Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief

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Abstract

The purpose of this study is to understand the experiences of women who suffered treatment failure or spontaneous abortion after funded in vitro fertilization. A multi-modal strategy was employed to recruit eligible participants for in-depth interviews. Eight categories emerged from the inductive process of conventional content analysis, focusing on the pursuit of IVF, feelings of uncertainty, factory-like characteristics of clinics, insensitive fertility-based comments, and the emotional rollercoaster of undergoing fertility treatments. Additional findings included relationship changes, the taxing nature of treatments, and planning post-reproductive loss. The participants also provided recommendations for improving the program, like streamlining communication, expanding fertility services, and offering mental health care in conjunction with funded IVF. The findings suggest that women who suffer treatment failure or spontaneous abortion in the wake of funded IVF face an array of emotional responses, but primarily experience a sense of grief.

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Introduction

Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief

The number of Canadian families that experience infertility has doubled in the last four decades (Public Health Agency of Canada [PHAC], 2019). Currently, one in six families in Canada identify as infertile (PHAC, 2019). One option for people with infertility who wish to become pregnant is the use of artificial reproductive technology (ART), including in vitro fertilization (IVF) (Bhattacharya et al., 2013). The Ontario government introduced a fertility program in December 2015 that offers one funded IVF cycle, inclusive of all subsequent frozen embryo transfer cycles, to Ontario women under 43 years of age with valid provincial insurance coverage (Government of Ontario [GO], 2019). Unfortunately, 68% of all IVF attempts result in treatment failure (Canadian Fertility and Andrology Society [CFAS], 2019). Furthermore, 19.7% of successful IVF treatments end in spontaneous abortion (CFAS, 2019). Pregnancy loss can lead to post-traumatic stress disorder and increased levels of anxiety in women (Farren et al., 2016), as well as an increased risk of the spousal relationship dissolving (Gold et al., 2010; Shreffler et al., 2012). Research has also shown that the use of IVF itself has associated physical, psychological, emotional, and financial effects (Boivin et al., 2012). The prevalence of infertility, as well as the subsequent rates of treatment failure and spontaneous abortion, are widespread problems. Despite considerable research exploring infertility, treatment failure, and spontaneous abortion, the research surrounding women's experiences after using cycle-limited funding is sparse. Thus, this study explores the personal experiences of women who have suffered treatment failure or spontaneous abortion following funded IVF in Ontario.

Developing an understanding of this phenomenon, including perceived availability of care, the experience of burden, and the effect of funding limitations on decision-making, will have implications for the nursing discipline, public policy, and health of Canadians. As Allan

(2013) suggests, nurses can play an instrumental role in providing care and conducting research that could advance services in this field. Fertility nurses perform various medical interventions independently or in conjunction with other health care providers, such as medication administration, health teaching, and post-treatment care following egg retrievals or embryo transfers (D. Dubois, personal communication, April 22, 2019). Nurses' participation in fertility care throughout a patient's journey makes it essential that they understand the experiences of women with infertility, so that they are equipped to provide appropriate care and can actively advocate for their patients at the bedside and at a systemic level. Dancet et al. (2010) published a systematic review exploring patient experiences with fertility care, finding that couples require more than medical intervention, further reiterating the need for nurses to hold a dynamic role within the fertility team. By providing individualized emotional support and treatment information using effective communication techniques, nurses can decrease patient stress levels (Dancet et al., 2010). The Canadian Nurses Association (CNA, 2002) published a position statement dating back almost two decades recognizing that the role of the nurse in reproductive care includes the provision of "unbiased counselling", while using "health promotion and disease prevention approaches" (p.1). More recently, the Canadian Nurses Association (2019) supported this position by stating that advance practice nurses can "analyze the complex interaction of sociological, psychological and physiological processes, key determinants of health and clients' lived experience" (p. 30). Nurses are in a unique position that allows them to use a holistic approach to explore the gaps surrounding this phenomenon and ultimately address the medical and human needs of women who have suffered reproductive losses during provincially funded fertility treatments (CNA, 2019). Analyzing the experiences of women who have suffered treatment failure or spontaneous abortion during funded IVF may support the generation of new

nursing knowledge, standards of care, and a platform for patient and systemic level advocacy (CNA, 2019).

Personal Impetus

As a student nurse, I had the opportunity to complete a maternity placement with a group of community-based midwives. During my term with this organization, I was fortunate to gain experience working with diverse family units, including heterosexual couples, same-sex couples or electively single parents who used donor biological products, and families collaborating with volunteer surrogates. As I developed my assessment skills, I became comfortable exploring the obstetrical history of each patient. I heard stories depicting prolonged infertility and miscarriages. Fortunately, during my time at the organization, each challenge was overcome, and I was able to provide care to families who had successfully become pregnant. During this placement, I gained a glimpse into the lives of many families and learned to tailor my care based on their past and present experiences.

Since graduating, the majority of my career as a registered nurse has been based at a small rural hospital, primarily providing acute care to patients and families in the emergency department. In this role, I am able to work with patients at various stages of the lifecycle, from infancy to advanced age. Although the maternity nurses, midwives, and obstetricians at the hospital I work for provide exceptional maternal and newborn care, obstetrical complications occurring at less than 20 weeks gestation are treated in the emergency department. As such, I have witnessed the devastation of threatened pregnancies and reproductive losses firsthand.

The beauty and challenge of nursing is that it is all-encompassing. Nursing brings us face-to-face with the physical, psychological, and emotional complexities of human nature. As an emergency room nurse, I have provided emotional support to anxious women with vaginal

bleeding and abdominal cramping in early pregnancy as they wait to see if the ultrasound results confirm their worst fear: miscarriage. I have closely monitored hemodynamic statuses and held the hands of women as they learn that they require surgical intervention to remove retained products of conception following an incomplete abortion. I have witnessed the tears and embraces of families who have found out that their pregnancy is no longer viable, some of which came to fruition after years of infertility or invasive fertility treatments. I have seen the physical pain and mental anguish associated with reproductive loss, as well as the sense of helplessness felt by loved ones standing by.

After providing care to these patients for a short time, they are often discharged from the department as they ask me "now what?" on their way out the door. And the truth is, I never know what comes of the "now what?". What happens to these patients? What stories do they share about their experiences? This is where my curiosity for fertility care and reproductive loss grew from - from the families I have cared for and the devastation that I have witnessed. With the introduction of Ontario's Fertility Program, families who may not have had access to expensive fertility care, like IVF, now do. While, as a nurse interested in this area, I was excited by the new opportunity, I was also aware that not all IVF treatments result in the birth of an infant. After I realized that the provincially funded IVF cycle may be the only opportunity for families to access treatment in light of the financial burden associated with self-financed cycles, which cost upwards of $15,000 (Healthwise, 2018), I turned to the literature to further my understanding of the experiences of women who suffer treatment failure or spontaneous abortion following funded IVF, only to find that the literature is sparse.

Purpose

The prioritization of medical needs in fertility care often results in a disregard for the "human needs" and yet, respect, support, and a therapeutic relationship with healthcare providers are key factors influencing individuals' experiences with fertility care (Dancet et al., 2010, p.467). As such, it is important to explore the experiences of women who suffer treatment failure or spontaneous abortion after funded IVF and garner an understanding of how healthcare providers can meet these human needs. It is important to explore these factors as the prevalence of infertility in Canada and the accompanying need for IVF increases (PHAC, 2019). As previously mentioned, the personal experiences of women who have had treatment failure or spontaneous abortions following funded IVF are not widely explored in the literature. However, qualitative inquiry would bring this phenomenon to light and allow women to share in-depth, personal stories depicting their lived experiences (Creswell, 2009). Thus, the purpose of this study is to understand the experiences of women who suffered treatment failure or spontaneous abortion after funded IVF.

Research Question

The research question is as follows: How do women who have suffered treatment failure or spontaneous abortion after funded in vitro fertilization cycles describe their experiences?

Organization of the Thesis

This thesis is presented as a traditional monograph with five subsequent chapters. Chapter Two offers a review of the current body of literature focusing on the key concepts underpinning this study, the historical evolution of Ontario's funded fertility program, as well as lived experiences of infertility, reproductive loss, and grief. In Chapter Three, I detail the methodological processes and provide supporting rationale for these qualitative-based

approaches. Chapter Four explores the phenomenon through the eyes of the participants uncovering eight categories and several subcategories. In Chapter Five, the major findings are discussed, as well as implications for clinical care, education, policy, and research.

