

**THE IMPACT OF FINANCIAL AND GEOGRAPHIC BARRIERS TO
FERTILITY SERVICE IN NEWFOUNDLAND AND LABRADOR**

by

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A thesis submitted to the

School of Graduate Studies

in partial fulfillment of the requirements for the degree of

Master of Science in Medicine (Community Health)

Division of Community Health and Humanities, Faculty of Medicine

Memorial University of Newfoundland

May 2017

St. John's

Newfoundland and Labrador

ABSTRACT

In Newfoundland and Labrador (NL) accessing fertility services is challenging for many residents, as a result of lack of service availability within the province, geographical distance from location of services, and out-of-pocket expenses for both treatment and travel. The purpose of this study was to explore the challenges experienced by fertility patients in NL and how these challenges affect treatment. Semi-structured, in-depth interviews were conducted with female patients across Newfoundland and service providers from NL Fertility Services to gather the perspectives of both patients and providers. We developed a conceptual framework that considers patient group, therapeutic goal, and barriers when determining treatment impacts. We found that for heterosexual women (in couples) looking to become pregnant, the most commonly cited barriers were costs, including financial, opportunity, and emotional, geography, lack of service availability, nature of services, physical environment, partner separation, and social stigma. We also found that these factors created patient and provider-driven impacts on treatment.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank my co-supervisors, Dr. Maria Mathews and Dr. Shree Mulay, for their support, guidance, and time. Thank you to Dr. Mulay for suggesting the research topic. I would like to acknowledge the extra support provided by Dr. Mathews during data collection and analysis, as well as the writing process.

I would also like to thank my committee member, Dr. Daryl Pullman, for his thoughtful contributions and feedback, which helped me to consider this research from a more holistic perspective.

Thank you to Dana Ryan for helping me to practice interviewing, allowing me to conduct interviews in her workspace, and being flexible with her time.

Thank you to Newfoundland and Labrador Fertility Services, in particular Dr. Terry O'Grady and Heather Rees, for making this project possible and helping me recruit service providers to interview.

Thank you to the School of Graduate Studies and the Faculty of Medicine (Research and Graduate Studies) for funding me as a graduate student through the F. A. Aldrich Fellowship and the Dean's Fellowship, respectively. Also, to Research and Graduate Studies and the Division of Community Health and Humanities in the Faculty of Medicine for providing travel funding through the Barrowman Community Health Graduate Travel Award to allow for the dissemination of these findings.

Finally, thank you to my parents for their constant support and for showing me the value in education, and to my friends and family near and far for their support and encouragement.

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Glossary of Terms

Birth rate – the number of live births per 1000 people each year

Clinical pregnancy – pregnancy diagnosed by the presence of human chorionic gonadotropin or ultrasonographic visualization of one or more gestational sacs

Cryopreservation – freezing of gametes, zygotes, embryos, or gonadal tissue for storage

Fecundity rate – the total number of children that a woman is physiologically capable of bearing or the natural capacity to reproduce

Fertility rate – the number of live births per 1000 women between the ages of 15 and 49 years

Fertility services – this term refers to a broader range of services, including ARTs, intrauterine insemination, diagnostic services, as well as pre and post ART patient management

Fertility treatments – referring specifically to procedures, including intrauterine insemination and IVF; these may or may not be paired with drugs

Gametes – sperm or eggs

In vitro fertilization (IVF) – a medical procedure in which mature ova are retrieved from a woman's ovary then combined with sperm in a test-tube and the resulting embryo(s) is transferred into the uterus.

Intracytoplasmic sperm injection – a version of IVF in which a single sperm is injected into an egg

Intrauterine insemination (IUI) – the injection of sperm into a woman's uterus through the vagina

Therapeutic donor insemination (TDI) – IUI using donor sperm

Estradiol (E2) – the principal form of estrogen occurring naturally and responsible for sexual development, preparing the uterus for implantation of the fertilized ovum, and involved in the development of ova. In this study it is discussed by participants in relation to estradiol blood tests, which indicate if there are ovarian cysts.

Medicated cycles – fertility treatments in which drugs are used for the growth, development, and maturation of several follicles during a treatment cycle, thereby being

able to retrieve several ova or being able to increase the possibility of fertilization during timed intercourse.

Timed intercourse – intercourse that occurs when a patient is known to be ovulating, involves tracking fertility cycles. Normally service providers will monitor a cycle and advise a patient on when to have intercourse.

Diagnostic services – services used in diagnosing infertility or comorbid conditions

Trigger (to trigger ovulation) – medication used to release ovum or ova from their follicle

Zygotes – the zygotic stage of development occurs immediately after fertilization and before the multicellular embryonic stage.

List of Abbreviations

ART – Assisted Reproductive Technology

CBC – Canadian Broadcasting Corporation

HREB – Health Research Ethics Board

ICSI – Intracytoplasmic sperm injection

IUI – Intrauterine insemination

IVF – *In vitro* fertilization

LGBT – Lesbian, Gay, Bisexual, and Transgender

MCP – Medical Care Plan

NL – Newfoundland and Labrador

NLFS – Newfoundland and Labrador Fertility Services

OBGYN – Obstetrician/Gynecologist

PCOS – Polycystic Ovarian Syndrome

PEI – Prince Edward Island

RCMP – Royal Canadian Mounted Police

RPAC – Research Proposals Approval Committee

UK – United Kingdom

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1.0 Introduction

1.1 Background

Accessing fertility services is challenging for many residents of Newfoundland and Labrador (NL). The province is geographically vast and has only one fertility clinic located in the capital city of St. John's, forcing patients from outside St. John's to travel great distances in order to access services. NL's provincial health insurance, the Medical Care Plan (MCP), covers limited fertility services. These services are expensive and multiple rounds of treatment may be required. Furthermore, the province has a small and dispersed population with few residents accessing fertility services, which means that the full range of fertility services are not available locally and patients must often travel to other provinces to receive some treatments. Patients must pay out-of-pocket expenses for their travel to the clinic and for their fertility drugs and treatments. These costs often create financial strain for patients and their families.

This study provides NL-specific information about the financial and geographic challenges faced by patients accessing fertility services in the province and how these challenges affect treatment options. The study was done in collaboration with Newfoundland and Labrador Fertility Services (NLFS), which is a division of the Eastern Regional Health Authority responsible for providing reproductive care. The Eastern Regional Health Authority provides health care services to the eastern region of Newfoundland.

1.2 Research Questions and Objectives

What are the challenges experienced by patients in NL when accessing fertility services? How do these challenges affect the provision of fertility services?

The objectives of the study are:

1. To describe the challenges experienced by patients seeking infertility treatment.
2. To explore whether there are differences in the challenges experienced by patients seeking infertility treatment who live in St. John's or surrounding areas (within about 50 km of NLFS) compared to those who live in other areas of the province (farther than 50 km away).
3. To explore how these challenges impact decisions made by patients, including treatment and travel options.
4. To determine how the challenges patients face affect the provision of care from the perspective of service providers.

In this study, we expect that:

1. There will be financial and geographical challenges affecting patients' access to fertility services and patients travelling from farther than 50 km away will face geographical barriers that exacerbate financial challenges.
2. Patients' financial and geographical situations will affect treatment decisions from both the patient and service provider perspectives.

1.3 Rationale

As of 2010, about 16% of Canadian couples experienced infertility (Bushnik, Cook, Yuzpe, Tough, & Collins, 2012); this rate is more than double the 1984 rate of 5.4% (Balakrishnan & Fernando, 1993) and about twice as high as the 2006 global rate of 9% (Boivin, Bunting, Collins, & Nygren, 2007). With infertility rates on the rise in Canada, research related to infertility and fertility services is increasingly important.

Despite increasing need, fertility services may not be accessible to patients in NL. They are a highly specialized service, similar to orthodontics, prosthetics, and audiology, and may not be considered medically necessary under the *Canada Health Act*; however, they are critical for the well-being, especially emotional health, of residents (Domar & Gordon, 2011; Holley et al., 2015; Newton, Sherrard, & Glavac, 1999). According to care providers at NLFS, the challenges faced by patients accessing these services include, but are not limited to, the lack of service availability within the province, geographical distance from location of services, and out-of-pocket expenses for both treatment and travel (T. O'Grady & H. Rees, personal communication, May 25, 2015). Fertility services are arguably more difficult to access in NL than most other provinces; this topic has not yet been examined in the literature.

The status of fertility services in NL presents unique challenges for patients wishing to have a child through the use of these services. This study explored the experiences of patients and service providers in an effort to better understand the challenges faced by patients accessing fertility services in NL and how these challenges influence treatment decisions. It provides NL-based data on how health service access

and costs affect care and decision-making. We hope to make policy recommendations that will help improve access to these services for patients from NL.

2.0 Literature Review

Since the birth of Louise Brown in 1978, the first baby born through *in vitro* fertilization (IVF), there have been hundreds of books and thousands of articles published about infertility and assisted reproductive technologies. However, the scope of this literature review will be relatively narrow, covering topics that are most relevant to this study - the barriers to accessing fertility services in NL. The chapter will first overview infertility, as this condition establishes the need for fertility services. It will then address assisted human reproduction and its regulation in Canada, as well as health care management and funding, in order to give context to the NL case. Finally, the chapter will examine some issues related to health service access, specifically cost and geography, generalizing and applying these ideas to the NL case with fertility services.

2.1 Infertility

The definition of infertility varies from study to study. The World Health Organization defines infertility as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy [(diagnosed by ultrasonographic visualization of one or more gestational sacs or definitive clinical signs of pregnancy)] after 12 months or more of regular unprotected sexual intercourse” (Zegers-Hochschild et al., 2009, p. 1522). Gurunath, Pandian, Anderson, and Bhattacharya (2011) reviewed the literature to determine how infertility is commonly defined in prevalence studies and to suggest a consolidated and relevant definition. They found the greatest conceptual differences between demographic and epidemiological definitions. Demographic infertility is defined as “childlessness in a population of women of reproductive age”, while epidemiological

infertility specified an amount of time without achieving pregnancy in a population of women generally having unprotected sex (Gurunath et al., 2011, p. 575). They concluded that a uniform definition of infertility should be clinically relevant and include both time spent trying to achieve pregnancy and age of women (Gurunath et al., 2011).

Due to the variation in the definition of infertility, the prevalence also varies between studies based on how infertility has been defined (Table 2.1). While all of the following definitions specify a time period (i.e., 12 months) and the absence of contraception, they vary in terms of reporting sexual intercourse, intention to become pregnant, and partner surgical sterilization.

Table 2.1		
<i>Canadian Infertility Prevalence Studies with Definitions and Corresponding Infertility Rates</i>		
Study	Definition	Infertility Rate (%)
Bushnik et al. (2012)	Couples who did not use birth control in the preceding 12 months	15.7
	Couples who did not use birth control and reported having sexual intercourse in the preceding 12 months	14.0
	Couples who did not use birth control and reported having sexual intercourse in the preceding 12 months with the purpose of attempting to become pregnant	11.5
Collins et al. (1997)	A woman that did not use contraception in the past 12 months, that neither she nor her partner were surgically sterilized, and that she was not pregnant in the past 12 months	8.5
Balakrishnan and Fernando (1993)	Women in union who did not use birth control in the preceding 12 months	5.4

Using three different definitions of infertility, Bushnik et al. (2012) used infertility data from the 2009-2010 Canadian Community Health Survey to estimate infertility amongst couples where the female partner was between 18 and 44 years old. Not surprisingly, the results showed different infertility rates; 15.7% using the first definition, 14% using the second, and 11.5% using the third definition, with a significant difference only between the first and third definitions (Bushnik et al., 2012). Older studies by Balakrishnan and Fernando (1993) and Collins, Feeny, and Gunby (1997), used similar definitions to the first definition used by Bushnik et al. The variation in prevalence based on definition demonstrates the issues that arise when surveys fail to thoroughly report information. Balakrishnan and Fernando (1993) and Collins et al. (1997) did not report on sexual activity and intent to become pregnant. This means that the only comparable infertility rates are those for patients who did not become pregnant while not using birth control and did not report sexual activity or intent to become pregnant in the preceding 12 months. The Bushnik et al. study reiterates the problems associated with the lack of universally accepted infertility definition, as it used three different definitions of infertility, which produced three different infertility rates. Despite the varying definitions and rates, the prevalence of infertility has clearly increased over the last 20 years.

The rising prevalence of infertility is impacted by the variety of causes of the condition. Infertility may be the result of a single factor or multiple factors, either in the male or female partner. Blundell (2007) claims that female, male, and idiopathic causes are responsible for 45%, 30%, and 25% of infertility cases, respectively. In women,

infertility may result from various factors including age, blocked fallopian tubes, irregular menstruation, or uterine polyps and fibroids (Blundell, 2007; Soto & Copperman, 2011). In men, infertility may be linked to sperm morphology, motility, and concentration (Guzick et al., 2001). In both sexes, infertility may be related to stress, smoking, alcohol consumption, sexually transmitted infections, as well as being under or over-weight (Grodstein, Goldman, & Cramer, 1993; Negro-Vilar, 1993; Ochsendorf, 2008; Soto & Copperman, 2011). The causes of infertility are approached here from a biomedical perspective; however, infertility and its causes should be considered from a social constructivist perspective as well.

Although infertility is most commonly defined and recognized as a medical condition, it can be argued that it is also a social condition, as women often feel societal pressure to be mothers (Marwah, Venkatachalam, & Nayak, 2014; Montpetit, Scala, & Fortier, 2004; Scala, Montpetit, & Fortier, 2005). This pressure is derived from the social construction of gender and gender roles (Staikou, 2014). For women, motherhood is a role perpetuated by social, cultural, and patriarchal values (Staikou, 2014). Women may be ostracized because of their inability to conceive (Marwah et al., 2014). Interviews with Indian women found that women experienced social exclusion for not being able to have children, even if it was the result of their husband's infertility (Marwah et al., 2014). In an American study, questionnaires used to assess perceived infertility-related stress among male and female patients found that women experienced greater stress than men from infertility-related social concerns, sexual concerns, and the need for parenthood (Newton et al., 1999). This need for parenthood also demonstrates the constructed ideals

surrounding parenting, as society defines parenthood in terms of the “biological parent” and assigns value to individuals based on their ability to have biological children.

Biological parents are considered more legitimate than step or adoptive parents (Fisher, 2003).

Infertility is a complex condition impacted by biological, environmental, and social factors. Treatment to help patients overcome this condition is necessary for both biological and social reasons.

2.2 Assisted Human Reproduction

With the rise in reported infertility rates, there has also been an increase in the use of assisted reproductive technologies in Canada (Bushnik et al., 2012). The World Health Organization defines Assisted Reproductive Technology (ART) as follows:

All treatments or procedures that include the *in vitro* handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy. This includes, but is not limited to, *in vitro* fertilization and embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation [for future use], oocyte and embryo donation, and gestational surrogacy. ART does not include [intrauterine insemination] using sperm from either a woman’s partner or a sperm donor. (Zegers-Hochschild et al., 2009, p. 1521)

In this thesis the term “fertility services” is used to refer to a broader range of services, including ARTs, intrauterine insemination (IUI), diagnostic services, as well as pre and post ART patient management.

2.2.1 Fertility services.

Some of the more common fertility services include IUI, IVF, intracytoplasmic sperm injection (ICSI), and cryopreservation. IUI is the injection of sperm into a woman’s uterus through the vagina (Boyajian et al., 2014). The sperm is washed and a

more concentrated sample is obtained prior to injection in order to optimize the chances of achieving pregnancy (Veltman-Verhulst, Hughes, Ayeleke, & Cohlen, 2016). Patients may use this treatment if they are struggling to become pregnant on their own or if they are using purchased or donated sperm. Cochrane reviews reported that there is evidence of moderate quality demonstrating that there is no difference in the live birth rate of women who have IUI versus women who use timed intercourse¹ (Veltman-Verhulst et al., 2016).

Oftentimes, women undergoing IUI will also be taking fertility drugs to stimulate follicular growth. Although service providers err on the side of caution, stimulating follicular growth may mean fertilization of multiple ova, which can result in a multiple pregnancy. Multiple pregnancies can have serious consequences for both mother and child, with increased risk of complications, morbidity, and mortality (Brambati, Tului, Camurri, & Guercilena, 2004; McKelvey, David, Shenfield, & Jauniaux, 2009). These consequences may include low birth weight, neonatal death, premature delivery, pre-eclampsia, and postpartum hemorrhaging. The consequences of multiple pregnancies also negatively impact the health care system (McKelvey et al., 2009), as the costs of serial ultrasound examinations, maternal hospitalizations resulting from complications, and neonatal care in the case of preterm birth are covered by public health insurance in Canada. These costs are often substantial. Cochrane reviews show there is low quality evidence to assess the incidence of multiple pregnancies resulting from IUI compared to other treatments (Veltman-Verhulst et al., 2016).

¹ See glossary

IVF is a “procedure that involves extracorporeal fertilization” (Zegers-Hochschild et al., 2009, p. 1522), as the eggs and sperm are combined in a laboratory dish, and the embryo is then transferred to the uterus. Intracytoplasmic sperm injection is a version of IVF in which “a single spermatozoon is injected into the oocyte cytoplasm” (Zegers-Hochschild et al., 2009, p. 1523); this is most often used if there is a problem with sperm motility.

In 2014, IVF success rates were around 40% (of procedures done) in Canada based on self-reported success rates by Canadian fertility clinics (BORN Ontario, 2015). The rate varies depending on a woman’s age, whether the embryo transferred was fresh or frozen, how many embryos were transferred, and other factors that influence fertility (BORN Ontario, 2015). However, a Cochrane review cites a slightly lower success rate (35.5%) for clinical pregnancy² resulting from embryo transfer (Kroon, Hart, Wong, Ford, & Yazdani, 2012). Clinical pregnancies do not necessarily mean live births; therefore, the actual percentage of take-home babies may be considerably smaller.

Cryopreservation is the freezing of gametes³, zygotes⁴, embryos, or gonadal tissue for later use (Zegers-Hochschild et al., 2009). Patients will use this service if they are storing embryos for future transfers (frozen embryo transfers) or looking to preserve their fertility. They may preserve their fertility for a variety of reasons including postponing parenthood to focus on a career, receiving a cancer diagnosis that requires treatment that

² See glossary

³ See glossary

⁴ See glossary

will render them infertile (Jeruss & Woodruff, 2009), or undertaking hormone therapy and/or sex reassignment surgery if they are transgender (Coleman et al., 2012).

2.2.2 Assisted reproduction regulation in Canada.

Certain aspects of assisted reproduction and fertility services are tightly regulated in Canada in order to correspond with social and ethical standards, however, the regulation process occurred over a number of years.

