

Canadian Counsellors' Views of Working with Individuals Considering  
Third-Party Reproduction

By

Adelle Gwen Teneycke

Submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work

at

Dalhousie University  
Halifax, Nova Scotia  
June 2016

Copyright by Adelle Teneycke 2016 ©

## Table of Contents

Abstract.....	v
Acknowledgements.....	vi
Chapter 1 – Introduction.....	1
Statement of the Problem.....	3
The Gap.....	3
The Question.....	4
The Significance for Social Work.....	5
Overview of the Study.....	7
Definitions.....	7
Chapter 2 – Literature Review.....	9
Legislative Response to AHR.....	9
International Approaches to Law and Reproductive Tourism.....	10
Canada’s Legislative Response and the Development of an Industry.....	10
The Commission: a thoughtful and controversial examination....	11
Assisted Human Reproduction (AHR): treated differently.....	13
The Long Road to Legislation.....	14
The Quebec Challenge.....	15
Muddied Waters: the impact of the challenge.....	16
The Scope of Infertility in Canada.....	17
Reproductive Counselling in Canada.....	18
Reproductive Counselling Research.....	19
The Perception of Infertility.....	20

Reactions to Treatment.....	23
Research on Counselling Approaches.....	24
Looking Ahead to Future Research.....	28
Conclusions.....	29
Chapter 3 – Methodology.....	31
Design.....	31
The Question.....	32
Methodology.....	32
Recruiting Participants.....	32
The Interviews.....	34
Analysis of Data.....	36
Chapter 4 – Results.....	38
Demographics of Participants.....	38
Themes.....	39
Theme I. Counselling Role.....	39
Specialized Counselling.....	39
Education.....	40
Gatekeeping.....	41
Addressing Implications.....	45
Mandated Sessions.....	47
Theme II. Facing Challenges.....	48
Grief.....	49
Legislative Impact.....	49

Medicine and Business.....	50
Limited Time.....	53
Summary.....	53
CHAPTER 5 – DISCUSSION.....	54
Themes.....	54
Theme I. Counsellor’s Role.....	55
Specialized Counselling.....	55
Education.....	56
Gatekeeping.....	56
Addressing Implications.....	57
Mandated Sessions.....	58
Theme II. Facing Challenges.....	58
Grief.....	59
Legislative Impact.....	59
Medicine and Business.....	59
Limited Time.....	59
Strengths and Limitations.....	60
Conclusion.....	62
References.....	65
Appendix 1.....	74
Appendix 2.....	76

## **Abstract**

Assisted Human Reproduction has altered the way people can achieve parenthood; individuals, families and nations have had to adjust. In Canada the lack of legislation for this rapidly growing area of privatized medicine has meant there are complex issues that must be grappled with by both donors and prospective parents. Many Canadian fertility clinics require people who consider participating in third-party reproduction see a counsellor before they proceed. The focus of this research is to understand how Canadian counsellors view the role they play in their work with third-party pre-treatment clients.

This question was explored through a qualitative study. The data gained through interviews and email surveys were analyzed using thematic analysis. The study found that counsellors see themselves in a role that requires specialized skills they use to create a forum for discussion in which they educate, broaden clients' context and reluctantly have influence on whether or not clients proceed with treatment. They face pressures from a poorly regulated system. The counsellors balance the needs of their clients for information and support with those of the physicians to whom they report. Often concerned with the income patients bring to their practice, physicians prefer interactions with patients to be simple and unencumbered with emotion.

## Acknowledgements

I would like to express my gratitude to my advisor Dr. Catrina Brown and my second reader Dr. Cassandra Hanrahan. Your support has made this project possible. I thank you both your insight and help with this project from its very beginning. I thank the friends and family that read the many drafts of this thesis - Coleen, Kristin, Shari and Cory. Your input challenged me and improved this writing. To the participants who agreed to be interviewed for this project- I appreciate your time and depth of knowledge shared. Joan your willingness to help and support Connor and I meant I could do this. My parents are my greatest teachers and supporters in this and all things; the depth of my gratitude for them has no end. Finally Connor, my IVF baby and the inspiration for this research who continues to be the source of so much joy and the reason I have taken this and many other journeys.

## Chapter 1 - Introduction

In chapter one I will describe my interest in this field, the question that is the focus for my research, and identify what I perceive to be the gap in knowledge that has motivated the project. These three sections will be followed by a description of my study's approach, the significance of this thesis to social work, the organization and intent of the thesis, and, finally, a short list of definitions useful to the reader.

I stumbled into the world of assisted reproduction when my life took an unexpected turn. A foster parent for the first half of my twenties, then a social worker in a facility for youth, I was surrounded by children for much of my young adulthood. Through those experiences, I gradually felt prepared for parenthood and decided that I would like to have a baby by age thirty. When the baby I desired had not arrived, my concern began to rise and my life changed. There were supplements, surgeries, doctors and, after five years, a fertility clinic. I recall as I sat in the waiting room of the clinic, I was not the only one emotional and overwhelmed by the process in which my partner and I were about to engage. Making matters even more challenging, I was surprised to learn there was neither a counsellor employed by the clinic nor one they recommended. I sought out my own counsellor, was artificially inseminated and gave birth to a baby boy. Home with my much desired baby I could not stop thinking about my experience in the clinic waiting room and what seemed to be an unaddressed area of mental health. Driven to explore the problem I applied to graduate school in order to have more time and resources to formally investigate the nature of the mental health services that are often required by those seeking infertility treatment and the corresponding resources (or lack thereof) that were available. In this process I quickly learned that there is indeed a field of counselling called *infertility or reproductive counselling* that attempts to support this population. I was immediately

curious about this specialized field of counselling, especially those services involving sessions with women considering using procedures that require donated eggs, sperm or the use of a surrogate.

The stance taken in this thesis is autoethnographic. My decision to pursue this line of inquiry came from the personal experience I describe above. This, and my work as a social worker, shaped and directed the research. Autoethnography is an approach to “...research, writing, and method that connects the autobiographical and personal to the cultural, political and social context” (Ellis, 2004, p. xix). Although autoethnography is not front and center in the thesis, the thesis is an attempt to connect my personal experiences using infertility services to the larger Canadian socio-political context as it relates to assisted human reproduction. Using autoethnography allowed my challenging search to find support for myself to be better understood as having been inextricably connected to a larger culture of politics, policy, counseling, and medicine that was not immediately clear to me. According to Ellis, Adams and Bochner (2011), autoethnography is an approach that “acknowledges and accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters or pretending they don’t exist” (par. 40). Because of my belief in humanism, I see people as basically good, capable of creating and finding solutions for their problems. I view counsellors in particular as people who help others find or create meaning from experience; therefore, I embarked on this study to explore what counselors are doing to assist women who pursue infertility treatment.

My experience of AHR was limited to my story, thus as a relative outsider, the whole field of AHR, not only the counseling aspect, seemed unclear to me. It was, in truth,



overwhelming, and I was skeptical of how counsellors could approach the topic with patients/clients in a single therapy session. Reproductive technology has both challenged and changed the ways people think about reproduction, particularly in the area of third party reproduction where more people than ever before can be involved in varying degrees in the making of a baby. I had many questions, I wondered how in one or two sessions all the issues relating to the process of surrogacy, which seems to me to be an emotionally and socially complex arrangement, might be addressed. Further, I had questions about the implications of sperm and/or egg donations.

From a structural perspective, I could also see some potential challenges. As a professional social worker I understand all too well how legislation and policy inform my work, and the particularly close connections they have to what is known as mandated services. While social welfare policies and laws create jobs for social workers on the one hand, such policies and laws are often experienced as restrictive because they can dictate the types of interventions used, and the amount of funding available for programs and services. My professional experiences thus also lead me to want to understand the political context in which infertility counsellors worked. To that end, the interviews were designed to explore how the counsellors saw their role within the personal and political contexts within which they worked.

### **Statement of the Problem**

In recent decades, advances in both medical research and technological innovation have greatly increased the range and degree of activity in the field of Assisted Human Reproduction (AHR). Most highly profiled are procedures and technologies aiding and/or enabling the physical aspects including in vitro fertilization, fertility drugs, use of donor eggs and sperm. However, while

those endeavors are the territory of medical health research and practitioners, AHR also calls for involvement of mental health professionals to assist those exploring the possibilities now offered by AHR. The investigation of current work underway by this latter group – specifically, Canadian therapists offering psychosocial support to individuals and couples (both donors and recipients) pre-AHR, and particularly with regard to third-party reproduction (see expanded definition later in this section) – informs the question for this thesis. Though the ethical, social, and political issues have been raised consistently in both academia and the media since the 1980’s my initial efforts searching the literature proved difficult; there was relatively little literature available that explored the Canadian context in regard to Assisted Human Reproduction. It was difficult to determine how Canada ended up in the current situation with regard to AHR. In particular, the practice of third-party pre-treatment counselling lacked supporting literature. However, the need for knowledge in the area of mental health is, and should be, regarded as an undeniably important component. Such absence forms the “gap in knowledge” to be investigated in the third part of this thesis.

### **The Question**

There is a gap in the Assisted Human Reproduction (AHR) literature regarding how counsellors work with individuals choosing to participate in third-party reproduction, both those donating reproductive material and also the intended parent or parents. The desire to become a parent, to create a unique and intimate bond with a child is strong and if that desire goes unfilled, people often will seek a range of solutions. Both adoption and surrogacy have been options in solving that problem from before recorded history to the present day; evolutions in modern medicine now offer vastly enhanced possibilities. Assisted Human Reproduction has broadened the biological scope for accessing reproduction.

The available research reflects recent and ongoing work by counsellors and therapists who work with clients struggling with the complex and often unresolved issues arising from AHR. Such research, however, is limited meager and points out the need for further studies with some urgency in order to keep pace with the needs from medical advances in AHR. The strong desire for a child coupled with advances in reproductive technology has created a new field of counselling. Although no longer required by law in Canada, some fertility clinics call for their patients to visit a counsellor before beginning procedures involving third-party reproduction. Clients arrive at these sessions with a diagnosis of infertility, a strong desire to be parents, and the need to make decisions around the implications of both “carrying” (pregnancy) and raising a child who may not be genetically related to them. Potential patients may be uncomfortable participating in something that differs from societal norms; they may anticipate feeling stigmatized and unsure of their capacity to raise children to whom they are not genetically related. My project seeks to learn how counsellors assist and work to orientate individuals and couples who must deal with challenges arising from these and other associated complex issues. My pursuit of this question was first provoked, then motivated and enhanced, by experiences in seeking fertility treatment for myself. I wanted insight into how counsellors cover this relatively new scientific, emotional, and social ground, and I was curious about how those sessions were managed in a practical way. Further, my desire to understand the nature of the sessions led me to ask: *How do counsellors view and perform their role as pre-treatment counsellors?*

## **Significance for Social Work**

Social workers are currently employed in the all areas of health care including the field of infertility counselling. National Association of Social Work writes about how social work contributes in health care in general:

Professional social workers are well equipped to practice in the health care field, because of their broad perspective on the range of physical, emotional, and environmental factors that have an effect on the well-being of individuals and communities (NASW, p. 6, 2005).

The AHR is a field of rapidly growing complexity, presented by medicine as a technology these third party medical procedures involve more people assembled attempt to make a human being. Those involved have different reasons for their involvement; the medical personnel, intended parents, the surrogate and/or the people donating reproductive materials are motivated by their individual emotional, social and economic interests. The comprehension of associated mental health aspects must keep pace with that growth and address its complexity. Social work research in this area can contribute in understanding how to deal with the current Canadian situation regarding Assisted Human Reproduction (AHR). By applying a lens that views individuals within social contexts, social work research provides a unique perspective, and can therefore shed light on how the current legislation impacts people. Social work person-in-environment (PIE) perspective is particularly helpful in this area where the legislation is ambiguous and leaves clients somewhat vulnerable (NASW, 2005).

My aim is that this research will contribute to social work by encouraging the circulation of knowledge about AHR and about the implications currently being generated by counsellors

and therapists assisting clients who are grappling with questions and challenges arising during pre-AHR treatment.

### **The Overview of the Study**

To explore my question I interviewed social work counsellors who offer third-party reproductive counselling. The interviews explored the counsellors' views regarding the purpose of those sessions, client goals, counsellors' roles, counselling approaches used, and the associated challenges they faced. The interview data were analyzed using thematic analysis and revealed commonalities in the ways the interviewees see their work. This work was not begun with a hypothesis. In the following chapters I will explain the process used to gather and examine the information generated by the interviews.

This thesis is organized into five chapters. Following the introduction in chapter 1, chapter 2 provides a literature review and presents some of the history of Assisted Human Reproduction in Canada in order to situate current context in terms of policy and practice. Chapter 3 presents the design and methods used to investigate the research question. Chapter 4 presents the themes found in the data gathered both from the interviews and email responses. Chapter 5 brings forward the findings arising from an analysis of the data.

### **Definition of Terms**

The following terms are used throughout this thesis:

*Assisted Human Reproduction (AHR):* A process used to aid human reproduction. These include prescription fertility drugs, in vitro fertilization, and donor insemination (Health Canada, 2014).

*Counsellor:* One who gives information/guidance in response to personal, social, and psychological difficulties. The counsellors whose work forms the focus for my research all hold

a minimum of a Master's degree in an area of mental health counselling. Included are those with backgrounds in psychology, social work, and educational psychology.

*Donor:* A person who provides their own sperm, eggs, or embryos for reproductive or research purposes (Health Canada, 2014).

*Human reproductive material:* Reference to the eggs, sperm, or human cells or genes that are used in procedures of Assisted Human Reproduction (Health Canada, 2014).