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Chapter Two

Literature Review

Literature Review

Chapter Two offers insight into the key concepts that form the foundation of this thesis, including infertility, in vitro fertilization, reproductive loss, and grief. More specifically, these concepts will be explored in light of the provincially funded fertility program, including the program's history and evolution of fertility care over the last four decades. Furthermore, the existing literature describing couples' experiences of infertility will also be explored through the examination of population demographics, spousal relationships, and quality of life.

Explanation of Key Concepts

There are three main concepts that provide the conceptual underpinnings of this study: infertility, reproductive loss, and grief. Each of these concepts will be discussed in detail throughout Chapter Two (Appendix A).

Infertility

The first concept that creates the study's foundational framework is infertility, which also encompasses IVF. The definition of infertility varies widely across the literature, spanning from the inability to achieve a successful pregnancy (Practice Committee of the American Society for Reproductive Medicine [PCASRM], 2020) or a clinical pregnancy (Zegers-Hochschild et al., 2009) to the inability to "sustain a pregnancy to birth" (Pillitteri, 2014, p.163). Equally perplexing, there are inconsistencies pertaining to the length of time that a couple must be actively participating in unprotected vaginal intercourse to be considered infertile, with durations spanning from 12 months (PCASRM, 2020; Zegers-Hochschild et al., 2009) up to two years (Royal College of Obstetricians and Gynecologists, 2013). Gurunath et al. (2011) attempted to address the disparity in definitions by completing a systematic review of 39 articles published between 1975 and 2010. After a thorough review of the available literature, the authors

concluded that the definition of infertility should be “based on an estimated chance of spontaneous conception that is driven by duration of trying for a pregnancy and the female partner’s age” (Gurunath et al., 2011, p.587). Mascarenhas et al. (2012) also recognized that the varying definitions of infertility create discrepancies in estimates of prevalence. Mascarenhas and colleagues (2012) developed a set of recommendations associated with defining primary and secondary infertility, suggesting that the following definitional components should be included: “exposure time”, “couple status”, “contraception”, “intent”, and “outcome” (p. 9). For the purpose of this study, the definition presented collaboratively by the International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization will be used (Zegers-Hochschild et al., 2009). As such, infertility is defined as the inability to conceive despite frequent, unprotected sex over the span of one year (Zegers-Hochschild et al., 2009).

There are several causes of infertility, encompassing both male and female factors (Canadian Fertility and Andrology Society [CFAS], 2019a). The Canadian Fertility and Andrology Society’s (2019a) most recent publication of the Canadian Assisted Reproductive Technologies Register (CARTR) discloses the most prominent reasons for accessing artificial reproductive technologies. The list includes male factors (32.9%), advanced female age (19.6%), unexplained infertility (19.1%), diminished ovarian reserve (16.8%), preimplantation genetic testing for aneuploidy (12.9%), polycystic ovarian syndrome (8.9%), tubal factor (8.6%), endometriosis (6.9%), and a broadly stated category titled other female factors (4.9%) (CFAS, 2019a).

The subpopulation of individuals who are of low socioeconomic status experience additional factors that can cause infertility. Individuals of low socioeconomic status are more

likely to work and live in environments that perpetuate infertility due to environmental exposure to harmful substances (i.e. pesticides, lead, chemicals) (Bell, 2009; Curtis, 2018; Rim, 2017). In addition to environmental determinants, low-income families are at a higher risk of experiencing infertility due to biological factors (Curtis, 2018). There is a higher percentage of low-income women who experience infertility secondary to polycystic ovary syndrome and uterine fibroids (Merkin et al., 2011), as well as complications of sexually transmitted infections (i.e. tubal damage) (Bell, 2009; Harling et al., 2013; Tavares et al., 2016). Men also experience biological factors that contribute to infertility, including sexually transmitted infections, untreated endocrine disorders, and sperm abnormalities (Centers for Disease Control and Prevention [CDC], 2019). Infertility is a multifaceted concept that spans across the socioeconomic spectrum.

Infertility is a medical condition that currently affects 16.6% of Canadian families on a physical, psychological, emotional, and financial level, thereby making it a widespread issue of national importance (Boivin et al., 2012; Public Health Agency of Canada [PHAC], 2019). The research question is founded on the concept of infertility, because women would not experience the phenomenon of interest: treatment failure or spontaneous abortion following funded IVF, if they did not initially experience infertility. As a treatment for infertility, IVF has become embedded within this concept (Bhattacharya et al., 2013).

In Vitro Fertilization

By definition, IVF is the process of external fertilization of the egg with sperm, and the subsequent embryo transfer into the uterus (Zegers-Hoschild et al., 2009). This process of fertilization occurs within the confines of a laboratory setting as suggested by the term "*in vitro*", which is Latin for "in glass" (Heyworth, 2008; Pillitteri, 2014). IVF is embedded within the overarching concept of infertility, because it is a method of treating the underlying diagnosis.

ART encompasses “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” (Zegers-Hoschild et al., 2009, p.1521). Therefore, by definition, ART includes IVF and associated transfers, as well as egg or embryo donation, embryo freezing, and surrogacy (Zegers-Hoschild et al., 2009). In vitro fertilization, as a form of ART, has been used successfully within human and animal populations for several decades (Chang, 1959; Steptoe & Edwards, 1978). The operationalization of IVF in animal subjects dates back much further than in humans, with the likes of Chang (1959) who detailed the process of performing IVF on rabbits and clearly documented the subsequent successful delivery of 15 healthy kits. Almost two decades later, Drs. Steptoe and Edwards (1978) were the first to achieve a live birth through the process of human IVF; Louise Brown was born in England in 1978. On December 25th, 1983, the first Canadian conceived by IVF was born, largely in part due to the efforts Dr. Victor Gomel and his team (University of British Columbia, n.d.). Since then, IVF has made major advancements within the Canadian context, marked by the initiation of 16, 852 IVF cycles in 2018 and tangible improvements in reducing the rates of IVF-associated multiple pregnancies, like twins and triplets (CFAS, 2019b).

There have been significant developments in the field of reproductive medicine in the last four decades, however IVF has also gained notoriety for its costliness and associated exclusivity. Although nation-wide data on IVF utilization is not available, Vélez and colleagues (2014) noted a 192% increase in the use of IVF following Quebec’s implementation of universal IVF coverage. This noticeable surge of IVF use was likely related to the government of Quebec’s decision to offer expanded fertility services, including multiple cycles of IVF (D. Dubois, personal communication, March 23, 2020; Gouvernement du Quebec, 2010; Kashmeri, 2020).

Alternatively, Ontario's program operates within a defined budget that prevents an increase in the volume of patients that can access the program on a yearly basis; as a result, this caused the waitlists associated with Ontario's Fertility Program (OFP) (Assal et al., 2019a; Blackwell, 2016; D. Dubois, personal communication, March 23, 2020).

Outcomes of In Vitro Fertilization.

The intended outcome of IVF is the healthy live birth of a singleton (Stillman et al., 2013). In Canada during 2018, 32.3% of IVF cycles using one's own genetic material resulted in an ongoing clinical pregnancy (CFAS, 2019a). Among those ongoing clinical pregnancies (2017 data), 68.9% of pregnancies resulted in a singleton live birth and 7.2% resulted in multiple live births (CFAS, 2019a). Ideally, a pregnancy results in good perinatal and maternal outcomes. However, the risk of experiencing obstetrical and perinatal complications is higher in pregnancies conceived through IVF in comparison to pregnancies achieved through natural conception (McDonald et al., 2005; Pandey et al., 2012). Two systematic reviews with meta-analysis, explored the risks of obstetrical and perinatal complications in singleton pregnancies conceived through IVF. In both studies, authors concluded that the use of IVF resulted in an increased risk of perinatal mortality, neonatal death up to seven days postpartum, preterm birth, small for gestational age, and congenital anomalies (McDonald et al., 2005; Pandey et al., 2012). Pandey et al. (2012) also found a statistically significant increase in the risk of ante-partum hemorrhages, hypertensive disorders, and gestational diabetes within the maternal population. The use of IVF increases the risk of experiencing a complication or detrimental pregnancy outcome (McDonald et al., 2005; Pandey et al., 2012).

Multiple live births are also a potential outcome when using IVF (CFAS, 2019a). A recent systematic review with meta-analysis exploring the potential for pregnancy complications

in the gestation of multiples, found that women who used ART to conceive have a higher risk of premature rupture of membranes, pregnancy-induced hypertension, gestational diabetes, preterm birth, low birth weight infants, and congenital malformations when compared to women with multiples who conceived naturally (Qin et al., 2015). Resounding similarities were found through another study, however the authors also reported higher rates of neonatal intensive care unit admissions and perinatal mortality in twins conceived using ART in comparison to spontaneously conceived multiples (Moini et al., 2012). Clearly, there are more maternal and infant risks associated with higher order pregnancies, specifically those conceived using artificial means (Moini et al., 2012; Qin et al., 2015).