In Canada, the federal government set up the Royal Commission on New Reproductive Technologies in 1989 with the purpose of creating policy recommendations for the management of ARTs (Royal Commission on New Reproductive Technologies, 1993). According to Montpetit et al. (2004), the Royal Commission was expected to examine

the medical and legal issues involving these technologies; their implications for women's reproductive health and well-being; their social and legal arrangements, such as surrogacy; and 'ownership' rights and economic and commercial considerations, such as research funding and marketing regulations. (p. 145)

The Commission released their final report, *Proceed with Care*, in 1993. The report recommended a ban on human cloning, surrogacy, the creation of human/animal hybrids, and the sale of gametes (Miller Chenier, 1994). It also recommended the regulation of

sperm collection, storage, and distribution, and the provision of assisted insemination services; assisted conception services, including egg retrieval and use; prenatal diagnosis; research involving human zygotes (embryo research); and the provision of human fetal tissue for research or other specified purposes. (Royal Commission on New Reproductive Technologies, 1993, p. xxxiii)

The Commission was criticized for their poor consultation process, including “an intimidating and dismissive hearing atmosphere” (Jones & Salter, 2010, p. 424), lack of

assistance with costs associated with travel and child-care, and socio-cultural insensitivity (Jones & Salter, 2010). After the Commission received negative feedback, the government held consultations with the public through Health Canada (Montpetit et al., 2004). The Human Reproductive and Genetic Technologies Act (Bill C-47) was then introduced in 1996, but died on the order paper, when an election was called (Montpetit et al., 2004).

Following the failure of Bill C-47, the government transferred the responsibility of preparing a bill to a Special Project Division within Health Canada and commenced new consultations with a diverse group of interested parties, including allied health workers, bio-ethicists, women's organizations, infertility counselors, and family planning counselors (Montpetit et al., 2004; Scala et al., 2005). In 2004, An Act Respecting Human Reproduction and Related Research (Bill C-6), which prohibited payment for reproductive tissues and services among other technologies, was finally adopted (Jones & Salter, 2010). This Act led to the recommendation that the Assisted Human Reproduction Agency of Canada be created in 2006 (Jones & Salter, 2010), which was "mandated to protect the health of Canadians in relation to ARTs and apply ethical principles in embryo research" (Montpetit et al., 2004, p. 153). The agency was never formally established, and disbanded in 2012 because it failed to implement regulatory regimes for ARTs due to bickering amongst different factions asking for strict regulation of fertility clinics and those that wanted self-regulation by the clinics (Mulay & Boscoe, 2014).

In Canada, many ARTs are legal, and in a few cases, publicly funded. The process of regulating ART access began in the 1980s and became necessary in order to ensure

that social and ethical aspects were fully considered (Montpetit et al., 2004). During the process of implementing federal legislation related to ARTs, Québec was particularly vocal about the inappropriateness of federal policies on reproductive health issues, as health is a provincial responsibility (Mulay & Boscoe, 2014). Provincial governments have since implemented their own policies on reproductive service coverage (Health Canada, 2014).

2.3 Health Care Management and Funding in Canada

Although the federal government has implemented regulations that criminalize certain reproductive technologies in Canada, they have little power when it comes to the management and coverage of these services. Fertility services are considered a health service and as a result provincial governments get to decide whether or not these services are “medically necessary” and the extent to which they are covered.

2.3.1 Federal government responsibilities.

The federal government is responsible for developing national baseline standards for health care services under the *Canada Health Act* (Deber, 2014). As health care is under provincial jurisdiction, provinces and territories are provided with financial support from the federal government for these baseline services if they meet the national standards outlined in the *Canada Health Act* (Deber, 2014; Health Canada, 2011). This federal financial contribution, under what is now called the Canada Health Transfer, is based on various factors, including population size and fiscal capacity (Deber, 2014; Health Canada, 2011). The federal government is also responsible for funding and delivering health care for specific populations including “First Nations people living on

reserves, Inuit, serving members of the Canadian Forces, eligible veterans, inmates in federal penitentiaries, and some groups of refugee claimants” (Health Canada, 2011, para. 18).

The *Canada Health Act* has five governing principles: public administration, comprehensiveness, universality, accessibility, and portability (Health Canada, 2011). Public administration means that a public authority managed by the provincial or territorial government must administer health services (Deber, 2014; Health Canada, 2011; Madore, 2005). Comprehensiveness implies that provincial and territorial health plans must insure all medically necessary services provided within a hospital or by physicians. Universality means that everyone who is eligible is insured and that everyone who is insured is entitled to equal service coverage. Accessibility is that governments must provide all who are insured reasonable access to the insured baseline health services, without cost-associated barriers. Portability means that health coverage applies between provinces and usually for emergency and other necessary treatment received abroad (Deber, 2014; Health Canada, 2011).

Outside of health insurance, the federal government is responsible for health protection and regulation (e.g., regulation of pharmaceuticals), consumer safety, disease surveillance and prevention (Health Canada, 2011). Additionally, it provides support for health promotion and research and health-related tax credits or deductions for particular groups of people, for example deductions on health insurance premiums for those who are self-employed (Health Canada, 2011).

2.3.2 Provincial and territorial government responsibilities.

The provincial and territorial governments are responsible for administering and delivering the majority of health care services, held to the national standards of the *Canada Health Act* (Health Canada, 2011). The provincial/territorial health plans cover all medically necessary hospital and physician services without requiring payment for the service by the insured patient (Health Canada, 2011). Medically necessary services are not defined by the federal government in the *Canada Health Act*, but rather by provincial and territorial governments in consultation with physician groups (Health Canada, 2011). Many governments will also cover additional benefits for certain groups (i.e., seniors and low-income residents), including the cost of ambulance services and medications prescribed outside of hospitals, as well as audiology, optometry, and dental services (Health Canada, 2011). These services are normally not covered by public health insurance, but by private or employment-based insurance or they may be paid out-of-pocket by patients. Fertility services are also not universally covered by Medicare, which means that they may be less accessible depending on the province in which one lives.

2.3.2.1 Provincial reproductive service coverage and access.

As each province and territory individually manages and delivers their own health plans, there are usually many differences between them (Health Canada, 2014). Even though infertility treatments are not considered medically necessary by most provincial governments, Québec and Ontario publicly fund some treatments (Morin, 2015; Motluk, 2015). Manitoba provides a tax credit for up to 40% for fertility treatment costs with a maximum tax credit of \$8,000 each year (Boyajian et al., 2014; Motluk, 2015). Ontario

used to cover only the cost of IUI, but in late 2015, it started covering the cost of one round of IVF (Motluk, 2015). In contrast, due to unsustainability and strain on the health care system, the Québec health plan, which used to cover three rounds of IVF treatment, now only covers one round (Morin, 2015). However, it continues to cover the cost of IUI for women aged 18-42 (Morin, 2015).

In NL, the provincial health plan (MCP) covers infertility diagnosis, including blood tests, sperm counts, laparoscopy, and ultrasounds, as well as doctor appointments, but not fertility drugs, sperm washing for IUI, or IVF (T. O’Grady & H. Rees, personal communication, September 15, 2015). NLFS offers services such as prescription and administration of fertility drugs to stimulate increased egg production, cryopreservation of male gametes for medical reasons, and IUI (T. O’Grady & H. Rees, personal communication, May 25, 2015). However, there are no IVF (or intracytoplasmic sperm injection) services available in the province and the procedure is not covered under the provincial health plan, which means that patients pay not only for the procedures, but also for the costs associated with travelling out-of-province to access the services. Patients who want to access IVF (or intracytoplasmic sperm injection) have to travel to Halifax, Ottawa, or Calgary. An estimated 80 to 100 couples travel outside the province to access IVF each year (T. O’Grady & H. Rees, personal communication, May 25, 2015). NL is one of two provinces (the other is Prince Edward Island [PEI]) that does not offer IVF services in the province (Canadian Broadcasting Corporation [CBC], 2014). According to O’Grady and Rees (personal communication, September 15, 2015), this is due to a lack of funding from the provincial government. Moreover, given the province’s small

population, the demand for service is expected to be low and, therefore, the quality of service would likely also suffer. Even though both NL and PEI do not offer IVF services, the challenges that NL residents experience are likely greater due to the isolation of the province, but this has not been explored in the literature. Therefore, the purpose of this study is to examine challenges faced by NL fertility patients.

2.4 Access Issues

Cost is often a factor for those accessing fertility services. It may affect the type of service they choose, where they go to access services, or both. Out-of-pocket costs and socio-economic status create inequity in service access: people who are more financially secure can access fertility services more easily.

2.4.1 Out-of-pocket costs and socio-economic status.

Collins et al. (1997) examined the prevalence of infertility, infertility service distribution, and the costs associated with certain reproductive treatments in Canada in 1995. They used survey results from the Royal Commission for New Reproductive Technologies and from the Canadian Infertility Treatment Evaluation Study, as well as cost-related information from Chedoke-McMaster Hospital in Hamilton, Ontario in order to determine the cost of infertility treatments (Collins et al., 1997). They found that of the 330,000 Canadian couples experiencing infertility in 1995, less than half accessed fertility treatment, and 13 diagnostic and treatment categories covered the majority of the services utilized (Collins et al., 1997). Costs associated with infertility treatment ranged from \$229 per clomiphene⁵ administration to \$41,000 for IVF per live birth (Collins et

⁵ Clomiphene is a drug used to stimulate ovulation

al., 1997). They concluded that the annual cost of infertility care in Canada was \$415 million, which was 0.6% of the annual cost of health care at the time (Collins et al., 1997). In 1995, one cycle of IVF (including clinic visits, injections, medications, monitoring, and physician, hospital, and lab fees) cost \$5,700 (Collins et al., 1997). In Canada today, one IVF cycle may range between \$7,000 and \$15,000 (Picard, 2011). Clinics in Halifax, Ottawa, and Calgary all quote a basic IVF fee over \$6,200, which includes pretreatment evaluation, consultation, monitoring, as well as surgical, anaesthetic, and laboratory fees. It does not include drug costs.

Patients often have to rely on personal finances to cover the costs of fertility services, but some private health insurance plans have limited coverage for infertility drugs, which can help lower out-of-pocket expenses. In 2015, 24 million Canadians had some level of supplementary health insurance (Canadian Life and Health Insurance Association [CLHIA], 2016). Most private health insurance comes from employers, which means that private coverage is less available to those who are unemployed (Hurley & Guindon, 2008). Those who are underemployed, seasonally employed, or working certain types of jobs, such as some retail positions, may also be lacking private health insurance. Both Smythe (2001) and Bhatti, Rana, and Grootendorst (2007) found that those with higher incomes were more likely to have private health and dental insurance. With the high cost associated with infertility treatments, patients accessing fertility services are more likely to be in middle or upper income brackets, and have some level of private health insurance coverage.

Many global studies demonstrate the inaccessibility of infertility care for low-income individuals (Inhorn & Fakih, 2006; Makuch, de Padua, Petta, Osis, & Bahamondes, 2011). Jain and Hornstein (2005) examined the demographic and socioeconomic characteristics of patients accessing fertility services in Massachusetts. The Center for Reproductive Medicine Clinic at Brigham and Women's Hospital mailed questionnaires to collect demographic information. They found that the majority of people accessing these services were Caucasian, educated, and financially well off (Jain & Hornstein, 2005), which suggests that socio-economic conditions, especially income level, affect a patient's ability to access fertility services. Even though the Canadian and American health care systems differ greatly, neither has universal coverage for fertility services. Therefore, Canadians may also be less likely to access fertility services if they have a lower income, as seen in the American study by Jain and Hornstein.

The literature seems to be lacking up-to-date information about the cost of fertility services in Canada and how cost impacts service access. This study examines the costs patients are faced with when accessing fertility services, considering factors such as socioeconomic status, insurance coverage, and location of residence to contextualize the data.

2.4.1.1 Effect of costs on treatment decisions.

The cost of health care services and medications often impacts treatment decisions made by patients. Bayliss, Steiner, Fernald, Crane, and Main (2003) interviewed 16 adults from Denver, Colorado with comorbid chronic diseases about the barriers they face when practicing self-care. Financial problems were cited among half of

the participants, specifically that paying for medications made adhering to self-care difficult. Cotton, Aspy, Mold, and Stein (2006) interviewed nine family physicians in Oklahoma about clinical decision-making in blood pressure management of patients with diabetes. They found that treatment options were limited for these patients most frequently by high cost of medications and inadequate insurance. Patients were being treated differently based on financial situations. Bernheim, Ross, Krumholz, and Bradley (2008) interviewed 18 physicians in Connecticut about how patient socio-economic status influenced clinical management decisions and found that physicians would change their treatment plan to improve patient outcomes, but struggled to balance treatments that were financially feasible for the patient with established standards of care. These studies are all American and unrelated to fertility care, however they highlight how treatment decisions may be affected by the cost of fertility services, a publicly uninsured service.

When considering infertility care specifically, it is clear that high financial costs prevent patients from accessing services and impact treatment decisions (McDowell & Murray, 2011; Redshaw, Hockley, & Davidson, 2007). Makuch et al. (2011) interviewed Brazilian infertility health professionals and patients and found that patients oftentimes could not afford their treatment medications. Therefore, these patients rarely received treatment. In a study by McDowell and Murray (2011), IVF patients at a centre in New Zealand were surveyed over a 3-year time period. The survey collected demographic information, treatment outcomes, and reasons for discontinuing treatment, if applicable. Patients reported discontinuing treatment due to failure to achieve pregnancy, cost (e.g., exhaustion of available public funding and high cost of private treatment), and stress. The

discontinuation of IVF treatment as a result of exhausted financial resources was also reported by Turkish patients in a study by Akyuz and Sever (2009). These studies demonstrate the financial barriers associated with accessing infertility care worldwide. We were unable to find Canada-centric data related to these challenges and how treatment is impacted. Unlike the United States and most other countries, some fertility treatments are covered in Canada by public health insurance; this varies from province to province and as a result, financial burden also varies depending on geographic location. This study addresses the gap in the literature on how infertility treatment decisions are affected by cost in Canada.

2.4.2 Rural residents.

Access to health services is especially challenging for rural residents who often travel great distances for routine appointments and treatments (Fuchsia Howard et al., 2014; Kornelsen & Grzybowski, 2006; Mathews, West, & Buehler, 2009). In terms of fertility services in NL, rural residents must not only travel to access IVF out-of-province if they so choose, but must also travel to St. John's for diagnostic services and preliminary treatment.

Furthermore, rural residents are less likely to have private health insurance and are more likely to be underinsured than urban residents (Bennett & Dismuke, 2010; Ziller, Coburn, & Yousefian, 2006). This is due to the types of employment that are more common in rural areas (e.g., working for small businesses and self employment), lack of unionization, and limited availability of group coverage (Bennett & Dismuke, 2010; Probst, Moore, Glover, & Samuels, 2004; Ziller et al., 2006).

Redshaw et al. (2007) surveyed women in the United Kingdom (UK) who had been treated for infertility about the nature of their treatment and associated financial costs. Some of the women reported financial and emotional costs resulting from the lack of locally available infertility care. They experienced difficulties associated with travelling for treatment, time lost from work, and scheduling childcare (Redshaw et al., 2007). Although we were unable to find Canadian studies related to geography and fertility service access, this study highlights some of the challenges that might be experienced by rural fertility patients in Canada.

A local example of the impact of geography on treatment decisions is provided by an NL cancer study. Mathews, West, and Buehler (2009) surveyed NL cancer patients between September 2002 and June 2003 and found that rural residents were more likely to report that costs resulting from travel, drugs, and childcare were important to their treatment decisions. Those without private insurance and those with low income also reported the same concerns. The study demonstrates the inequity in the health care system, as rural residents, those without private insurance, and those with low incomes are more affected by financial barriers related to accessing care. Although this study examines the experiences of cancer patients, all patients who are isolated from the service they wish to access, as well as those without private insurance and/or those with low income, may encounter similar challenges. If cost affects the treatment decisions made by cancer patients, whose care is often considered necessary, then it will certainly impact the treatment decisions made by fertility patients. The impact of cost on fertility treatment

decisions, specifically for rural Canadian patients, has not been examined in the literature; this research attempts to fill that gap.

2.4.3 Service provider perceptions.

When examining the challenges patients face while accessing fertility services, it is important to consult service providers to obtain a holistic picture of these challenges and how treatment is impacted. Mathews, Buehler, and West (2009) interviewed NL cancer care providers about their perceptions of how patients and providers try to limit out-of-pocket costs resulting from cancer care. These out-of-pocket costs were separated into three categories: (1) drugs, medical supplies, and equipment; (2) travel and lodging; and, (3) loss of income. Service providers reported patients trying to curtail costs by substituting or rationing medications, choosing radical treatments, lengthening the time between follow-up appointments, choosing inpatient care, and working during treatment to minimize loss of income. Service providers would try to minimize costs for patients by changing chemotherapy and supportive drug prescriptions, shortening radiation treatment protocols, admitting patients to hospital, and arranging follow-up with physicians closer to a patient's home. Some of these methods of minimizing cost obviously affect patient treatment and care, such as changing or rationing medications, shortening treatment protocols, and spacing follow-up appointments farther apart.

Although this study is about cancer care, it offers insight into service providers' perspectives on the ways that patients and providers alter treatment plans based on out-of-pocket costs. We could not find anything in the literature specifically about how the

challenges associated with fertility care affect treatment decisions of patients and providers from the perspective of service providers, so this research aims to fill this gap.

2.5 Summary

This chapter presents a case for research related to the challenges patients face when accessing fertility services in NL. By describing the variation in infertility definitions in the literature and highlighting the rising prevalence of infertility, it demonstrated the demand for fertility services. It also placed fertility services in the context of the Canadian health care system and NL's provincial health plan, and borrowed from literature on other health conditions and service access issues. Finally, it summarized findings from studies on cost impact on uninsured care in general and on health services in Canada, which highlighted the need for evidence that reflects the local circumstances.

3.0 Methods

This project used in-depth qualitative interviews and consisted of a patient study and a service provider study. We adopted a pragmatic epistemology, which incorporates both realist and idealist ontologies, and approaches research practically, suggesting that real-world problems guide the interests of researchers (Giacomini, 2010). It asserts that “phenomena operate independently of our ideas, but also grants that we must apprehend these phenomena through our ideas” (Giacomini, 2010, p. 132).

In-depth qualitative interviews are helpful for understanding and documenting the experiences of study participants (Miller & Glassner, 2011). They allow for the interviewer to explore the participant’s point of view and to represent it as truthfully as possible. This method can be used “for examining the social world from the points of view of research participants” (Miller & Glassner, 2011, p. 137). Green and Thorogood (2009) describe an interpretative approach to research in which the researcher seeks to understand people’s interpretations of ‘reality’; the in-depth interviews are useful for this approach as they target participant “accounts of the world, not direct representations of that world” (p. 102). In-depth interviews offer data that represent the interaction of the researcher and the participant to reveal information about what participants believe and how they behave, classify the world, and categorize knowledge; interview data are valid as long as they are not taken out of context and used as a representation of another reality (Green & Thorogood, 2009).

