, it is very patriarchal and we need to be sensitive to that, respect that but at the same time address it and have the men come in to the conversation as well, and accompany the women and make it a little bit more easier for them to access those services, easier for men to access those male-specific tests and things like that, so make it a little bit easier for them to access those services....uh as far as immigrants, whether they be Arab or non-Arab. (Health and Wellness coach, Mississauga).

This informant further explained that it is the responsibility of the Arab immigrant community and the medical community to further educate its population in order to normalize infertility as it is with any other medical problem. This particular key informant further emphasized education, awareness and the inclusion of men when speaking about

infertility as important factors in enhancing culturally and appropriate care for this population.

Chapter 4: In-depth interview results

Participant characteristics

We conducted 5 interviews with Arab immigrant women. Regarding immigration status, four of them were first-generation immigrants and one was a second-generation immigrant. Of the first-generation immigrants, one participant immigrated before the year 2000 while the other three immigrated after 2000. Regarding the second-generation immigrant, her parents immigrated to Canada in the late 1980s.

Participants averaged 22 years in age and ranged between 20 and 25 years old The women we interviewed held primary residency in Toronto (n=3) and London (n=2),

At the time of the interview, one participant was single, two were in long-term relationships and two were married. Four of these women were in the process of completing their bachelor's degree and one had only completed high school.

Participants identified as Muslim (n=3), Catholic (n=1), or did not associate with any religion (n=1). The participants all suffered from primary female factor infertility due to either endometriosis (n=1) or polycystic ovarian syndrome (PCOS) (n=4). All participants stated that their primary sources of emotional and social support consisted of friends and family members.

Mona's story

Mona is a 20-year-old Arab-Nigerian woman who lives in Toronto. She is a student at the University of Toronto completing her bachelor's degree and has been with her boyfriend for a little over 2 years.

She immigrated to Canada with her family in 2008 from Abu Dhabi. She explained that her family left Nigeria and moved to Abu Dhabi due to better job opportunities. Her family then decided to immigrate to Canada in order to build a better life. She says that she doesn't remember much of the immigration experience to Canada because she was still a young kid, but she remembers the process of approval taking a very long time. She explains that upon their arrival in Canada, her parents had a very hard time finding jobs and a home, but they currently all live together in a house.

Mona describes her reproductive health status overall as being very weak since her diagnosis with PCOS. She explains that she has suffered two miscarriages, one at the age of 18 and the other at the age of 19. She said she didn't know she was pregnant either time until she had miscarried. Mona was referred to a gynaecologist from her family doctor after her first miscarriage, and shortly after, she was diagnosed with PCOS.

She says that her plans for the future regarding her infertility are to continue to attend the appointments with her doctor and undergo more testing. She explains that her condition will be monitored and she is waiting on receiving further information and treatment options in the coming months.

Experiences with infertility

The women that were interviewed in this study all suffered from female factor infertility. One participants suffered from endometriosis, that is, growth of endometrial tissues outside the uterus and four women suffered from PCOS, a condition in which a woman's level of estrogen and progesterone are out of balance.

The woman that suffered from endometriosis described having extremely painful menstrual cramps, and abnormal and heavy periods. She described symptoms of her

endometriosis and explained how it has been affecting her life. The treatment options offered to this participants from her family doctor, at the time of diagnosis, were combined oral contraceptive pills. This participant explained that she was not looking to get pregnant at the time of her diagnosis, but was unable to utilize the treatment offered to her due to cultural beliefs.

> I mean I've always had um, really painful menstruation and whatnot and… my parents, I mean at one point, you know my father wanted me to, you know *sigh*, I should say he didn't want me to, hehe, there was discussion of me being on the birth control pill because there was a lot of endometriosis-type symptoms and really heavy bleeding and whatnot, so the pill would've really helped calm that down. So there was a lot of debate about that in my household, um… It didn't end up happening …and then I got married. (Jamila, age 23)

This participant further explains that she has never tried the oral contraceptive pills even after marriage, because she and her husband tried to get pregnant shortly after marriage and were unsuccessful. She describes her infertility experiences as being "life changing."