Multiples conceived through ART is not a new phenomenon, because multiple embryos are transferred with hopes of increasing the rate of pregnancy and maximizing the potential for success, while also limiting the cost of repeated procedures (Balasubramanyam, 2010; Gleicher & Bard, 2013; Moini et al., 2012). Leese and Denton (2010), as well as Balasubramanyam (2010), found that families often preferred the prospect of a twin pregnancy instead of a singleton or unsuccessful treatment, thus further supporting the practice of double embryo transfers from a patient perspective. In the last decade, the Assisted Reproductive Agency of Canada has made concerted efforts to decrease the rate of multiple births associated with IVF use and the subsequent detrimental outcomes linked to high-order births (CFAS, 2019b). In 2018, Canada saw the all-time lowest rate of multiple pregnancies in IVF at 7.4%, which is down from 32% in 2009 (CFAS, 2019b).

Sadly, not all embryo transfers and IVF attempts result in live births (CFAS, 2019a). In 2018, only 32.3% of all IVF cycles using the patient's personal genetic material resulted in the detection of a fetal heartbeat using ultrasonography (CFAS, 2019a). Inversely, that means that

67.7% of families experienced an unsuccessful IVF attempt or treatment failure (CFAS, 2019a). In addition, 19.7% of ongoing clinical pregnancies achieved through IVF using one's own oocytes resulted in miscarriage in 2017 (CFAS, 2019a). In broad terms, reproductive loss is an outcome associated with the use of IVF treatments that patients must recognize and consider.

Reproductive Loss

Although treatment failure and spontaneous abortion are two separate terms, they will be grouped as one concept as they are both outcomes of IVF treatment and represent reproductive loss. Reproductive loss can be defined as any voluntary or involuntary "absence of innate function, missing of a promised child, or a tangible loss surrounding the natural human cycle of propagation"(Abi-Hashem, 2017, p.246). This encompasses a continuum spanning from pre-conception to the post-partum period that includes infertility, spontaneous abortion, and the failure of fertility treatments, as well as the loss of the expected infant (Abi-Hashem, 2017). More specifically, spontaneous abortion is defined as "the spontaneous loss of a clinical pregnancy before 20 weeks of gestational age" (Zegers-Hoschchild et al., 2009, p. 2687). While treatment failure in regard to IVF is typically defined as the absence of a live birth (Bhattacharya et al., 2013), this term subsequently encompasses a variety of occurrences, including spontaneous abortion, ectopic pregnancies, and stillbirth. For the purpose of this study, the term treatment failure takes on a narrower definition, referring to the insertion of an embryo into the uterus via IVF and the subsequent failure to produce an ongoing clinical pregnancy as indicated by the identification of a fetal heartbeat on ultrasound, which typically occurs prior to 12-weeks gestation. Essentially, despite the biological matter and environment to create a child, a clinical pregnancy does not ensue. This concept is important, because nearly 70% of people who use IVF experience treatment failure as described above (CFAS, 2019a). Therefore, understanding this

phenomenon and its effect on families is essential, because a large percentage of the treatment seeking population will ultimately experience treatment failure or spontaneous abortion and health care providers must be able to provide appropriate care.

History of Ontario's Funding Model

In 1985, the Ontario government began to fund up to three cycles of IVF regardless of the underlying clinical condition precipitating the prescription of artificial reproductive treatments (Boyajuin et al., 2014). Ontario pioneered this movement, becoming the first province in Canada to fund this service (Boyajuin et al., 2014). In 1994, the Ministry of Health and Long-Term Care (MOHLTC) collaborated with the Ontario Medical Association in an effort to reduce physician billing (Giacomini et al., 2000). During this reform, the joint commission removed IVF from the fee schedule, with the sole exception being women who experience infertility secondary to "bilateral fallopian tube blockage" (Mediratta, 2016, p.4). However, women who experienced this condition as a result of voluntary sterilization were not eligible for the funding (Boyajuin et al., 2014). The restructuring of the fee schedule prevented families with clinical indications other than bilateral fallopian tube blockages from accessing funded IVF treatments (Boyajuin et al., 2014; Mediratta, 2016). The resources previously used to fund IVF inclusively for Ontarians was to be "reallocated to fund clinical trials for unproven but promising techniques" (Royal Commission on New Reproductive Technologies, 1993, p.564).

In 2008, the Government of Ontario commissioned an "Expert Panel on Infertility and Adoption to provide advice on how to improve Ontario's adoption system and improve access to fertility monitoring and assisted reproduction services" (Expert Panel on Infertility and Adoption, 2009, p.5). The report detailing the panel's recommendations was published in 2009 (Expert Panel on Infertility and Adoption, 2009). The panel recommended the continuation of

provincial funding for basic fertility testing and the integration of newer, more precise fertility tests (i.e. “Anti-Mullerian Hormone”) (Expert Panel on Infertility and Adoption, 2009, p.95). The panel also recommended that the province “fund up to three cycles of in vitro fertilization” as a means of decreasing barriers faced by Ontarians with infertility and decreasing healthcare associated costs stemming from high-order pregnancies, which are sometimes conceived through privately funded IVF cycles that capitalize on the transfer of more than one embryo at a time (Expert Panel on Infertility and Adoption, 2009, p.110). Despite these recommendations, fertility care in Ontario remained largely unchanged until 2014.

In 2014, under provincial-level liberal leadership, discussions surrounding the state of Ontario’s fertility care came to the forefront, with the focus centered on a reformation of the existing funding model (MOHLTC, 2014). Kathleen Wynne, Premier of Ontario at the time, used twitter and an associated press release to announce the expansion of IVF services (MOHLTC, 2014; Wynne, 2014). On December 21st, 2015, the province introduced the OFP, which offers one IVF cycle per lifetime to women under the age of 43 with provincial health insurance coverage (Appendix B) (Government of Ontario [GO], 2019).

In 2016, the OFP treated 4828 individual patients (CFAS, 2019a). During the first year of the program, 5673 IVF cycles were initiated, and 1811 pregnancies were confirmed using ultrasonography, subsequently supporting a 32.8% ongoing clinical pregnancy rate per embryo transfer (CFAS, 2019a). Of the reported 1811 ongoing clinical pregnancies, 95 (5.25%) were multiple gestations (CFAS, 2019a). The top five reasons reported for using the OFP in 2016 were as follows: “male factor” (34.8%), “advanced female age” (21.4%), “unexplained infertility” (18.3%), “diminished ovarian reserve” (12.3%), and “PGT-A/PGT-M” (11.7%) (Preimplantation genetic testing for aneuploidy/monogenic diseases) (CFAS, 2019a, p. 86). The

majority of women who accessed the program in the inaugural year were less than 35 years of age (38.1%), followed by the age groups ranging from 35 to 37 (23.3%) and 38 to 40 (23.1%) (CFAS, 2019a, p. 87). In total, 1489 live births resulted from fertility care provided through the OFP in the first year of the program's inception (CFAS, 2019a).

The Canadian Andrology and Fertility Society has been providing national data on assisted reproduction since 2001 using the Canadian Assisted Reproductive Technologies Register (CARTR). In addition, the Better Outcomes Registry and Network (BORN) has been used to track patient encounters in Ontario dating back to April 2012 (BORN Ontario, 2019). These two resources provide insight into trends, outcomes, and demographic characteristics at a national and provincial level using annual (CFAS) and biennial (BORN) reports that are available to the general public (CFAS, 2019a, BORN Ontario, 2019).

Exploring Funded IVF Since the Inception of Ontario's Fertility Program

A search for information pertaining to funded IVF in Canada produced four resources in addition to the CARTR and BORN databases discussed above. First, there is a link to a survey titled, "We Want Your Thoughts About Publicly Funded IVF" on the national Fertility Matters (2017) website. However, as of November 27th, 2019 the link is inoperative and there are no identified results stemming from the survey.

Secondly, there is a recently published study exploring patients' perspectives surrounding the allocation of funds for provincially supported IVF treatments in Ontario (Assal et al., 2019b). The findings suggest that the distribution of IVF funding should be public knowledge and that each family should have an equal opportunity to access funding (Assal et al., 2019b). Participants also suggest that a hybrid distribution program should be implemented based on a scoring system and first-come, first-served basis (Assal et al., 2019b). The authors concluded

that fair distribution of funds and transparent allocation methods could decrease barriers to care, including “lack of communication, associated costs and stress of experiencing infertility” (Assal et al., 2019b, p. 385).