3.1 Patient Study

For the patient study, we used semi-structured, in-depth interviews with patients

from NLFS to realize the first three research objectives. These were (1) to describe the challenges experienced by patients seeking infertility treatment in NL, (2) to explore whether or not there is a difference in the challenges experienced by patients seeking infertility treatment who are from St. John's and surrounding areas (within 50 km of NLFS) compared to those who are from other areas of the province (farther than 50 km away), and (3) to understand how these challenges impact patient treatment and travel decisions.

3.1.1 Participant recruitment.

Participant recruitment began in March 2016 and ended in June 2016. Three approaches were used to recruit participants. First, we messaged the administrators of the Facebook groups, "Infertility Support – Newfoundland and Labrador" and "Parents helping parents with everyday questions about parenting – NL", explained the study, and requested that they share information about the study as well as the research team's contact information on their page. We also placed recruitment posters in the NLFS clinic. Finally, we asked participants to pass along the research team's contact information to anyone they knew who might be interested in participating. Potential participants contacted the research team in order to participate or to ask for more information about the study.

3.1.2 Inclusion and exclusion criteria.

To be included in this study, the participants must have been referred to NLFS between December 2010 and December 2014, to ensure that they had been treated relatively recently, thereby improving their ability to recall experiences. Only women

were included in the study because the fertility drug treatments, IUI procedures, and IVF procedures involve women. Moreover, men and women likely experience infertility differently (Newton et al., 1999). Examining the difference between how men and women experience infertility was beyond the scope of this study. Participants had to be between the ages of 25 and 50 at the time of recruitment, which was defined as the appropriate age range for reproduction in this study, as patients in this age group were more likely to be accessing or to have recently accessed fertility services. Patients who did not intend to personally become pregnant as soon as possible were excluded from this study (e.g., those who used surrogacy or cryopreservation). We confirmed participant eligibility over email and during the interview by asking about time of referral, sex, birth year, and what services were accessed.

Participants were purposefully sampled based on location of residence. An attempt was made to interview patients who traveled to the clinic from farther than 50 km away and patients living within 50 km of NLFS.

3.1.3 Data collection.

Participants were offered the option of an in-person or telephone interview. All interviews were held over the phone and conducted in a private room. Participants were required to sign and return a consent form before participating in the study. In addition, consent was reconfirmed verbally at the beginning of the interview. The patient participants completed a brief questionnaire at the beginning of their interviews to collect demographic information, including age, location of residence, whether or not they have private health insurance, marital status, and household income. The questionnaire is

presented in Appendix I.

The interviews consisted of semi-structured questions related to the patient's journey to accessing fertility care, the types of services accessed and considered, the factors that influenced the services accessed and considered, the types of costs that they incurred throughout the treatment process, how the cost of treatment and travel influenced treatment decisions, and whether the patient would consider accessing services in the future. The interview guide is presented in Appendix II.

The interviews were recorded digitally and transcribed verbatim. Recruitment and interviews continued until saturation of themes and concepts occurred, which means that no new ideas were raised in the interviews (Mathews, Beuhler, & West, 2009). In order to maximize the credibility of the data and ensure that participant responses were properly interpreted, we used respondent validation or member-checking, which entails summarizing the responses and repeating them back to the participant for verification (Flick, 2014; Mathews, Buehler, & West, 2009). Participants had the opportunity to leave their contact information with the research team in order to receive the study results.

3.1.4 Data analysis.

The qualitative interviews were analyzed using thematic analysis, concurrent to data collection (Green & Thorogood, 2009). Two members of the research team (Dr. Maria Mathews and I) began by individually reading through three of the interview transcripts looking for and marking common ideas (Huston & Rowan, 1998; Mathews, Beuhler, & West, 2009). Based on this initial reading, we assigned names and colours to these common ideas, while being careful to keep the preliminary codes as distinct as

possible. We then compared and consolidated our coding template and coded transcripts that were developed from these first three interviews in order to describe codes, clarify misunderstandings, and develop consistency among the codes (Mathews, Beuhler, & West, 2009; Rowan & Huston, 1997). During this meeting we also began to define and describe the codes. We finalized the code descriptions and then used the coding template to re-code the first three interviews. We coded by going back through the transcripts and highlighting ideas related to the codes in the same colour as the code. The remaining interviews were coded with this final coding template and then coded quotations were grouped using NVivo 11 software (QSR International [Americas], Cambridge, MA, U.S.A.). NVivo is used to group coded interview or focus group data in order to organize quotations under a specific theme.

3.2 Service Provider Study

For the service provider study, we used semi-structured, in-depth interviews with service providers at NLFS to realize the fourth research objective, which is to determine how the challenges that patients face affect the provision of care from the perspective of service providers.

3.2.1 Participant recruitment.

Participant recruitment began in May 2016 and ended in June 2016. To recruit nurse participants, we presented at a nurse staff meeting. We briefly explained that the study intended to determine the barriers to accessing fertility services in NL and that they would be asked to participate in a recorded interview. During this meeting, the nurses decided on times that we should come to the clinic for interviews and coordinated

amongst themselves who would be interviewed based on their interest and who was answering patient phone calls and not working directly with patients in the clinic. We emailed out consent forms following this meeting so that they could read and sign the form prior to the interview.

We also sent an email to physicians employed at NLFS. The email contained information about the study and those interested in participating were able to contact the research team to schedule an interview. Administrative staff identified times when interested physicians were available. To ensure that participation was voluntary, consent was confirmed verbally in a private room before the interview began.

3.2.2 Inclusion and exclusion criteria.

To be included in this study, the service providers were physicians or nurses employed at NLFS. There were no other healthcare professionals that worked at the clinic. They also had to be employed at the clinic for at least 2 years to ensure that they had experience dealing with a variety of patients.

3.2.3 Data collection.

The service provider interviews were held in-person in various offices at NLFS. The interview guide is presented in Appendix III. Participants were required to sign a consent form before participating in the study and consent was re-confirmed verbally at the beginning of the interview. The interviews consisted of semi-structured questions related to the common barriers patients face when accessing fertility services, how geography and service availability impact cost and how patients finance their treatments, how these barriers affect the delivery of fertility services, and the assistance available to

patients struggling to access fertility care. The interviews were recorded digitally and transcribed verbatim. Interviews were done until saturation of themes and concepts was achieved. In order to ensure that participant responses were properly interpreted, we used respondent validation or member-checking (Flick, 2014; Mathews, Buehler, & West, 2009), as described in Section 3.1.3. All participants had the chance to give their contact information in order to receive the study results.

3.2.4 Data analysis.

We analyzed the transcripts from this study using thematic analysis, as described in the patient study. However, instead of highlighting text in the same colour as the corresponding code, lettering and numbering schemes were assigned to each code and then used to mark sections of text that contained the same idea. The interview transcripts were coded and coded quotations were grouped using NVivo 11 software (QSR International [Americas], Cambridge, MA, U.S.A.).

3.3 Quality Management

Various steps were taken throughout the research process to ensure the quality of the methods, data collection, and analysis.

3.3.1 Pre data collection.

Before beginning data collection, we pretested the interview questions by posing them to colleagues to assess responses, improve ways of posing the questions, and improve probes. We then conducted a pilot interview with someone that had previously used fertility services. The pilot interview was recorded, played back, and critiqued by Dr. Maria Mathews. The purpose of this was to listen for appropriate and inappropriate

responses to sensitive information, question phrasing, probe use, and participant responses. This interview was not used in the study.

3.3.2 During data collection.

Once data collection began, we recorded interviews to improve dependability and confirmability of the data (Green & Thorogood, 2009). We also reviewed completed interviews to improve how questions were being asked, to identify new probes for subsequent interviews, and to assess saturation of themes and concepts. In order to maximize the credibility of the data, we used respondent validation or member-checking, (Flick, 2014; Mathews, Buehler, & West, 2009), as described in Section 3.1.3.

3.3.3 Post data collection.

To maximize dependability and confirmability, we kept records of the interviews, including transcripts and audiotapes, as well as coding template drafts (Green & Thorogood, 2009; Mathews, Buehler, & West, 2009; Mays & Pope, 1995). We also used two members of the research team to create a coding template and code three interviews from each study to improve confirmability (Cope, 2014; Green & Thorogood, 2009). To improve credibility and dependability, we used thick description, which thoroughly describes the context of quotations and research (Green & Thorogood, 2009; Huston & Rowan, 1998; Mathews, Buehler, & West, 2009). We also described the methods and inclusion/exclusion criteria in detail to improve transferability and allow readers to compare the findings to similar situations or projects (Cope, 2014; Green & Thorogood, 2009). Finally, we reported disconfirming evidence in our results in order to maximize credibility (Cope, 2014).

3.4 Ethical Considerations

This research was approved by the Newfoundland and Labrador Health Research Ethics Board (HREB Reference #2016.028) and the Research Proposals Approval Committee (RPAC), which is responsible for the approval of research taking place in Eastern Health.

For patient recruitment (section 3.1.1) the research team contacted administrators for parenting and infertility Facebook groups asking them to post a participant recruitment message in the group. We also had posters put up in NLFS. In both of these cases, we had no contact with patients unless they contacted us themselves to participate in the study. For the service provider study, administrative staff helped the research team recruit participants at NLFS, as described in section 3.2.1. However, the research team was careful to ensure that all service providers were participating voluntarily. The interviews were conducted in a private room, away from coworkers and administrative staff. All participants in both studies were informed of their right to withdraw from the study at any time and were required to read and sign a consent form before interviews began.

The risks of this study were low because the questions were limited to the direct experience of patients seeking and obtaining fertility services in relation to distance and cost. However, it was possible that patient participants may have felt stressed or emotional when discussing their experience with infertility and accessing fertility services; therefore, we were prepared to recommend support services through NLFS if

necessary. Dana Ryan, Dr. Mathews' research assistant who has a Master's degree in counseling, was also present to provide emotional support in case it was needed.

Confidentiality of all participants was maintained by using numbers to identify participants in transcription and analysis. Additionally, letters were used instead of names for physicians that were identified in patient interviews (e.g. Dr. X). Participants were not and will not be identified in publications or presentations; this means that any specific information that could identify participants was and will be edited in publications and presentations, such as age or gender of NLFS staff.

In order to keep all data secure, they were stored in locked rooms, out of sight. Electronic files were password protected with only Dr. Mathews, Dr. Mulay, and myself able to access the data. After the 5 year time period outlined in the university research guidelines has passed, the interview data will be destroyed.

4.0 Patient Study Results

4.1 Description of Sample Population

There were 14 women who expressed interest in this study and 11 (78.6%) of the 14 completed interviews. The remaining three women did not respond to follow-up emails. The interviews lasted between 20 and 45 minutes. Participants were from across the island of Newfoundland, but none were from Labrador. They were between 30 and 45 years of age at the time of interview. Three participants (27.3%) lived more than 50 km away from St. John's. All but one participant were married or in common law relationships. One (9.1%) was single. Participant household incomes ranged from less than \$20,000 to over \$100,000, however the majority of participants (63.6%) fell in the \$100,000 and above income bracket. Four of the 11 participants (36.4%) had already had children through fertility services. One (9.1%) was actively seeking treatment and two (18.2%) were pregnant at the time of the interview, while others were taking a break or had stopped treatment altogether.

In order to give context to quotations, some patient information is provided, including an identification number, location of residence (urban or rural), treatment received, and pregnancy outcomes.

4.2 How and Why Patients Use Fertility Services

Before using fertility services, most patients reported trying to get pregnant for at least a year. Patients tried ovulation kits, different fertility tracking smartphone applications, and tracking their body temperature in order to optimize their chances of becoming pregnant. The women were referred to fertility services for many reasons.

Some had no obvious reasons to explain why they were not getting pregnant, others needed sub-specialist expertise to treat co-morbid conditions to become pregnant, and many suffered from multiple miscarriages before finally being referred to fertility services.

One woman started trying to get pregnant in 2010 and was referred to the fertility clinic in 2011. She tried various methods to get pregnant before seeking specialized care. Her menstrual cycles were regular, so there was no obvious indication of why she could not become pregnant.

Prior to fertility [services] I was tracking my cycles, tracking my temperatures, ovulation kits etc. just so I would know roughly when I was ovulating and all of that stuff. So I had lots of data when I finally went to the fertility clinic (Patient 7, urban, IUI and IVF, 1 child).

Another woman tried for a year to get pregnant before being referred to fertility services. She also reported trying different methods to become pregnant before accessing fertility services and having regular menstrual cycles, but still could not become pregnant.

We were doing the ovulation strips and I was tracking my basal temperature and all that stuff, so we felt like we knew when I was ovulating, like it was pretty clear from all of that, so we knew that we were getting the timing right and my cycle was fairly regular. So we thought that every month we basically had a good shot of getting pregnant, but we never did (Patient 8, urban, medicated cycles, 1 child).

Other patients with more apparent symptoms of infertility and comorbid conditions were treated by their family doctor or obstetrician/gynecologist (OBGYN) before going to fertility services. When these women did not become pregnant with this treatment, they chose to move on to sub-specialized fertility care to improve their chances. For example, one woman from a rural area was initially treated by her

obstetrician on the west coast of Newfoundland before being referred to fertility services. She found out after visiting the fertility clinic that she had blocked fallopian tubes and that IVF was her only option to become pregnant.

I had been doing fertility treatment with my OBGYN for a few years... say 2008, 2009, then I was referred to a new OBGYN once my [old OBGYN] retired. So same kind of thing, doing fertility drugs, Clomid and Femara, and nothing was working... so I think it was probably around 2011 [that] I was referred to Newfoundland and Labrador Fertility Services (Patient 1, rural, IVF, 1 child).

Another woman had Polycystic Ovarian Syndrome (PCOS), a condition that prevented her from becoming pregnant. After months of receiving treatment from her OBGYN in St. John's, she was referred to fertility services.

My family doctor sent me to an OBGYN and she did a bunch of tests and we eventually figured out that I have...PCOS. So I did 3 months of a drug called Clomid that was prescribed by the OBGYN and actually got pregnant in July of 2014 and I miscarried at 10 weeks...[the OBGYN] had referred me to fertility services in January when I first saw her...because she said she could only prescribe 3 months of the fertility drug and after that it would have to be taken over by fertility [services] (Patient 6, urban, IUI, pregnant).

Many patients suffered multiple miscarriages while trying to become pregnant, due to comorbid conditions or for other unknown reasons, which pushed them to access fertility services directly. One woman had a heart condition, which made achieving and maintaining a pregnancy difficult. After a year of trying to get pregnant with tracking and ovulation kits, she was referred to the fertility clinic after a miscarriage.

My partner and I had been trying to get pregnant for quite a while and we finally did, and then at about 9 weeks I started having a lot of pain, went for an ultrasound and found out that I miscarried. So my doctor at the time had referred me to [fertility services] (Patient 5, rural, diagnostic services, 1 child).

After two miscarriages, one patient pushed for a fertility services referral even though she said physicians normally withhold referrals until after three miscarriages. By the time she actually saw fertility services she had had four miscarriages.

My husband and I first started trying to get pregnant and have a child in [2010]. So we got pregnant in 2010 and I had my first miscarriage...we got pregnant fairly quickly, it just took a few months of trying so no one at that point in time thought there would be any sort of an issue or didn't feel there was any need to do any investigations. So the summer of 2011 I got pregnant and I had another miscarriage at about eight weeks and so at that point in time...I felt that there was some sort of an issue that prompted me to see my family doctor and really push to get a referral despite the fact that they don't like to do that until you've had three losses. By the time I finally saw [fertility services] in 2012, I was after having four [miscarriages] (Patient 7, urban, IUI and IVF, 1 child).

The women in this study all tried to achieve and maintain a pregnancy on their own before using fertility services, but could not because of unknown reasons, comorbid conditions, and multiple miscarriages.

4.2.1 Services used and considered.

Participants accessed and considered a variety of services both locally and in other provinces, including diagnostic services, drugs, IUI, IVF (both fresh and frozen transfers), ICSI, cryopreservation, male sterilization reversal procedures, gamete purchasing or donation, and treatment for comorbid conditions. The most common reasons for patients accessing services were their inability to conceive, suffering multiple miscarriages, and advanced age.

Patients reported trying multiple rounds or types of services before achieving a pregnancy. A woman from the St. John's area who used IUI six times and IVF three times began with IUIs at the local clinic. She and her husband decided to "try IUI and see if it works, so we did six consecutive cycles of IUI and didn't have a single pregnancy"

(Patient 7, urban, IUI and IVF, 1 child), which motivated them to move on and try IVF. Many patients reported that they started with IUI in St. John's and after multiple IUI failures they moved on to IVF.

4.3 Barriers to Accessing Fertility Services

Through the interviewing process, we looked to identify the largest challenges that patients face when accessing fertility services in NL and how these challenges affected decision-making. The main barriers identified by patients were cost, the nature of fertility services, the physical environment, lack of service availability, and geography.

4.3.1 Costs and financial burden.

There are both direct and indirect costs that result from using fertility services. Direct costs are any costs specifically related to fertility treatment, including procedures, cryopreservation, and drugs. Indirect costs contribute to the overall cost of using fertility services, but are not part of treatment itself, such as travel-related expenses and time taken off work.

Direct costs of fertility treatment result mainly from IVF related costs and drug costs for all treatments, as IUI is largely covered by NL's provincial health plan. Without private insurance coverage patients may pay thousands of dollars for fertility drugs. For example, one patient who had used all of her insurance coverage after her first IVF cycle paid for her second fresh IVF cycle out-of-pocket, noting that the drug costs were probably around six or seven thousand dollars. She also described the additional costs associated with her second IVF cycle, saying "we paid the standard IVF cost, plus we had

to pay for ICSI for fertilization for that cycle so that's an extra cost, plus they did assisted hatching so that's an extra cost" (Patient 7, urban, IUI and IVF, 1 child).

Although direct costs can be substantial, especially for patients availing of IVF, indirect costs can be as equally burdensome. Some patients reported losing money from the time they take off work for their appointments and treatment-related travel. They described situations of having exhausted their sick leave and vacation time forcing them to take days off without pay. For example, a woman who travelled to Calgary for IVF said, "I actually exhausted all my sick leave...I have zero sick days right now...I just got back from Calgary in September with failed cycles...so I take days without pay. That's the only way that I can go to my appointments" (Patient 1, rural, IVF, 1 child). Another patient who had five IUIs in St. John's also reported using all of her sick leave. She intends to leave the province to access IVF by the end of 2016:

A lot of my [sick leave] time went towards [fertility] appointments and if I didn't have any sick leave left I was taking my vacation leave... and now when I go away for IVF I have to take that all unpaid sick leave because I have no time left vacation or sick leave... and that would be for myself and my husband...even if we do have a higher income you still don't save for that kind of expense (Patient 11, urban, IUI, no children).