Similar to Mona's story, three other women that we interviewed suffered from PCOS. Women first noticed an issue due to their irregular menstrual cycles or due to a ruptured ovarian cyst.

> [W]ell I've always had difficulty since 12 because I wasn't getting a period so, you know, it started late and then it would be that I wouldn't get one or if I did get one it was really painful and just too much and…and then I was diagnosed with PCOS. I did have more than one time; I had a cyst burst which was very painful. (Maha, age 25)

This participant further explained that she was given oral contraceptive pills to help treat her PCOS but she was only on the contraceptive pills for about a year. She

explained that she and her husband had been trying to get pregnant and had been to the fertility clinic to seek treatments and had a success, but she suffered a miscarriage.

The women we interviewed mainly sought infertility-related services at their family doctors, obtained referrals to gynaecologists and sought infertility-related treatments at fertility clinics. Similar to Mona's story, several women mentioned that their plans for the future consisted of having their conditions monitored and reviewing their treatment options.

Jamila's story

Jamila is a 23-year-old university student living with her husband. She is from an Algerian background and came to Canada with her family in order to build a better life and have more opportunities.

Jamila described her reproductive health as being "not good" and explains that she has always had issues with her menstrual cycle. She was diagnosed with endometriosis before marriage and it was suggested that she use oral contraceptive pills to help control her symptoms, but her family was very traditional and didn't allow it. She was married at the age of 19 and briefly used condoms as her method of contraception before she and her husband started actively trying to conceive a few months into their marriage. Jamila has experienced a few miscarriages and sought services at a fertility clinic, but has not been able to keep a pregnancy.

She explains that her experiences with services in Ontario were positive and the fertility clinic was very extensive in the testing that they ran. She mentions that her fertility specialist has worked closely with her and suggested that she try an IUI, but her husband isn't on board. She explains that she doesn't feel any support from her spouse and shares that he has never attended any of the appointments with her because he feels like they should give it more time to see if they can conceive on their own.

Jamila has not openly disclosed her fertility struggles to all of her family members and friends because she feels like it is difficult to talk about. She considers herself flawed and feels like this is something that she needs to keep secret and cannot openly discuss due to the stigma. She points out that speaking of infertility is very female-focused and so she feels embarrassed that her body is not cooperating.

Stigma and gendered responsibility for infertility

Consistent with Jamila's story, infertility is highly stigmatized among the Arab immigrant women we spoke with and is very female focused. Many women we interviewed used words such as "flawed", "defective", and "less of a woman" to describe the way they felt about their fertility struggles. Women felt pressure of having a baby from their families and friends and as a consequence blamed themselves for not being able to take on their perceived role in society as mothers.

> Well it's…all the pressure is on me, and if it doesn't happen, you know, I feel defective and, you know, even sitting in the room, in the waiting room, I feel ashamed of myself. Like I said my mother-in-law has been pretty good but the pressure from my mom…like I can only do what I can do, but it doesn't seem like it's just okay, you know, like it if doesn't work, it doesn't seem like it's just going to be okay, and that makes me really ashamed that I can't just be okay if I don't get pregnancy, that there's something wrong with me and I don't know how that will ever go away, because it's just assumed that's what you got to do. It's how my mom talks, you have children, so I can have grandchildren, so we can carry all the, you know, the blood thing and she is always talking about how important it is and family and I feel ashamed that I can't do that, at least not yet. (Maha, age 25)

The majority of women found it difficult to talk about their fertility experiences and disclose this information to their family and friends. Women who did share their diagnosis explained that they felt a lack of understanding from their loved ones and felt like they were alone in their journey.

> I just feel really flawed, it is difficult to talk about it…it feels like something I need to keep secret and I can't just openly discuss because I shouldn't have to go through this much to make it work and my sister had no problems, my mom had no problems. I don't know I just feel like the odd ball that's all…I have one friend that I've talked to a little bit about it, but she can't really relate the same because she is not really in a similar situation. (Jamila, age 23)

The unmarried women spoke about the stigma of infertility combined with the stigma of premarital sex. Women described infertility as being a 'burden' on its own, but openly speaking about their diagnosis considering that they engaged in sexual activity before marriage would be shameful to them and their families.