Gotz and Jones (2017) investigated the processes used by Ontario fertility clinics to prioritize patients receiving provincially funded IVF. There are various methods used to prioritize patients across the 50 publicly funded fertility clinics in Ontario, including first-come, first-served basis, lottery systems, and patient factors like age, funding status, and duration of infertility (Gotz & Jones, 2017). When patient factors are considered, the selection process is often directed towards older clientele (Gotz & Jones, 2017). Gotz and Jones (2017) conclude that public awareness of the selection processes is vital to the patients’ understanding of their fertility care and access to funding.

Finally, Cattapan (2020) explored how IVF came to be viewed as a medical necessity and how that classification impacted Ontario’s ability to offer publicly funded services independent of the Ontario Health Insurance Plan. Cattapan (2020) explains how three factors were operationalized in the process of deeming IVF a medical necessity and creating the OFP. The author examined the intricate process in which Ontario’s IVF policy unfolded using a three-pronged framework, including medical, efficiency, and immediacy. The health service must be deemed adequately medical in nature, efficient in terms of having appropriate outcomes for the level of investment, and “must be seen as involving an issue of immediate concern” (Cattapan, 2020, p. 63). Cattapan (2020) also explained how the framework was applied to topics such as fetal and maternal health outcomes, social infertility, and the increasing incidence of infertility, rationalizing the controversial funding package allocated for the OFP.

To the best of my knowledge, there continues to be a gap in the literature encompassing the experiences of women who have accessed cycle-limited IVF funding and subsequently experienced treatment failure or spontaneous abortion since the Ontario government introduced the province-wide program in 2015.

Patient Experiences

Demographic Characteristics of IVF Users

The literature highlights the dominant views of parenthood, by depicting the typical IVF user as Caucasian with a high socioeconomic status (SES), education level, and household income (Bell, 2009; Bushnik et al., 2015; Jenkins, 2005; Nachtigall, 2006; Tavares et al., 2016). These studies highlight the perceived and often tangible exclusivity of fertility treatments based on income and SES (Bell, 2009; Bushnik et al., 2015; Jenkins, 2005; Nachtigall, 2006; Tavares et al., 2016). The provincially funded fertility program aims to create equal access to IVF treatments for all Ontario families, irrespective of gender, SES, or family characteristics (MOHLTC, 2015). Following the introduction of publicly funded IVF in Quebec, there was an increase in IVF use by persons with low-incomes, lower levels of education, and who did not speak either of the two official national languages (Zelkowitz et al., 2015). Public funding allows a larger proportion of individuals who need ART, like IVF, to access the required treatment (Adamson, 2009), by removing financial barriers to treatment. As such, it is important to note that the experiences of women who have accessed funded fertility treatments may be different from those previously characterized in the literature; the expanded IVF services are designed to encompass all families, including those that do not fit the mould of past IVF users.

Psychological Effects of Infertility

In 1997, Greil examined the body of literature pertaining to infertility and psychological distress. In that review, he discussed the division of opinions pertaining to whether infertility is a medical condition subsequently resulting in psychological side-effects or if infertility is caused by an underlying psychological condition. Greil (1997) also discovered that the experiences of men and women vary when it comes to infertility. A few years later, Lee and Sun (2000) claimed that women tend to be more distressed with the experience of infertility than their partners, further supporting Greil's (1997) conclusions that male and female experiences differ in the realm of infertility. However, in their more recent review of quantitative and qualitative studies, Wischmann and Thorn (2013) report that the degree to which men and women are emotionally affected by infertility is more similar than previously portrayed in the literature.

Based on the findings of two systematic reviews with meta-analyses that synthesized the results of 45 studies, it appears that stress has little to no impact on the outcome of ART (Boivin et al., 2011; Matthiesen et al., 2011). However, individuals who experience infertility, ART, and reproductive loss tend to suffer from higher levels of stress in comparison to the general population; this is often quantified using anxiety and depression scales (Bhat & Byatt, 2016; Ezzell, 2016; Pasch et al., 2012; Pasch et al., 2016). A Swedish study revealed that most people from a mixed-sex sample were still processing their infertility and trying to adapt to childlessness three years after undergoing an unsuccessful IVF treatment, regardless of their gender (Volgsten et al., 2010). As such, it is clear that the psychological effects of infertility, treatment, and the associated outcomes, extend beyond an acute phase, and the experiences of men and women are parallel in some instances and divergent in others.

Women.

Within the population of infertile women, experiences vary greatly, as depicted through the identification of 22 unique difficulties reported by women undergoing infertility treatments (Benyamini et al., 2005). This study allowed women to prioritize which difficulties were most significant in their personal lives; the variability noted within the answers supports the notion that women's experiences are unique and individualized (Benyamini et al., 2005). Despite the variability within experiences, one systematic review noted specific trends when exploring how infertility impacts couples psychologically, maritally, sexually, and in terms of quality of life (Luk & Loke, 2015). Two studies within this review noted that infertile women are subject to increased levels of emotional distress and psychiatric disorders, including anxiety and depression (Albayrak & Gunay, 2007; Noorbala et al., 2009). Another study looked at women's experiences following unsuccessful IVF treatment, finding that women living with infertility had higher levels of depression and anxiety after IVF failure (Pasch et al., 2012). Furthermore, women who conceived using ART and subsequently experienced a miscarriage, were more negatively affected by the loss than those who conceived naturally (Cheung et al., 2013). These women experienced increased hyperarousal symptoms, reflecting the traumatic nature of the miscarriage (Cheung et al., 2013).

While examining the detrimental psychological effects of experiencing infertility, it is also important to look at the impact of resiliency. One study found that infertility-related emotional distress is negatively associated to resilience, suggesting that as one's level of resilience increases, their level of distress decreases correspondingly (Sexton et al., 2010). Another study also examined the resilience of women who have experienced unsuccessful fertility treatments, finding three phases in the adaptive process: "appraisal", "stepping away

from treatment", and "building self up for next attempt" (Bailey et al., 2017, p. 324). During this process, the women initially assess their ability to continue with treatment; those who appraise their situation as lacking in vital resources choose to step away from treatment for a period of time (Bailey et al., 2017). The women then use this period of time to muster up needed resources and self-reflect prior to continuing to pursue pregnancy (Bailey et al., 2017). The literature depicts women's experiences of infertility, treatment, and the pursuit of pregnancy as both unique and extraordinarily similar depending on the context and the specific elements being explored.

Men.

In North America, it is estimated that 4.5-6% of males are infertile, assuming that 20-30% of infertility cases in the data set are due to male factor infertility (Agarwal et al., 2015). Luk and Loke's (2015) systematic review includes studies focusing on the male experience, two of which highlight the fact that men with infertility have increased levels of psychological distress in comparison to fertile men (Dyer et al., 2009; Gao et al., 2013). After evaluating the findings of fourteen studies, Luk and Loke (2015) determined that several factors contribute to the lower mental health scores seen in infertile men, including "educational level, will to have children, poor marital relationship, previous in-vitro fertilization attempt and duration of infertility" (p. 101). Additionally, individuals are at a higher risk of developing a mental illness or experiencing associated symptoms if they lack social support and experience fertility treatment failure or a reproductive loss (Bhatt & Byatt, 2016). This is significant considering men are less likely than women to disclose their infertility diagnosis to friends or family, thus decreasing the potential for social support (Fisher & Hammarberg, 2012).

Not only does infertility negatively impact the emotional and psychological well-being of men with the diagnosis, but it also changes their self-image (Hanna & Gough, 2019). Infertile men often perceive themselves as being less masculine in the wake of an infertility diagnosis (Hanna & Gough, 2019). In addition, infertile men often feel stigmatized by a social context that fixates on reproduction and the thought that men are abundantly fertile, while also feeling that their experiences are underappreciated and overshadowed by the predominant view that women shoulder the weight of infertility (Hanna & Gough, 2019). One publication reported that 63% of men felt that the health care team largely directed communication towards their partner, leaving 72% of the men who were surveyed feeling that they did not have adequate information to understand the psychological effects associated with male factor infertility (Mikkelsen et al., 2013).