*Third-party reproduction:* A process that can include one, or a combination of, donated sperm, egg, or embryo and surrogate that are used to create a pregnancy. Those who donate do not raise the child (Health Canada, 2014).

*Infertility:* The inability to conceive offspring. There can be many causes of infertility in both males and females. Health Canada defines *infertility* as “Not being able to get pregnant despite having frequent, unprotected sex for at least a year or for at least six months if the woman is age 35 or older. Infertility may be due to a single cause in either the woman or her partner, or a combination of factors that may prevent a pregnancy from occurring or continuing” (Health Canada, 2014, par. 20).

*Social infertility:* a term used in the lay literature and media to describe those who cannot get pregnant due to social circumstances such as being single and/or without ready access to sexual partners, or those in a same-sex relationship.

## **Chapter 2 - Literature**

This thesis explores the role of counselling in relation to the medical intervention of Assisted Human Reproduction (AHR). The first section of the literature review will explore the legislative response to the technology, both in Canada and in other countries. The second section of this review will focus on the research relevant to both the need for, and the use of, counselling by individuals involved with AHR procedures.

### **Legislative Response to AHR**

#### **International Approaches to Law and Reproductive Tourism**

The laws that govern use of Assisted Human Reproduction and access to AHR vary from country to country. Health Canada (2004) describes the varying legislation of several different nations highlighting how some exert a higher degree of restrictions than others (Health Canada, 2004). In Australia and the United States types and levels of legislation regarding third-party procedures vary amongst states as the passing of legislation is the responsibility of each individual state (Health Canada 2004). Some countries flat-out ban surrogacy while others allow it. France, Germany, Spain, Portugal and Italy prohibit all surrogacy (Prag & Mills, 2015). Italy carries the most restrictive legislation. Prior to 2003 there were no Italian laws regarding AHR; however, in that year the Italian government passed legislation limiting the procurement and provision of procedures to “stable heterosexual couples that live together and are of childbearing age”(par. 10, Health Canada, 2004). Spain has set no requirements at all (Blyth & Landau, 2004). Other countries including Japan and Singapore have no legislation regarding AHR activities; however, they offer professional guidelines. Egyptian laws completely prohibit the use of third-party reproduction (Inhorn, 2010).

These global differences in legislation and enforcement, combined with the ease with which services in some countries can be accessed online, have created a phenomenon that the media has dubbed “reproductive tourism.” Reproductive tourism, also called “reproductive exile” (Inhorn & Pasquale, 2009) or “cross-border reproductive care” (Blyth, 2010), is the practice of travelling outside of one’s home country for fertility treatments. The reasons for individuals’ going to receive treatment elsewhere are numerous but include difficulty with the legal regulation of the procedure in their home country, the cost of the procedure, and/or the availability of donors or surrogates (Inhorn & Pasquale). A study by Blyth in 2010 examined both individuals who had received AHR care in other countries and also those who were considering doing so. The majority of the respondents were Canadian, but there were also participants from Australia, Greece, and the UK. The majority of the participants (54%) in the study who had received AHR services from other countries had procured oocyte (egg) donation. Destinations for AHR treatment reported by the Canadian respondents were the U.S. (most preferred) as well as Mexico and India (Blyth, 2010). With eggs, sperm, and surrogacy all highly accessible in the U.S, both through clinics and online, it is clear why significant numbers of Canadians choose to travel to the U.S. in order to receive AHR services.

### **Canadian Legislative Response and the Development of an Industry**

Literature that focuses on the development of AHR in Canada is sparse and from diverse areas of study: law, political science, women’s studies, and social policy. A recent publication is an exception to this *Fertile Ground: Exploring Reproduction in Canada* published by McGill-Queens University Press in (Paterson, Scala & Sokolon, 2014) contains academic work that examines the social policies developed around this technology and its implications. The



following discussion provides a brief explanation of the history of AHR in Canada and this nation's attempt to deal with the ethical and legal issues surrounding this topic.

**The Commission: a thoughtful and controversial examination.** In the late 1980s and early 1990s, private Canadian clinics began delivering AHR services (CBC News, July 3, 2007). In these early days Scala (2014) notes that doctors were given discretion over who received treatment and there was little government involvement. Public interest in accessing this technology began to increase and university hospitals (mainly because of their research interests) were providing the service to some, but there were no regulations around the procedures (Snow, 2009). Politicians were reluctant to weigh in on this controversial topic so the clinics were able to operate without any clear regulation (Scala, 2002). In Canada, the Royal Commission on New Reproductive Technologies RCNRT, (hereafter also referred to as the Commission) convened in 1989. The Commission was assembled by Prime Minister Brian Mulroney (leader of the Progressive Conservative Party) in response to public demands for examination of this newly emerging and quickly changing field. Patricia Baird was appointed as chair; its mandate was to study the ethical, social, research and legal implications of the new reproductive technologies in Canada (Scala, 2002).

The Commission was given a broad mandate to examine reproductive technologies including the ethical, legal, social, and economic implications of the procedures. The purpose of this examination was to form the basis for developing recommendations for government action (Neilson, 2012). More than 15,000 Canadians participated in the process through surveys, focus groups, and/or questionnaires (Neilson). The Commission's final report, *Proceed with Care*, released in November 1993, comprised 1,275 pages and included 293 recommendations (1993). A summary of the report prepared by the Federal government (1994) and written by Chenier

sums up the views of Canadians derived from the extensive surveys and consultations as having “serious concerns about the technologies, including their potential threat to health, the ethical dilemmas they create, and their adverse impact on particular groups such as woman, children, families and the disabled” (Chenier, 1994, par 3). It recommended the forming of a regulatory body and changing the criminal code to criminalize certain practices involving AHR the selling of human eggs, sperm, zygotes of fetal tissue; advertising for, paying or acting for an intermediary for surrogacy arrangements; using embryos in research related to cloning, making of hybrids and any unwanted treatment or interference with a pregnant woman. The second part of the report defines infertility and viewing it primarily as a medical condition and explains the procedures and drugs used in AHR and recommends supportive counselling, informed consent, protection of privacy and confidentiality, and reasonable access to the technologies (Chenier, 1994).

Though the work of the commission is criticized and some concepts in it may seem antiquated it should be noted that Baird’s Commission was formed almost 30 years ago, an enormous undertaking at the time, and was looking at a new technology. The research that the Commission undertook cast a wide net with thousands of Canadian’s views taken into account as well those of diverse interest groups from academia, medicine, religion, pro-life and women’s groups. There are several analyze of the Commissions work; including Cattapan in the afore mentioned book *Fertile Ground* (2014) who aptly describes the function of the Commission as: “to find some sort of moral middle ground between those lauding reproductive technologies for their libratory potential and those condemning their capacity to be used in ways oppressive to woman and disrespectful of human dignity” (p. 163). Scala (2014) sees the Commission and the law that came from it as leading to both commodification and medicalization of AHR. Scala

explains how Commissioners adopted the approach of Evidence Based Medicine (EBM) which uses evidence from research to make decisions on whether or not certain procedures should be used by physicians. The use of EBM led the commission to recommend that AHR procedures should not be covered under the Canada Health Act. Scala concludes “consequently, IVF provision was relegated to the market, effectively excluding low-income earners from accessing the treatment (Scala, 2014, p. 68). Both Scala and Cattapan note that the Commission’s focus on the medical aspects of the procedures and the costs of the procedures distracted from other social aspects like the underlying causes of infertility. The feminist concerns brought forward about these procedures further medicalizing child birth and doctors having increasing control over women’s bodies. (Cattapan, 2014)

**Assisted Human Reproduction (AHR) – treated differently.** Canada has treated AHR differently than it has most other areas of health care in that AHR has been splintered away from the services offered by the Canada Health Act. Assisted human reproductive services began as an experimental treatment offered in some university hospitals. Overtime, the services of in vitro fertilization were de-insured and thus no longer included under the Canada Health Act (Giacomini, 2000). This resulted in the formation of private fertility clinics in Canada. The move to de-insure had satisfied several governmental policy goals: namely, to save money through a decrease in physician billing, and to move toward applying some of the recommendations of the Royal Commission on New Reproductive Technologies (Giacomini, 2000). Giacomini (p. 1492) asserted that “Because ‘medical necessity’ is the basis for coverage mandated by the 1984 Canada Health Act, this term has high currency in debates over which services belong in provincial health insurance plans.” The de-insuring of the service coupled with the lack of legislation meant that determination of which AHR services were available was

decided by physicians and by the market (Baylis, 2011). The Ontario report *Raising Expectations* looked at the costs of these procedures to individuals and to the health system: “Even for those who can afford IVF, the process can be financially devastating. The average cost of a single cycle of IVF is \$10,000 including medications – almost 14% of the median family income in Ontario” (Raising Expectations, 2009, p. 109).

**The long road to legislation.** Fertility clinics continued to operate unregulated through private and university clinics until March 2004, when the federal *Assisted Human Reproduction Act* was passed. Nearly 15 years had lapsed between the release of the Commission’s report and the passing of the legislation. The reasons for this lengthy period between report and legislation are numerous, with three attempts dying on the order paper before a law was finally passed (Snow, 2009). The *Assisted Human Reproduction Act* that was finally passed by Pierre Pettigrew, Minister of Health in Prime Minister Paul Martin’s cabinet, set the operational parameters for all AHR clinics in Canada. The law closely followed the recommendations of the Commission. It regulates research, and prohibits sex selection as well as the buying and selling of embryos and other human tissue including eggs and sperm. There is also a section of the law forbidding payment to egg and sperm donors and for surrogacy services. Other potential actions including human cloning and sex selection were banned, and breaches of the legislation could lead to fines of up to \$500,000 and ten years’ imprisonment. The law further designated that a body be created to regulate the Act and ensure that the necessities of the Act be met and prohibitions enforced. The Assisted Human Reproduction Agency of Canada was established in January of 2006 and became operational in December of that year, when a board of directors was appointed by the federal government (CBC News, 2010). There is a portion of that law specific to counselling, stating that those involved in third-party reproduction participate in counselling

sessions. Paragraph 14(2)(b) of the act states:

Before accepting a donation of human reproductive material or an in vitro embryo from a person or accepting health reporting information respecting a person, a licensee shall, to the extent required by the regulations, make counselling services available to the person and ensure that the person receives them. (Assisted Human Reproduction Act, 2004).

**The Quebec challenge.** In order to understand what happened subsequent to the Assisted Human Reproduction Act, a practical understanding of Canadian government is useful. Under the constitution, most of the legislative power for health care is granted to the provinces. The federal government's influence lies in its spending power (Makarenko, 2008). The Canada Health Act is a federal policy; provinces are expected to live up to the general provisions of that act in order to continue to receive federal funding (Baier, 2008). It is this division of power between the federal and provincial governments that allowed the *Assisted Human Reproduction Act* to be challenged. Quebec, with the support of Saskatchewan, Alberta, and New Brunswick, launched a challenge to several provisions of the 2004 Act, alleging that certain sections violate the federal/provincial division of power (Gruben & Cameron, 2014). Quebec argued that the sections challenged were not matters of criminal justice and did not put the public's health at risk and, therefore, should be governed by provincial legislation. The Supreme Court heard the appeal in the case of Attorney General of Quebec v. Attorney General of Canada in April 2009. On December 10, 2010, the Supreme Court released a 5 – 4 split decision (CBC News, 2012). Four of the justices argued that AHR as a beneficial medical practice while the others argued that it as part of a larger issue with moral and ethical implications (Lemmens, 2011). The court found in favor of Quebec and struck down several portions of the law.

**Muddied Waters: the impact of the challenge.** The impact of the Federal Supreme Court's decision has been extensive: the AHRA is now less comprehensive. The decision has left a gap in regulation and, as a result, it now is up to provincial governments to decide what legislation should govern this area (Baylis, 2011). Quebec is, to date, the only province that has passed associated legislation. The other provinces remain unregulated (Gruben & Cameron, 2014). Gruben and Cameron describe the impact of this decision, specifically its effect on women:

For a number of economic and political reasons, provinces and territories have a spotty record in protecting women's biological and social reproductive autonomy. . . . Even if legislation is enacted at the provincial level, it will almost certainly be a patchwork approach. Women and children in different provinces will be subject to varying levels of protection. (p. 146)

The portions of the law that remain include prohibition of the paying of a surrogate beyond expenses, and paying for eggs and sperm, and sex-selection..

Besides the concerns about what was struck down in the law there are also concerns about what remains. Cattapan (2014) raises this in her article about social rights and assisted reproduction:

Since the passage of the AHRA, a number of challenges to its legitimacy have been raised. For example, there have been charges that the Act has resulted in threats of prosecution that have intimidated many would-be-parents, donors, and surrogates, keeping them from participating openly and safely in assisted reproductive procedures. As a result, the criminalization of sperm and egg purchase has led to a dearth of available gametes and surrogates, driving patients abroad and "underground" (p. 165).

The literature argues that the Assisted Human Reproduction Act's treatment of the gay, lesbian, bisexual and queer (LGBTQ) community is mixed. Corbett, Frecker, Shapiro and Yudin (2013) in their study of the services offered by Canadian fertility clinics to lesbian patients, note that though there are some barriers, Lesbian women's access to AHR services does not seem to be limited. The authors point out that the AHR Act prohibits the discrimination of access to procedures due to sexual orientation or marital status (Corbett, et. al, 2013). Cameron (2008) however raises concerns about the Act's prohibition of artificial insemination outside of licensed facilities combined with the donation requirements that discriminate against the queer community; "[q]ueer men and women who want to reproduce together, biologically, without having sexual intercourse. These donation requirements, which stipulate that a queer man may only donate sperm to a willing donor with a special application by their doctor, a medical screen, and a dispensation from the Minister of health" (Cameron 2008, p. 110). These requirements put gay men in a very difficult situation if they are to comply with the law. Cameron also notes that the prohibition of commercial surrogacy also discriminates against gay men who require a surrogate in order to proceed.