A woman who had eight IUIs in St. John's reported losing as much as a full day of work during each month of treatment.

There's the not so upfront cost of having to take time off work for all of the appointments that you go to. I mean six/seven appointments per cycle. That's a pretty substantial amount of time off work to go to those appointments, especially because there are times when you have an appointment at 9 o'clock in the morning and you don't get seen until 11. By the time I leave work, drive there, have the appointment, come back...[it could be] 7/8 hours per month, so a full day's work really that I would lose per month (Patient 3, urban, IUI, pregnant).

Patients reported travelling both within the province and between provinces to access services, which increased the costs they incurred throughout the treatment process. Travelling within the province contributed to the cost of fertility treatments, as accommodations, food, and gas increased costs. For example, a woman who was being treated in St. John's had to drive roughly two hours to get to her appointments. She noted that hotels were necessary at times due to poor weather conditions.

There's the travel expenses. So I mean you're driving in, so first of all you're losing a day at work, and then gas and accommodations and meals because you're in there a for full day and sometimes a day and a half...you're probably spending 60 or \$80 on gas and then a hotel and everything else if need be (Patient 5, rural, diagnostic services, 1 child).

Women who had to travel to other provinces in order to access IVF services reported even more substantial costs. Normally, their flights were expensive and their stays were long, which all contributed to cost. For one woman, travelling to Calgary to receive IVF treatment impacted her overall treatment cost:

Our [IVF] procedure was just shy of \$8,000. Then you have the drugs. Luckily my insurance...covered a lot. So I probably had to spend around \$1,500 in drugs. Then of course our airfare which was around \$2,000 and...we didn't have to pay for a hotel, so you know we did it I guess as cheaply as possible...I would say we probably spent in total our first time...around \$12,000 (Patient 1, rural, IVF, 1 child).

Similarly, another woman who also travelled to Calgary for IVF noted the costs associated with travel.

If I think about my first [IVF] cycle, the cycle itself was probably 10 or 12 thousand, the drug cost I would say that was probably six or seven thousand, flights you're looking at \$1,200 a person. I mean we were lucky we didn't have to pay for accommodations but most people would and you're lucky if you can get accommodations for under \$100 a night and if you happen to have a child with you, which we didn't for our first cycle, but if you did and you didn't know anybody well you're looking at trying to find childcare in a strange city and pay

for that, which is not necessarily an easy feat either...Our medical costs for 2015 were \$25,000 out-of-pocket (Patient 7, urban, IUI and IVF, 1 child).

Furthermore, a woman who is planning to access IVF this year after five failed IUI procedures and two miscarriages, described the substantial cost of leaving the province for service resulting from accommodations, food, and airfare.

I definitely think it could be a lot cheaper if the [IVF] services were here because...we wouldn't have the accommodations and we wouldn't have the hotels and we wouldn't have food and we wouldn't have airfare so it would save us probably four or \$5,000 for sure (Patient 11, urban, IUI, no children).

The costs associated with out-of-province travel for IVF made it more difficult for patients to use this service.

Partners working out-of-town or out-of-province also affected treatment cost. For one couple, the husband working out-of-town made IVF more expensive, as they were paying for multiple flights for each round of treatment. The patient, who travelled to Halifax for IVF, reported substantial flight costs in addition to the typical travel costs because her husband works outside NL.

When we did up our income tax this year we had a \$30,000 medical expense. It was like with travel to Halifax because we had to go there several times, my husband didn't go for the [IVF] cycle with me, he flew there he left his sperm sample there cause he was going to be gone [for work], I flew back - my mom went with me - in August, so that was two flights there and then when that failed we were trying to figure out what's going on so [my husband] needed...a sperm function analysis test...and they don't do that here in Newfoundland so that was another trip back to Halifax...so then it's hotels, meals, travel, car rentals...it cost a lot of initial money for the IVF that it's just actually crazy the amount of money we've spent (Patient 10, urban, IUI and IVF, no children).

The financial burden associated with fertility services is exacerbated in NL by time lost from work, geographical isolation of patients and distance from the fertility clinic, and the lack of IVF services in province.

4.3.1.1 Information about services and cost.

Patients sought information from a variety of sources when researching fertility services. When they were asked about where they received their information about fertility treatment and cost, they mentioned Internet blogs, clinic websites, friends and family, family physicians, and fertility specialists and clinics. One patient said she got her information about procedures and costs from the clinic websites and that she “had a consultation with the doctor from Ontario and [that the doctor] went over all the costs and sent [her] an email on it as well” (Patient 11, urban, IUI, no children).

4.3.1.2 Methods of payment and financial facilitators.

Patients paid for the costs associated with their fertility treatment through a variety of methods, including out-of-pocket (with credit cards or lines of credit), private insurance, and family and friend contributions. The affordability of treatment was facilitated by wealth, low lab fees, MCP coverage, proximity to services, and family and friend financial and in-kind (place to stay) assistance to offset costs. Most patients could afford their treatment and related costs, or at least were able to pay for some of it out-of-pocket. Private insurance coverage for fertility drugs also helped patients pay for treatment. The low cost of sperm washing and MCP coverage for the other aspects of IUI helped with the costs of locally available treatments. Many claimed their fertility-associated costs on their income taxes. Some patients chose to take out loans in order to make the cost of their treatment more manageable. One woman with blocked fallopian tubes, whose husband did not have full-time, permanent work, reported using a line of credit to pay for IVF.

We just basically had no option and there was no point to try [IUI] in St. John's, it wouldn't work, my eggs can't get down through my fallopian tubes, they're so scarred. So we knew [IUI] was just wasting time and at the time I was 30 and I didn't want to wait any longer. So we had no choice, we certainly didn't have the money. We put it on a line of credit and just did it (Patient 1, rural, IVF, 1 child).

Other patients were given money to help pay for their treatment by family and friends.

For example, a woman who had three IUI and two IVF cycles said she received help from various family members.

My mom and dad gave us a couple thousand dollars and one of my sisters had given me \$2,000...and then when we went to Calgary my cousin had offered to pay for our flights... and when we were in Calgary [my husband's] friend...was going on a family vacation for a couple of weeks so they actually offered us their home (Patient 10, urban, IUI and IVF, no children).

Due to the substantial cost of fertility services, patients often employed multiple methods of payment in order to afford their treatment.

4.3.2 Nature of fertility services and infertility.

Patients reported having difficulty using services due to the number of times they needed to be at the clinic each cycle, the time sensitivity of the procedures, the low success rates for IUI, and treatment cycle cancellations. A patient's experience with an IUI cycle cancellation was described by a woman when her cycle was cancelled after her estrogen levels were outside of the optimal range for a successful procedure.

I remember everything was going good. I had taken the medications and everything, and then they did the blood work and there was something wrong with one of the levels, like my estrogen level was too low or too high or whatever. I remember the nurse called me and she said you know it's just as well to cancel it like it's not going to work... I just remember being so devastated (Patient 10, urban, IUI and IVF, no children).

This example shows how the variable nature of infertility and patient response to medication may lead to difficulty in using fertility services, as treatment cycles can be easily compromised.

4.3.3 Physical environment.

The weather in Newfoundland and Labrador also created challenges for some patients. A woman who lived a couple of hours outside of St. John's found accessing services challenging, especially during the winter when storms are inevitable, due to the need to travel back and forth to the clinic.

It is a pretty substantial drive, it's almost 2 hours to get in [to the clinic]. So when we had to go in especially like winter you'd probably have to take a couple of days off work because if I had an appointment Friday [and] they were calling for any snow, I'd take Thursday off and then stay in St. John's Thursday night just in case I couldn't make my appointment. So I mean I don't know how anybody would do it if they lived say on the west coast or something (Patient 5, rural, diagnostic services, 1 child).

In this instance, the patient had to extend her trip because of bad weather. Her experience was made more difficult by the distance she lived from the fertility clinic, as she needed to come into St. John's a day early to avoid a lengthy drive in a storm.

4.3.4 Geography.

Geography can pose an issue for patients, as the sole fertility clinic in the province is located on the east coast of Newfoundland in St. John's. Few patients who were being treated at the local fertility clinic had to travel for treatment from areas that are geographically isolated or far from the clinic. An IUI patient from the west coast of Newfoundland stayed in St. John's for a week during her treatment cycle to ensure that she could attend her appointments, saying "I was probably [at the clinic] three times for

the whole procedure but within [a] week” (Patient 4, rural, IUI and IVF, no children). As a result of the distance she lived from the clinic, she decided to stay in town and not return home between appointments.

4.3.5 Lack of service availability.

In addition to the issues associated with travelling in the province to access fertility services, many patients also have to travel out-of-province to access IVF services. A patient who accessed IVF in Halifax noted that residents of NL face additional challenges compared to other provinces when trying to access IVF, as they must fly in order to avail of the treatment.

Right now there [are] two provinces that don’t offer IVF and that’s Newfoundland and PEI, but PEI has a bridge attached to another province that they can drive to (Patient 4, rural, IUI and IVF, no children).

Another woman, who accessed IVF in Calgary, described the challenges associated with leaving the province for IVF and how these challenges make the service less accessible to residents of NL. She compared the NL case with people living in western Canada.

I have numerous friends out in western Canada who have gone through this process and a lot of them just skipped IUI and went straight to IVF because there you go from your house to the clinic and it’s not this whole big thing of having to travel outside of the province. I mean yes, you still have to pay for the treatment but having to go somewhere where you’re not at your own home province it’s a big thing... When I went for my second cycle [my husband, son, and I] hopped in a plane and went out to Calgary. Then I had to take time off work [and] my husband had to take time off work. So it’s a very difficult [decision to make] because of the extra cost and logistics associated with having to travel out of province for the treatment (Patient 7, urban, IUI and IVF, 1 child).

As this woman described, the out-of-province travel required for IVF makes the decision to use the service more difficult for patients.

4.4 Impact on Patients and Treatment Decisions

Cost of treatment and travel, the nature of fertility services, NL's weather and physical environment, the geographic location of the fertility clinic, and the lack of IVF services in NL not only create difficulty for patients using fertility services, but also have an impact on patient well-being and treatment decisions.

4.4.1 Substituting IUI for IVF.

Some participants chose to use IUI and to forego IVF altogether because they could not afford it. One patient, who did eight IUIs at the St. John's clinic and is now pregnant, did not use IVF because of the financial challenges associated with leaving the province to have the procedure.

When we had gone through I think it was about four IUI's the clinic started bringing up the idea of IVF for us and leaving the province to have that done and as much as we would have liked to have done that, I mean financially it's just not feasible for us (Patient 3, urban, IUI, pregnant).

Similarly, another patient, who was a single woman in her forties buying sperm and having IUI, did not consider IVF because of the high cost. She is of low income, making the service unaffordable due to the cost of the procedure and associated travel. She said, "I would absolutely be interested in [IVF or other fertility procedures] except I would not be able to afford them...so yes, am I interested? Absolutely. Can I afford them? Absolutely not, completely inaccessible for my current financial situation" (Patient 9, urban, sperm purchasing and IUI, no children).

Besides not being able to pay for IVF, patients were also motivated to opt for IUI because it is largely covered under MCP in NL. A woman from the west coast of Newfoundland began her fertility treatment with a round of IVF in Halifax, but then

chose to do IUI in St. John's due to the cost of additional IVF procedures and MCP's coverage of IUI.

If we had the money obviously we would have done a second round of *in vitro* versus going for IUI because IUI is practically free [in NL] in comparison to *in vitro*... the only cost you have for IUI are the drugs which are minimal compared to IVF and the actual procedure itself is covered by MCP...so you're just paying for your sperm washing...so it's about 1,000 bucks versus [\$15 000] (Patient 4, rural, IUI and IVF, no children).

As a result of the high cost of IVF and the low cost of IUI in NL due to MCP coverage, many patients chose to use IUI over IVF, the provider described "gold standard" treatment.

4.4.2 Delaying IVF.

Participants not only chose IUI over IVF, but some chose to delay IVF and use IUI initially partly because they did not want to pay for IVF treatment and travel. For example, one patient started with six unsuccessful IUIs before deciding to access IVF treatments, which she noted was a decision heavily influenced by the cost of IVF treatment and travel.

Obviously IVF had the highest likelihood of success but we knew we would have to go out of province to do that which has much more cost associated with it, so at that point we said let's try IUI and see if it works...It was never a decision of can we do [IVF] or can't we do it, it was can we do the lower cost option and get success, and it obviously would have prompted us to try [IUI] a little bit longer than had we not had to travel [for IVF] (Patient 7, urban, IUI and IVF, 1 child).

Another patient from the St. John's area had three unsuccessful IUIs at the local clinic before deciding to move on to IVF in Halifax, which was partly due to the cost of IVF treatment and travel.

I knew it was going to cost a lot of money to go even to Halifax to have [IVF] done and that was another factor in the prolonging the IUIs it was just that I didn't

want to go that route because you think oh God I could just come here and... pay \$150 to the lab here to do the sperm washing...I mean \$150 versus \$10000. So the financial piece alone was huge in deciding to continue with IUI and not go the IVF route (Patient 10, urban, IUI and IVF, no children).

Furthermore, one woman had intended to start with IVF instead of IUI because of the greater success rate. However, when she and her husband ran into trouble with house renovations, they decided to go with IUI because it was the cheaper option.

IUI was costing us about \$250 versus 12,000 [for IVF]...The doctor had recommended that IVF was probably a greater success rate than the IUI, so we were leaning towards going to do IVF, but with the house and the amount of money it cost we said well why not try [IUI] because we haven't tried that at all and maybe it will work (Patient 11, urban, IUI, no children).

After five failed IUI cycles, this woman was looking into IVF in Ottawa and Calgary at the time of her interview. The failed IUI cycles were emotionally damaging for her and she was taking time off of work. If she follows through with IVF, she will have to take days without pay from her job, pay additional money for treatment and travel, and face the possibility that IVF will not work either. The strategy of going with the cheaper treatment option to save money ended up costing patients more money and time in these cases, as they had multiple unsuccessful IUIs and then tried IVF.

In contrast, some patients delayed IVF and were able to save money. According to a woman who used fertility services in St. John's, the local fertility clinic recommends exhausting IUI before moving on to IVF, even though IVF is described (by providers) as the "gold standard" for fertility treatment. She said that IVF was not something she and her husband considered to be an immediate option due to the travel necessary to avail of the treatment.

In my mind there really is only IUI here so obviously IVF would be way down the line in terms of what we would consider and ... [Dr. Y] said IVF is the gold standard, that would be our most successful option, but obviously because it's not available here and because of the exorbitant cost of going away to get it that they would recommend exhausting the IUI options first (Patient 8, urban, medicated cycles, 1 child).

This woman was able to have a child without using IVF and was able to save the money that would have been necessary for the treatment and travel. Additionally, a patient, who is now pregnant, had four IUI procedures and multiple cancelled cycles throughout 2015. She reported postponing IVF because of the need to leave the province and the costs that would result from out-of-province travel. She said "...if there was an IVF clinic here, [my husband and I] probably would have done IVF by June of [2015]" (Patient 6, urban, IUI, pregnant), rather than continuing with IUI and medicated cycles with timed intercourse until the end of the year. She was lucky enough to become pregnant and did not need to use IVF. This delay of IVF treatment would be less likely to occur if the service was available in NL.

Many patients reported delaying IVF in order to save money. However, some were more successful than others as not all women were able to become pregnant without using the provider described "gold standard" treatment.

4.4.3 Site selection.

When patients are making decisions about their fertility treatment and IVF, they must consider where they would like to go for IVF treatment. Some patients reported treatment and travel costs impacting where they chose to undergo IVF treatment. If patients had family or friends near a specific clinic, they might choose that clinic so they would have a place to stay and not have to pay for accommodations. For example, one

woman chose to travel to Calgary for IVF because she and her husband had previously lived there and could stay with friends, which would save them money. Her husband was also able to work thereby offsetting the financial burden substantially.

[My husband and I] had a conversation around which clinic and because we spent time living in Calgary and my husband works for an oil [company] and would be able to work while we're up there, we said let's just go to Calgary. We can stay with friends and he can work while I'm doing appointments...I really didn't look at other clinics because of the fact that we had accommodations in Calgary (Patient 7, urban, IUI and IVF, 1 child).

Patients might also choose a specific clinic because closer locations would have lower flight costs. One patient chose to travel to Halifax for her first round of IVF because flights from St. John's to Halifax are cheaper than to other locations (i.e., Calgary). The doctors had told her that the clinics would provide the same quality of service and that it did not matter which one she chose, so she and her husband chose Halifax: "Halifax was closer, it was going to cost [my husband and I] less to get there with flights and it was going to just be closer to home" (Patient 10, urban, IUI and IVF, no children). Social support, free accommodations, and low flight costs were some of the more frequently cited reasons for choosing one IVF clinic over another.

4.4.4 Stopping treatment.

Financial challenges also forced patients to take a break from treatment or stop it altogether. Some patients reported that treatment and travel costs limited the number of times they could access treatment, and therefore the size of their family. One woman, who had a daughter through IVF and was taking a break from treatment, was unsure whether or not she would be able to have any more children using the procedure due to the substantial financial burden.

We're very fortunate that we had one daughter... but it took us years to pay off the \$12,000. Like I'm a teacher, my husband, he's an electrician, he works odd jobs, so I mean we are a one income household for the most part. So it is very damaging financially. Now with the two frozen cycles that we did that had failed, you know that was around six or seven thousand, we're still working to pay that off. So you know it's a really big struggle in terms of deciding, you know, do we move ahead, do we go back again now and start all over from scratch and spend another \$12,000 on a fresh cycle (Patient 1, rural, IVF, 1 child).

This decision to take a break from treatment, or potentially end treatment altogether because of financial situations, was more commonly reported among IVF patients than among patients who stayed in NL for fertility care.

4.4.5 No perceived barrier.

Even though many women discussed the impact of financial barriers on their treatment decisions, there were some who said that treatment and travel costs were not enough to deter them from using fertility services. However, all of the women who said that cost did not prevent them from using fertility services were patients who accessed services only in St. John's and lived within 50 km of the clinic. A patient who used IUI in St. John's and did not have drug coverage, got pregnant on her third IUI. She said that "[cost] didn't really matter...if it would end up in a child then fine" (Patient 2, urban, IUI, 2 children). Another patient accessed IUI at the local clinic and got pregnant after her fourth IUI. She was able to do whatever the doctors recommended in terms of treatment and drugs because of financial stability, although her insurance coverage for drugs was minimal.

We were kind of just happy to follow what the doctors recommended, you know as much as we could. My husband has a really good job, so we were lucky that we could [afford the treatment because] the injectable drugs are really expensive too (Patient 6, urban, IUI, pregnant).