Men experiencing infertility not only feel like outsiders in a clinical settings as described by Mikkelsen et al. (2013), but also in relationships extending to their social circles and work environments (Hadley & Hanley, 2011). Furthermore, some men find the stress of infertility and the required time off for treatment to negatively impact their productivity in the workplace, which has been linked to loss of employment and being passed over for promotions (Hanna & Gough, 2020). This can be seen as traumatic within a work culture that continues to portray being a breadwinner as a masculine characteristic, while also feeling that their masculinity is threatened by the vulnerability associated with infertility (Hanna & Gough, 2020). Infertile men describe the condition as traumatic in nature due to ongoing mental health challenges and grief surrounding the loss of having biological children, as well as the assumption of guilt for how their infertility affects their partner (Hanna & Gough, 2019). Another source of infertility-related stress is the associated financial strain of treatments, which was found to afflict 47% of

participants in the study performed by Elliott and colleagues (2016). In this same study, 64% of participants reported spending more than $15,000 on fertility treatments (Elliott et al., 2016). A man's yearning to father children peaks between 30 and 40 years of age, before beginning to decline; however, the desire to be a father never recedes in its entirety, further highlighting the long term effect of infertility (Hadley & Hanley, 2011). Men are significantly affected by infertility on a psychological level, both in the short-term and over an extended period of time, regardless of whether they are infertile or the partner to someone who is infertile.

Relationships.

The impact of infertility on the spousal relationship has been characterized as variable within the body of literature. Some research reflects the detrimental effects of infertility on a couple's relationship (Nyarko & Amu, 2015) and the increased risk of the relationship dissolving (Gold et al., 2010; Shreffler et al., 2012), while other studies have found that experiencing infertility has strengthened the couple's bond (Peterson et al., 2011; Volgsten et al., 2010).

Male infertility has not been shown to have a negative impact on the marital relationship, but infertile men tend to be more content with their marriage than their female counterparts (Tao et al., 2012). Two Taiwanese studies echoed this finding by reporting that women who are infertile experience more distress and are typically less satisfied with their marriages than their husbands (Lee & Sun, 2000; Lee et al., 2001). However, distress is not the only factor that dictates one's level of marital satisfaction. Several factors linked to marital dissatisfaction in infertile couples were identified in a systematic review, including: age greater than 30, longer durations of treatment, unsuccessful ART attempts, low income, and low levels of education (Tao et al., 2012). Infertile couples actively undergoing IVF treatment are more likely to report

poor marital quality as well, highlighting the importance of having support outside of the spousal partnership (Ying et al., 2016).

When discussing the emotional ramifications of infertility and dyadic relationships, it is also vital to consider the associated sexual aspects. One study examined the level of sexual satisfaction of infertile men and women in comparison to a control group (Güleç et al., 2011). The authors found that there was no significant differences between the level of sexual function between fertile and infertile individuals across both sexes (Güleç et al., 2011). However, Nyarko and Amu's (2015) study found that 64.3% of participants no longer found sexual intercourse pleasurable following a diagnosis of infertility, because sex changed from being a gratifying experience to one with the sole focus of reproduction. Volgsten et al. (2010) reported that some participants in their qualitative study ended up temporarily separating from their partners, because "the lust and enjoyment of sexual life disappeared during IVF treatment and had not returned" (p. 1293). Onat and Beji (2012) also echoed these findings, identifying the need to schedule sexual intercourse as a problem faced by couples who experience infertility.

An increasing number of fertility-related arguments were also found to cause marital problems, negatively influencing the strength of the couples' marriages (Nyarko & Amu, 2015). Contrastingly, some research shows that individuals can experience a strengthening in their partner relationship (Volgsten et al., 2010). Another study that looked at the experiences of Danish couples over a five-year period of unsuccessful fertility treatments, found that nearly one in three women considered high levels of martial benefit as a positive outcome of infertility (Peterson et al., 2011). Chochovski and colleagues (2013) found that marital quality initially contributed to increased levels of distress, as couples meditated on their experience of unsuccessful IVF. However, over time, marriage quality promoted recovery from this traumatic

experience (Chochovski et al., 2013). A recent systematic review found that psychosocial interventions can be effective in decreasing psychological distress and increasing rates of clinical pregnancy for couples undergoing infertility treatment (Frederiksen et al., 2015). As such, it is vital to understand the experiences of infertile couples undergoing treatment and the implications regarding the spousal relationship.

Infertility Associated Quality of Life.

Chachamovich and colleagues (2010) performed a systematic review of 14 studies exploring quality of life in infertile participants. This review revealed that quality of life is substantially decreased in infertile women when compared to their fertile counterparts and infertile men (Chachamovich et al., 2010). Although infertile men may also experience quality of life impairments, it is of less intensity compared to women living with infertility (Chachamovich et al., 2010). Onat and Beji (2012) also found that infertility results in lower quality of life, noting that the "effects varied depending on the stage of infertility, process, gender, and the quality of the relationship" (p.39). As previously mentioned, Luk and Loke (2015) examined infertility with a focus on psychological well-being, spousal relations, sexuality, and quality of life. In this systematic review of 20 articles, including both quantitative and qualitative methods, there was inconclusive evidence determining the effect of infertility on the marital relationship or quality of life (Luk & Loke, 2015).

Quality of life in the wake of infertility has also been explored more broadly, focusing on the longitudinal aspects of the experience (Kuivasaari-Pirinen et al., 2014). In a Finnish study, authors found that women who had a live birth following the use of ART were significantly more satisfied with their lives for the initial three years post-delivery, compared to women who were unsuccessful in their ART attempt ($p=0.003$); however, this difference dissipated over a period

of six to nine years post-ART (Kuivasaari-Pirinen et al., 2014). This finding suggests that with passing time, the negative aspects of infertility appear to diminish and one's quality of life recovers. In addition to time, a couple's resiliency acts as a defense strategy against quality of life impairments and psychological distress associated with infertility (Hermann et al., 2011).

Although there is a growing body of literature exploring the impact of infertility on quality of life, Chachamovich and colleagues (2010) point out that the family unit as a dyad is often overlooked, which limits the potential development of couple-oriented resources and interventions. In conclusion, there continues to be gaps in the literature surrounding infertility associated quality of life, despite being examined from male and female perspectives, as well as on a continuum extending retrospectively and prospectively. Conceptualizing the impact of infertility on quality of life, allows for a more profound understanding and appreciation of the experiences of infertile couples.

Grief and Infertility

Fenstermarcher and Hupcey (2013) determined that perinatal bereavement is the multifaceted emotional reaction exclusively evoked by a reproductive loss, that is most commonly referred to as grief and characterized by mourning. This experience of grief is similar to that inflicted by other types of losses (i.e. the death of a family member) (Brier, 2008) and with it comes a sense of loss, sadness, and emotional distress (Abi-Hashem, 2017). Grief associated with perinatal loss is not a new concept. Nearly three decades ago, Hutti (1992) found that grief was a concept relevant to the experiences of individuals undergoing a perinatal loss and subsequently developed the Hutti Perinatal Grief Intensity theoretical framework. Hutti's (1992) framework outlines factors that significantly impact the intensity of grief experienced in the wake of perinatal loss, including perceptions regarding the *reality* of the pregnancy,

congruence between the lived experience of loss and how the woman believes the loss should be experienced, and the woman's ability to *confront others* about unsupportive behaviours. The 14-item Perinatal Grief Intensity Scale (PGIS) was later created (Hutti et al., 1998), which is able to predict the intensity of grief likely to be experienced following a perinatal loss (Hutti et al., 2017), as well as symptoms of severe anxiety and depression three to five months post-loss (Hutti et al., 2017). Evidently, grief continues to be a key concept in the experience of perinatal loss, which encompasses spontaneous abortion as per Hutti's (1992) definition. Similarly, treatment failure and subsequent infertility results in grief related to the loss of prospective children (James & Singh, 2018).

A study conducted in Taiwan explored women's emotional responses and coping strategies in the wake of IVF failure (Lee et al., 2010). Lee and colleagues (2010) discovered that all coping strategies used by women who experienced IVF failure were correlated to their grief responses. Another study also found that infertile women experience grief prior to initiating IVF treatment, throughout the treatment process, as well as following the completion (Lukse & Vacc, 1999). This suggests that by gaining an understanding of one's experiences of grief, healthcare providers may be better equipped at providing support and promoting effective coping strategies. Another qualitative phenomenological study conducted by Harris and Daniluk (2010) explored the experiences of women who conceived using ART and subsequently suffered spontaneous abortion between two- and 16-weeks gestation. A profound sense of loss and grief was a central theme (Harris & Daniluk, 2010). However, feelings of grief can vary in intensity and duration on an individual level (Abi-Hashem, 2017). The sense of grief described in the previous studies is not always easily identified, as the grief experienced by individuals who have suffered a reproductive loss is often less openly recognized by society (Bhat & Byatt, 2016; James &

Singh, 2018). Using a design similar to the one proposed for this study, Volgsten and colleagues (2010) discovered that women continued to face challenges and feelings of grief associated with childlessness several years after undergoing unsuccessful IVF. Grief is a dominant theme within the infertility literature that warrants investigation in diverse settings and contexts. Although Harris and Daniluk (2010) explored the experiences of Canadians who suffered spontaneous abortions, the effect of using cycle-limited funding was not incorporated, thus making it challenging to transfer the findings to the proposed study context and population.