> I didn't tell anyone else just because like culturally like I think the idea of a 20-something-year-old from a Muslim family who is unmarried who knows that she is infertile through a miscarriage...I think that is extremely, it would just look bad on my family and I've been conditioned to just not say things that would affect them, but I didn't tell my friends or my partner just because...I don't know like I remember when I heard, when I heard like the bad...Like the doctors when they said it would be difficult, he said all women have maternal instincts and they wanted to have children, so it just feels like...Um, I don't know...So it feels like I am less of a woman because of this, and I don't like to publicize it I guess. (Yasmine, age 23)

Consistent with Jamila's story, several women that we interviewed took full responsibility and blame for childlessness. Very few women mentioned having their partners tested for potential male factor infertility and put no responsibility on their partners. Some women stated that they felt blamed for their childlessness, and that family and friends took pity on their partners because their wives haven't been able to 'give' them a baby.

One woman explained that the stigma and shame she felt was so high that it would affect her daily life, and she would think twice before attending family and friend gatherings and social events in general.

> [S]o those were the difficult moments, when you're in front of people, when you're in gatherings and you withdraw from those gatherings…You shrink away from them because you know what your facing and what you're expecting, why would you want to get into that kind of situation if you didn't have to? So, I tried to steer clear of those kinds of situations but then there's the obligation…Oh the obligation, so and so had invited us to their wedding, so we have to go and we can't make excuses for you, so you have to come too, so by hook or by crook they invite you to these events and weddings or parties and things like that and you just know that

at least one or two people are going to make some kind of comments to bring you down (Maha, age 25)

Maha's story

Maha is an Algerian woman in her mid 20's; she comes from a Muslim background, but currently doesn't associate herself with any religion. Maha has been married for about 3 years now and is mainly a stay-at-home wife. Maha considers her family and friends as her sources of emotional and social support, but explained that she constantly feels pressure from her mother to have a baby and to contribute to the family lineage.

She described her reproductive health as being bad and explained that she's had issues with her period since the age of 12. She described her period as being very painful and irregular. She explained that she was diagnosed with PCOS and has had cyst ruptures on her ovaries. She said that she has only ever used condoms and oral contraceptive pills as contraception methods, but they started trying to get pregnant relatively early after their marriage. She shared that she saw a fertility specialist and was on Clomid for a few months, but they needed to take a break because they couldn't afford to pay for the medication. She shared that she did have a success using Clomid, but she experienced a miscarriage shortly after. Maha disclosed her infertility struggles to her family and friends shortly after having a mental breakdown and sought counselling services to help her cope with her struggles.

Maha says their plan right now is to save up some money to pay for more rounds of Clomid. She said that her husband is very supportive and they have discussed other family building options such as adoption and surrogacy.

Facilitators and barriers to obtaining infertility services in Ontario

Consistent with Maha's story, some women mentioned that cost of services was a barrier to accessing care and utilizing certain treatments. Women believed that there should be more OHIP coverage around treatment options, whether it is as simple as covering the cost of certain medications, or covering the cost of ARTs, a number of them mentioned that health coverage was lacking.

Some women talked about the new fertility program that was implemented in December 2015. Many women believed that it was a great step forward. One woman explained how cost has been a major factor preventing her from trying IVF, and said that

she is going to speak with her fertility doctor to make sure she makes it onto the waiting list, but that this would be her only shot at getting pregnant through ARTs. Another woman stated that the new Ontario fertility program wouldn't be enough considering that it was limited to one cycle only and it would usually take several IVF rounds before a success resulted.

> [I]t is a waiting game, but it sounds like I do have access to it by my only concerns about IVF is that it is only covered once. It's like a one shot because it's very expensive procedure so if it doesn't' work on the first try, then I'd be looking at thousands of dollars out of pocket, so that's not going to be an option (Jamila, age 23)

The majority of women were aware that the new fertility program would cover certain treatments but fertility medications such as Clomid, a drug with the purpose of helping women ovulate, would need to be paid for out-of-pocket. Women voiced their disappointment that these essential fertility medications are still not covered through OHIP and coverage from private health insurance plans is limited. A few women believed that the province should subsidize these medications because they are crucial in family building and would make a huge difference for those struggling to conceive on their own.