Additionally, a woman who had medicated treatment cycles, but no IUI, reported that the low cost of IUI in NL (due to MCP) would have allowed her to access services without restriction.

IUI, luckily, is essentially covered [in NL]. You have to pay for the medications and I think like a \$150 lab fee or something like that. So that really for us that was very minimal cost and wouldn't have influenced how many cycles that we were able to do of it or anything like that (Patient 8, urban, medicated cycles, 1 child).

The cost associated with fertility treatment and travel was a factor that impacted treatment decisions for most patients, especially for those considering leaving the province for IVF. Only patients using IUI and living close to the St. John's clinic claimed that the cost of treatment and travel did not play a role.

4.4.6 Emotional impact.

In addition to the financial challenges, many women also discussed emotional challenges, which resulted from infertility, failed procedures, and the financial cost associated with treatment. One patient, who took eight rounds of IUI to become pregnant, expressed concern about being able to continue with IUIs after her pregnancy due to the financial and emotional costs. She said, "I would love to have more kids than this but financially and emotionally I don't know if it's worth it...especially if my prescription drug coverage is up...I don't know if it's something that I will go for" (Patient 3, urban, IUI, pregnant). Another patient had diminished ovarian reserve, forcing her to use IVF technologies. After a successful IVF procedure, which gave her a son, and two unsuccessful procedures, she and her husband decided to stop trying for another child due to the financial and emotional challenges.

I mean after you spend that much time, effort, and money going through that process so many times, and especially given the infertility diagnosis that I have, it comes to a point where you just have to accept the diagnosis and move forward (Patient 7, urban, IUI and IVF, 1 child).

This woman has reached a place of acceptance with her infertility after a success and multiple failures. For some women who have not had any success with fertility services, accepting their infertility is more difficult and continuing with treatment may be their only option.

Some patients reported that financial stress resulting from treatment and travel costs worsened their already fragile emotional states. One woman, who had multiple failed IVF cycles, reported struggling emotionally throughout the duration of her treatments. The failed IVF cycles were even more devastating and disappointing due to the amount of money that was invested without success.

I remember going in to see [Dr. X] and I asked if I could have a note for work and [Dr. X] said, 'why are you off work' and I said, 'because I just went to Calgary and I invested all that money to try to get pregnant and I'm not pregnant' (Patient 10, urban, IUI and IVF, no children).

Another patient, who has had five IUI cycles and is planning to avail of IVF, described her interpretation of the emotional cost of failed out-of-province IVF cycles.

I haven't gone to have IVF done, but I think if I did that and it was unsuccessful it would be very emotionally hard. It would be really stressful at that point and then having to decide to spend more money under more stress. I really think if the service was here it would save a lot of stress for people as well, it would do so much more than just save money (Patient 11, urban, IUI, no children).

Infertility and going through fertility treatments affected the women in this study not only financially, but also emotionally. The emotional costs of using fertility services

can often create additional challenges for patients making use of services that much more difficult.

These results represent patient experiences and opinions regarding the barriers to accessing fertility services in NL, but we must also consider the perspective of the service providers in order to have a more holistic view of the NL case.

5.0 Service Provider Study Results

5.1 Description of Sample Population

In this study, there were 11 fertility services staff members eligible to participate. Eight (72.7%) of the 11 completed interviews. The interviews lasted between 15 and 45 minutes. There were five nurses (62.5%) and three physicians (37.5%) that participated. Service providers had an average of 9 years of experience working at NLFS. Limited service provider information is given to maintain participant confidentiality.

5.2 Organization of Services

Based on our interviews, we were able to gather information about the history of the clinic and the organization of services. The fertility services program started being offered in NL in 1997. The program was initially quite small, with only one physician and one nurse, and operating out of the Grace Hospital. Over the years, the demand for the service increased, as did the number of staff, and the program continued to expand, eventually moving to the Women's Health Clinic in the Health Science Centre and then, with government funding, on to the Major's Path clinic in 2006. The Major's Path fertility clinic is currently the only one in NL, and therefore relies heavily on telemedicine and treating patients by distance to make service delivery available across the province.

Most service providers who were interviewed described the services that are and are not offered by the fertility clinic. They said that the clinic has never been able to offer IVF and related services, including female fertility preservation, ICSI, and frozen embryo transfers. Additionally, gamete donation and purchasing is not offered locally and the

psychology program is underdeveloped because the psychologist is shared with the women's health clinic. The service providers also noted that the clinic offers fertility assessment and diagnostic testing, tracking, medicated cycles, donor insemination, couple's IUI, sperm banking for medical reasons, and prenatal care for high-risk fertility patients.

Clinic staff also described how the clinic compensates for limited service provision by satelliting with other clinics to make IVF services more accessible to residents. Satelliting means that patients can have their tracking and monitoring for IVF done in St. John's, but they must travel to an IVF clinic out-of-province to actually receive the procedure. A service provider explained the role of NLFS in the treatment process for patients accessing IVF.

We unfortunately don't offer IVF to our patients, but we do refer them to clinics outside of the province and even outside of the country for IVF and donor egg, donor embryos, those type things. So we track those patients and help them with the referral process and then we follow up after their treatment, but we don't actually provide [IVF] to our patients here (Service provider 2).

This satelliting process helps patients because they do not need to leave the province for their entire treatment cycle, but rather just for the egg retrieval and IVF procedure. NLFS satellites with IVF clinics in Ottawa, Calgary, and Halifax, in particular.

5.3 Patients Groups and Therapeutic Goals

Staff reported that patients used fertility services to treat unexplained infertility, including inability to conceive or maintain a pregnancy, to preserve fertility, and to gain access to gametes. However, women and transgender men attempting to preserve their

fertility and people who are looking to access gametes face additional challenges because these services are not offered in NL and often not covered by provincial health insurance.

5.4 MCP and Provincial Coverage Variation

NL's provincial health insurance, MCP, covers most aspects of fertility services that are offered within the province, except for the IUI lab fee for sperm washing. IVF services used by patients outside NL are not covered. One service provider described the fertility services covered under MCP:

Everything else that we do here [besides medications] is covered under MCP like the ultrasounds, the blood work, the physician assessments, the nurse teaching - we have a nurse phone line - that's all covered. Patients when they're doing treatment cycles here will pay lab fees for sperm wash[ing] (Service provider 1).

This level of coverage, however, is not universal across Canada. There is variation between provinces, as many staff members noted. Some provinces fund IUI, a round of IVF, or offer tax credits, while other provinces do not even cover infertility investigations. A service provider described the situation of a patient who had Alberta health insurance and had to pay the clinic in St. John's for treatment that is covered under MCP.

We have a patient right now that is an evacuee from Fort McMurray, so she would have Alberta Health, not MCP, [and it] just made sense for her to come back here. She's in the middle of a cycle for IVF, so she needs some scanning done and we're happy to do that for her, but...some provinces don't cover that type of treatment (Service provider 2).

According to a service provider, NL is better off in terms of public health insurance coverage than some other provinces.

In Nova Scotia patients have to pay for investigations and things like that and when they start doing an IUI cycle they have to pay a lot more than you do in Newfoundland, because in Newfoundland the medical piece is covered but the lab

part is not. In Nova Scotia none of it is, so in Newfoundland we are better off than a lot of places for IVF or fertility treatment (Service provider 5).

In addition to the variation among provincial health insurance plans, there are also differences in coverage among private insurance providers and plans.

5.5 Variation in Private Coverage

Most private health insurance plans often offer some level of fertility drug coverage, however this is not always the case. Some patients at the clinic have little or no fertility drug coverage. A service provider who had been at the clinic for years described the differences in private insurance fertility drug coverage. She also mentioned that some insurance plans might cover some of the travel costs as well.

Some people [have] good drug plans, like the public service drug plan is about 80% coverage [for fertility drugs] I think. Like military may have 100% coverage, but other people may have zero coverage in their health plans for their fertility drugs... Some people have some travel allowance in their individual health plans where it says that you can have up to \$500 for travel for medical appointments. So we often provide notes to patients saying that we saw them on this day in clinic and they had to travel here because I guess they're using that to go back to their insurance and say I had to travel (Service provider 5)

Another service provider described the types of patients the clinic sees in terms of the level of drug coverage they have available through their insurance plans and what the level of coverage can mean for treatment.

I would think 60% of people have pretty good coverage. Another 20% probably have okay coverage, but there's a cap out amount, which is difficult for certain conditions where it requires a significant amount of [medication] and then what happens to a lot of our patients is sometimes they cap out before they even go to do IVF. Then there's a group of people who have no insurance, so people who just either they have the type of jobs where you don't have insurance or they're lower income and they actually don't have a lot of access to a lot of fertility treatments (Service provider 8).

Although there is coverage in many insurance plans for fertility drugs, there is usually not coverage for any fertility treatments. The exception to this, as reported by a provider at the clinic who has had discussions with patients about their insurance coverage, is some federal government employee insurance plans, such as the Royal Canadian Mounted Police (RCMP).

RCMP will cover IVF if it's the member's problem. So if you have a male member [with] low sperm counts for example they'll cover an IVF cycle for him, but if it's a problem with the female partner they won't cover the IVF cycle (Service provider 1).

Differences between insurance plans make fertility services easier from some patients to use than others due to the cost of treatment.

5.6 Types of Costs

There are a variety of costs that residents of NL must incur when accessing fertility services other than costs directly associated with treatment. Treatment costs are dependent on the type and amount of treatment, as well as the type and amount of medication prescribed. For example, one service provider addressed the cost of IVF and how it increases based on the drugs required for the procedure and the patient's condition, saying "An IVF cycle will cost you maybe in the neighbourhood of \$10,000, for the IVF cycle and a reasonable number of drugs...[however] the drugs are dependent on other circumstances, the drugs may be way more than that" (Service provider 6).

Another service provider described the cost of a frozen embryo transfer, which is cheaper than a full IVF procedure. The frozen embryo transfer is used to transfer a frozen embryo saved from a previous IVF cycle.

There is still the cost of going back and getting a transfer, but it's significantly less. You're just paying for the procedure, you're not paying for the drugs to stimulate, you're not paying for [an egg] retrieval, it's just the transfer, which I think is probably \$1,500/\$2,000, very affordable compared to the \$15,000 (Service provider 2).

The treatment and drug costs are often magnified by costs resulting from travel and its associated factors. Travelling for treatment often means paying for gas, rental cars, flights, accommodations, meals, and sometimes childcare, as well as losing time from work. The additional costs associated with travelling out-of-province for IVF were described by one service provider, who noted that these costs are somewhat unique to residents of NL.

The IVF cycle itself is going to cost money, the drugs are going to cost money depending on your coverage that you have with your drug plan, but then there's the travel on top of that. So it's extra punitive for our patients. In addition to that they have to be away for up to 2 weeks at a time. So they're off work, if you're self-employed you're not getting paid for those 2 weeks, and you have to find somewhere to stay, if you have friends or family excellent, if not you have to stay in a hotel for 2 weeks. That's going to be extremely costly as well. So these are all extra costs, essentially punitive costs, for choosing to live in Newfoundland (Service provider 7).

Another service provider described how not being able to offer IVF in the province impacts work loss for patients. If the treatments were available locally, patients would have to take much less time off from work.

[If] we were doing IVF treatments here they'd probably only need 2 or 3 days off work. To go to an IVF clinic away they have to take about two weeks off, and a lot of the employers are actually not that accepting of it. I've had some patients that have been forced to take vacation to actually do their IVF cycle because it's not deemed medically necessary (Service provider 8).

Both the direct and indirect costs of fertility treatment can be burdensome for patients. They often pay for treatment through multiple means in order to be able to afford it.

5.7 Methods of Payment and Financial Assistance

The clinic staff discussed a variety of ways that patients pay for treatment. Patients have paid out-of-pocket with a credit card, a line of credit or a loan, remortgaged their home, sold their car, accepted fundraised contributions or help from family and friends, used their private insurance coverage, and claimed their treatment and travel on their income tax return. A service provider mentioned that they have seen patients make decisions to fund their fertility treatment with enduring consequences. The provider said, “I’ve had patients of relatively low income that work with low-income jobs that take out debt and they’re in debt for [5 to 8] years to pay for what is essentially a recognized successful therapeutic intervention that’s just not covered” (Service provider 7).

The staff also described some of the conversations they have with patients about drug coverage, the cost of treatment, and their financial options. For example, one provider said that she tries to remind patients that the cost of having a child is much more than the cost of fertility drugs. She said she tells them “once [they] have a child the cost of having a child is probably not even comparable to the medication that would be prescribed if they were paying out-of-pocket, but it’s more of a perception and priorities” (Service provider 2). The same provider also discussed another conversation staff members have with patients related to their total budget for treatment and how their budget should influence their treatment decisions.

We have this conversation with our patients, ‘how much money are you [going to] use towards IUI? If you are using up your 10,000 [dollar insurance] cap for just IUI with a 10 to 15% chance of getting pregnant each month, if you put that towards IVF and now your success rate goes up to 50% and you may end up there anyways’. Lots of times when you present [it] to them that way patients will move quicker to IVF (Service provider 2).

Financial situations may often inhibit a patient’s ability to avail of a service, however clinic staff will still present all treatment options to the patient. One of the service providers described the conversation that clinic staff have with patients about IVF and that patients might not use the service due to financial situations.

We have a discussion regarding is ‘doing more of these insemination cycles a futile endeavour?’ ‘Do we need to move on to the gold standard treatment, *in vitro* fertilization?’ A lot of patients will say ‘that’s just not something that’s financially viable for us’ (Service provider 7).

Sometimes the staff may try to offer helpful tips to the patients. For example, a service provider mentioned that staff members tell patients to save receipts because they can claim the treatment on their income tax. The provider said, “We always tell [patients] going for *in vitro* fertilization to save [their] receipts because [they’re] able to use it as part of [their] medical expenses in [their] overall income tax and get some of the money back that way” (Service provider 4).

Clinic staff will usually discuss financial matters with patients if they are related to treatment, however the conversations do not probe too deeply into patients’ financial situations. One service provider mentioned that the staff will have discussions with patients about their drug coverage and give them an information sheet to use when they talk to their insurance providers. However, the provider prefaced this by saying that she tries to stay out of patient finances.

My role as a [service provider] is not to discuss finances. It's actually an uncomfortable job for [providers] to talk to people about their finances because our role is emotional support. So we don't often, well hardly ever, discuss things like that. We may tell patients to check with their social worker or check with their drug plan and we give them a patient information sheet on that to see what their coverage actually is, but what's actually covered [by insurance companies] I don't know because we've never been taught that or told that information (Service provider 5).

What is said and not said to patients with regards to finances seems to be somewhat dependent on the individual staff member and is not a clinic-wide policy, as some providers are more comfortable than others offering their opinions and advice.

5.8 Barriers to Accessing Fertility Services

When asked about the challenges patients face when using fertility services in NL, staff noted many different factors. Those most commonly mentioned were cost, geography, and service availability, while the nature of fertility services, partner separation, social stigma, and gender were also mentioned.

5.8.1 Cost.

Some staff noted that the majority of patients using fertility services seem to be from middle to upper socioeconomic class. One service provider said that income limited the extent of treatment patients could access. She said, "We do see some in a lower socioeconomic group but they can't go as far with treatments as some of the more affluent couples" (Service provider 1). She also noted that she thought people might not avail of services because they may not understand what is covered and they may believe they cannot afford them. Another service provider, while discussing the financial issues that some patients have, also mentioned that some people do not access service at all because they cannot afford it. She said, "There are all these other people out there that haven't

even gotten through our doors cause they know they're going to need help and they simply can't afford it" (Service provider 2). The cost of fertility services makes it difficult for many patients to afford the services, specifically those of lower socio-economic status.

5.8.2 Geography.

Besides financial circumstances, patients may also face challenges related to the distance they live from the fertility clinic. A service provider explained how geographical distance poses an issue for patients wishing to use fertility services because there is only one clinic in the province and patients must travel to receive treatment.

The biggest barrier to access truth be told is geographic because it's a sub-specialized service, this is the only fertility clinic in Newfoundland. We've got adequate physician staff and nursing staff here, but it's the only [clinic] in the province...anyone that needs our services oftentimes has to come here (Service provider 7).

Patients travelling to access service experience more challenges than those who live close to the clinic. For example, a provider discussed the additional challenges for patients that live outside of St. John's and surrounding areas, as they may miss multiple days from work each round of treatment.

I think it makes a big difference if you can just take a late lunch break and come on over to the clinic for your appointment and only miss a few minutes of work versus having to take the whole day. We hear from school teachers all the time [who] live all around the province, it's a big deal for them to take the whole day even though we provide them with a note and stuff because they may miss 2, 3, 4 or more days per cycle just for their fertility treatments. So it's a big commitment (Service provider 2).

For patients on the west coast of Newfoundland and from Labrador coming to St. John's for fertility care is a long and expensive trip. According to one service provider,

these patients might choose to do IVF in Halifax before coming to St. John's for IUI because the trips would be comparable.

This is the only clinic in the province so we have some patients that might be in Labrador, some patients that are in Port-aux-Basques, it's a long travel to come in to do an IUI cycle. Sometimes for example patients that are in Port-aux-Basques instead of travelling in here to do a cycle, like an IUI cycle, sometimes they opt to skip doing IUI's and go straight to doing an IVF and go to Halifax because it's almost closer in a way (Service provider 3).

The distance that patients live from the fertility clinic makes a difference in the amount of difficulty they have when trying to use the services. However, this is not the only challenge that patients must face related to distance, as patients wishing to use IVF services must leave the province to do so.

5.8.3 Lack of service availability.

The lack of IVF services in the province was also an issue cited by the clinic staff. Without IVF technologies, patients must travel to access all IVF related treatment; this includes female fertility preservation, frozen embryo transfers, and ICSI (a more advanced IVF procedure). One service provider said that the lack of IVF services means that patients in NL do not have access to the most effective fertility treatment available.

The lack of *in vitro* fertilization in the province [is] one of the biggest obstacles for fertility treatments because IVF truth be told is the gold standard for almost all forms of infertility whether it's male factor, tubal disease, reduced ovarian reserve, whatever the case may be, unexplained infertility, that is the gold standard for a lot of it (Service provider 7).

Another service provider discussed the impact of not having egg preservation services available in NL, which affects women specifically⁶. Due to this disadvantage, some staff viewed gender as a barrier to equitable access to service.

We rarely have any [cancer patients] that can actually avail [of fertility preservation] because when you're staring down the barrel of cancer it's kind of hard to take 2 weeks and go to another province and do egg freezing. So we've only had a couple people actually go and I think that's something that we often don't talk about in terms of not having an IVF clinic and what that means. I think not having IVF here is a real disservice to the women (Service provider 8).