Grief is fundamentally associated with infertility, broadly encompassing the diagnosis, treatments, and related reproductive losses, like treatment failure and spontaneous abortion. Recognizing the centrality of grief within the exploration of infertility is key in understanding the pillars of this study. In conclusion, it is important to reflect on the three main concepts of this study: infertility, reproductive loss, and grief, in an effort to conceptualize how they link together to depict the phenomenon of interest, which can be further articulated through Blenner's Stage Theory of Passage Through Infertility (Blenner, 1990).

Theoretical Underpinnings

Blenner (1990) conducted a grounded theory study that explored the experiences of 25 married couples who had undergone infertility treatment. As Blenner (1990) explains, "a stage theory of passage through infertility treatment emerged from the data analysis" (p. 153). This theory consists of three concepts: engagement, immersion, and disengagement, as well as eight stages: experiencing a dawning of awareness, facing a new reality, having hope and determination, intensifying treatment, spiraling down, letting go, quitting and moving out, and shifting the focus (Table 1) (Blenner, 1990).

Table 1

Summary of Blenner's (1990) Stage Theory of Passage Through Infertility

Concept	Stage		Description
ENGAGEMENT	1	Dawning of Awareness	This phase occurs prior to the couple receiving a diagnosis of infertility, during a time in which they do not differentiate themselves from fertile couples. As menses continues and pregnancy does not ensue, the couple may begin to have a "dawning of awareness", in which they begin to consider the possibility that they are experiencing infertility. Within a year, growing concerns, confusion, and suspicion, generally leads to consultation with a general practitioner or gynecologist.
	2	Facing a New Reality	This phase encompasses the time period in which the couple receives a diagnosis of infertility. During this phase, one or both parties participates in "accounting", where an attempt is made to identify the cause of infertility (p.155). The infertile spouse is also susceptible to feelings of guilt at this point as he or she feels responsible for inhibiting the partner from becoming a parent. Couples begin to differentiate themselves from fertile individuals and subsequently seek information in the literature and from other infertile families, while limiting the personal information they share with their fertile relations. The infertile couple begins to idealize pregnancy and face the "'what if' phenomenon", which leads to thoughts about future regret if treatment is not pursued (p. 155).
	3	Having Hope and Determination	This phase coincides with the start of treatment. During this phase, couples feel motivated by the thought of being able to actively participate in the process. This enthusiasm is accompanied by "selective perception and strong discounting of negative information" (p.155). In essence, couples are unable to comprehend the reality of predicted success rates, because they believe that fertility treatments are a definitive solution to their problem.
IMMERSION	4	Intensifying Treatment	This is the first stage within the concept of immersion. This stage is accompanied by significant stress resulting from the couple's dedication to treatments. Women begin to take on an identity centered on infertility, often diverting energy away from other aspects of their lives, such as their careers. Heightened emotional responses coincide with menstruation as "hopeful anticipation" fades to disappointment and frustration (p.156). Couples may seek emotional support from infertility groups during this stage. During this phase, couples often delay or reschedule events

			due to the uncertainty that comes with infertility treatments; this process is called "suspending" (p.156).
	5	Spiralling Down	In this stage, couples are faced with repeated failure or pregnancy loss and limited remaining treatment options, causing them to feel more hopeless and exasperated. Couples report an inability to "tolerate the feeling of being out of control" (p. 156), which is sometimes accompanied by decreased energy levels and suicidal ideation.
DISENGAGEMENT	6	Letting Go	This phase is characterized by a "mental shutdown" resulting in the mindless undertaking of treatment (p.157). Eventually, effort is put forth to return to a "normal life" and "revitalization" may result in a purposeful break from treatment (p.157). During this phase, couples can let go of their what if mindsets and begin to think about setting a treatment deadline (i.e. termination after one more cycle). This point may be reached collaboratively, however, when one individual reaches this point first, it can cause conflict in the relationship.
	7	Quitting and Moving Out	This stage occurs when a couple decides to terminate treatments. There is a sense of relief and they look forward to "getting on with their lives" (p. 157). The process of moving forward is variable and may include permanent childlessness, grieving dreams of parenthood, the pursuit of adoption, or the re-initiation of treatment following the initial decision to terminate fertility care.
	8	Shifting the Focus	As infertile couples transition into stage eight: shifting the focus, there is a sense of "peaceful resignation" (p. 158). The focus shifts from infertility to other important aspect of life, like parenting in families who have chosen to adopt. Regardless of whether a couple adopted or remained childless, they begin to come to terms with their infertility.
Blenner, J. L. (1990). Passage through infertility treatment: A stage theory. *Journal of Nursing Scholarship, 22*(3), 153-158. https://doi.org/10.1111/j.1547-5069.1990.tb00199.x			

In summary, Blenner's (1990) framework depicts the "psychosocial responses of couples to their infertility from prediagnosis to posttreatment" (p. 153). This theory explores the passage of time as couples become *engaged* in their diagnosis, *immersed* in the associated treatments, and finally *disengaged* in the wake of ongoing infertility (Blenner, 1990). Within the social context of infertility, Blenner (1990) identifies a time continuum that parallels psychological and

emotional reactions experienced by couples throughout their journey. Blenner (1990) substantiates his "stage theory of passage through infertility treatment" (p.153) through the use of direct quotations and the retelling of participant experiences. In conclusion, Blenner's (1990) theory highlights the psychosocial affects that correspond with each step of a couple's journey with infertility, predating the initial diagnosis and extending into the posttreatment period.

Blenner's (1990) framework helps me to reflect on how individuals experienced infertility three decades ago, while approaching the present-day experiences of infertility with an open mind. In keeping with the inductive, emergent design of this study, Blenner's (1990) Stage Theory of Passage Through Infertility is not the foundational framework from which data collection and analysis was centered, but rather a starting point for the exploration of a relatively uncharted phenomenon. It should be noted that to the best of my knowledge, this theory has not been applied to studies focusing on funded fertility treatments.

To my knowledge, Blenner's (1990) work on the passage through infertility treatment has been cited in 76 publications. Two of these publications describe the theory in detail, discussing the main concepts or associated stages (Covington & Burns, 2006; Gerrity, 2001a). In addition, several doctoral dissertations offer comprehensive discussions of the theory (Fontenot, 2008; Glynn, 1991; Mounce, 2017). However, the majority of the citations present Blenner's (1990) original work by reducing the theory to a singular focus or, alternatively, making broad, superficial references to the model (Boivin et al., 1995; Johnson & Fledderjohann, 2012; Wischmann et al., 2001). Ten of the studies that reference Blenner's (1990) theory are exclusively published in a language other than English and were not analyzed due to personal language limitations. Despite the fact that Blenner's (1990) publication has been cited multiple times, there were no studies identified in which this theory was used as the guiding framework.

As Gerrity (2001b) explains, it may be difficult to operationalize each stage of the theory as individuals will spend diverse amounts of time in each stage, undergo varying treatments, and may revisit or skip certain stages. Therefore, some researchers may find it challenging to utilize this theory within their chosen study design (Gerrity, 2001b). As mentioned above, it is common practice to focus on specific stages of this theory rather than all stages in their entirety, which may decrease the challenges identified by Gerrity (2001b).

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Chapter 3

Methodology

Methodology

This chapter provides an overview of my underlying paradigmatic view, the research design, the study sample and recruitment strategies, methods of data collection, analytic approach, as well as strategies employed to ensure that the study is ethical and rigorous.

Paradigmatic View

This study is situated within the constructivist paradigm, formally known as naturalistic inquiry (Lincoln & Guba, 1985). The ontological underpinnings of this paradigm are based on relativism, suggesting that multiple realities can exist that reflect subjective constructions of social experiences (Guba & Lincoln, 1994). The epistemology supports a process in which the data emerge throughout the study based on the transactional relationship between the researcher and participant(s) (Appleton & King, 1997; Guba & Lincoln, 1994). As Appleton and King (1997) explain, in-depth interviews and concurrent, inductive data analysis are foundational concepts of qualitative research conducted using a constructivist lens. These approaches have been employed throughout the study, reflecting not only the study design and nature of qualitative inquiry, but also the constructivist paradigm. As the experience of infertility can include various different causes, treatment plans, and outcomes, each journey is individual and personal. The reality of infertility and in vitro fertilization is constructed by each individual who lives through the experience, thereby situating the research question within the constructivist paradigm.