Additionally, a prevalent barrier that emerged throughout the interviews was the lack of support that women received from their health care professionals.

> I think…like support form family members and friends…I do feel supported, but I do not feel supported by doctors and medical staff right now…like I don't know if it is because I am having to wait, you know, or because it is so early or because you know the doctor being a new physical…like I don't know but I feel like there could be…I feel like there could have been more that was done. (Yassmine, age 23)

An additional barrier that was revealed by women as influencing their health-seeking behaviours was the cultural stigma that prevented them from being open and seeking information or treatment option.

Yasmine's story
Yasmine is a 22-year-old Bahraini Muslim woman presently finishing up her bachelor's degree. She is currently in a long-term relationship that her parents do not know about. She considers her friends as being her main sources of emotional and social support and explains that her family supports her as well, but due to their traditional beliefs, she cannot come to them with things that aren't culturally acceptable.

She described her reproductive health as not being great. She was diagnosed with PCOS at the age of 15 and was taking oral contraceptive pills in order to help regulate her hormones. She wasn't able to continue taking the contraceptive pills because she developed a blood clotting side effect to them. The main contraceptive methods that she has been utilizing with her partner are the male condom. She explains however, that they experienced a contraceptive failure and she got pregnant about a year ago. Yasmine's pregnancy resulted in a miscarriage that she hid from her family and some of her friends.

She sought various fertility-related services, but felt like services were lacking and there was no support from the medical professionals. She says that the most positive experience that she's had with services in Ontario, was the counselling she received at a women's reproductive health clinic that she just happened to drive by.

Ways in which information and services could be improved

Consistent with Yasmine's experiences, three women felt that services and information related to infertility were lacking. These women mentioned that they did not feel any kind of emotional support from their health care professionals and at times felt judged by other staff members.

> The doctor was really nice; he was very easy going…I wasn't really comfortable with some of the other staff. I felt…It may have just been my mood, but I felt a little bit of judgement, like I did not, I felt like like it was my age, my appearance, my race, or I don't know if it was just an age thing or what, but I just felt like the rest of

> the staff, I don't know how to explain it, but I just didn't really feel comfortable with the rest. (Maha, age 25)

The stigma surrounding infertility is a major barrier to information and access, women suggested that there needs to be more awareness around infertility in hopes of stigma reduction. It was mentioned that there is a strong female focus surrounding infertility within the culture and that there is not much talk around male infertility.

> It is very female focused and it's kind of, you know, it's all I'm ever asked, I mean once you are married it's all you're ever asked. Where are my grandchildren? So it is difficult to open up because I feel embarrassed and my body isn't cooperating, not my husbands. I think it's a gender and a cultural issue because my mother always stayed at home so her main focus was always children, so she could never understanding if my life went without children, and because it's a gender thing, we are expected to, and I never thought I would be having such difficulty. (Jamila, age 23)

In order to raise awareness, they suggested that there be more community outreach about these issues. Women feel like if these taboo issues were openly discussed and normalized within the community, stigma wouldn't act as a barrier to seeking information or services. For some of the Muslim women, they suggest that these issues be discussed from religious leaders.

> [S]ince I'm Muslim I think that it's up to talk…to have imams or something like that talk about it…and the imam should be spreading more body-positive messages and things like that, and so hearing such things from our imam because he is highly valued and appreciated, he can affect different families and make them more aware of issues that should be talked about. (Celine, age 21)

Many women believed that improving information around services needed to start by education within the community. Women suggested that there exist a pamphlet or website containing information about available services in the province. Women said this would be

a useful tool for immigrant populations who have newly arrived in the province, but also for immigrants that have resided here but do not have enough resources or networks. Women suggested that this information be readily available and presented in a clear and accessible manner.