### **The Scope of Infertility in Canada**

Despite extensive searching, I was unable to find a specific count for the number of third-party procedures performed in Canada within any timeframe. However, the relative number of procedures can be inferred from the following statistics that were available. Statistics Canada reported that in 2011 the nation's population was 34,482,779 and that there had been 378,762 babies born (Stats Can, 2011). A 2012 article in Human Reproduction by Bushnik, Cook, Yuzpe, Tough and Collins examined data from the infertility component of the 2009-2010 Canadian Community Health Survey. This study found that about 16% of couples experienced infertility.

The article states: “Regardless of the definition, the present study suggests that over time, the prevalence of current infertility has increased in Canada” (par. 29).

With knowledge of the current rate of infertility in Canada, an understanding of the numbers of those seeking services of fertility clinics would be helpful in ascertaining the number using third-party conception. A 2013 media release by the Canadian Fertility and Andrology Society (CFAS), lists that in 2012 there were 14,953 in vitro fertilization treatment cycles undertaken in 30 IVF centers in Canada. The resultant pregnancy rate was 32%; however, the number of live births resulting from those pregnancies was not given (Stats. Canada, 2011). The statistics from CFAS did not specify how many of those cycles involved third-party reproduction (CFAS, 2013). However, they do give an idea of how many patients completed treatment. It would seem that only a small percentage of people experiencing infertility seek help using AHR and that an even smaller number of those would choose to be involved in third-party reproduction. An examination of these statistics indicates that the number of people seeking third-party procedures is small.

### **Reproductive Counselling in Canada**

The Assisted Human Reproduction Act as it was originally passed required that those seeking treatment attend counselling prior to any further third-party procedures. Such mandated counselling was designated to aid in ensuring that those entering into third-party reproductive procedures would not be coerced in any way and would have full understanding of the various implications of what lay ahead. The successful challenge to the law discussed above meant that there was no longer a regulatory body and no requirement for counselling. The loss of this counselling requirement as well as the loss of clarity about what was allowed regarding attaining surrogates and egg donors made an already complex situation more complicated. So although



reproductive technology has been underway in Canada for more than thirty years and has undergone close study by the Royal Commission, there remains little direction available to that seeking third-party reproduction. In practice, some fertility clinics still ask that a counsellor see potential patients prior to their beginning treatment. The actual number of fertility clinics and, within that, the number performing third-party procedures are low, and constitute a small field. As a result, the number of Canadian counsellors doing the associated counselling work is relatively few, and they are mostly private practitioners who receive referrals from privately run clinics. This low number of counsellors became evident as I progressed through this research and searched for participants.

### **Reproductive Counselling Research**

The literature presented regarding counselling in AHR can be categorized as follows: the effects of diagnosis and treatment, research on counselling approaches, and looking ahead to future research. The following section is a review of the literature that gives context to where this young field of counselling began, how practice has changed over time, and where current research sees the role of counsellors. It begins in a somewhat general way to lay a groundwork and understanding of the field of infertility counselling and leads into a discussion that is more specific to counselling with prospective third-party clients.

How clients see themselves is an important part of counsellors' understanding as to how to work with them. The researchers in the following section investigated individuals' reactions to an infertility diagnosis. This led to examining the research into how fertility treatments impact people as an understanding of these areas is critical to the counselling interventions discussed later in the chapter. Interventions of counsellors are influenced by that understanding.

## **The Perception of Infertility**

There are varying views throughout the literature in regard to how infertility should be defined and how people who are found to be infertile react. How infertility is defined depends on whether it is viewed as a social condition or a medical one. In a medical sense, infertility is defined as the inability to conceive a child after one year of unprotected sex (Domar, 2002). Infertility is a problem around the world and across time, with (globally) 10 percent of heterosexual couples meeting the above definition of infertility (Zatylny, 2008).

The medical definition of infertility leads us to the point where people are diagnosed and have become patients. This can also be referred to as medicalization. Conrad and Leiter (2004) explained that “[m]edicalization occurs when previously nonmedical problems are defined and treated as medical problems, usually in terms of illnesses or disorders”(p 158). These researchers looked at how changes in the medical marketplace have influenced the medicalization of certain conditions including infertility. They investigate what societal factors influence medicalization and argue that the effect of medicalization” narrows the definition of health and widens the definition of sickness” (p. 171). Conrad and Leiter note that non-pregnancy is not an illness and it is this argument that has been used by insurance companies in court when they lack of coverage for AHR procedures.

Cousineau (2007) noted that the medicalization of infertility had led to an underestimation of the psychological response of individuals diagnosed with infertility. According to Cousineau, infertility can affect many aspects of a person’s life: his or her marriage, self-concept, and levels of anxiety and depression. This anxiety can then increase the number of patients that choose to “dropout” of treatment and perhaps even decrease pregnancy rates.

It is important to note that the medical definition excludes social infertility, those people whose access to reproduction is not medically defined rather is determined socially. In the 2009 view of the literature that examines the impact of infertility, Greil, Blevins and McQuillan note that medical sociology views health and illness as socially constructed and that this social construction is particularly evident in regard to infertility;

No matter how medical practitioners may define infertility, couples do not define themselves as infertile or present themselves for treatment unless they embrace parenthood as a desired social role. ... the presence of infertility is signaled, not by the presence of pathological symptoms, but by the absence of a desired state (par.3).

Greil, Blevins and McQuillan in their review of the literature make an important point about the study of the reactions to infertility, they point out that a weakness in all the studies is that they do not study those people who are infertile but do not seek treatment. The study of this population of infertile people who do not seek treatment is estimated at nearly fifty percent and the lack of information on these people means there can be no comparison between those who seek treatment and those who do not (2009).

There was an early meta-analysis of the literature and research in 1991 by Dunkel-Schetter and Lobel, who looked at 61 articles focusing in some way on psychological reactions to infertility. The authors offered an excellent description of the experience of infertility: "Indeed in most cases, it is the possibility rather than the reality of infertility that is at issue, because there is some degree of ambiguity about the outcome. This situation initially involves a threat rather than a loss" (p. 29). This description of infertility as something that may evolve into a loss is different than the usual description, which is a medical definition. The authors found that in descriptive research there were emotional effects including grief and depression, feelings of loss

of control, and effects on self-esteem and identity as well as social effects within marriage and within social networks. In the empirical research, however, they found that “the large majority of studies of this type do not find abnormally high levels of emotional distress of problems in esteem, marital, or sexual function among infertile individuals” (p. 46). This discrepancy in the two types of research was addressed by Dunkel-Schetter and Lobel, who suggested that “One possibility is that the empirical research to date has not adequately tested the issues. Another possibility is that the descriptive literature exaggerates or misrepresents the experience of infertile people” (p. 51).

My own view of the literature also yielded diverse explanations of the psychological consequences of infertility. Domar (2002), an important researcher in the field, found that infertility diagnosis and fertility treatment can be difficult and stressful for patients. In particular, Domar, Emery (2003), and McNaughton-Cassill (2002) noted symptoms of anxiety and depression in infertility patients. Becker (1997) saw the stress arising from a disturbance in identity that individuals were faced with when they were diagnosed as infertile. Becker viewed reproduction as a basic expectation that people have about themselves so a discovery of infertility threatens this identity and can lead to feelings of failure and to other negative emotions. Domar described the level of stress created by an infertility diagnosis as equivalent to being diagnosed with a life-threatening illness.

Hynie and Burns (2006) wrote about how individuals’ interpretations of infertility are impacted by culture. They caution that counsellors should be aware of the difference between attitudes held by individualist and collectivist cultures: “In collectivist cultures, social pressure resulting in strained marital, social and/or social relationships is the predominant stressor. In individualist cultures, stressors that involve personal loss (e.g. sense of self) are more significant

and profound “(p. 71). Hynie and Burns emphasize the need for counsellors to be culturally sensitive. This sensitivity can be achieved in part by asking questions to gain an understanding about the client’s spiritual and cultural beliefs.

### **Reactions to Treatment**

In 1978, after Louise Brown (the first baby conceived using in vitro fertilization) was born, the popular thinking surrounding the meaning of fertility began to change (Kovacs et.al., 2003). There existed now the possibility of a biologically related child for those diagnosed with infertility and those considered socially infertile (a term found in a 2001 guideline for counsellors used to describe gay, lesbian, and single people) (Boivin et al., 2001).

Eugster and Vingerhoets (1999) explored the early literature regarding patient reactions at various stages of treatment. They found that there was consensus about the phases that are experienced as most stressful; namely, waiting to find out if a successful pregnancy occurs as a result of the treatment and the intense disappointment following an unsuccessful IVF treatment where pregnancy is not achieved. Their review also found that both men and women go through anxiety during the treatment; however women are more likely to bear it more acutely. Eugster & Vingerhoets (1999) report that anxiety decreases during treatment while others have found that it increases during the treatment itself. Research is needed to show why these differences might exist.

Significant in part because of its scope, a 2006 article by Verhaak, Smeenk, Evers, Kremer, Kraaimaat, and Brast reviewed 706 articles written over the previous 25 years that explored women’s reactions to the different stages of IVF. This review found that while most women adjusted well to treatment, unsuccessful treatment cycles produced significant distress. These authors identified a clinical implication of this study, that “psychological support should

be specifically targeted to help the woman adjust to the possibility of treatment failure and eventual childlessness rather than to help her to cope with the impact of the treatment itself” (p. 36). They suggested also that the meaning of childlessness should be a clinical focus.

Verhaak and Burns divided the literature another way, according to how it appeared to change over time:

[T]he initial focus of research on stress and infertility was based on the psychogenic hypothesis (i.e. the psychological consequences of infertility). Recently the research has focused on a related hypothesis, which contends that stress may be a causal factor in infertility, particularly in terms of the impact of stress on treatment outcomes. This may be referred to as the psychological outcome hypothesis (p. 171).

It is useful to think about the literature from a historical perspective. The authors pointed out that many of the ways in which Western medicine has viewed the connection between the body and the mind more recently have shifted and therefore changed the way in which patients are treated with regard to infertility.

### **Research on Counselling Approaches**

Researchers have asked about the forms of support needed for those embarking on IVF treatment, at what stages in the IVF cycle is support most useful, and if the provision of counselling can reduce the emotional distress that people are likely to experience.

Covington and Hammer Burns’ influential 2006 text *Fertility Counseling: a comprehensive handbook for clinicians* provides a thorough overview of this field of counselling. The book is intended to be a practical guide for counsellors in the field and lays out common problems that arise with clients as well as tables that clearly list the areas that should be covered in sessions with both donors and prospective parents. The information presented is

firmly grounded in research and relevant literature is presented in each chapter. It includes a substantial focus on third-party reproduction and provides guidelines for counsellors working with those involved in donor insemination as well as oocyte and embryo donation (all third-party procedures). Four of the thirty-one contributors to this handbook are Canadians and still active today within the field of infertility counselling.

The chapter by Boivin (2006) was critical to my understanding and contextualization of the literature on this topic. Boivin, a psychologist, professor and researcher has focused her research on psychological issues in reproductive health. Her work has influenced many other researchers and services offered to patients of AHR. Boivin's contribution to this field of study is considerable; at last count her work has been cited nearly 1600 times and is cited in nearly every article used in the counselling portion of this literature review. Boivin's study of reproductive counselling interventions found that they could be described as either one of two categories: educational and counselling based. "Though there was some overlap between the two, they provide skills training, for example, improve stress management, coping skills, or a combination of skills" (Boivin, 2006, p. 119). Counselling interventions were further divided between cognitive behavioral therapy (CBT) and infertility-focused counselling. The goals of counselling interventions were; "emotional expression and support, and/or discussion of thoughts and feelings related to infertility" (p. 119). Boivin found that the interventions involving skills and training were the most effective. The educational programs occurred for the most part in groups where participants could normalize their experiences and find support. Counselling may have been found to be less effective because goals set in counselling may be more difficult to achieve and to measure.

The following two examples show how both education and counselling were blended in their approach to clients. Stammer (2002) described a university hospital fertility program in Germany that offered counselling for all patients. Based on what impressed him in that program, the author advised that the therapist should normalize patients' feelings of isolation and loss as a mechanism for externalizing the experience of infertility. Further to this, the author suggested that the counsellor should inquire about a couple's sexual behavior to assess if there were any current problems and, if so, to provide helpful information. Additionally, he advised that the counsellor lead a discussion on sorrow and loss and explore how the couple has faced past difficulties and whether they have planned a life without children (Stammer, 2002). This article was a description of an intervention and did not measure its effectiveness.

There is a lack of research examining the experiences of those involved with the various third-party reproductive procedures. This may be due to the secrecy that surrounds its use, the lack of tracking of the number of those using the technology or the newness of some of the procedures. For example the technology that allows human eggs to be donated (oocyte donation) has only been available since the 1980's. Sperm donation is not a new procedure and is perhaps the oldest form of AHR as physicians have been performing procedures for more than 100 years (Thorn, 2006). Kalfoglou and Gittelsohn (2000) investigated the motivation and experience of oocyte donors. They found that donors often exhibit a history of sexual trauma and/or abortion and may be attempting to "make up" for a loss through oocyte donation. They also discussed the importance of separating counselling from psychological screening. Purewal and Van den Akker (2009) did a review of 64 articles on the topic of oocyte donation. In discussions regarding the motivation of donors, they found that patterns concerning the reasons given by donors depended on the type of donor - known, volunteer, or commercial donor. Typically, known donors reported



that they donated because of their relationship to the recipients. These are often sisters or close friends. Volunteer donors stated they generally donated for altruistic reasons, and the motivation for commercial donors was found to be mixed with both financial gain and altruism. However, these latter results regarding commercial donors were harder to determine as there were more variables involved such as rate they would be paid and whether or not the donors were students (students answered more frequently that they were motivated by financial gain). While such patterns were identified in this review of the extant literature (Purewal & Van den Akker, 2009), it should be noted there is no way of verifying the altruism asserted by donors, and given the lack of education and circulating moral judgments about reproductive technologies, I suspect few volunteer donors would admit they did it for the money.