Access to gametes is also limited in the province, as gamete donation and purchasing services are not available. One of the clinic staff mentioned that not having access to gametes locally makes services more expensive and less accessible to patients. She said, "If someone is using a sperm donor, that is about \$1,000 a cycle because they have to buy the sperm [and] get it shipped here because we don't have a sperm bank here for that type of donor sperm" (Service provider 1).

Not having certain services available in the province makes accessing these treatments more challenging for residents of NL than residents of most other provinces. Besides these three commonly cited barriers, there are some secondary challenges that also contribute to making fertility services difficult for patients to use. Some additional challenges worth noting are the nature of fertility services, partner separation, and the social stigma associated with infertility.

⁶ Cryopreservation for sperm is available in NL for medical reasons (e.g., if a patient has testicular cancer and would like to preserve sperm)

5.8.4 Nature of fertility services.

While some health programs offer travelling clinics in NL, the nature of fertility services prevents the provision of care across the province. The service is specialized with highly trained staff and equipment that is not portable, and patient cycles cannot be timed and scheduled. A service provider described the nature of fertility services and how that limits where services can be delivered.

The perinatal program do what's called travelling clinics. They go out and they visit and they see all their premature babies at 1 year old in Corner Brook. We can't really do that because we only have one lab that has very specialized people that do this work, they're all here. The equipment is all here, you can't take it on the truck and go...and people's cycles are very variable like you start people on fertility drugs and then on day 10 you bring them back in and you do an ultrasound, some of them are going to be ready, some of them aren't. So it's not an easily timed procedure, you can't just give someone an appointment for a particular day and stick with it. So it's not possible or feasible to do it as a mobile service, so people have to come to you [and] that's a big disadvantage (Service provider 5).

The nature of fertility services means that patients must travel to the fertility clinic in order to receive treatment.

5.8.5 Partner separation.

In NL, partners may often work out-of-province or in offshore oil drilling, which limits the amount of time a couple has together and their chances of becoming pregnant. It also makes timing cycles through fertility services more difficult. Many of the staff mentioned partners working away as a barrier to women becoming pregnant on their own, but also to accessing fertility services. Timing treatment with the partner being home and ovulation can be difficult. One service provider described “the issue of the

partner that works away” and how that prevents patients from being able to access services or achieve pregnancy through the use of fertility services.

There’s the issue of the partner that works away...sometimes both of them work away or the husband or the wife works in the oil patch or offshore and physically getting them [to the clinic] is hard. Then things are so dependent on their cycle and timing that they just can’t make it work (Service provider 2).

Another service provider mentioned that having partners working away from home prevents the staff from being able to schedule back-to-back cycles, which will prolong the process of trying to get pregnant. The provider said, “In Newfoundland we have a lot of people working away which impacts our ability to allow them to do continual [IUI] cycles” (Service provider 8). Partners who work away from home create additional challenges for those who wish to use fertility services, as service providers struggle to coordinate treatment plans that fit with their schedules. These challenges are exacerbated by the lack of cryopreservation services.

5.8.6 Social stigma.

The stigma surrounding infertility also makes it difficult for patients to avail of fertility services. Many people see infertility as a private matter and do not want others knowing that they are being treated through the fertility clinic. According to one service provider, some patients create their own barriers because of the social stigma.

People create their own barriers because they don’t want to tell somebody that they’re infertile or they’re having trouble getting pregnant. They don’t want to share that. So they probably aren’t going to tell their employer and so their employer thinks oh this person is taking a lot of sick leave they were just gone to St. John’s for the long weekend...So they’re often isolated in terms of support I guess. Sometimes their families don’t even know because they’re very private and don’t want to share. Even when people come into the clinic they’re afraid someone is going to see them from their community and they don’t want other people to know that they’re having trouble getting pregnant (Service provider 5).

Social stigma can worsen a patient's experience with infertility and fertility care, as they may feel that their condition is private. It is just one of the challenges that patients may face when being treated for infertility and is particularly relevant in a community-centric province, such as NL.

The challenges described above create both service provider and patient driven responses. The service provider responses will be described in the following section (5.9) and patient responses will be described in sections 5.10 and 5.11.

5.9 Service Provider Responses to Barriers

In NL, geography and service availability are relatively unique challenges associated with using fertility services and tend to exacerbate the financial burden. These factors often have an impact on how service providers treat their patients. Health care teams try to make the services as affordable and geographically close to patients as possible. Some of the ways in which they alter standard treatment plans are by changing drug protocols, manipulating ovulation, offering consultations by telemedicine, and minimizing clinic visits for patients.

5.9.1 Changing drug protocols.

Sometimes physicians will opt for a cheaper drug regimen to help patients who do not have insurance. For example, one service provider described what a conversation with a patient without insurance would look like and how they would alter that patient's drug protocol.

I will say, 'look you've got no insurance, let's maximize what we can do with the oral pills instead of just adding the injections that are way way more expensive'.

Maybe I'd push that a little bit further in a patient with no insurance than I would if she had the insurance I might have moved on quicker (Service provider 6).

Prescribing cheaper medication for a patient without insurance is not the only way that physicians may alter drug protocols. According to a service provider, physicians will prescribe different drugs to better accommodate a patient's specific coverage under their health insurance plan.

If [physicians] know somebody doesn't have drug coverage, [they] will try to change it to a drug that they actually have coverage for which may or may not impact on their success rate sometimes. [We] try to delay using injectable drugs if [we] can but sometimes that's not in the best interest of the patient, so if they can afford the injectable drugs [we] try to encourage it (Service provider 8).

Changing drug protocols in these ways to better suit a patient's financial situation and drug coverage helps make fertility treatment more affordable.

5.9.2 Manipulating ovulation.

Another way the clinic staff members make changes to a patient's treatment is by manipulating menstrual cycles. In situations where a patient or their partner works away from home, the clinic will try to ensure that the patient is ovulating at the same time that they or their partner are home and receiving treatment. This is done through the use of birth control pills. The process of timing fertility with birth control was described by one of the clinic staff.

For the women or men whose partners aren't working here we can use birth control pills and things like that to try to sync them up. So we do things to help manipulate the [woman's] cycle so they can actually be around each other when they're actually in a fertile period of time. So that involves a lot of nursing time and nursing conversation and timing things with the patient (Service provider 8).

Making sure that a patient is fertile while she and her partner are together is one way that treatment plans can be altered to optimize the chance for pregnancy.

5.9.3 Teleconsultations.

NLFS provides teleconsultations to compensate for geographical challenges and bring fertility care to rural and remote areas of the province, specifically central and western NL. One service provider explained how the clinic tries to make fertility services more accessible for patients across the province through telemedicine.

We're in the northeast Avalon and everybody else is a thousand kilometers or more away, so we've tried to make access better for patients by telemedicine. So we do some telehealth where we can do video conferencing and see patients that way (Service provider 5).

Another service provider mentioned that they were holding teleconsultations, rather than making patients travel to St. John's unnecessarily, on the same day as their interview.

We try to provide telemedicine appointments for patients that live far away. So that's where I was this afternoon I was actually doing a telemedicine clinic and I saw a variety of people from Labrador to Grand Falls [to] Corner Brook. So I saw people all across the province so that they don't have to come to St. John's just to see us because for most of it it's a history taking thing (Service provider 8).

Teleconsultations are another way that the fertility clinic alters traditional service delivery to minimize the challenges patients face due to geographical isolation.

5.9.4 Minimizing clinic visits.

Another way in which the clinic tries to make fertility services more accessible for patients in rural and remote regions is by working with health care teams across the province in order to minimize patient visits to St. John's when possible. They can offer blood tests instead of ultrasounds to these patients to determine whether or not the patient can begin a treatment cycle. For example, one service provider discussed how the clinic would handle a patient from Corner Brook. The patient would have blood work done in her hometown rather than driving across Newfoundland to St. John's for an ultrasound.

So if someone was in Corner Brook instead of coming here on day 3 for their ultrasound to start this treatment cycle, we'll do blood work in Corner Brook and have them fax that to us, so that's what we call that distance cycle so that's one way we can do it, it's not as good as seeing them here but it's an acceptable substitute (Service provider 1).

Another service provider explained how the blood work would indicate if there was a cyst and whether the patient could proceed with treatment, again noting that the blood work was not the best level of care in this situation.

What we do are distant [estradiol blood tests], so blood work that they can get done [close to home] and usually if the estradiol is low they don't have a cyst and they can start a cycle, but that's secondary care, that's not the gold standard. The gold standard is the ultrasound. So already we wonder is their cycle compromised because we're already starting out in less than ideal circumstances because physically the patient couldn't get in her car and drive 8 hours for a 15 minute appointment (Service provider 2).

Additionally, a service provider elaborated on this process and how "patients at a distance" differ from patients living east of Clarenville (within 150 or 200 km of the clinic).

"Patients at a distance" sometimes will do blood work instead of doing ultrasounds... What we're looking to see is that there isn't a cyst in the ovaries and you can check the estrogen in the blood to see that. Obviously the best test is to do an ultrasound, but if you live in Corner Brook or Labrador and it means one extra trip in here for that, we'll probably do a secondary test, which is a blood test, which is easy [and] you can get done in your hometown. So we do modify plans and we actually call those "patients at a distance" cycles and they are different than patients that live in the St. John's area or the greater St. John's area, you know like [Conception Bay South] and Carbonear and those areas, like all those patients anywhere really east of Clarenville would probably come in for those tests rather than have the blood test (Service provider 5).

Most of the clinic staff noted that the blood test was not as good as an ultrasound, but given the distance the patients would have to travel to get to the clinic, it sufficed as a substitute.

5.10 Impact on Patient Decision-Making.

The barriers to accessing fertility services not only affect how health care providers deliver care, but also impact patient treatment decisions. According to clinic staff, financial burden has the largest effect on patient decision-making. The cost of treatment and travel can affect patient treatment decisions in a number of ways, including patients choosing cheaper drugs, delaying IVF, not using IVF, opting to transfer multiple embryos, and stopping treatment.

5.10.1 Choosing cheaper drugs.

Patients may opt for cheaper drugs if they feel that they do not have the financial means to afford the more effective and expensive medications. One service provider described the situation of a patient who exhausted her drug coverage, could no longer afford medications that stimulate oocyte production, and was back to using oral medications for ovulation induction (oocyte release) even though the clinic staff thought it to be futile.

This one particular patient her insurance is gone, done. So she's gone back to using oral medication, she did not stimulate. She's had probably three or four blood draws now to check her estradiol [because] she lives out in central [Newfoundland], so [it's] not feasible for her to come [to St. John's] all the time [for an ultrasound]. We know there's no point [because] she's not stimulating at all for the oral meds. So there's really was no purpose in her doing a cycle at all, but she felt she needed to do something and she wanted to take the chance that maybe it would work and it did not (Service provider 2).

Without insurance, patients may not be able to afford medications that optimize their chance for a successful treatment cycle. Choosing cheaper drugs is just one way that patients try to minimize their treatment costs.

5.10.2 Delaying IVF.

Besides choosing cheaper drugs, patients may also choose to delay IVF treatment to avoid the cost associated with treatment and travel. Most commonly patients will choose to do IUI longer than clinic staff advises because it is cheaper. A service provider explained this situation where patients opt for additional cycles of IUI beyond what has been advised by their health care team because they consider it to be more affordable.

If we were in a province that had *in vitro* fertilization patients would probably do one to two cycles of insemination and then move very quickly to IVF. [Since] IVF is not offered here patients will often do many more cycles of insemination hoping that they're going to get pregnant and they won't have to foot the big bill of going for IVF and having to travel outside the province and all that kind of stuff. So they kind of stay in that first stage of care longer than they would in other provinces [that offer IVF] (Service provider 4).

5.10.3 Not using IVF.

Some patients cannot afford to use IVF services at all. Without IVF being available in NL, these services are out-of-reach financially and geographically to many of the province's residents. The clinic staff normally recommends that patients try IVF after six to eight cycles of IUI, however some patients do not consider IVF to be a financially feasible option.

What we do here if [a patient hasn't] gotten pregnant within six to eight cycles of IUI, in addition to the time they were trying to get pregnant on their own, it's unlikely to happen. So we have a discussion regarding is doing more of these insemination cycles a futile endeavour, do we need to move on to the gold standard treatment, *in vitro* fertilization, and a lot of patients will say that's just not something that's financially viable for [them] (Service provider 7).

5.10.3.1 Women with cancer are particularly affected.

Women who require fertility preservation after a cancer diagnosis are particularly affected by the lack of IVF in NL. This service provider described what a conversation

with a woman in this situation normally looks like. The provider tells them that they would have to travel, spend a substantial amount of money, and be away from their friends and family in order to preserve their fertility. Most women cannot handle all of this on top of their cancer diagnosis and therefore do not use the treatment.

I have this discussion with patients. [I] say, ‘yes, you know you’re dealing with [a] cancer diagnosis, you’ve been sent here to have a discussion regarding fertility preservation. Is there something we can do to preserve your fertility to help you have genetic offspring? Absolutely, yes there is. It’s of proven benefit, it’s been around for years...but it’s not covered by MCP. So you have to pay for it yourself [and] you have to do it in the next 2 weeks. So you need to scrounge up \$15,000 to do this within the next 2 weeks. Also, while you’re dealing with [a] new cancer diagnosis you’re going to get dragged away from your support system, if you have the money to do this. [You’re] going to fly away to the IVF clinic that’s out of province, where you don’t know anybody, don’t have any friends, don’t have any family, and you’re going through this stressful cancer diagnosis, stressful fertility treatments, and we’ll send you off to do that’. Most patients truth be told just don’t have it with them to do it, they can’t deal with all of that at the same time (Service provider 7).

Not having IVF in the province also means that patients are more likely to take extraordinary measures to try to ensure pregnancy if they leave the province to receive the treatment.

5.10.4 Opting to transfer multiple embryos.

The high cost associated with using fertility services makes patients more likely to transfer multiple embryos and risk multiple pregnancies because of their financial commitments. Health care teams will avoid transferring multiple embryos and over stimulating a patient in order to minimize the risk of a multiple pregnancy because multiple pregnancies can be dangerous for both the mother and foetuses. According to one service provider, some patients that go away for IVF will have multiple embryos transferred, even though most health care teams recommend transferring one embryo.

Usually as a rule of thumb [they] only transfer back one [embryo]. A lot of our patients will opt for two even though that's not the recommendation, but they feel like they've travelled, they put all this money into it, [and] it's hugely inconvenient to go back. So they're willing to take the risk of multiples, which is not really advisable, but I can see why the patients do that (Service provider 2).

Another service provider noted that if the service was available here patients might be more likely to transfer one embryo.

Oftentimes when patients would go away for IVF sometimes they would put in two embryos for example instead of one because it's not so easy for them to go back for a second IVF cycle because of the expense and geographics [sic] of it all... So then they would be at higher risk for having twins as opposed to if [IVF] was here then maybe they would have just transferred the one embryo (Service provider 3).

Additionally, a service provider said that clinics will recommend transferring one embryo to minimize the risk of multiple pregnancy, but that the patient has some say in the number that are transferred because they own the embryos. The provider noted that the financial investment pushes patients to choose more dangerous approaches.

The fertility clinic would say, 'listen we should put one embryo in here to minimize the risk of multiple pregnancy and the complications that are associated with that'...[but] the patient says, 'I want to put in as many embryos as you will put in'. Most clinics will say, 'the most we'll do is two', every now and then someone might put in three under extreme circumstances, but [the financial investment] does drive the patient to [take] a bit more of a riskier approach to things (Service provider 7).

5.10.5 Stopping treatment.

Another way in which patient treatment decisions are impacted by financial challenges is that sometimes patients will choose to stop treatment altogether. One service provider told the story of a couple from central Newfoundland who stopped doing fertility treatment because they had to choose between a kitchen renovation or continuing with treatment because they could not afford both.

We have one particular couple from central and they weren't on the same page. She was very keen to continue with treatment which was costly because they were using injectables for a long period of time to get a stimulation, but he actually said this: 'a \$10,000 renovation on the kitchen or continued [IUI] treatment'. They already have a child. His perception is that why are we putting money into something that's probably not going to work. The woman was very keen to just continue treatment, but he saw that there was a limited amount of money and [that they were] either going to do the renovation or [were] going to continue to try to have another child (Service provider 2).

Another service provider said that sometimes patients stop treatment because they cannot afford to take on more debt.

I've seen a lot of patients that have just kind of given up hope for it. A lot of people might already have some debt, whether it's home debt, vehicle debt, education debt, and they say 'can I afford to take on even more'. A lot of patients just say 'it's not something that's an option for us'. I see that not infrequently, they just give up on it (Service provider 7).

Cost is something that patients must consider before choosing to use fertility services, and at times may affect their treatment decisions, specifically preventing them from continuing with treatment.

5.11 Impact on Patient Well-Being

Patients are emotionally affected by their fertility care as well. They tend to experience grief, desperation, isolation, and often feel as though they are treated unfairly.

5.11.1 Grief.

Many staff members talked about the emotional cost of accessing fertility treatment and the resiliency of the patients. Fertility patients are faced with disappointment and grief with every failed treatment cycle. For example, a service provider described the resiliency of patients by telling the story of a specific patient who had multiple pregnancy losses and is still undergoing fertility treatment.

I'm amazed at how resilient some of these patients are...the extent that some of the patients are willing to go to have a family. I mean [I know a patient] that had a still birth...another loss at [5 months], and...other early miscarriages and she's still willing to go through the process. I mean tough as nails right, but it's hard to go through that emotionally. It's a huge time commitment, it's a huge financial commitment, but even more so it's a huge emotional commitment. My God the stuff that these women go through it's unreal (Service provider 7).

Another service provider compared infertility to cancer, saying that it is extremely difficult emotionally for patients and that they are willing to do what it takes to have a child.

A lot of people think if you can't have a baby it's not a big deal, but for some of these people it's no different than having cancer. I mean it is different, but emotionally it's a very difficult thing and if there was a treatment that you knew could possibly cure your cancer you'd probably take that expense and I think that that's the mindset of a lot of people (Service provider 8).

The patient experience of being treated for infertility is often emotionally difficult, as patients will experience a lot of stress, grief, and disappointment from rigorous and unsuccessful treatment cycles.

5.11.2 Desperation.

Due to the emotional and financial toll that fertility treatment takes, patients are more likely to make decisions out of desperation. One participant told the story of a patient from the west coast of Newfoundland who was receiving IUI treatments in St. John's and triggered herself (for ovulation) in order to speed up her treatment so she would be able to return home and to work sooner.