> I think that the information that I got initially was…it was very difficult to go through, I mean there were all these terms and conditions and I mean, they were written to be accessible, I think that I myself because I am a university student, I had much easier time reading it, but it was still…like why is this that way…but I think that the information, it takes a lot of effort to find it, it takes so much effort and I feel like if you already suspect that you are infertile or you are sad about being pregnant, or like you don't have the mind to process all of these legal terms or all of these medical terms and you don't have the energy to just go looking everywhere, you just need to have like one source, I mean it is easy to find information on STD testing, I ran into that a lot, so I think that the infertility in women and women's reproductive health should be as easy to find too. (Yasmine, age 22)

Women believed that if these pamphlets were made, they could be available for pick up at women's health centres, general physicians' clinics, and walk-in clinics. Other women suggested that a website be created, which would contain information about infertility in general, treatment options and the available services organized by geographic locations. Women said this could be advertised through ads on social media, or even on television, and that it should be available in a range of different languages.

> I think what needs to be done firstly, there I needs to be a provincial website thing about women's health in the same way that there is like an STD thing, or a smoking thing, like there needs to be something through the whole province or throughout all of Canada, but I think that it's better to focus on province by province because each province has different services and I think that there should be…In Saudi Arabia websites are English or Arabic or French, like you have the option to hop between them and I think that in Canada, especially in Ontario, like the population isn't just French and English, we peak a million different languages and there should be other…there should be default options to pick from. Um so Id like to see that too and I would like to see, instead of walls of text, I would like to see the points instead because I know that that is easier for people to process, it is not necessarily as informative but I think that the website needs to be like there are your options, there

are what you could do and then if you want to know more, you can clock on those or go to referring website, but I think that the most important thins it to have a provincial standard website that people can go to and I think it needs to be publicized.
(Yasmine, age 22)

Chapter 5: Discussion

Discussion and integration of results

Among the Arab immigrant population, infertility is considered by some as being a sensitive and taboo topic that is not openly discussed. Infertility struggles are highly stigmatized and predominantly blamed on women's reproductive health failures. Women described feeling defective, embarrassed, and less of women, due to their fertility struggles. The stigma of infertility was commonly noted as being one of the main reasons that women did not disclose their diagnosis or fertility struggles to their family, friends and community.

As mentioned by both key informants and participants, lack of support from family and friends played a role in the information and services that immigrant women sought. Women felt that they lacked support and understanding regarding their infertility, and, even though some of them managed to be open with their families and friends about their struggles, women still felt like they were isolated and alone in their journey.

Key informants and several participants emphasized the importance of support from a spouse or partner during the infertility struggles of the couple. Lack of support from partners can dampen a woman's mental health and influence her access to available fertility treatments. Support from spouses and partners can act as a facilitator that influences health-seeking behaviours, and influences the timing of when treatment is sought.

A further barrier mentioned by both key informants and participants surrounding treatments was the high cost associated with a lot of fertility medication and ARTs.

Improvements that were suggested around infertility-related information and services by both key informants and participants, mainly surrounded reduction of stigma and an increase in awareness within the community. Informants and immigrant women believed that infertility should be discussed openly and that men, husbands, and partners should be included in the conversation, because this is an issue that does not just affect women, but also affects men. Key informants and women both mentioned that through education and community outreach, the stigma of infertility can be reduced and the availability of services and information regarding available services in the province can be enhanced.

When speaking of support, two key informants mentioned that there were counselling services offered through their centres in order to aid women on their journeys. On the flip side, women spoke of a lack of support or focus on emotional health or emotional and social support from their health care providers.

Arab women indicated that during their fertility appointments, counselling services were not offered to them, and they felt like staff members were not empathetic to their struggles. This was very interesting to observe because this was one of the main differences that emerged from both components of the study.

Additionally, emphasis on improvements suggested by informants differed from that suggested by women. Key informants put greater emphasis on educating the community on available services and stated that these services should adopt a more integrative approach. Whereas women believed that the emphasis should be on making information on available services readily accessible through a brochure or website, and advertised through clinics and hospitals as well as by the government. Arab immigrant

women also pointed out that this information should be made available in a wide range of languages, to eliminate language as being a barrier and to target a wider range of the immigrant population struggling with infertility. Of the Muslim women we interviewed, limitations surrounding third party ARTs was mentioned.