From a personal standpoint, I believe that no two individuals will have identical experiences within the same situation, because their perceptions and emotional reactions will be unique. I believe that multiple people can share similar experiences, but there will inevitably be some variation. As such, the constructivist paradigm is not only congruent with the chosen topic,

but also with my personal belief system. From a constructivist standpoint, I recognize that my understanding of this phenomenon is primarily founded in clinical experiences, discussions with frontline care providers, and the current body of literature. As such, I recognize and respect that my perceived reality of infertility may vary drastically from other healthcare providers. Furthermore, as the researcher looking at this phenomenon through a constructivist lens, it is important to understand that I inevitably contribute to the development of emergent data by playing an active role in a transactional relationship that allows the participant to depict their realities through storytelling and conversational interviewing (Appleton & King, 1997; Guba & Lincoln, 1994).

Despite coming from various backgrounds and having diverse infertility histories, the women in this study share a common bond in that each has suffered treatment failure or spontaneous abortion following a funded IVF cycle. Although each individual has experienced the same phenomenon, each woman has created a personal, subjective reality based on her perceptions of her experiences. As such, the individualistic nature of perceptions allows the women in this study to share diverse viewpoints, while continuing to be unified by a common thread: unsuccessful IVF treatments. The exploration of subjective experiences lends itself to qualitative inquiry, because experiences are personal and context dependent, often requiring a freedom of expression afforded through storytelling and the use of words that would not be captured adequately through quantitative methods (Creswell, 2009). Therefore, in the wake of this understanding and through reflection on my own belief system, the constructivist approach led me to qualitative research.

Qualitative Research

In Polit's (2010) textbook on nursing research, she states that qualitative data "consists of verbal, narrative pieces of information" (p. 3), but the overall realm of qualitative research is much more complex than a fragmented conglomeration of individual pieces of data. Qualitative research is a form of naturalistic inquiry that strives to "make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 2008, p.4). Furthermore, qualitative inquiry is aimed at "describing and clarifying human experience as it appears in people's lives" (Polkinghorne, 2005, p. 137). In order to do so, qualitative research designs are typically fluid and focus on cyclical data collection and analysis to ensure that the emergent understanding of the phenomena is holistic (Lincoln & Guba, 1985). The beauty of qualitative research is that it transcends various fields of study, disciplines, and paradigms, while giving voice to subjective experiences within a specific social context (Denzin & Lincoln, 2008). This type of research takes on a non-numerical feel, often collecting language-based data in the form of verbal or written communication (Polkinghorne, 2005). As such, data is often derived from interviews and focus groups (Gill et al., 2008); however, documents (i.e. medical charts), researcher observations, and culturally relevant mementos also lend themselves to qualitative research (Polkinghorne, 2005).

Traditional evidence hierarchies have typically depicted qualitative designs as inferior to quantitative methods, like randomized control trials, quasi-experimental designs, and cohort studies, due to the lack of environmental control and objectivity, as well as the use of small sample sizes (Hammarberg et al., 2016; Polit & Beck, 2017). Polit and Beck (2017) use a modified evidence hierarchy to explain that qualitative designs cannot be considered lesser than their quantitative counterparts based solely on the strength of evidence; the nature of inquiry

must also be examined. Based on this modified hierarchy, single in-depth qualitative studies are only second to systematic reviews when exploring questions rooted in meaning and process (Polit & Beck, 2017). In essence, the strength of the evidence is determined, in part, by the appropriateness and congruency between the underlying line of inquiry and the subsequently chosen methodology. In addition, Guba (1981) recognized a need to enhance the trustworthiness of naturalistic inquiries and subsequently developed associated criteria, which include: credibility, transferability, dependability, and confirmability. Guba and Lincoln (1986, 1994) furthered the discussion of trustworthiness in naturalistic inquiry by highlighting the role of authenticity in research and went as far as to add authenticity to their trustworthiness criteria (1994). With Guba and Lincoln's (1994) criteria and a conceptualization of Polit and Beck's (2017) redesigned hierarchy of evidence, it becomes apparent that qualitative research cannot be considered an inferior or superior alternative to quantitative research without exploring the nature of the founding research question and the methodologies supporting the acquisition of data.

Without qualitative inquiry, the corner of the research world exploring personal perspectives, experiences, values, and meaning would be cast in half-darkness under the hazy glow of quantitative research. As mentioned above, qualitative inquiry lends itself to the exploration of personal experiences and perspectives, while providing meaning to phenomena that is not well understood (Creswell, 2009). It is often difficult and inappropriate to force these subjective experiences to conform to the principles of quantitative research, because exclusive quantification can prevent the holistic portrayal of lived experiences (Hammarberg et al., 2016). Broeder and Donze (2010) also highlight the importance of including qualitative research in the evidence base, as it often reflects the artistic aspects of nursing, presents the realities of patients

in a way that makes their experiences relevant to nursing care practices, and supports the individuality of patients within a broader healthcare context. In conclusion, it is evident that qualitative research has a lot to offer to the current evidence base of nursing and can complement the findings from quantitative research in a way that supports best practice guidelines and patient care experiences (Broeder & Donze, 2010).

Research Design

A qualitative research design was chosen as it allows for the intricate exploration of diverse experiences of infertility and reproductive loss. This study employs a qualitative descriptive design as described by Sandelowski (2000), which she then further clarified a decade later (2010). This design is appropriate for the purpose of this study as "description of the phenomena" (Sandelowski, 2000, p. 334) is the underlying goal. As Sandelowski (2010) explains, qualitative description is fluid, thus requiring the researcher to "describe the particular combination of sampling, data collection, and data analysis techniques they used" (Sandelowski, 2010, p. 78). These facets will be discussed in the subsequent sections and further supported by rationales and applicable references (Sandelowski, 2010). Sandelowski (2004) concludes that the fear of being overly interpretative can act as an excuse for qualitative researchers to limit the depths of inquiry and interpretation; however, without some level of interpretation, researchers would not be able to "make something of their data" or convey meaningful results (Sandelowski, 2010, p. 79). Therefore, it must be noted that there is, inevitably, some degree of interpretation within this qualitative descriptive study as the findings are operationalized and shared (Sandelowski, 2010).

Setting

This study is set in a city in Eastern Ontario with a population of nearly one million, primarily English-speaking residents (Statistics Canada, 2012, 2017a). The support group from which participants were recruited provides services to individuals in the region, spanning urban and rural communities. This support group is not affiliated with any fertility clinic and is organized by a volunteer facilitator. Most individuals in the support group receive care from a multidisciplinary team of six physicians, one psychologist, 18 nurses, lab technicians, and sonographers at a local fertility center (D. Dubois, personal communication, April 22, 2019). This support group was a logical choice of setting, because it provides support to individuals who may have accessed funded IVF from the only funded clinic in the area (Ministry of Health and Long Term Care [MOHLTC], 2019). However, it must be noted that not all of the participants of this study receive care from the local clinic.

The OFP is a means to a funded IVF treatment cycle for medical and/or social conditions causing infertility with several potential outcomes (treatment failure and spontaneous abortion). This refers to fertility treatments that are publicly funded rather than paid out-of-pocket or through private insurance (Government of Ontario [GO], 2019). In this study, funded fertility treatments enable women under 43 years of age with valid provincial health insurance to access one funded IVF cycle (GO, 2019). As such, it is important to consider the provincially funded IVF program as the context in which this study occurs. This program increases accessibility for families by removing some of the financial barriers that may have previously prevented women with infertility from accessing treatment (MOHLTC, 2015). Therefore, the population being explored within this context is those who have accessed funded IVF.

Research Sample

Sampling Strategy

Convenience sampling is a strategy used to choose readily available participants who have experienced the phenomenon of interest and meet the eligibility criteria (Etikan et al., 2016). The sample in this study was derived from a larger population of support group attendees and was composed of a subset of individuals who were willing to discuss their experiences, while also meeting the eligibility criteria. Convenience sampling is an inexpensive and efficient means of obtaining participants, which made it a feasible and appropriate strategy to use based on the time and fiscal constraints of the study (Etikan et al., 2016). It is important to recognize that a limitation of this approach is that the sample may not accurately reflect the population as a result of participants self-selecting (Etikan et al., 2016; Polit & Beck, 2017). The sample of individuals that volunteer to participate in the study may possess qualities that make them more willing to discuss their experiences or may have perceptions of their journey that do not reflect those of the population (Etikan et al., 2016; Polit & Beck, 2017). Despite this limitation, Etikan et al. (2016) explain that convenience sampling is a cost- effective, time-efficient method of initiating sampling.