We always scan our patient before insemination to make sure if they've taken medication that they didn't over stimulate because we don't want to wind up with multiples. So we need to know how many follicles are there and [this] patient was feeling a lot of pressure to get her insemination done on the weekend and she came in for her ultrasound. She wasn't ready and we sent her to get blood work done and she came back tearful in a few minutes because she didn't let on in her

appointment that they wanted to get back home before Monday so she had gone ahead and triggered herself thinking that was going to speed it up. Well in fact what we were seeing on the ultrasound was that she had already ovulated. We didn't know she had done that. It didn't fit the whole picture, which is why we sent her for blood work. That's how desperate the patient felt, to take it upon herself to give a medication to herself, a needle an injection that was not ordered yet and ended up sabotaging an entire cycle (Service provider 2).

A service provider described a similar situation where a patient took more drugs than the health care team had prescribed, so they told her to not continue with the cycle to avoid multiple pregnancies. The patient triggered herself and had intercourse anyway hoping to get pregnant, which could have had serious consequences.

I know of one patient that gave herself more drug than we prescribed, we advised her against continuing with the cycle and against triggering herself to make herself ovulate and she should contracept when she does ovulate to avoid the risk of pregnancy, so she definitely took her own trigger shot when she went home and she had intercourse at home in the hopes of conceiving a pregnancy and that she could have easily had quadruplets out of that. At that point in time she says, 'I don't care if I have four babies, I just want a baby' (Service provider 7).

Many fertility patients experience this desperation for successful treatment, especially after multiple failed treatment cycles, which can have a serious impact on patient well-being.

5.11.3 Isolation.

Patients may also feel isolated during their treatment. For example, one service provider described how sending patients away for IVF is emotionally draining because the patients are separated from their support systems.

You're taking [IVF patients] out of their environment. So they're not around their circle of support and so psychologically it can be pretty draining for those patients. It's very isolating because they have to leave their family and all their friends to go do IVF (Service provider 8).

This separation from social support systems is emotionally costly for patients that must leave the province to avail of IVF and makes fertility treatments even more difficult.

5.11.4 Injustice.

Patients and service providers often feel that it is unfair that patients have to pay to use fertility services. According to a service provider, patients are penalized financially for their infertility.

If you're infertile you're penalized [because] you have to financially pay to grow your family... if you viewed it as a medical problem and the only treatment or cure was a baby then why isn't it covered (Service provider 2).

Another service provider at the clinic compared infertility to smoking, saying that smokers choose to smoke and their treatment is covered, but people who are infertile do not choose to be and have to pay for treatment. The provider then compared infertility treatment to hip replacements, as both are related to quality of life, questioning why patients do not pay for hip replacements, but pay for infertility treatment.

You can smoke all your life and have your third heart surgery and it's covered, but through no fault of your own you just don't get pregnant and don't have babies and that's singled out as something that's not covered. Then when they say well it's not life threatening. Well then neither is a bad hip, but the prosthesis is something like \$6,000 and of course you're going to need another one. So that's [\$12,000] and that's just the piece of hardware that's not the surgery or anything else. So I mean when you're trying to cover something that's a quality of life situation as opposed to life threatening...[Having children is] an innate right (Service provider 6).

The specific issues IVF access, both financially and geographically, were also considered to be unfair for patients. One participant noted this lack of fairness in terms of not having access to IVF in NL and having to pay for it out-of-pocket.

Not having access to a treatment that is proven to be of benefit to patients, of proven success for patients, and to have to pay out-of-pocket for that and not have

access to it in your own province with your own support network is really unfair (Service provider 7).

Service providers and patients both felt as though fertility services should be considered medically necessary and covered under provincial health plans, as the financial burden has a serious impact on patient quality of life.

The challenges that patients face when accessing fertility services have an effect on patient well-being and treatment decisions, as shown through the service provider interviews. They also affect how patients are treated from the perspective of the health care team. These barriers to service access create immediate challenges for patients, but also have a long-lasting impact in other areas of their lives.

6.0 Discussion

In NL, accessing fertility services presents unique challenges for the province's residents. This project used interviews with patients and service providers to explore the barriers that patients face when using fertility services in NL and how these barriers impact treatment decisions.

6.1 Overview of Conceptual Framework

Through the interviews, a conceptual model emerged that describes the combination of three factors: patient groups, therapeutic goals, and barriers (Figure 6.1). These factors collectively influence the impact on fertility treatment. The model explains how different patient groups, when seeking specific therapeutic goals, will experience different types of barriers that contribute to decisions about treatment.

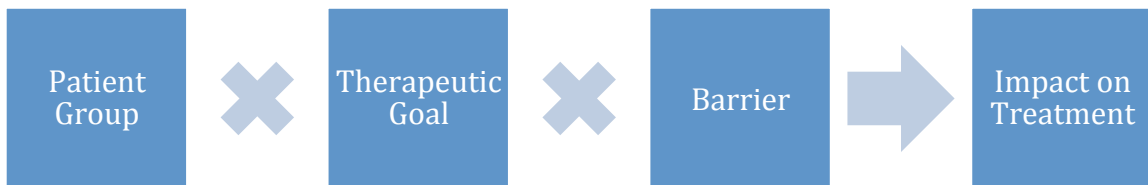


Figure 6.1. General model for conceptual framework demonstrating the relationship between patient group, therapeutic goal, barriers, and impact on treatment.

This figure illustrates the relationship between barriers, patient groups, therapeutic goals, and impacts on treatment. Although there were a number of barriers, patient groups, therapeutic goals, and impacts identified, this thesis largely explored barriers and impacts for heterosexual women (in couples) looking to become pregnant

(Figure 6.2). However, the data also identified other patient groups, alternate therapeutic goals, and barriers that may be relevant to only these patient groups or goals. A specific example based on this model is as follows: a heterosexual couple whose therapeutic goal is to become pregnant may face financial barriers that may force them to stop fertility treatment.

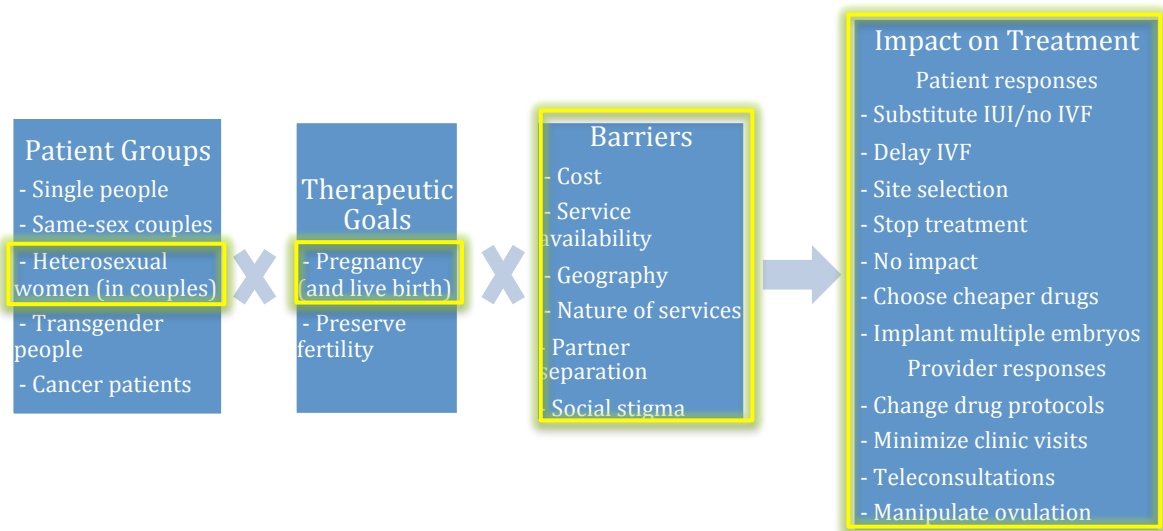


Figure 6.2. Conceptual framework demonstrating the relationship between barriers to accessing fertility treatment and impacts on treatment for heterosexual women (in couples) looking to become pregnant.

This figure illustrates the factors that were discussed and focused on in this research. This is a comprehensive list of barriers and impacts for heterosexual women (in couples) with the goal of having a baby, however the barriers and treatment impacts for other patient groups with other therapeutic goals have not been explored in this research.

6.2 Patient Groups

Although heterosexual women (in couples) unable to achieve or maintain a pregnancy were the main patient group examined in this project, other groups were also identified including single women, same-sex couples, cancer patients, and transgender individuals. Many studies currently frame infertility from the perspective of heterosexual couples (Bushnik et al., 2012; Collins et al., 1997; Gurunath et al., 2011) and neglect these other patient groups. The World Health Organization also defines infertility in a heteronormative manner, as a period of time in which a woman having regular unprotected sex fails to become pregnant (Zegers-Hochschild et al., 2009). Jin and Dasgupta (2016) reviewed fertility centre websites and found that patient education was heavily focused towards heterosexual couples and did not provide similar information for Lesbian, Gay, Bisexual, and Transgender (LGBT) couples or individuals.

Some recent studies have begun to examine infertility from the perspective of other patient groups; in particular, cancer patients looking to preserve their fertility have been the focus of recent studies. Yee (2016) surveyed 188 Canadian women between the ages of 18-39 who had been through cancer treatment. The study found that 76% of patients had discussions with their oncologists regarding fertility preservation, 26% of the women consulted a fertility specialist, and 9% underwent fertility preservation. For transgender patients, fertility preservation services seem to be underutilized, especially for female-to-male patients (Jones, Reiter, & Greenblatt, 2016), who must undergo more expensive and invasive procedures.

Even though research is beginning to consider other patient groups using fertility services, these groups are still generally overlooked when discussing infertility and associated issues. Examining infertility, prevalence, and fertility service uptake among the many patient groups identified in this study should be an area for future research and will hopefully continue to broaden the health and research communities' ideas of infertility.

6.3 Therapeutic Goals

Therapeutic goals also determine how barriers affect treatment. Patients and providers described two main reasons for patients using fertility services: to become pregnant and to preserve fertility. These reasons for treatment are similar to those reported in the literature, as multiple studies discuss patients looking to become pregnant (Domar & Gordon, 2011; Veltman-Verhulst et al., 2016) and preserve their fertility (Jones et al., 2016; Yee, 2016). These therapeutic goals, along with barriers to accessing treatment and patient group, create varying impacts on treatment decisions from both the provider and patient perspectives. The impacts that were uncovered in this research are based on the barriers faced by heterosexual women (in couples) with the goal of having a baby from the perspective of female patients and service providers. Further research should explore the barriers associated with these alternative therapeutic goals, such as fertility preservation, for other patient groups.

6.4 Barriers to Treatment

Patients and service providers similarly described barriers to treatment. Both groups reported costs associated with accessing fertility services, geography, lack of

service availability, and the nature of fertility services as challenges that patients face when being treated for infertility. As stated in the study expectations, patients faced financial and geographical challenges that affected their ability to access fertility services. In addition, interview participants described additional factors, like stigma and partner separation, that we had not anticipated.

6.4.1 Costs.

Costs were generally described in financial terms, however there were other costs uncovered through this study, including opportunity and emotional costs. Financial costs are straightforward, monetary payments for treatment received. Opportunity costs are lost opportunities due to time or money needed for treatment. Emotional costs are related to the emotional burden of infertility and undergoing fertility treatment.

6.4.1.1 Financial.

Financial costs were most commonly cited by patients and service providers. These costs included treatment, drugs, travel, accommodations, and loss of pay from time off work. The financial costs described did not vary between patient and provider groups. These financial challenges are well documented throughout infertility literature, as patients have cited treatment costs (Akyuz & Sever, 2009; McDowell & Murray, 2011), drug costs (Makuch et al., 2011), travel costs, and loss of income (Redshaw et al., 2007) as barriers to accessing treatment. The costs reported in this study by patients and providers were also similar to those reported by cancer patients in NL in Mathews, Buehler, and West (2009) and Mathews, West, and Buehler (2009), as both studies found travel, lodging, drugs, and loss of income to impact financial costs. Rural cancer

survivors from northern British Columbia experienced difficulty accessing medical and support services due to travel and the associated costs (Fuchsia Howard et al., 2014). When hemodialysis patients did not have to travel for treatment and were able to receive treatment in their own communities, they had lower overall costs, better outcomes, and higher quality of life (Diamant et al., 2010). In general, travel related costs created challenges for many different patients.

Service providers thought that patients of low socioeconomic status were particularly affected by cost, as they would not seek out fertility services at all. Providers based this observation on the majority of their patients being middle to upper class. This corresponds with the literature, as Jain and Hornstein (2005) found patients using fertility services had higher incomes. Financial costs are one of the biggest challenges facing infertile people in NL.

6.4.1.2 Opportunity.

Patients and service providers both discussed the loss of vacation time and sick leave for patients attending multiple appointments and traveling for care. They also described patients choosing to pay for treatment instead of going on trips or home renovations. Both groups noted the sacrifice of opportunities made by fertility patients. Redshaw et al. (2007) also reported the loss of vacation time for medical appointments and treatment among fertility patients in the UK. Mathews, Buehler, and West (2009) discussed the loss of sick leave that cancer patients face for their treatment, however it was mentioned in the context of income loss and financial costs, rather than an opportunity cost. Although lost opportunities might not be the most obvious cost of using

fertility services, they have a large impact on a patient's experience with infertility and fertility care. Future research should examine the multitude of opportunity costs patients undertake when availing of fertility treatment.

6.4.1.3 Emotional.

The emotional costs of infertility and fertility treatment were described somewhat differently by patients and service providers. Even though the emotional costs were not directly explored with patients, they mentioned feeling depressed, disappointed, and stressed. Providers noted that patients experienced grief, desperation, isolation, injustice, and stigma. The sadness, disappointment, and stress that patients felt were described similarly by service providers. However, service providers discussed the emotional aspects of fertility treatment more objectively, addressing many more areas. This may be in part due to the patients who came forward, as there would be participant selection bias; that is, patient participants had likely overcome difficulties related to social stigma and therefore did not report this as a challenge. Additionally, service providers were more likely to discuss the desperate acts of patients, like triggering ovulation after being advised against doing so, because patients would not want to report a socially undesirable response.

These emotional costs, including stress and disappointment (McDowell & Murray, 2011; Redshaw et al., 2007), are largely supported in the literature. Domar and Gordon (2011) surveyed couples that had difficulty getting pregnant to determine the emotional impact of infertility. They found that women who received hormone injections often reported being upset about failed treatment and having anxiety throughout their

treatment, demonstrating the impact fertility drugs have on patient emotional well-being. Women also mentioned feeling flawed as a result of their inability to conceive. Many respondents disclosed that they often felt frustrated and impatient and that they hid their diagnosis from family and friends. Holley et al. (2015) found that of 174 women being treated for infertility, 39% of them had major depressive disorders. Infertility and undergoing fertility treatment is a highly emotional experience, as shown by patients, providers, and the literature.

6.4.2 Geography.

Patients travelling from farther than 50 km away had geographical challenges that exacerbated the financial burden associated with treatment. At times these patients would face greater costs because they were more likely to leave the province for IVF, especially if they were from the west coast of Newfoundland. Patients from the west coast would be more likely to leave the province for IVF treatment because the distance and cost of travelling out-of-province would be comparable to travelling to St. John's for treatment. However, patients from around St. John's (living within 50 km of the fertility clinic) who left the province for IVF would face similar financial challenges to those using IVF from other areas of the province.

Previous studies have corroborated these results and found that income (Jain & Hornstein, 2005), factors impacting cost (e.g., travelling for treatment) and geography (Mathews, West, & Buehler, 2009; Redshaw et al., 2007) prevent access to a variety of health services. Rural residents, those without insurance, and those with low income reported that the costs associated with treatment and travel were more likely to impact

treatment decisions (Mathews, West, & Buehler, 2009). Living outside of St. John's and surrounding areas created challenges for fertility patients in NL, as they were forced to travel great distances for treatment and take on additional costs. The unique challenges that geography presents for fertility care in NL are largely determined by the nature of these services, which is further discussed in section 6.4.4.

6.4.3 Lack of service availability.

The lack of IVF related services available in NL posed a great challenge for patients, especially because of the isolation of the province. Women in the UK who sought infertility care reported having difficulty availing of services due the lack of locally available treatment and the costs associated with travelling for treatment (Redshaw et al., 2007). In a Canadian study looking at rural parturient women in British Columbia, the women reported geographic isolation, inavailability of local health services, and cost of travelling to give birth as challenges and realities that they face when they are pregnant and about to deliver (Kornelsen & Grzybowski, 2006). These challenges are similar to those described by participants in this study, as patients had to leave a geographically isolated province to access IVF services.

6.4.4 Nature of services.

The nature of fertility services makes availing of treatment more difficult for NL fertility patients than for many other patients in the province because patients must be treated at NLFS in St. John's. Unlike the perinatal program, which does travelling clinics, fertility services are not portable and patients must travel to the clinic for treatment. Even though NLFS uses teleconsultations for history-taking appointments, patients must come

in to St. John's for their actual treatment. In contrast, psychiatry can manage all treatments through telemedicine appointments (Elford et al., 2001). Additionally, alternative providers close to home cannot be used, as they are for follow-up care for oncology (Mathews, Buehler, & West, 2009), because fertility service providers are highly trained to provide this sub-specialized treatment. Finally, fertility treatment must be carefully managed and timed in order to maximize the chances for conception, which creates further challenges for patients, as treatment cycles are easily compromised. According to patients and providers, these factors often made accessing services challenging for patients and contributed to treatment costs.

6.4.5 Physical environment.

Participants in both studies mentioned the physical environment, specifically the winter weather, as a barrier to accessing fertility treatment. Patients would have to come into St. John's early and take on additional costs for accommodations if a snowstorm was forecast, so that they would not compromise their treatment and be able to complete their treatment cycle. The weather creating challenges for patients has been reported by cancer patients in northern Ontario (Lightfoot et al., 2005).

6.4.6 Partner separation.

Partner separation was another barrier described by patients and providers. However, providers discussed this more frequently because of their experience with a variety of patients and circumstances. In NL, it is not uncommon for partners to work out-of-province, most commonly in the oil sands of Alberta or offshore oil drilling, due to high unemployment rates in the province (Schmidt, 2014). Patients and providers often

tried to alter treatment in order to compensate for partner separation, which increased the financial costs associated with treatment and could have contributed to failed or cancelled treatment cycles and ensuing stress.

6.4.7 Social stigma.

The social stigma associated with infertility and using fertility services was primarily discussed by service providers. This was likely a result of providers being able to draw from their knowledge of many patient experiences and patients who felt stigmatized being less likely to come forward for an interview. The stigma associated with infertility and the stress this stigma causes is well documented in the literature (Whiteford & Gonzalez, 1995). Stigma has been proven to increase fertility-related distress and patient perceptions of low social support, which increases overall stress (Slade, O'Neill, Simpson, & Lashen, 2007). While social stigma may not be an obvious challenge that patients encounter (like financial costs), it contributes heavily to the emotional costs of accessing fertility treatment.