Policy implications

The issues of cost proved to be one of the greatest barriers that participants faced when seeking infertility-related care and treatments. Before December 2015, treatment for infertility through ARTs, with the exception of IUI, was not covered by OHIP. There was no public funding for ARTs in the province, which meant that most Ontarians (with the exception women treated for blocked fallopian tubes) needed to pay for infertility services out-of-pocket (Ministry of Children and Youth Services, 2010).

In December 2015, Ontario launched a new fertility-funding program, which offers treatment for artificial insemination, IVF and fertility preservations. A number of participants mentioned this new program, but were aware of the limitations. For example, women under the age of 43 are eligible for one cycle per lifetime of IVF (Ministry of Health and Long-Term Care, 2016). For a couple of a lower socioeconomic status that cannot afford to pay for IVF, this program is definitely a step in the right direction.

However, the odds of a success after one round of IVF are slim and women are aware of this, so although a number of women mentioned the IVF program, they were aware of the reality associated with being successful after one cycle. Women believed that there should be more health coverage through OHIP and that the government

should subsidize some of the fertility medication, because for those who do not have private insurance, the cost of medication alone is unaffordable.

Furthermore, the fertility program can fund up to 10,000 rounds of AI and IUI per year, and 5,000 rounds of IVF and FP. This means that women seeking to be put on the fertility funding list, can be waiting years before it is their turn and for women who are nearing the age of 43, this becomes problematic. Additionally, the province announced that 52 clinics participated in the fertility funding program, and were free to decide how patients would be selected. Some clinics opted for a 'first come, first served' basis, while others opted for a lottery method, so selection is completed at random (Ministry of Health and Long-Term Care, 2016b).

Funding regarding fertility services and treatments is a step in the right direction for the province of Ontario, but it is not yet ideal, as noted by Maha and Amana, and there should be more available resources for men and women seeking to build families. Provincial coverage surrounding infertility medications would aid couples in alleviating the burden of cost and would allow them to redirect that cost towards assisted reproductive technologies such as IVF.

Positionality and reflexivity

An important strength in qualitative research surrounds the researcher's ability to create a relationship with the participant to deeply explore their experiences. However, the subjectivities of individual researchers must be acknowledged throughout the research process. Through extensive interview training that I have done under my thesis supervisor on a directed study focusing on immigrant women, my attendance in

regular group meetings, and participation in a qualitative methods workshop, I was prepared to collect my data in an appropriate and ethical manner.

The skills that I acquired from my training allowed me to set up a private, safe and non-judgemental environment for all participants, all while ensuring them that their participation was strictly voluntary. Through my training, I was able to engage in active listening, listen non-judgementally, and heighten my sensitivity to each participant's story.

Positionality can play an important role and have an impact on the recruitment, data collection, interview and analytical process. My status as a Canadian graduate student necessitated that I collect my data in an appropriate and ethical manner. Additionally, my graduate student status allowed me to reach out to community based organizations and women's health centres and allowed me to gain their help in advertising this study.

My status as a first-generation immigrant allowed me to set up a culturally sensitive and appropriate environment for my interviews as well as permitted me to engage in non-judgemental active listening.

My position as a Lebanese woman and my ties with the Arab community facilitated the diversity of different recruitment avenues within this community. More specifically, my strong ties to the Lebanese community allowed me to advertise this study on the CHIN multicultural/multilingual radio station for free. In contrast, advertising myself as an Arab graduate student on air may have impeded participant's willingness in participating in the study.

My status as a young woman with no infertility-related experiences may have influenced the dynamic of the in-depth interviews that I conducted with women. Although I am aware that infertility is a sensitive issue, my lack of infertility experiences may have made it difficult for me to relate to some of these women's stories. However, my position as an Arab Muslim woman facilitated my understanding of cultural and religious limitations when it came to limitations regarding infertility treatments and the factors that influence the decision-making process.

Limitations

As is true of all qualitative research, our findings are not generalizable or representative. Our study focused on the experiences of infertile Arab immigrant women in the province of Ontario. Recruitment of Arab immigrant women was a long and challenging process, which resulted in a very small number of participants to the study.