Disclosure is an issue specific to third-party reproduction, and the term is used in the literature in two ways. The first way regards legal requirements, which are the laws of certain jurisdictions that make information available to the prospective parents and children that come from these procedures. The other way disclosure is used is in regard to whether parents reveal to their child its conception via donated oocytes, sperm, or use of a surrogate. The current literature supports information-sharing. When Turner and Coyle (2000) studied children who accidentally discovered that they had been conceived using donor insemination, those children expressed feelings of indifference, mistrust, and abandonment. Lycett, Daniels, Curson and Golombok (2004) studied 46 families who had children conceived by donor insemination. The children, parents and children's teachers were interviewed to determine the quality of the marital bond, the parent/ child bond and the child's psychological adjustment. The researchers then compared 28 nondisclosure families to the 18 families that had disclosed. The results indicated that,

fewer difficulties among the disclosers than among the non-disclosers. Mothers who were inclined toward disclosure reported less frequent and less severe arguments with their children. They also considered their children to show a lower level of conduct problems and to be less of a strain. In addition, disclosing couples viewed themselves as more competent as parents than their nondisclosing counterparts did. (p.177)

The use of third party reproductive techniques may mean that in some cases the intended parent(s) will have to cope with grieving the loss of having a genetically related child.

Applegarth (2006) lists this as one of the important issues to be addressed in counselling intended parents involved in third party reproduction. The author cautions counsellors to ensure that this grieving be given sufficient time to occur before proceeding with third party procedures or other choices.

### **Looking ahead to future Research**

When looking ahead to the role of third-party AHR counselling and for future research, Boivin (2006) makes an important point about the need for research to be connected with practice. Boivin alerted counsellors to link their practice to current research:

There is increasing pressure from third-party payers, government agencies, and professional organizations on practitioners to demonstrate both the effectiveness and efficiency of their services. Infertility counsellors need to find a way to integrate research and research findings into their everyday practice if they are to meet these challenges. (p. 117)

Similarly, Covington (2006) also expressed the need for counsellors to be involved in research because of the need to maintain contact, and to follow up with clients and children impacted by this technology. According to Covington; “as much as infertility counsellors may advise patients

about the implication of these technologies, no one can predict how someone will feel tomorrow about his or her decisions, let alone ten years from now” (p. 506). Research that focused on the experience of AHR third party counselling from the perspective of the counsellor was difficult to find.

From amongst my research, the article by Goedeke and Payne (2010) most closely aligns with the focus of this thesis. Goedeke and Payne examined the role and practices of counselling by interviewing counsellors who worked with people considering embryo donation. They concluded that counsellors have a role in shaping the future of the field. According to Goedeke and Payne, “counsellors have a role to play in educating and making visible the long-term psychosocial consequences of the practices of ART not just to the client but also to the rest of the team, and ensuring that services remain ‘client-centered and responsive’” (p. 2826). This research sees counsellors as having an important role in facilitating the donation process as well as to the emotional well being of the parties involved. These counselling sessions are different than what occurs in Canada as New Zealand requires them by law so the counsellors are part of the team, and their role within the team is not ambiguous to the team or to the people being counselled.

### **Conclusion**

The context in which infertility counsellors’ work in Canada has been influenced by this nation’s legislation which has in turn shaped the choices and processes of application of AHR. The academic research in the area of counselling has also helped form the context in which counsellors both see and interact with clients, and it influences both the types of counselling interventions used and required for individuals involved in AHR. There is little literature on how AHR counsellors manage within the legislative context of where they practice. This is relevant

because there is a strong correlation between legislation and counselling. Canada's legislation around AHR is, like all legislation, value laden and influenced by assumptions and judgments. Though Wursten is discussing primarily about how a country's culture affects its economic policy in this article it is relevant to AHR policy, he notes; "there are deeply rooted values that differ between cultures that make a significant difference to the way societies are organized, the kind of role government plays, and how the various organizations within societies work" (n.d., par. 1). Wursten notes that "culture influences the ways in which good leadership is defined, on how the decision-making process is structured, as well as on the way people monitor how policies are implemented" (n.d., par. 18 ). This thought is relevant with regard to AHR in Canada as the current legislation reflects Canada's secular culture. It aligns with what the Royal Commission on New Reproductive Technologies recommended in regard to human tissue as well as attempts to be neutral by respecting individual human rights as laid out in the Charter of Rights and Freedoms. The current legislation allows for individuals to access the technology largely at their own expense and criminalizes the commodification of human tissue. The emphasis on choice is similar to the position taken on abortion and how Canada manages blood products or organs transplant which also can not be purchased nor sold. Law and policy set the context in which people access and experience AHR and shapes the possibilities of that for which people receive counselling. This context affects how AHR counselling is undertaken and forms the basis for this study of Canadian counsellors.

## **Chapter 3- Methodology**

The design and method of this study will be outlined in this chapter. I will briefly reiterate my question then describe the qualitative approach chosen for my research. After outlining the recruiting process used to assemble my participants, I will present my methodology for the interviews. The chapter concludes with a description of my analysis of the data. Throughout, I was informed by my practice as a social worker in dealing with difficult human experiences. My expectation was that effective methods and strategies were evolving to assist clients contemplating third-party reproduction, and I sought to find a path possibly created by those mental health professionals.

### **Design**

#### **The Question**

My method supports my investigation into the psychosocial supports currently used to assist patients involved with Assisted Human Reproduction. My research question is: *How do counsellors view and perform their role as pre-treatment counsellors?* I sought to understand how mental health professionals are helping people orient themselves during pre-treatment counselling given the realities of third-party reproduction. Further, I aimed to gather supporting data by investigating how counsellors viewed and performed their own role in this counselling, and also whether counsellors see themselves as “gatekeepers” to third-party reproductive assistance. Finally, although mandated counselling pre-treatment third-party AHR varies across Canada, many clinics do require it. I will explore the expectations imposed on counsellors by the clinics that require mandatory sessions.

## **Methodology**

I interviewed counsellors about their experiences of working with clients who were considering third-party reproduction. I explored how they addressed the complex issues that patients bring to mandated counselling. Via open-ended semi-structured interviews, I explored whether counsellors created their own, or used an existing, model to help clients navigate their experiences. Other data collected during the interviews examined how counsellors perceived their role in this work, their experiences structure, content and approach to the sessions.

## **Recruiting Participants**

After receiving approval from the ethics board the next stage of the project began. Recruiting participants for the interviews proved to be more difficult than I had anticipated. My estimate, based on the number of counsellors listed on-line and the number of clinics in the country, is that fewer than thirty counsellors in Canada currently provide sessions of this specific nature within clinics designed for AHR purposes. Beyond those, doctors provide informal counselling and more structured counselling is provided by general therapists to people seeking consultation during their own decision-making processes regarding AHR.

I initially contacted the Canadian Fertility and Andrology Society (CFAS) by email and asked if it would send my recruitment letter out to its counselling subgroup. CFAS asked me for additional information and upon receiving it they forwarded my recruitment letter as per my request. I received three responses through that CFAS initiative and interviewed those individuals between April 26 and June 3, 2013. Next, I attempted “snowball sampling,” a method that uses information from one participant to identify potential additional participants who are community network affiliates (Handcock & Gile, 2011). Accordingly, I asked the respondents I interviewed if they would suggest other possible contacts. Two were unwilling due to

confidentiality concerns and the third offered names of individuals I had already approached. I sent out emails to fertility clinics but receive no participants from that initiative.

Due to the low number of responses, I decided to attend the Canadian Fertility and Andrology Society (CAFS) conference in Victoria in September of 2013 with the intention of using a more direct approach to recruiting interview participants. Although my experience at this conference was enjoyable and informative I was discouraged by how difficult it was to recruit subjects for my research. The conference was interesting because I had the opportunity to hear about AHR research from many different disciplines including social work and psychology, but no one who practiced affiliated counselling was willing to be interviewed. When I was questioned about my own experience and level of education, I was told by one individual that aiding data collection for my Master's thesis was not worth her time and that my interview was too long. Though this feedback was painful to hear, it did inform my next phase of recruitment for which I shortened the interview length and also made it available via email. I proceeded by proposing to potential participants either (1) the original 30-minute in-person or telephone interview, (2) a shortened in person or telephone interview, or (3) the interview questions delivered via email.

Further, the lack of response at the CAFS conference made it clear that I had exhausted that body as a source for participant recruitment. However, a conference participant had sent me an online link to a list of counsellors on the Infertility Network website, a charitable organization that offers support and information about AHR and adoption in Canada. That link proved very helpful because it contained a list of counsellors in each Canadian province who specialized in the area of AHR. I emailed each of those counsellors and five responded and subsequently were

interviewed for the study. I also emailed every fertility clinic listed on the site, requesting that they forward my study information to any practitioners they used for counselling.

In the end, eight individuals participated in the study. These comprised one Skype interview, four telephone interviews, one in-person interview, and two email responses. The size of the pool of possible participants was small, (I estimate thirty people). The small number influenced the number of participants I could ask as well as made potential participants concerned about confidentiality. The community is small they felt they could be easily identified. Even those participants that agreed to be interviewed expressed concerns about confidentiality I tried to limit all information that might be identifying from the data. All participants were women; although this was not intentional it is also not surprising as the majority of people in the field are women.

### **The Interviews**

The interview questions are both open and closed and were designed to learn about the counsellor's practice and education and then their role in session. The questions are meant to be exploratory. I believed that counsellors in there collective conversations with many, many people would have found a way to work with in their restrictions and to create a useful way to assist their clients going through the third party reproductive experience. That belief also helped shaped questions for my interviews and affected my responses with in the interviews.

When a potential participant agreed to take part in the research, the interview was arranged and scheduled. Although my preference was for in-person interviews, my budget limitations made this impossible. Because I wanted this project to be national but was unable to afford face-to-face meetings with all participants, the next best alternative was to record



telephone and Skype interviews. I designed semi-structured interviews to collect the data, and recorded the conversations.

The participants were verbally informed of the aim of the research before the interviews, and they were told that they could withdraw from the research at any point during the interview. Telephone and Skype interviewees were read an oral consent form (see Appendix 2), and those who participated via email were sent a copy of the consent contract by email. All participants were asked if they wished to be sent a copy of the research results by either postal mail or email and also whether they wished to receive either a summary or complete version of the thesis.

In the interviews, I queried the counsellors about their background and experience, their role in the sessions including gate keeping, purpose of the sessions, counselling approaches used, challenges, and ethical issues. I also asked the participants about any recommendations that they might have for Health Canada regarding counselling for third-party reproductive assistance. I questioned participants regarding whether they were employed by a clinic or in private practice, their years of experience, their education, and where their practice was located. All participants had graduate degrees in one of three areas, either master of educational psychology, master of social work, or master of counselling. Half (4) of the participants had MSW degrees. Respondents' geographical locations were clustered where the greatest numbers of clinics are located, the population-dense areas near Toronto and Vancouver.

The audio-recorded interviews were transcribed verbatim. The audio file was transferred from my telephone to my computer, both of which are password-protected. Identifying information such as names and locations were removed from the transcription, and only my advisor and I have had access to the data. Files will be stored on a data stick for seven years before being destroyed.

## **Analysis of Data**

The research for this thesis was exploratory. It was designed to gain insight into what counsellors think about their sessions with people considering pre-treatment AHR third-party reproduction by focusing on identifiable themes from the data gained through the transcripts of interviews with those counsellors. I chose thematic analysis as the method to examine the data generated from the interviews. Components of thematic analysis are present in most forms of qualitative analysis. It is accessible, appropriate, and has been used effectively in similar research. Goedeke and Payne (2010) used thematic analysis to examine New Zealand fertility counsellors' roles and practices in embryo donation (ED), one type of third-party reproduction. Similar to this New Zealand study on AHD, I also adopted a thematic approach to data analysis. Thematic analysis complements my research questions because it is not bound to a specific theory. My study is fairly novel and there was no cohesive theory to rely on. What guided my thinking was the belief that because people are doing this counseling they will have found a way to be effective.

Braun and Clark (2006) have clearly outlined the six phases of this popular approach. First, the researcher must familiarize herself with the accumulated data through repeated reading of the transcriptions. In the next phase, the researcher begins generating initial codes, the intent of which is to “identify a feature of the data that appears interesting to the analyst” (p. 18) who thereby is able to organize the data into meaningful groups. The third phase involves searching for themes (the codes are sorted into potential themes). Themes are reviewed and a “thematic map” of the data can be created in the fourth phase. During phase five, data analysis identifies and further refines the “story” each theme tells. The sixth and final phase is producing the report. For my analysis, I began by reading through all the interviews to gain an overview. I then

returned to each interview transcript, reading and making margin notes for the purpose of gaining a single overall impression of each individual interview. Recognizing the need to further focus at this point, I divided the responses according to answers to specific questions. This manner of organization made it easier to draw out themes.