6.5 Impact on Treatment

Patients and service providers both described the impacts of barriers on treatment for heterosexual women (in couples) looking to conceive. As we expected, both patients and providers reported that patients' financial and geographic situations affected treatment decisions, and therefore the impacts on treatment can be separated into patient and provider-driven responses.

6.5.1 Patient driven responses.

A patient driven response results from a specific barrier that a patient has encountered, and is something that the patient has the ability to control with regard to their treatment. Patients often reported barriers affecting where they chose to undergo treatment, for how long they chose to be treated, and the type of treatment they used. Patients and service providers differed slightly in their identification of patient-driven responses to treatment barriers. Both groups mentioned that patients would stop treatment due to financial and emotional challenges. Additionally, patients would substitute IUI for IVF or avoid IVF when they could not afford the treatment. Patients noted that financial challenges impacted their decision on the location of their treatment, limited family size, and some patients said that the financial challenges had no impact on their treatment decisions. Service providers reported that patients would choose cheaper (and sometimes less effective) drugs, delay using IVF, and opt to transfer multiple embryos.

Financial and emotional costs causing patients to end treatment was also found in the infertility literature. Patients reported exhausting financial resources and enduring high levels of emotional stress, which lead to their decision to end their treatment (Akyuz & Sever, 2009; McDowell and Murray, 2011). Some of these patient impacts on treatment decisions were corroborated by a NL study on cancer care (Mathews, Buehler, & West, 2009). Service providers reported that cancer patients will substitute or ration medications, choose radical treatments, lengthen the time between follow-up appointments, and choose inpatient care (Mathews, Buehler, & West, 2009) to ease financial burden. Fertility patients choosing cheaper drugs and opting to transfer multiple

embryos may be seen as comparable to cancer patients substituting/rationing medications and choosing radical treatments, respectively.

Even though patients may make the final decisions on their treatment, oftentimes they make these decisions with the help of service providers. The service providers also work to make treatment more affordable and geographically close to patients when possible.

6.5.2 Provider driven responses.

A provider driven response results from the same barriers as the patient driven response, however it is an aspect of patient care that the provider has the ability to control to make treatment more accessible to their patients. Providers noted that they would try to alter care systematically when possible; for example, by making certain aspects of care closer for patients from rural areas and changing drug protocols. Although patients and providers have power over different aspects of the treatment process, oftentimes when it comes to making treatment decisions both groups make these decisions together.

Provider-driven responses were mainly identified by service providers, although patients did note some treatment decisions that were strongly influenced by providers. Patients and providers mentioned that providers would encourage patients to use IUI before IVF and allow them to continue using IUI beyond the recommended number of cycles.

Providers also reported that they changed drug protocols, manipulated ovulation to time fertile periods, used teleconsultations, and minimized patient clinic visits. Technology was used as an alternative to face-to-face care, as seen by the use of teleconsultations, when necessary and if possible. In Newfoundland, telemedicine has been useful in

reducing medical-related travel costs, especially for specialized services (Elford et al., 2001). For example, telepsychiatry was found to have high patient satisfaction and to be useful in reducing costs resulting from travel (Elford et al., 2001). However, in this study, telemedicine could not entirely replace the need for in person care during the fertility care process, as it has done for psychiatry.

These provider-driven responses are somewhat similar to those found in the Mathews, Buehler, and West (2009) study on cancer care in NL. Providers tried to help cancer patients minimize out-of-pocket costs by changing drug prescriptions, admitting patients to hospital, shortening radiation treatments, arranging follow-up appointments close to home, and changing appointment schedules. The provider-driven responses described here overlap with our study, as both included changing prescriptions and adapting appointments (by minimizing visits to the clinic and using teleconsultations in this study). We were not able to find any similar studies that were IVF focused.

The patient and provider reported impacts vary as one would expect based on perspective and what the groups perceive to control. Providers focused on how services are delivered, while patients discussed the logistics surrounding treatment. Providers were also more likely to mention aspects that patients may have been uncomfortable discussing, such as choosing cheaper drugs and opting to transfer multiple embryos. As previously noted, many of the treatment decisions are made together and the patient and provider-driven responses overlap heavily.

The quality of patient care, and at times patient safety, when patients neglected to follow provider recommendations, was compromised as a result of the barriers patients

encountered. Overall, the barriers to treatment and their impact on treatment decisions were found to affect patient care.

6.6 Mitigation Strategies for Financial Costs

As a result of financial barriers, patients would look for a variety of ways to help fund their fertility treatments.

6.6.1 Methods of payment and facilitators to treatment.

Patients and service providers cited many of the same methods of payment for treatment and travel. These include out-of-pocket methods like credit card and lines-of-credit, funds from family and friends, and private insurance. There is little in the literature about methods of payment, however few patients reported having family members offer to help them pay for fertility treatment (Domar & Gordon, 2011) and many cited out-of-pocket payments (Wu, Odisho, Washington, Katz, & Smith, 2014).

Facilitators to accessing treatment were more heavily focused on by patients, however were also mentioned by service providers. Patients noted that affording treatment was made easier by proximity to services, wealth, MCP coverage, low lab fees, claiming their treatment and travel on their income tax, and family and friend monetary and in kind contributions. Service providers also mentioned patient wealth, MCP coverage, claiming treatment on income tax, and family and friend contributions as factors that made it easier for patients to avail of treatment. A few of these facilitators were corroborated by the literature, including family contributions (Domar & Gordon, 2011) and wealth (Jain & Hornstein, 2005).

These facilitators largely focus on financial aspects and do not consider other barriers. This is likely because of how the interview questions were posed and the study being framed around costs. Future studies could look to identify ways to address other non-cost related facilitators to fertility treatment in order to potentially improve patient experiences.

6.6.2 Knowledge and information about costs.

Many patients would look to blogs and clinic websites for information about cost and rarely received information about cost directly from their service provider. There was a lack of understanding among patients and providers about what is covered and not covered by MCP and private insurances. This could impact patient treatment decisions, as patient comprehension of information has been shown to improve compliance with provider recommendations and treatment outcomes (Simpson et al., 1991).

The literature largely supports these findings of under-informed patients, as multiple studies have demonstrated poor patient education in fertility care. Patient-centredness, including the quality of information that patients receive about their fertility treatment (van Empel et al., 2010), has been largely overlooked (van Empel, Nelen, Hermens, & Kremer, 2008). Additionally, Mourad et al. (2009) found that Dutch fertility patients believed information provision to be an important part of their care. However, many were not properly informed according to national standards and did not receive enough information about their diagnosis, causes of their condition, and the risks associated with treatment. Patient education specifically related to fertility treatment costs seems to be an area that is overlooked in the literature. Future studies should explore

patient knowledge surrounding treatment cost, insurance coverage, and financial assistance to improve information provision for fertility patients.

Based on these findings, NLFS should consider hiring an employee, such as a social worker, who is specifically trained to have conversations and provide direction about cost, MCP and private insurance coverage, and financial assistance opportunities. More thorough discussions could help patients with making informed decisions. Given the significant costs associated with accessing fertility care, NLFS should provide more information about managing costs.

6.7 The Right to Reproduce and Injustice

Both fertility patients and service providers consider fertility services to be medically necessary, which is the basis for their perspectives. They believe that not having public insurance coverage for these services is a form of inequality. There was a lot of discussion in the interviews about fairness and the right to reproduce. Service providers and patients claimed that being able to have biological children was an innate right and infertility treatment should be considered medically necessary in NL.

This perceived injustice can be linked to critical theory. Critical theory examines the relationship between political, economic, social, and cultural factors to gain insight into the reasons for inequality (Buchanan, 2010). This is relevant to fertility service access because policy-makers, government, and physicians decide what services MCP covers as per the *Canada Health Act*. These groups have power and are making decisions for the general population, often not considering the needs of specific or minority populations. This introduces a power dynamic and oppresses patients using fertility

services.

The patients' and providers' beliefs that there is a right to reproduce and that fertility services should be deemed medically necessary are likely influenced, to some extent, by social constructs, such as motherhood and biological parenting. As previously discussed, women often feel social pressure to be mothers (Staikou, 2014) and experience greater stress than men from infertility (Newton et al., 1999). Furthering this point, there is often pressure to be a biological parent, as society defines parenthood in terms of biology. These social constructs create ideas among patients and providers about what is fair and what is a right based on what is socially "normal".

Taking all of this into account, it should be acknowledged that how infertility is defined frames what policy options are considered. Defining infertility as a disease creates a stronger argument to include fertility treatment as medically necessary under the *Canada Health Act* (Picard, 2011). However, those who believe Medicare (or more specifically in NL, MCP) should cover fertility services are generally those who will benefit from this coverage. Providers benefit from expanding the number of billable services and patients benefit from not having to pay out-of-pocket for the service. However, where provinces (e.g., Ontario and Québec) have insured fertility treatments, they have used public insurance as a means to regulate services, by specifying the conditions under which billing Medicare is allowed, for example by limiting the number of embryos that can be transferred, establishing age limits for eligibility, or limiting number of insurable IVF attempts (Picard, 2011).

The lack of comprehensive public health insurance coverage for fertility services,

particularly in NL, creates access inequality in the provincial health care system. Policy-makers and others at the forefront of change for social justice issues should begin to reconsider what they believe to be “medically necessary”.

6.8 Strengths

6.8.1 Study design.

This project had many strengths. We began by pretesting the interview questions to ensure that the questions were posed in the best way possible and by training the interviewer to ensure professionalism (Berg, 1995). We described the methods in detail to make the study transferable (Cope, 2014; Green & Thorogood, 2009). We also used triangulation within the study by interviewing both patients and service providers and with the literature by comparing study results to the literature. The similarities between patient and service provider interviews, specifically in terms of the challenges patients face when accessing fertility services and how these challenges impact treatment decisions, add credibility to the results of this research.

6.8.2 Data collection and analysis.

All patient interviews were done by phone and all provider interviews were done in person, while both groups were given the choice on interview method, the uniformity within each group makes each study internally consistent. The patient and provider studies were treated independently with their own interview guides, coding templates, and results. Additionally, all interviews were recorded, transcribed, and coded independently to maximize dependability and confirmability (Cope, 2014; Green &

Thorogood, 2009). Furthermore, we reported negative cases, such as patients not perceiving cost as a barrier, to maximize credibility (Cope, 2014).

This project combines information from first hand patient experiences with perspectives of providers who were able to draw from a range of patient experiences. Finally, this project identifies areas for future research and is the first of its kind in NL, which is a unique case.

6.9 Weaknesses

6.9.1 Recruitment.

There were also weaknesses to this research. First, there was a limited time frame for recruitment, which impacted the number of interviews we were able to conduct. The majority of recruiting of patient participants was done through Facebook, which means that many of the people targeted by recruitment were regular Internet and social media users. Posters were put up in NLFS late in the recruitment period, which meant that few responses could have been a result of the posters. Also, patients who chose to participate were more open about their infertility and often not actively seeking treatment, possibly because those who were undergoing treatment were faced with too much emotional stress to participate.

Furthermore, we had a limited sampling population. Patient participants were only from Newfoundland and none were from Labrador. Also, despite efforts to recruit more broadly only three patients were from rural areas of Newfoundland and the remaining eight patients lived within 50 km of the fertility clinic. In the future, studies should try to

have a more comprehensive sample, including more patients from rural and remote regions of the province.

6.9.2 Data collection.

Recall bias may have been an issue because participants may not remember an event or details exactly how they happened (El-Masri, 2013). As time passes, memories can change and be influenced by external factors. Oftentimes, people better remember significant life events. In this case, those who had a more difficult experience with fertility services may have remembered more than those who got pregnant more quickly or with less treatment.

Bias responses to interview questions may have affected the data, as participants would look to provide responses to questions that they expect to be socially acceptable (Furnham, 1986), such as not disclosing that they may not have followed service provider health or treatment recommendations. Patients and providers also tried at times to direct the research and interview with their responses, which meant that interview questions were not answered as well as they could have been.

It was also clear through the interviewing process that patients were interested in discussing the emotional costs of fertility treatment and service providers often mentioned the resilience of their patients. However, exploring these ideas was beyond the scope of this project. Future studies should look at the emotional impact of infertility and patient resilience throughout their journey.

Finally, it is important to note that these study results may not be transferable to populations or health systems outside of NL due to the unique health care system in the province.

7.0 Conclusion

This project explored the barriers that residents of NL face when accessing fertility services and how these barriers impact treatment decisions. Eleven interviews were conducted with female fertility patients from across Newfoundland and eight interviews were conducted with service providers from NLFS to gather the perspectives of both patients and providers.

Based on this research, we developed a conceptual framework. The framework considers patient group, therapeutic goal, and barriers when determining how treatment is impacted. This project in particular explored the barriers that heterosexual women (in couples) looking to have a baby experienced when accessing fertility services from the viewpoints of female patients and service providers and how all of these factors impacted treatment. The framework can be used to conceptualize and conduct studies to examine how alternate patient groups with different therapeutic goals experience barriers and their impact on treatment.

For heterosexual women (in couples) seeking to become pregnant, the most frequently described barriers were costs, including financial, opportunity, and emotional, geography, lack of service availability, the nature of services, partner separation, and social stigma. Both patient and provider-driven responses to barriers were reported to have impacts on treatment decisions. Patient-driven responses included delaying IVF, substituting IUI for IVF, choosing a specific location for treatment, stopping treatment, choosing cheaper drugs, and opting to transfer multiple embryos. Provider-driven

responses included changing drug protocols, minimizing clinic visits, using teleconsultations, and manipulating ovulation.

Although health and social service access issues are common for rural residents (Fuchsia Howard et al., 2014; Kornelsen & Grzybowski, 2006), fertility services present a unique set of challenges for NL residents. Many specialized and sub-specialized services can be made more accessible to patients through technology (e.g., teleneurology, telepsychiatry, etc.), alternative providers (e.g., primary care, follow-up care for oncology, etc.), or visiting clinics (e.g., perinatal program, oncology, etc.). However, fertility services require that patients be treated in-person; only initial history counseling and blood work can be done by distance. Fertility service requires the expertise of sub-specialists to provide treatment. The lab equipment is not portable, making mobile units unviable. Finally, there is a limited, individualized, and somewhat unpredictable period when conception can occur, ova can be harvested or embryos can be transferred. Even small delays can render a cycle of treatment useless, especially given the unavailability of gamete preservation services in NL. As a result, and unlike most other types of care, fertility services require that patients attend in person, in an urban center, and be available on multiple and often unpredictable visits over the course of their treatment.

In addition to resources to pay for financial costs, information and knowledge were important facilitators to accessing fertility services. However, few patients were well informed on factors influencing the cost of treatment. MCP coverage was also a key financial facilitator for patients and was framed as a social justice issue by patients and

providers, who believed that these services should be more comprehensively covered under the provincial health plan.

The following recommendations could help to make fertility services more accessible to NL residents. The clinic should consider hiring an employee, such as a social worker, who is specifically trained to have conversations and provide information about cost, MCP and private insurance coverage, and financial assistance opportunities. This could help patients make more informed decisions about treatment and help them to better manage their finances throughout treatment.

Based on the current provincial economic situation, it is unlikely that IVF services will be available in NL for a long time, unless they are privatized. With that being said, travel subsidies should be put in place by the government to make travelling out-of-province for treatment more affordable for NL residents. These subsidies must be actively promoted by the Department of Health and Community Services and by NLFS to ensure that patients are aware that they are available.

In addition, NLFS is actively working to make services more accessible to rural and remote residents of the province, through teleconsultations and by doing some monitoring by distance. However, the clinic staff should advocate for travel subsidies available to patients travelling within the province to minimize costs for these patients.

Finally, future research should examine infertility, prevalence, and fertility service uptake among the many patient groups identified in this study other than heterosexual women (in couples). This research will broaden the health and research communities' ideas, definitions, and understanding of infertility.

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Appendix I: Patient Demographic Questionnaire

1. In what year were you born? _____

2. How far do you live from Newfoundland and Labrador Fertility Services? _____

3. What is your current marital status?
 - Married/living with partner
 - Single - divorced/separated
 - Single – never married
 - Single - Widow

4. Besides Medicare (MCP), do you have any other health insurance?
 - Yes
 - No

5. Thinking of all the family members in your household, last year in which category was your 'before tax' household income? Please include income from all sources such as wages, pensions, rent and employment insurance.
 - Less than \$20,000
 - Between \$20,000 and \$39,999
 - Between \$40,000 and \$59,999
 - Between \$60,000 and \$79,999
 - Between \$80,000 and \$99,999
 - \$100,000 and above

Appendix II: Patients Interview Questions

1. How did you come about using Newfoundland and Labrador Fertility Services?
 - a. When did you start receiving treatment? From where?
 - b. Were you actively trying to get pregnant? Was there anything special you were doing?
2. What services did you consider? What services did you use?
 - a. What treatment did you receive?
 - b. When did you receive drugs? How often?
 - c. How many rounds of treatment, etc.?
3. What influenced what services you considered?
 - a. cost,
 - b. age,
 - c. geography play a role?
4. What types of costs did you incur?
 - a. Did you access multiple services that increased your costs?
 - b. Did you access multiple rounds of treatment that increased your costs?
 - c. How did travel affect cost?
 - d. Was financial assistance made available to you?
 - e. Where did you get your information about cost?
5. How did these costs affect your decision-making? How did costs and travel influence your care and decision-making?
 - a. Were there certain services and courses of treatment unavailable to you because of
 - i. Cost?
 - ii. Travel?
 - b. Were there certain services and courses of treatment that were more practical because of
 - i. Cost?
 - ii. Travel?
6. Where are you now? Where will you go from here?
 - a. Will you have any more children?
 - b. Will you try to access services again?
7. Is there anything else you would like to add?

Appendix III: Service Provider Interview Questions

1. Tell me about yourself
 - a. When did you start working at the clinic?
 - b. How did you start working there?
 - c. What services are offered? What services are not offered? What services are covered and what services are not covered?

2. What are the common barriers that patients face when accessing fertility services?
 - a. Where are patients travelling from when accessing services? Where to?
 - b. Why must patients travel outside of the province for care? How often does this occur?
 - c. In what ways does this travel impact costs?
 - d. How do patients normally pay for the costs of treatment and travel (private insurance or out-of-pocket)? What is your knowledge around private insurance and what it does and doesn't cover for patients?

3. How do these barriers affect the delivery of fertility services and treatment?
 - a. What is the procedure for managing the care of a patient travelling from outside the St. John's area compared to someone travelling from within the region?
 - b. How do costs (travel and otherwise) affect treatment plans? What is the procedure for managing the care of a patient who does not have the financial means to be treated? Are certain treatments impractical?

4. What assistance is available to people struggling to access fertility care?
 - a. What forms of financial assistance, either provided by the provincial government or another organization, are available?
 - b. What support services are available?

5. Is there anything else you would like to add?