A number of non-Arab women approached us or showed interest in the study and identified themselves as being 'part' of the community through cultural similarities or religious beliefs. Some of the non-Arab women that we conducted interviews with were not properly screened before the commencement of the interview, while others claimed to be Arab but belonged to neighbouring immigrant communities. One of the non-Arab participants that we interviewed for this study considered herself as belonging to the Arab community because she was married to an Arab man. Self-identification which emerged through religion or cultural beliefs influenced the inclusion of non-Arab immigrant women. It is important to mention that the non-Arab participants were not included in the results of this study and the sole focus of this thesis is on Arab immigrant

women. That a number of women approached or responded to our ads who weren't Arab suggests that there is a need for a qualitative study with broader eligibility criteria.

Additional limitations to women's participation or interest in this study may have been due to the high stigma associated with infertility within the Arab immigrant community. There were a number of women that showed interest in the study and sought further information about it, but their partners were not comfortable with them participating.

Additionally, recruitment of key informants began in mid-fall 2015 and was extremely challenging. A possible cause to this was the launch of the Ontario Fertility Program in December 2015, soon after the commencement of recruitment for this component. Getting a hold of fertility centres, clinics and health care professionals was extremely difficult as these services were extremely backlogged in appointments.

Furthermore, the number of interviews conducted for this study was nowhere near the intended range. Due the very small number of interviews that were conducted, thematic saturation was not reached and so the findings are not generalizable by any means. Further research on this issue, focusing more on the immigrant population as a whole, would be beneficial.

Statement of contribution

As the principal investigator (PI) of the study, I completed this study in partial fulfillment of the requirements for the Master of Science in Interdisciplinary Health Sciences program at the University of Ottawa. Consistent with my role as a PI, I conceptualized

the study, designed the study instruments, collected and analyzed the qualitative data and led the development of this manuscript.

However, this project could not have been a success without the help and guidance of my thesis supervisor Dr. Angel M. Foster, who worked closely with me in designing this study. Dr. Foster guided me throughout the research process in helping me create the proposal, getting approval from the REB, providing me with feedback and guidance on the study tools, and being readily available for all of my concerns. Dr. Foster oversaw the project in its entirety including listening in on the first few interviews that I completed, reading over the memos and the transcripts and approving the codebooks and the overall analysis of the study.

The next steps include preparing a brief report of the findings to be disseminated to the participants and key informants of the study. The results that were gathered could be utilized to further investigate and expand the study on infertility among different populations in Canada. Results from further research could potentially create change and improve immigrant populations' access to information and services.

Conclusion

Infertility has been on the rise globally affecting millions of men and women of reproductive age. Despite its high prevalence in both men and women, infertility is still predominantly viewed a result of women's reproductive health failures. This is especially true in the Middle East and North Africa region where parenthood is culturally mandated and children are highly desirable. Availability and accessibility of services and

treatments vary tremendously in the MENA region and a number of factors may influence couples' infertility-related treatment options.

For Arab immigrant women in Canada, infertility remains female-focused and takes a toll on women's emotional and mental health. Women struggling with infertility commonly refer to themselves as flawed, defective or lacking femininity. Childlessness among Muslim Arab immigrants may threaten a woman's marriage and may negatively impact the dynamics of her relationship with her partner.

Some barriers to accessing information and services mentioned by participants included stigma, lack of support from family and friends, gender responsibility, lack of support from the medical community, and the issue of cost.

With the implementation of the new Ontario fertility program, one IVF cycle for women under the age of 43 is funded through the government. Several participants mentioned that this was a step in the right direction, but that funding and access to treatments through this program were still lacking.

Recommendations and improvements from participants in enhancing available information and access to care consisted of further education and awareness within the community, providing emotional health options to women and couples facing fertility struggles, building bridges between organizations and the community and subsidizing fertility related medications.

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Appendix

File Number: 02-15-10 **Date (mm/dd/yyyy):** 03/26/2015

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: http://research.uottawa.ca/ethics/submissions-and-reviews.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: http://research.uottawa.ca/ethics/submissions-and-reviews.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Catherine Paquet
Director
For Barbara Graves, Chair of the Social Sciences and Humanities REB

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