## **Chapter 4 - Results**

My goal for this chapter is to bring forward the themes that emerged from the data. The counsellors I spoke with, especially those I interviewed were very forthcoming with their opinions and their explanations of their work. I have used pseudonyms rather than the counsellor's names for the reason of confidentiality. At the same time, the use of names and quotes from participants humanizes the data. Some of the responses here are controversial, perhaps because participants knew their identity would be kept confidential. The data generated from the discussions was interesting and gave me much to analyze and consider. Some of what I found was anticipated, and other themes that arose were unexpected. Two broad themes arose: Roles in Session and Pressures Experienced by Counsellors.

### **Demographics of Participants**

All eight participants in this study had counselled clients who were considering taking part in third-party reproduction. All were in private practice and one recently had retired. Six of the participants provided mandatory sessions as required by clinics before individuals could move forward with treatment. All practiced in Canada. My original aim anticipated a greater number of participants; however, for the reasons described in chapter two, recruiting participants was difficult. As a result, the participants were clustered in Ontario and British Columbia with only one from the prairie provinces, which reflects the reality that (excepting the prairie participant) the largest concentrations of both population and fertility clinics are in those provinces. All my participants were women. This was not intentional but also not surprising as the majority of the counsellors practicing in the area of my investigation are women. Reflecting the interview design, the themes below are organized according to the counsellors' reports of what they actually do in session followed by how they feel about what they do in those sessions.

## Themes

### Theme I - Counselling Role

The first questions I asked respondents were about their role as counsellor to third party clients as is evident in the first emergent themes. The functions that counsellors saw themselves responsible for in their session with clients were related primarily to and influenced by AHR procedures their clients would potentially be involved in.

**Specialized counselling.** Participants clearly stated that they were *not* providing general counselling. I asked specifically about what counselling theories counsellor's employed most and they spoke of a mixed approach. One respondent stated: "I have been working in this field for so long I am not married to one way or another". Another said, "It is a bit mix but obviously a big part of it is psycho-educational...I draw on different modalities." A third offered a similar response "Well I'm a bit of a mixed bag...my approach is interventions are informed by a bigger perspective which is my responsibility to follow up on."

What followed was not an explanation of a theoretical approach rather an explanation of what they do in session:

The big thing I [the counsellor] can offer during this session is some really practical pragmatic logistical things for people to think about, that they would have no way of doing on their own. Even if they access the supports of another counsellor who is really qualified as a counsellor to deal with the emotional aspect, that person would not be qualified to deal with this part of it. (Janet)

Another counsellor also describes how she considers her work to be different than general counselling;

My colleague, a real fence sitter on that issue, will always say, "Well, our role is to be

completely neutral”. My perspective was, the patients don’t find that very helpful. That’s all right with therapy, but we’re not doing therapy with everybody who walks in here that’s wanting to know more about donor conception. They want some genuine help and advice and information and guidance (Marie).

**Education.** Education is a keyword that is repeated throughout the data in response to my question asking participants to describe their role in clinical sessions:

I have probably more than one role. . . . I would say to inform and educate, to support, and, if necessary, to have a therapeutic role and I separate that from a more clinical role. This is more about behavioral change, getting more into coping strategies. If I’m looking at just a third-party conception, I think education and preparation. I’m really more of an implications counsellor (Marie).

Janet explains this education role further:

So, I feel like what I can offer that nobody else in their life can offer; it is really pragmatic, practical, logistical things to think about and consider. Help make sure that their relationship with their surrogate goes well. Help make sure that in 15 years they don’t go back on the decisions they made when choosing an egg donor and how they made the arrangements to set them up and think like, “Oh my God, now our kid is sick and now we can’t access medical information” any of those things (Janet).

Dianne notes that she does not see her role as providing education.

I actually don’t give them a lot of information on their options, their choices. I leave that to the infertility support group because that group does a really good job of being current . . . of giving resources and things like that. I actually don’t do a lot of that (Dianne).

She adopted a different approach than the other respondents in this study, one which was

more client-centered general– that is; counselling led more by the client than by counsellor. As she was not mandated or required to play a gate keeping role, she focused more on providing general support than providing psycho-education... Her sessions focused on “being open to different ways of finding your baby.”

**Gate keeping.** Respondents were asked whether they thought they had a gate keeping role in the sessions. Responses were emotional and varied, and most had a lot to say. The level of emotion was high:

I find that whole concept disgusting. . . . it is morally and ethically repugnant to me that somehow the dynamic would be set up that I pass judgment on whether someone is a fit parent or not. [I’m in agreement with](t)he old argument that I can’t pass judgment on someone that gets drunk and knocked up one night you don’t need anyone’s permission to do that. Now whether you should or shouldn’t, that is another argument. That is irrelevant because in our society and in our value system – you know, in a democracy and from a social justice point of view you can’t legislate someone’s reproductive freedoms. And yet, of course, it happens (Ann).

Another strong response to the question about gate keeping was:

I feel very strongly that my role is not as a gatekeeper for intended parents so I am very careful not to pass judgment about whether someone would be a good parent or a bad parent or whether they are prepared to be a parent or not. I feel strongly that is not my role with intended parents (Janet).

While Janet, above, indicates that she is not a gatekeeper, she later acknowledges that she sometimes does occupy that gate keeping role. This reveals one kind of internal struggle and ambivalence that counsellors may experience:

I guess professionally I would say I do sometimes find the gate keeping role to be challenging. I work very hard at not doing that and it is not always easy. Some people on a personal level you just think are just making - you think bad choices. Sometimes it is not easy for me not to make judgments about it (Janet).

I also asked about what the clients seemed to want from the sessions and some of the responses related back to gate keeping or to the perception of gatekeeper. Perhaps because most of the sessions were mandatory, counsellors frequently described the clients as arriving somewhat confused and disgruntled. Ann states:

I don't think I have met a single person yet who really understands why they are in to see me. More often than not, what I hear when they call me is "I have been told I have to see you - I don't know why!" (Ann)

Janet further explains clients' uncertain perception:

So some of them are quite resentful when they come in to me - it is an expensive process to go through third party. They have to pay through their pocket. It is not covered [by health care] and so a lot of them, they are actually a little hostile. A lot of them are very anxious because they view - they think [that] until I start talking and they see the kind of questions I ask them, they think it is going to be an assessment and I am there to decide if they should do this or not (Janet).

Ann further attempts to explain client's misunderstanding of the counsellor's role:

What they really hope to get before they meet me is my permission to proceed. The way it [this misunderstanding] is presented to them is not on purpose but the way they understand things is that I am the next obstacle to them getting what they need (Ann).

Ann goes on to explain how she clarifies her role to the client:



I reassure them that I am not going to tell them – I am not going to be the gatekeeper. That is the role that we are thrust into all the time – and that is the role that we protect against. Some counsellors will [take that role because] like every person manages that requirement differently. My understanding from informal chats with other colleagues is that we do our very best to have the clients be in control – and we all understand if we are in this field how important it is that they be in charge as much as they can of their fertility choices, given that they are already very limited if they are in our office (Ann).

When Janet was asked if she had ever denied someone access to the treatment, she responded:

I have had a few situations where I had concerns about the mix between the surrogate and the intended parents. That was not about an intended parent that could not go forward or a surrogate that could not go forward; it was that you [the two parties] can't move forward together. That has happened a few times. I don't feel like I am gate keeping. I feel like that is specifically my role: I am not stopping someone from doing something. I am just saying it would be very dangerous for you to do this together for whatever reason. (Janet)

Janet acknowledged how it can be difficult when she is approving or evaluating pretreatment client when the purpose, at least in part, is to report back to the physician who has referred the client to her. Her responses were halting and contradictory at points. She appears to struggle with the gate keeping role. Another respondent explained how her concerns about gate keeping:

It would come to the gate keeping issue sometimes and I have to be selective about cases that I raise concerns about, about ones I put on hold. Most often I get knocked down on those so I have to be very strategic about how I approach that (Marie).

Janet explains both how she executes the gate keeping role and how she avoids it:

The letter on the other hand does have to come from me – if I say “No, this is inappropriate.” The doctors do sort of say like “Yes” or “No”, but I don’t buy into that and this is something very important that I learned from my mentor. This was invaluable for me to learn as a counsellor that doctors need to know that they [the clients] have been seen but they [the doctors] don’t care what is in the letter in terms of the language I use – [so I try to be] be as vague as possible but still give them what they needed. That was my way of handling the responsibility put on me to be the gatekeeper. So the language that I use for all of the letters I write - they are things like, “I observed no contraindication” – that sort of thing – “There appeared to be no reason to flag this case.” I am extremely lucky that I have not had a case that needed to be dealt with in a red-flag crisis sort of way. It is extremely rare that that does happen (Janet).

Diane’s sessions were not mandated and did not require a gate keeping role. This shaped her sense of counselling sessions for third-party procedures in a different way. When describing what she believed to be the purpose for the sessions, Dianne’s assessment was very relaxed and open:

I’m just trying to give them a way of redeeming some sense of control in their life. Sometimes we go the spiritual route; sometimes we don’t. Sometimes we go into the values or just the way you are starting to think about this child. Most of the time I try to encourage a lot of fluidity and also looking at what their dreams were as to how this child would come to be. It seems to me most people just get stuck on having a genetic child. . . . I believe in being very fluid in finding your baby. Where is your baby going to come from? The whole thing is to regain some sense of hope, some sense of control and some

fluidity so it's not stuck on one particular method or one particular place your baby is going to come from (Dianne).

Dianne's approach was relaxed and supportive without needing to play a gate keeping role. She, therefore, did not describe struggling with this as the other respondents did. Taken together, the participants were not comfortable with their gate keeping role.

**Addressing Implication of AHR .** Some of the counsellors described exploring the implications of third person reproduction as a central focus in the counselling session. One respondent said her counselling role involved: "Informing and protecting the client from possible implications that they may not have otherwise been prepared for" (Norma). In conversation with other counsellors about their role, they explained that they help clients to see a "bigger picture", including the future implications of their choice to proceed with treatment. Ann explains this:

We all care deeply about our clients and how we can give them the best service but really, what we are doing is we are cutting to the heart of existential meaning about what it means to be a human being, what goes into family, and how do you define family. We are into the biggest possible questions there are in two sentences, you open up and two minutes later, you are having the biggest possible conversation you can have (Ann).

These conversations pull in discussion about the potential children who will result from these procedures and about how these children will grow up and have questions:

Look at the big picture. Look at the societal issues. How are you going to help somebody that shows up twenty years later and says, "Why didn't you help my parents deal with these issues better?" I have had that happen (Marie).

The respondents spoke about needing to explore the importance of the impact on the intended child: "They have to think beyond [that] they are bringing a life so you have to think about how

you are going to deal with it. It is not just a procedure” (Claire). Another respondent similarly said, “The child is a life-long experience. There are all sorts of family relationships that come into it. Even with sperm donation, too. There are unspoken concerns that the couple might have that needed to be discussed” (Nancy).

Most counsellors saw their role as including raising issues about donors and about disclosure:

It was facilitating discussions, exploring ramifications of what was happening, consequences of what was happening that they had never thought about but were going to have to deal with. For instance, if a sister was donating an egg, and that baby is born, how do they deal with the developing attitude of the sister? (Nancy)

Use a social work reference). In the context of this research, questions about disclosure arose about whether the intended parents planned to tell their child that they were created with the use of a donor egg or sperm or with the help of a surrogate mother. The respondents were consistent in their approach that parents should disclose to their children Anne states:

More and more of the counsellors are taking this on – not just me – we are all taking on a role, donor conceived children. The history of how this evolved . . . we have this first generation of donor- conceived children who have now grown up, and they are now able to tell us how much we have messed up in the earlier attempts. At clinics, people are now running into problems twenty years after the process because they [the parents] didn’t disclose, and now their son or daughter, now they are about to get blown out of the water because they [the parents] have to disclose (Ann).

The strength and clarity in Claire’s response reflects her years of working in this field, understanding of her clients and comfort in leading their clients through the sessions:

They [clients] have struggles of how to deal with disclosure, ongoing contact and those

types of things. It is really a chance to address those and give those in terms of if they are doing late disclosures versus early disclosures what I talk about sort of in terms of helping them make that decision. . . . Most people are very nervous about how to handle that and haven't given it thought or they don't understand what it involves. Usually they are thinking just what is best for the child – but are being guided by their own fears, like “I'm not the mother,” “I'm not the father,” that sort of stuff. (Claire)

Claire is also talking about broadening the perspective of the client, encouraging him/her to think beyond the immediate goal of pregnancy to what possibly unforeseen issues may result from the procedure- and to what the intended child might require in the future.

**Mandated sessions.** All respondents, though clear in articulating the challenges in their work, seemed genuinely to have enjoyed the pre-treatment counselling role in these sessions and believed them to have been useful to their clients. The respondent cited below speaks about the importance of mandated sessions. I initially was unsure regarding how to code this clearly powerful statement. My current interpretation of it is that the respondent was frustrated that her clients had not been properly educated in preparation for both the procedure and the emotional consequences of having a child who is not genetically related to them:

Last month I had an experience where a couple had first went to do an egg donor cycle and recently they did an egg donor and a sperm donor [cycle] and it is a nightmare because he [the intended father] is saying, “These are not my babies. I was coerced by the clinic.” This is why it [mandated counselling sessions] should happen. This is why it needs to be a mandatory thing. They spoke to no one and now she [the intended mother] is pregnant and the relationship is in dire straits. None of this was addressed prior to any of the [treatment] cycles in the States (Claire).

The counsellors believe it is helpful to their clients to educate and inform them about the procedure and its significant consequences (physically, emotionally), and for the intended child.

The following response acknowledges the difficulties of the work but also its richness:

The dilemmas are always challenging but one thing that I really love doing the mandated visits. The mandated visits are wonderful. So we are talking about the dilemmas and the challenges, but I love it because it is a fascinating process to sit with clients and throw these existential challenges to them and see them work it through and generally speaking, the clientele that we see are extremely resourceful, very articulate. They have put a lot of thought into this already and, in my experience, I have seen far more open-minded people than closed-minded people.

## **Theme II. - Pressures and Challenges**

I asked the counsellors to describe any specific difficulties they found in their role. All interviewees clearly experienced a variety of challenges. It was clear that these counsellors dealt with clients grappling with a lot of external pressures. I anticipated some of the pressures, and others that arose were unexpected. The participants were emotional and descriptive as you will see in the quotes used. The participants used strong language to make their points, especially when speaking about some of the structural issues apparent in their work.

**Grief.** Helping clients deal with their pain and grief was cited by several of the participants as an area of difficulty. Olivia identified grief as a challenge for her: “The knowledge that some of my clients will likely not realize their dream of conceiving, and the raw grief inherent in that realization.” Nancy also acknowledged this: “The loss and grief is very emotionally draining. I feel touched by it too, the tremendous sadness and loss”. Janet also addressed how much pain and grief her clients have experienced:

Not everybody's story is bad but there are some people's that like you can't even believe what they have been through. It [doesn't seem] possible that one couple could have been through all of this and that is always really sad and heartbreaking (Janet).

Because of their ongoing involvement in this work, sometimes over many years, most of the counsellors had a realistic and accurate idea about the situations their clients face and the difficulties that surround third-party procedures in particular. Despite this experience, one particularly difficult challenge identified was with regard to surrogacy:

I feel like I have to be really careful about surrogates – with who I say no to, when without them someone may not be able to have the baby –I take that very seriously and there are some days that part of it is hard” (Janet).

**Legislative Impact.** The respondents expressed significant concern about the lack of legislation governing and their work. This lack of legislation they describe as creating frustration and a lack of clarity in their counselling roles.

Sometimes the desperation, dealing with the desperation involved . . . the frustration when it comes to surrogacy, that's a real problem. That's really frustrating because of the lack of surrogates and the lack of the law. It's like the Wild West there. We don't know what is really legal and what isn't, and if we do something is it going to be legal and can it be deemed non-legal later on? It's just a scary area because there is nothing really established, firmly established . . . even how to find a surrogate. You can't advertise, necessarily. That's a frustration (Dianne).

The frustration resulting from a lack of guidance is echoed by Ann:

This [field] is a dog's breakfast of legislative nightmares – federal and provincial “hot potatoes” that no one wants to take on, literally. We are not wrong when we go looking for guidance and there isn't any. The Supreme Court didn't want to rule on it. (Ann)

**Medicine and Business.** While I did not enquire directly about the business aspect of third-party reproduction, the phrase “big business” came up in several responses. A feeling of powerlessness emerged in relation to an industry which had grown too big from which to protect their clients or exert any influence over: According to Ann: “When they get to me, they are already really a part of a big giant machine that they have no control over (Ann).” Similarly Marie responds: “Commercial interests have prevailed and it is now business. I feel very sorry for patients because they have no real protection. They don't know one clinic from another”.

This latter respondent implies that clients are not necessarily getting the best or sometimes even adequate counselling, because sometimes any or all of the counsellors, doctors and clients involved can be disproportionately motivated by money over professional ethics:

It's a business. It's become a huge business. This is a multi-million-dollar business in Canada. In the [United] States it's a forty-billion-dollar business. You can do anything as long as you write a big enough cheque. Nobody will care whether it's applicable or appropriate. So in Canada, sadly, we're going there too. When I started out, most of the clinics were in hospitals, but that changed as provinces stopped funding fertility treatment. So that's where private medicine really started to grow. (Marie)

The business aspect produced a conflict between Ann's ability to meet her personal and professional ethics and to satisfy the need of the doctor to procure patients:

Depending on the clinic where you work, they [the doctors] can be very aggressive in terms of pressuring their counsellors. Just make sure you get your numbers up, which I



don't feel is ethical at all. Or it can be unspoken pressure – if you keep doing [implications counselling] with people ....then you've got patients that keep bailing.

Then I don't think the doctors are going to keep you on as an employee. Really, you are just a hoop that they need to jump through to start the treatment (Ann).

In addition to working within a business model, the counsellors are also working within a medical system. This exerts challenges and pressures as well. One counsellor speaks about this by comparing it to working within other systems:

Because people are coming into a hospital for a health-related thing, they are not accustomed to saying “no.” That's not where you go and get turned away. Whereas if you go for adoption, it's a community-based service where there are all kinds of checks and balances in place. Indeed, you may not be approved for fostering or adoption (Marie).

In one interview, I asked a follow-up question when the respondent was speaking about the attitude of doctors. I asked her why she believed that some doctors were negative about pre-treatment counselling. Marie's response also indicates the influence of the business aspect of the fertility clinics:

One, they [the doctors] see it as a frill that they don't really need to offer. There was the expense of counselling. A session of counselling costs about as much as a shot of medication. For the patient, it's extra financial strain, some of them probably see it as slowing the process down. I don't think they understand what counselling can do so they don't see the value of it and they don't buy into it. They think everything ought to be handled by their nurses. Nurses are in over their head pretty quickly on some issues. They [doctors] may also be concerned that counsellors are going to raise a lot of issues, either in their practice or in the patient, that they won't know what to do with or will call into

question the way they are treating the patient. . . . maybe some less than ethical practices (Marie).

This general lack of respect for the field of counselling by clinic doctors is made clear in Ann's comment:

The doctors need to "cover their asses" legally and they do that by sending them to us. All they want is to have the letter in their file. My experience is that doctors of course care about their patients but they don't actually care about the psychological processes (Ann).

Dianne appeared to be more removed from the business and medical aspects of "the industry" compared to other respondents as she was not offering mandated sessions or work for a doctor. She spoke about the "false hope" offered through medical procedures:

There's so much money and so much energy that's being spent on trying to conceive. I think that there needs to be more of an awareness raising on the success rate and the failure rate of those medical interventions because they are pretty high. I think people are not being told honestly. I wish there was a more public awareness (Dianne).

**Limited Time.** Ann speaks about the pressures of time: "There is also a pressure created by time, or the lack of it. Most clients have only one session with a counsellor before deciding whether or not to proceed with treatment." Different counsellors offer different information and services but one shared variable is limited time. Ann further describes this pressure: "So counsellors have to walk a very fine line between making sure that clients understand the full measure of what they are dealing with and the reality that you have a service to deliver. You have one session to do it in (Ann)."

## Summary

There was a high rate of consistency across the responses of the survey participants, particularly with regard to how they viewed their counselling roles. It was clear that most saw their role to be one of education and of helping to broaden the clients' perspectives, and also of exploring issues they may not have considered such as disclosure of medical information to their potential children in the future. The counsellors clearly asserted that they believed they provided a specialized rather than a general type of counselling. However, while some unarguably declared that they were not gatekeepers, others were ambivalent about and struggled with this issue. All the participants described feeling some form of pressure in their work that involved meeting their clients' needs while also working within both a medical system and the growing fertility business. Dianne, offered responses that were often different from those of the other respondents her sessions were not mandated. A further compounding pressure cited was counsellors' efforts to work with their clients in accordance with the ethics of their profession.

## **Chapter Five - Discussion**

The goal of this chapter is to create meaning from the research interviews and literature. My research was driven by the desire to see what was “in the black box.” I was unable to clearly imagine what occurred in mandated sessions that counsellors were having with prospective third-party patients because the topic area seemed highly complex and potentially “messy.” There appeared to be such a great deal going on and at stake, considering the needs of all involved and the ethical issues that could be provoked. I wanted access to a world I have since learned is small, and secretive, protected in part by the shame that surrounds procedures for creating children in ways western culture is not yet entirely accustomed. I could not find what I was seeking within the available literature but through the research I have done for this thesis, I now have a glimpse. The counsellors I interviewed regularly participate in situations which many lawmakers in this country are unwilling to enter – the world of third-party reproduction. My research led me to conclude that the therapists were able to effectively support their clients. They genuinely wished to provide a helpful service but felt a variety of challenging pressures from the clients themselves, from the doctors who referred clients to them, and the system within which they work. Despite these pressures, however, they did believe they were capably providing useful counselling to those who came to them seeking help.

### **Themes**

The themes fell in to two broad areas: the Counsellor’s Role in the sessions and the Pressures and Challenges within the work. These broad themes were expected and easily identified as that is what my interview questions asked about. Some of the subthemes contained within each theme were surprising to me. The emotion that arose for participants when discussing both their role and the pressures they feel was intense at points and their lack of

transparency with their client about their role and purpose was unexpected to me as well.

### **Theme 1 - Counsellors' Roles**

When I asked respondents what they did in session, they tended to answer by first telling me what they did not do. In other words, their answers describing actual content of the conversations tended to be prefaced by descriptions of topics *not* addressed. As evidenced by their words, these respondents are not providing general counselling. Client-centered counselling tends to be led by the client, who brings forward what he/she wants to talk about. However, the counsellors' role in third party reproductive counselling is often directive as it involves both gathering information and providing information. Further, counsellors were faced with time limitations that in some situation might be urgent. They needed the client to understand well a range of factors and aspects involved in the reproductive procedures they were considering as well as things like disclosure, some of which might not yet have occurred to the client. The sessions would not have been completely confidential because some information from the session would be shared with the doctor involved.

**Specialized Counselling.** Participants were clear when I asked what their role was in these sessions. They saw themselves in a specialized role. They spoke of their experience and knowledge about the issues their clients face. As well, they described their role as being somewhat directive. They have some knowledge to impart and a short amount of time to give it. The counsellors were asked directly about what counselling approaches they used and their answers mentioned (a) variety of approaches. Those mentioned included CBT and mindfulness, grief/loss attachment, psycho-educational and feminist therapeutic approach. However they spent almost no time going in to into further description and several described using a mixed bag approach. They described instead a specialized role which the following themes further outline.

**Education.** Education was a focus of the counsellors. Education ensured that those receiving the counselling, the potential patients of the doctors who referred them to counselling, clearly understood the medical procedures that they may be consenting to consistently occupied a significant amount of the discussion time. Though not explicitly stated by respondents, the intention was to ensure that clients' consent was informed consent. Further, in addition to the ethical aspect of client education, informed consent limits the doctor's liability if something were to go wrong.

**Gate keeping.** Prior to the interviews, I had assumed that gate keeping would be declared as one of the roles of the counsellors. From across the spectrum of conversations with participants, the discussion about gate keeping provoked greatest emotional intensity. The answers were stronger and longer, and at times participants contradicted themselves. This may indicate an area where counsellors experience some inner conflict, indecision and perhaps feel some tension in their role.

This tension in the counselling role can be found in the literature. Haase and Blyth (2006) explored the debate about whether pre-treatment counselling should have an assessment role:

One of the most debated issues among counsellors themselves is whether infertility counseling should include an assessment component to evaluate the suitability of individuals for assisted conception services, and if such an assessment essentially places the counselor in the role of 'gatekeeper'. Opponents of the assessment role claim that it can undermine the therapeutic relationship with clients; create tensions; inhibit open discussion; focus on personal deficits rather than strengths; and reinforce the impression that the counselor's role is to screen them for their suitability as parents. (p. 552)

The respondent's high level of emotional response does flag this as an important area for focus in future research because it may indicate something that needs to be resolved. I think the lack of clarity in the role is what needs to be resolved, both the counsellors leading the sessions and the clients coming to the sessions should have a clear understanding of the sessions purpose. As the sessions are endorsed by doctors, and were at one point legally required, suggests that mandated counselling may both ensure informed consent for legal purposes and be used as a means for screening. There is a lack of clarity concerning the role of gate keeping in the relationship that counsellors have with clients. This is likely the reason for the tension and contradiction in their responses when asked about it.

Emphasizing the importance of transparency in the counselling relationship Goedeke and Payne (2010) observe, "if the counselor's role does involve gate keeping, then this needs to be clearly communicated to the clients at the outset (p. 552)". . Some participants did report that they their clients seemed suspicious and uncertain of their (the counsellors') role. It did seem that although the counsellors were ambivalent about gate keeping they knew they had this was part of their role. They seemed to suggest they rarely had to say that someone was not suitable to proceed with their wishes and this was a relief. If the role counsellor's played was communicated more clearly to their clients they may have been less distrustful. A greater level of transparency may have eased both the concerns of the counsellors and the fears of their clients.

**Addressing implications.** The counsellors described this in several different ways. They saw a need to "pan back" and show clients a wider view of the implications of their decision. They wanted to move clients beyond focusing on just the baby and the procedure, to what the success or failure of the procedure might mean. They talked about counselling which explored the broad implications of potential procedure and also where various outcomes may take them in

the future. This expansion of clients perspective to me makes sense, the need to broaden their thought beyond their current focus of wanting this child and all the tasks that are involved in third party procedures, to look at if the child is born what their needs will be.

Respondents also discussed the question of how the intended parents might wish or intend to deal with letting their potential child know their genetic history. Respondents described helping to broaden the client's awareness of the implications surrounding the issue of disclosure. This was a dominant theme regarding descriptions of the respondents counselling work. Further, they described clients being solely focused on the desire for a child and that they felt it was their role to have the client think beyond that. In broader terms, the counselling role takes into consideration both the needs of the individual as well as those of the intended child.. There was often certainty in the responses of the counsellors which indicates they are confident and comfortable in this part of their role.

**Mandated sessions.** This study centers on the mandated pretreatment counselling sessions for those considering third-party reproduction. This research indicates that the counsellor's relationship to these sessions is complicated and at times even contradictory; it is perhaps this contradiction that created some of the emotions in people when they expressed what they loved about their work. The counsellors I interviewed saw the mandated sessions as valuable despite being pressured for time and frustrated by the system in which they operate. They expressed deep compassion for their clients and passion for their work, describing it as necessary for clients negotiating the complex AHR system in this country.

### **Pressures and Challenge**

Counsellors reported that their work was personally challenging as well as useful for their clients. They cited examples of people who had travelled out of country for third-party



procedures without a counselling component, and how that lack of forethought or assistance had negatively impacted the client. They acknowledged both challenges and difficulties, but two respondents said they “love” the work. Their passion when they spoke about their work was present and was an indicator of the importance of giving clients a safe forum to work through their issues. The pressures that affect counsellors and their clients naturally impact their session together. The respondents referred to stresses regarding the client’s grief, the lack of legislation, and their ambivalence about gate keeping. This reveals the importance of establishing legislation in Canada, in particular around the issue of mandated sessions, and establishing greater clarity on the issue of gate keeping within counselling session.

**Grief.** While this theme is not exclusive to third-party AHR it is nonetheless, one of tremendous significance to the counsellors. Counsellors were clearly moved by their work with their clients. Some of them had undergone personal experience with infertility and this may have contributed to their connection and identification with their clients’ situations.

**Legislative impact.** Canadians interested in using AHR services at this time have a difficult system to negotiate. The lack of legislative structure and the policy vacuum that was created by the Quebec Supreme Court challenge to the federal *Assisted Human Reproduction Act* resulted in closing the national agency that was designed to oversee the AHR process. There are few laws or policies to give direction to Canadians interested in seeking out these services. Another review is needed, perhaps not as large in scope as the Royal Commission, but a review of the current situation with the purpose of making recommendations for legislators on how to best fill in the holes left by the Quebec challenge. Counsellors expressed concerns regarding clients’ uncertainty about how to access surrogates and the legal status and implications of that process.

**Medicine and Business.** The de-insuring of fertility treatment opened the door to the creation of fertility clinics in Canada. Currently there are more than thirty clinics operating in the country it is a profit industry that continues to grow. The theme of “big business” was cited in several of the interviews. The respondents were concerned about the ethics of the big business agenda. The counsellors who participated in this research appeared to feel powerless about the big business direction of the fertility field. Their insights and experience carried little impact when up against the big business of fertility. The demands of the fertility clinics and doctors seemed powerful relative to the needs of the client or the counsellor’s ability to advocate for the client. Both the counsellor and the patient are dependent on the doctor, the counsellor for referrals and the client for the fertility treatments that they hope the doctor will provide for them. The respondents’ personal values and ethics were being challenged within the fertility business. This business got in the way of their ability to work with clients in the way they would like to. The respondents were critical of working for the big business of fertility and viewed their clients as vulnerable within this system. Respondents saw their clients as having too little choice or control.

**Limited Time.** An inadequate amount of time counsellors have with their client is an area that I anticipated might be an issue because of how much information they are required to impart to their clients. It is my experience when a service is mandated, clients are more difficult to engage because they are put in a situation in which they may not want to be a part or don’t understand the value in. Mandated services tend to be for a specified amount of time (for example one or two sessions) which leaves little time or willingness, from the client’s perspective, to form a therapeutic relationship. Some participants indicated they were pressured for time in their sessions with mandated pre-treatment clients.

## **Strengths and Limitations**

Finances and time imposed limitations on my research in that I could not afford the travel costs for meeting all interviewees in person, nor did I have the travel time that would have been needed. The study would be strengthened by the inclusion of data from more research participants. The email survey that was returned by two of the eight respondents yielded very short and less useful responses than those interviewed with the same questions.

There were benefits in the direct oral conversations with counsellors that I had not considered previous to undertaking the interviews. While all the respondents I interviewed had some level of experience with third-party reproduction clients, several of them had invested their entire career in the field of reproductive counselling. Those respondents had experienced the opportunity not only to work with many clients, but also to see the whole general area of AHR evolve. Their insights in the field of AHR were valuable to my research.

Although the number of participants was fewer than I had originally wanted, their extensive experience coupled with strong commitment to their clients and to this area, yielded rich responses. If I were to continue to conduct further research in this area I would explore the format of a typical session. While I now have a good idea of what counsellors believe is important in their sessions and how they feel about their work, I would like to learn more about how they perform in these sessions. To observe recorded sessions or to observe sessions would be helpful to understand exactly how they perform the roles they told me about in interview.

The next logical step for study in this area would be to research whether and/or to what extent the sessions were useful to those receiving the service. Do prospective AHR third-party patients find the pre-treatment sessions helpful? Do counselling sessions ease their anxiety in going forward or influence the way they think about factors such as disclosure? The results of

such a study could influence doctors who perhaps are unsure about the need for counselling sessions, as well as politicians who might be in the process of drafting associated legislation.

Currently only Quebec has a comprehensive law in the area of AHR, but I would like to see others provinces follow this direction. If provinces decide to fill this legal vacuum, one component they may consider legislating is mandatory counselling. Research such as this study could help guide that process and state clearly the purpose of mandatory sessions.

Very likely, Canadians born as a result of these third-party reproductive treatments will eventually seek an explanation of their origins. Indeed, one of the counsellors I interviewed spoke about children conceived through third-party procedures having returned to clinics and asked such questions. The experiences of those individuals born as a result of AHR procedures and their opinion as to what pre-treatment counselling should address would be a fascinating and valuable area for further exploration.

## **CONCLUSION**

Canada's previous laws and institutions were set up to serve heterosexual nuclear families that attained children through sexual intercourse and adoption. Assisted Human Reproduction allows reproduction to occur in a way that may have previously been unimaginable. This technology has potentially revolutionized our understanding of reproduction and what a family is. The development of AHR has occurred alongside, rising divorce rates and reconstituted families, increased single parenthood by choice, and a growth in LGBTQ rights. Together these phenomena influence a change in how we see families.

This thesis examined Canada's attempts to react and manage this technology. The legislative attempt to adapt to these changes our federal law was fractured by Quebec's legal challenge leaving Canadians in a situation one interviewee describes as "a dog's breakfast of

legislative nightmares.” Currently in Canada AHR is expensive, challenging for users to access and confusion about what is legal and what is not. This lack of clarity in the legislation affects Canadians seeking out AHR interventions involving a third party the most. There is not a clear message as to how to access surrogates, egg and sperm donors. This is further complicated by the legal constraints within Canada for attaining these precious goods. Access beyond our borders allows Canadians to pay for the egg and sperm donors and surrogates needed for third party reproduction from other countries. Increased clarity in this field is of pressing concern for all the principal participants: prospective parents, donors, counsellors, doctors, and nurses. Counselling will benefit from this greater clarity.

The counsellors who participated in this study generously shared with me their experiences gained from many years of working with prospective third-party patients and showed me the path that I had hoped was there. Counsellors see themselves in a unique and valuable role where they help orientate their clients to a complex system. Counsellors did experience the pressure of being a part of the commerce and the emotionless medical process but found a way to address the education of this potentially vulnerable population of people that are seeking it out a medical solution to their desire to have a child. Counsellors revealed that sessions are not so much about preparing clients emotionally, but educating them about the difficult terrain of the Canadian AHR system. The counsellor’s in this research educate clients about “the bigger picture” stemming from their choice to conceive using third-party reproductive procedures. The counsellors face pressures and challenges that are created by the lack of legislation in Canada, as well as the big business context of their work that leaves them feeling like their clients lack protection and that they themselves lack in influence. They taught me that despite the social, legal, and physical complexities that arise for people considering third party

reproduction in this country they see themselves having a helpful role in their sessions with those seeking third party reproduction.

## References

- American Society for Reproductive Medicine, (2006) Third party reproduction (Sperm, egg, and embryo donation and surrogacy) a guide for patients, Retrieved from [http://www.asrm.org/uploadedFiles/ASRM\\_Content/Resources/Patient\\_Resources/Fact\\_Sheets\\_and\\_Info\\_Booklets/thirdparty.pdf](http://www.asrm.org/uploadedFiles/ASRM_Content/Resources/Patient_Resources/Fact_Sheets_and_Info_Booklets/thirdparty.pdf)
- Applegarth, L. D. (2006). Embryo donation: counseling donors and recipients. In S. Covington & L. Hamer Burns (Eds.), *Infertility counseling a comprehensive handbook for clinicians* (pp. 356 - 369). New York: Cambridge University Press.
- Assisted Human Reproduction Act. (2004, March 29). Retrieved January 2, 2016, from <http://laws-lois.justice.gc.ca/eng/acts/A-13.4/20040329/P1TT3xt3.html>
- Barbieri, R., Domar, A., Loughlin, K., (2000). *Six steps to increased fertility: an integrated medical and mind/body program to promote conception*. New York, N.Y.: Fireside.
- Barton, R., (1999) Psychosocial Rehabilitation Services in Community Support Systems: A Review of Outcomes and Policy Recommendations, *Psychiatry Serv*; 50: 525 - 534.
- Baylis, F., (2011). Supreme court of Canada decision on the assisted human reproduction act creates urgent need for action. In *Journal of obstetrics and gynecology Canada*. 33 (4): 317-9
- Becker, G. Nachtigall, R., Tschann, J., Seline, Q., Pitcher, L., (1997) Stigma, disclosure, and family functioning among parents of children conceived through donor insemination. *Fertility and Sterility* - July 1997, 68, (1), 83-89
- Blyth, E. & Landau, R., eds. (2004) *Third party assisted conception across cultures: social, legal and ethical perspectives*. Jessica Kingsley Publishers, London.
- Blyth, E. (2010). Fertility patient's experiences of cross-border reproductive care. *Fertility and*

*Sterility*, 99(1), 11 - 15.

Boivin, J., Appleton, T., Baetens, P., Baron, J., Bitzer, J., Corrigan, E., . . .Kentenich, H., (2001)

Guidelines for counselling in infertility: outline version, *Hum. Reprod.* 16(6). 1301-1304

doi: 10.1093/humrep/16.6.1301

Boivin, J. (2006). Evidence based approaches to infertility counseling. In *Infertility Counseling:*

*A comprehensive Handbook for Clinicians* (2nd ed., pp. 117-155). New York, NY:

Cambridge University Press

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in*

*Psychology*, 3 (2), 77-101.

Bushnik, T., Cook, J., Yuzpe, A., Tough, S., Collins, J., (2012) Estimating the prevalence of

infertility in Canada. *Hum Reprod*, 27(3): 738-746 Retrieved from ncbi.nlm.nih.gov

Callahan, S. (1997). Gays, lesbians, and the use of alternate reproductive technologies. In H.

Nelson (Ed.), *Feminism and families* (pp. 188 - 198). New York, NY: Routledge.

Cameron, A. (2008) Regulating the Queer Family: The Assisted Human Reproduction Act.

*Canadian Journal of Family Law*, 24, 101-21

Canadian Fertility Andrology Society (CAFAS). (2013). *Human Assisted Reproduction 2013*

*Live Birth Rates for Canada: Media Release*, Retrieved from

[http://www.cfas.ca/index.php?option=com\\_content&view=article&id=259&Itemid=274](http://www.cfas.ca/index.php?option=com_content&view=article&id=259&Itemid=274)

Cattapan, A. (2014). On Reproductive Citizenship: Thinking about Social Rights and Assisted

Reproduction in Canada. In *Fertile Ground: Exploring Reproduction in Canada* (1<sup>st</sup> ed.,

pp. 152-177). Montreal, Quebec: McGill-Queen's University Press.

CBC news, (2010) *Regulating and treating conception problems*, Retrieved from:

[www.cbc.ca/news/health/story/2009/02/05/f-reprotech.html](http://www.cbc.ca/news/health/story/2009/02/05/f-reprotech.html)



CBC news. (July 3, 2007). *Timeline: assisted reproduction and birth control*.

Retrieved from [http://www.cbc.ca/news/background/genetics\\_reproduction/timeline.html](http://www.cbc.ca/news/background/genetics_reproduction/timeline.html)

Chenier, N. (1994, April 22). Reproductive Technologies: Royal Commission Final Report (MR-12e). Retrieved 2015, from <http://www.publications.gc.ca/Collection-R/LoBdP/MR/mr124-e.htm>

Conrad, P., & Leiter, V. (2004). Medicalization, markets and consumers. *Journal of Health and Social Behavior*, 45(Extra issue), 158-176. Retrieved from [http://www.udel.edu/soc/tammya/socDev/conrad\\_leiter\\_on\\_medicalization,\\_markets\\_and\\_consumers.pdf](http://www.udel.edu/soc/tammya/socDev/conrad_leiter_on_medicalization,_markets_and_consumers.pdf)

Corbett, S., Frecker, H., Heather, S., & Yudin, M. (2013). Access to fertility services for lesbian women in Canada. *Fertility and Sterility*, 100(4), 1077-1080. Retrieved from <http://dx.doi.org/10.1016/j.fertnstert.2013.05.048>

Cousineau, T., Domar, A., (2008). The benefit of psychological interventions of female infertility patients. *U.S. Obstetrics and Gynecology*, 53-54. Retrieved from <http://www.touchbriefings.com/pdf/3185/domar.pdf>

Cousineau, T.M. M. "Psychological impact of infertility." *Baillière's best practice & research. Clinical obstetrics & gynecology* 21.2 (2007): 293-308.

Cousineau, T., Lord, S., Seibring, A., Corsini, E., Viders, J., Lakheen, (2004). A multimedia psychosocial support program for couples receiving infertility treatment: a feasibility study. *Fertility and Sterility*, 81(3), 532 – 538

Domar, A. & Kelly, A. (2002) *Conquering infertility: Dr. Alice Domar's mind/body guide to enhancing fertility and coping with infertility*. London, England: Penguin Books Ltd.

- Dunkel-Schetter, C., & Lobel, M. (1991). Psychological reaction to infertility. *In Infertility: Perspectives from Stress and Coping Research* (p. 29-57). New York, NY: Plenum Press
- Ellis, C., (2004). *The ethnographic I: a methodological novel about autoethnography*. Walnut Creek, CA: AltaMira Press.
- Ellis, C., & Bochner, A.P. (2000). Autoethnography, personal narrative, reflexivity: researcher as subject. In N.K. Dezin & Lincon (eds.), *Handbook of qualitative research* (ed.2, pp. 733-768). Thousand Oaks, CA : Sage.
- Ellis, C., Adams, T., & Bochner, A. (2011, January). Autoethnography: A Overview, *Forum: Social Research*, 12(1). Retrieved July 18, 2016, from [research.net/index.php/article/view/1589/3095](http://research.net/index.php/article/view/1589/3095)
- Emery, M., BeÂaran, M., Darwiche, J., Oppizzi, L., Joris, V., Capel, R.,. . . Human, M., (2003) Results from a prospective, randomized, controlled study evaluating the acceptability and effects of routine pre-IVF counselling, *Reproduction*, 18(12) , 2647-2653, 2003. DOI: 10.1093/humrep/deg501
- Eugster, A., & Vingerhoets, A. (1999). Psychological aspects of in vitro fertilization: A review. *Social Science & Medicine*, 48, 575-589.
- Giacomini, M., Hurley, J., Stoddart, G., (2000). The many meanings of deinsuring a health service: the case of in vitro fertilization in Ontario. In *Social Science & Medicine*, 50, 1485-1500.
- Giron, G. (1995) *Infertility and referral for psychological treatment*, Dissertation, Pepperdine University, Graduate School of Education and Psychology

- Goedeke, S, & Payne, D. (2010). A qualitative study of New Zealand fertility counsellors' roles and practices regarding embryo donation. *Hum. Reprod.* 25(11), 2821-2828. doi: 10.1093/humrep/deq233
- Green, J. and Thorogood, N. (2004). *Qualitative methods for health research*. London: Sage Publications.
- Greil, A., Slauson-Blevins, K., & McQuillan, J. (2009). The experience of infertility: A review of recent literature. *Sociology of Health & Illness*, 32(1), 140-162. doi:DOI: 10.1111/j.1467-9566.2009.01213.x
- Gruben, V., Cameron, A., (2014) Quebec's Constitutional Challenge to the Assisted Human Act: Overlooking Women's Reproductive Autonomy? In *Fertile Ground: Exploring Reproduction in Canada* (1<sup>st</sup> ed., pp. 125-151). Montreal, Quebec: McGill-Queen's University Press.
- Haase, J. (2003). Infertility Counselling: A Discussion Paper on Practice Standards and Guidelines. Prepared for Health Canada.
- Handcock, M., & Gile, K. (2011, August 2). On the concept of snowball sampling. *Sociological Methodology*, 41(1), 367-371.
- Health Canada, (2004). Assisted human reproduction implementation office- infertility counselling workshop report. Retrieved from website: <http://www.hc-sc.gc.ca/hl-vs/pubs/reprod/2004-infertilit/index-eng.php>
- Health Canada, (2004), Assisted Human Reproduction Internationally, <http://www.hc-sc.gc.ca/hl-vs/reprod/hc-sc/general/international-eng.php>

- Health Canada, *Glossary Assisted human reproduction*, (2014) Retrieved from the Health Canada website: <http://www.hc-sc.gc.ca/dhp/mps/brgtherap/legislation/reprod/glosseng.php>
- Harvison-Young, Alison. (2005). "Let's Try Again... This time with feeling: Bill C-6 and new reproductive technologies." *UBCLaw Review* 38(1): 123-145.
- Hynie, M., Burns, H. (2006). Cross-cultural issues in infertility counseling. . In *Infertility Counseling: A comprehensive Handbook for Clinicians* (2nd ed., pp. 61-82). New York, NY: Cambridge University Press
- Inhorn, M., Patrizo, P., Gamal, S., (2010), Third party reproductive assistance around the Mediterranean: comparing Sunni Egypt, Catholic Italy and multisectarian Lebanon, *Reproductive BioMedicine* Online 21, (pp. 848-853). Retrieved from: <http://www.marciainhorn.com/olwp/wp-content/uploads/docs/inhorn-article-rbmo-third-party.pdf>
- Kalfaglou, A., Gittelsohn, J., (2000). A qualitative follow-up study of women's experiences with oocyte donation. *Human Reprod.* 15, 798-805
- Kovacs, G., Morgan, G., Wood, E., Forbes, C., Howlett, D.,(2003). Community attitudes to assisted reproductive technology: a 20-year trend. *Medicine and the Community.* 179, 536-538
- Lycett, E., Daniels, K., & Curson, R. (2004). Offspring created as a result of donor insemination: a study of family relationships, child adjustment, and disclosure. *Fertility and Sterility*, 82(1), 171-179. Retrieved January 3, 2016, from [http://www.fertstert.org/article/S0015-0282\(04\)00528-X/pdf](http://www.fertstert.org/article/S0015-0282(04)00528-X/pdf)

- McGraw-Hill Concise Dictionary of Modern Medicine. (2002). Retrieved January 8 2016 from <http://medical-dictionary.thefreedictionary.com/medicalization>
- McNaughton-Cassill, M., Bostwick, J., Arthur, N., Robinson, R., & Neal, G., (2002). Efficacy of brief couples support groups developed to manage the stress of in vitro fertilization treatment. *Mayo Clinic Proceedings*, 77(10), 1060-6. Retrieved February 28, 2011, from *ProQuest Nursing & Allied Health Source*.
- National Association of Social Workers (NASW). (2005). *NASW Standards for Social Work Practice in Health Care Settings*. Retrieved July 30, 2016, from [www.socialworkers.org](http://www.socialworkers.org) In-line Citation: (2005)
- Neilson, L. (2012). Royal commission on new reproductive technologies. *The Canadian Encyclopedia*. Historia - Dominion. Retrieved from <http://www.thecanadianencyclopedia.com>
- Paterson, S., Scala, F., & Sokolon, M. (Eds.). (2014). *Fertile Ground: Exploring Reproduction in Canada*. Montreal: McGill- Queen's University Press.
- Pennings, G. (2002). Reproductive tourism as moral pluralism in motion. *Journal of medical ethics*, (28), 337 - 341. doi: 10.1136
- Prag, P., & Mills, M. (2015). Assisted reproductive technology in Europe: Usage and relation in the context of cross border reproductive care. *Families and Societies*, 43, 1-25. Retrieved July 1, 2016.
- Purewal, S., & Van den Akker, O. (2009). Systematic review of oocyte donation: Investigating attitudes, motivations and experiences. *Human Reproduction*, 15(5), 499-415. doi:10.1093/humupd/dmp018

- Recommendations of the expert panel on infertility and adoption, (2009). *Raising expectations*. Ontario, Retrieved from <http://www.children.gov.on.ca/htdocs/English/documents/infertility/RaisingExpectationsEnglish.pdf>.
- Royal Commission on New Reproductive Technologies. (1993). *Proceed with care: Final report Summary*. Ottawa, Canada: Minister of Government Services. Retrieved August 10, 2012 from <http://publications.gc.ca/collections/Collection-R/LoPBdP/MR/mr124-e.htm>
- Scala, F. (2002). *Experts, non-experts, and policy discourse: A case study of the Royal on New Reproductive Technologies*. Ph.D. dissertation, Carleton University, Canada. Retrieved February 10, 2011, from Dissertations & Theses: Full Text.(Publication No. AAT NQ71948).
- Scala, F. (2014). IVF Policy and the Stratification of Reproduction in Canada. In S. Paterson, F. Scala, & M. Sokolon (Eds.), *Fertile Ground: Exploring Reproduction in Canada* (pp. 48–73). Montreal: McGill-Queens University Press.
- Smith, J. (1995). Semi-structured interviewing and qualitative analysis. In J. Smith, R. Harré & L. Van Langenhove (Eds.) *Rethinking methods in psychology*. London: Sage.
- Snow, D. (2009) *From commission to conception: Commercial surrogacy and morality policy in Canada*. M.A. dissertation, University of Calgary, Canada. Retrieved January 30, 2011, from Dissertations & Theses: Full Text. (Publication No. AAT MR49730).
- Stammer, H. (2002) Counseling and couple therapy for infertile couples. *Family process* 41.1: 111-122.

- Statistics Canada. (2011). *Census of Canada tables of population and components of population growth*. (table 051-0005 and table 051-0004)Ottawa. Ont.: Retrieved March 2014 from Statistics Canada: [www.statcan.gc.ca](http://www.statcan.gc.ca)
- Thorn, P. (2006). Recipient counselling for donor insemination. In S. Covington & L. Hammer Burns (Eds.), *Infertility counseling: A comprehensive handbook for clinicians* (pp. 305 - 318). New York: Cambridge University Press.
- Turner, A., & Coyle, A. (2000). What does it mean to be a donor offspring? The identity experiences of daunts conceived by donor insemination and the implications for counselling and therapy. *Hum. Reprod.* 15, 2041-2051.
- Verhaak, C., Smeenk, J., Evers, A., Kreamer, J., Kraaijmaat, F., Braat, D., (2006). Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Hum. Reprod.* 13(1), 27-36
- Wursten, H., (n.d.) Mental images: the influence of culture on economic policy. Retrieved August, 2016, from <http://unpan1.un.org/intradoc/groups/public/documents/un/unpan002455>
- Zatylny, R. (2008). *Assessment of unity scale: an innovative counselling tool for assessing the relationship of couples facing infertility*, Kitchener-Waterloo: Wilfrid Laurier University: Faculty of Social Work. Retrieved from ProQuest Digital Dissertations.

## Appendix 1

### Interview Protocol

#### Background and experience

- What is your educational background?
- Do you work in private practice or for a clinic?
- How long have you been involved in counselling?
  - o Infertility counselling?
- What percentage of your practice does 3<sup>rd</sup> party pre-treatment counselling comprise?
  - How many sessions do you typically have with each client?

#### Role in session

- What goals do you typically set for clients in these sessions?
- What do you see as your role in these sessions?
- What counselling approaches do you typically use? (family systems, loss/grief models)
- What do you find challenging in these sessions?
- Is the fact that these sessions are mandated change the way you approach them?
- Do you feel that you have a gate keeping role in these sessions?
  - o Have you ever recommended that someone not be involved in a 3<sup>rd</sup> party reproductive procedure?

#### Recommendations

- How do you feel about your work in this area?
- Drawing from your own experience what advice would you give to other therapists working in this field?



- What recommendations (if any) would you give Health Canada in regards to their requirements for these sessions?

## Appendix 2

### Consent to Participate in Phone Interview

#### **Introduction**

I invite you to take part in a research study being conducted by myself, Adelle Teneycke a graduate student at Dalhousie University, as part of my thesis. Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience. Participating in the study might not benefit you, but I might learn things that will benefit others. Please discuss any questions you have about this study with Adelle Teneycke who can be reached by phone at (306) 651-6075 or by e-mail [ad972936@dal.ca](mailto:ad972936@dal.ca) .

#### **Purpose of the Study**

The purpose of this study is to gather information about how counselors view their mandated work with patients of third party reproduction.

#### **Study Design**

Adelle Teneycke is the only researcher involved in this study so will be involved in every aspect of the study's execution and the data analysis.

#### **Who can participate in the Study?**

You may participate in this study if you are a professional counsellor employed by a Canadian fertility clinic or working in private practice with patients of reproductive medicine.

#### **What you will be asked to do**

The interviews for this study will be by telephone or in person. Each participant will be interviewed once and each interview will be between 30 and 40 minutes and will be audio taped.

#### **Possible Risks and Discomforts**

The risks related to your participation are minimal.

#### **Possible Benefits**

Though there are few benefits to you personally, it is hoped that this research will create a picture of what methods of intervention are being used, how clinicians see their role in their session with mandated pretreatment participants in third party reproduction . Knowing the strengths and deficiencies of the existing supports could lead to more appropriate national standard for Canadian fertility clinics being proposed. My greatest hope for the research is that it will lead to further research which, would improve the way counselors dealing with these clients would work with them.

**Confidentiality & Anonymity**

The paper data gained from this research will be kept in a locked file and the data on my computer will be protected by a password. Participants will be offered a copy of the research when it is completed as well as given a copy of their interview notes. Interview respondents will be anonymized.

**Questions**

If you have any questions about this research or the results of this research please contact Adelle Teneycke at (902) 542-1743 or by e-mail at [at972936@dal.ca](mailto:at972936@dal.ca) .

**Summary**

Counselling can assist with the complex choices that individuals who choose third party reproduction must make. Counselling is a legal requirement in Canada but there is currently no standards with respect to its use. How therapists address this complex issue that is fraught with ethical dilemmas and is where my interest lies. Counsellors in this field have experience and may be using a model or several models that support this population. I want to ask Canadian fertility counsellors what they see as the purpose of these sessions and how they carry out this role. Knowing what counsellors see as their role when working with potential patients of third party reproduction could lead to clearer guidelines for these counsellors. My greatest hope for this research is that it can inform practice and help in the creation of recommendations for standards in these mandated sessions.

**Problems or Concerns**

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact my advisor Dr. Catrina Brown Associate Professor at Dalhousie University by e-mail [catrina.brown@dal.ca](mailto:catrina.brown@dal.ca) .