Once the initial participant pool was identified, the sampling strategy evolved from convenience sampling to snowball sampling in an effort to obtain additional participants (Naderifar et al., 2017). Snowball sampling is the process of asking previously recruited participants to refer people they know who may meet the eligibility requirements (Naderifar et al., 2017; Polit & Beck, 2017). These sampling strategies were employed, because they are appropriate in the recruitment of participants from a population that may be reluctant to talk about their experiences due to the sensitive and private nature of the subject, such as infertility

(Biernacki & Waldorf, 1981; Naderifar et al., 2017). A flexible sampling strategy was used throughout this study to ensure that the most appropriate data was collected and that an adequate number of participants were recruited (Naderifar et al., 2017; Polit & Beck, 2017).

Sample Size

Morse (2000) discusses various factors that affect sample size, including the scope of the study, topic, quality of data, and study design. The qualitative descriptive nature of this study and the precise research question, paired with the use of in-depth interviews suggested that the design, scope, and prospect of attaining quality data supported a small sample (Morse, 2000). Data redundancy is the point at which no new concepts or themes emerge, suggesting that the findings of subsequent interviews would reflect the data acquired from previous interviews (Moser & Korstjens, 2018). Moser and Korstjens (2018) suggest conducting "two or three more observations or interviews" (p. 11) after the perceived point of data redundancy to ensure that no new codes or categories emerge. This stopping principle was exercised throughout the process of data collection and analysis. The sample size was initially estimated to range from five to 12 participants based on previous studies with similar designs and methodologies (Honey & Wright, 2018; Ranse et al., 2012; Vicente et al., 2016). However, the perceived point of data redundancy occurred after performing six individual interviews. Two interviews were performed after that point to ensure that no new categories surfaced. In total, eight participant interviews were conducted throughout this study.

Eligibility Criteria

The provincial program restricts funding to women younger than 43 years of age who are Ontario residents with valid provincial insurance coverage (GO, 2019). Therefore, this study included women who met these criteria, experienced the phenomenon of interest, and spoke

English. Women who were unable to communicate in English were excluded due to the researcher's language restrictions and the limited resources available for translation. Women were also excluded if they experienced spontaneous abortion following spontaneous pregnancy, used ART other than IVF, or had undergone medical or elective abortion, because these individuals have not experienced the phenomenon in its entirety (Table 2).

Table 2

Participant Eligibility Criteria

Inclusion Criteria	Exclusion Criteria
Women under 43 years of age with valid provincial health coverage.	Men.
Women who can communicate in English, due to researcher's language constraints and limited resources for translation.	Women who cannot communicate in English.
Women willing to share their experiences of treatment failure and spontaneous abortion following the use of provincially funded in vitro fertilization cycles.	Women who have experienced spontaneous abortion after spontaneous pregnancy, or undergone infertility treatments other than in vitro fertilization (i.e. intrauterine insemination).

After the initial recruitment effort (which did not produce enough participants), I realized that some of the pre-determined eligibility criteria prevented potential participants from enrolling in the study, for reasons unrelated to the topic of interest. Specifically, at the outset of the study, I excluded women who had subsequent fertility treatments after their funded cycle and women who used donor products (i.e. sperm or gametes) from the population of interest. After discussion with the thesis committee, I removed these criteria and submitted an amendment to the Research Ethics Board at the University of Ottawa.

Recruitment

An effective and ethical recruitment strategy is the use of gatekeepers; face-to-face discussions with a recruiter who the potential participants trust increases participant engagement

(Dempsey et al., 2016; Polit & Beck, 2017). Participants were primarily recruited from a local support group for families with infertility. The monthly meetings generally draw a crowd ranging from 13 to 29 individuals. The support group facilitator distributed information regarding the study to potential participants via the chapter's e-mail list. I also attended two of the monthly meetings at which I introduced myself, provided an overview of the study, and answered questions. Participants were given the option to contact the principal investigator (PI) directly or have their email address or phone number provided to the PI for follow-up. In addition, the facilitator uploaded a recruitment poster to an online infertility support group hosted on the social media platform, Facebook (Appendix C). The poster briefly outlined the study and provided the PI's contact information, including e-mail address and phone number. A multi-pronged approach (support group email distribution list, monthly meetings, and Facebook group) was employed to maximize the potential of reaching out to and recruiting a sufficient number of individuals that met the eligibility criteria. In addition, these methods were chosen as they respect participant privacy and minimize feelings of coercion that may be associated with direct recruitment by the facilitator (University of California Los Angeles, 2019).

Situating the Researcher and Team

The principal investigator, M. Forgie, is a bachelor's prepared nurse with competence in qualitative research, who is pursuing a Master of Science in Nursing (MScN) at the University of Ottawa. She has experience working in a rural emergency department that provides acute care to pregnant women at less than 20 weeks' gestation, including the treatment of spontaneous abortion and situational crises associated with reproductive loss. As part of her MScN course requirements, she also completed four key informant interviews with a doctor, nurse, psychologist, and clinical director who provide fertility care in conjunction with Ontario's

fertility program, allowing her to gain an etic perspective of the phenomenon. This researcher is in a unique position as she has provided physical care and emotional support to individuals who have suffered treatment failure or spontaneous abortion following the use of IVF, but has not personally experienced the phenomenon of interest. As such, she is able to approach the study with empathy and respect, but also remain open-minded towards the experiences and stories shared by participants.

The other members of the research team offer expertise within the realms of mental health, maternal-newborn health, fertility care, and qualitative research. Dr. A. Vandyk (BScN, MSc, PhD, RN) has extensive experience exploring the mental health underpinnings of clinical encounters, while Dr. W. Peterson (BScN, PhD, RN) has a strong background in maternal-newborn health, as well as primary care initiatives. Both of the abovementioned committee members are experienced in qualitative research. Danielle Dubois (BScN, MHS, RN) has a comprehensive understanding of fertility care at both a provincial and national level. She is an active member of the Canadian Fertility and Andrology Society's Nurses Special Interest Group Executive Committee, has over 14 years' experience in the field, and has been involved with the Ontario Fertility Program since its inception in December 2015.

Considering the sensitive nature of the subject and the freedom of speech afforded with an open-ended interview approach, my experience as a Registered Nurse allowed me to respectfully explore the depths of the phenomenon. Further, I was able to offer debriefing sessions and suggest appropriate resources that may be beneficial to the participants, such as 24-hour helplines.

Data Collection

A dual approach to data collection was taken with the intent of gaining rich, in-depth data from the one-on-one interviews and exploring participant demographics through a brief questionnaire.

Interview

Data was collected through the use of individual semi-structured, open-ended interviews in person (Sandelowski, 2000). The goal of this approach was to discover the "who, what and where of events or experiences" (Sandelowski, 2000, p. 338) as described by individuals who have experienced the phenomenon. As McGrath et al. (2019) explain, this interview approach is preferable when exploring the "interviewee's subjective perspective of a phenomenon" (p. 1). In addition, semi-structured interviews are congruent with the qualitative, constructivist nature of the study and provided the opportunity for individuals to provide rich descriptions of their experiences, thus increasing transferability (Lincoln & Guba, 1985). The interview guide consists of seven questions or investigative statements, such as "Tell me about your experience of undergoing funded IVF" or "Tell me about when you found out that treatment had been unsuccessful" (Appendix D) (McGrath et al., 2019). Additional probes were used to gain more in-depth data, such as "How did you feel when that happened?" It is imperative to recognize that the interview guide, although semi-structured, allowed the flexibility for deeper discussion and further exploration of emerging topics (Turner, 2010). DiCicco-Bloom and Crabtree (2006) state that interviews can range from "thirty minutes to several hours" (p. 315) based on the interviewee's responses. Taking that into account, it was estimated that the interviews would take approximately 60 minutes to cover the topics discussed above. A general interview guide approach was employed to create the comfort and rapport of general conversation, while

pursuing the ever-present goal of data acquisition (Turner, 2010). The interviews were recorded and transcribed verbatim by the PI in an effort to ensure that the most accurate depiction of the phenomenon was captured.

Interview Details.

Over the span of approximately seven weeks, I completed eight one-on-one interviews. Six interviews were conducted at participants' homes, while one took place at a participant's workplace and one was held on the University of Ottawa campus. The interviews ranged in duration from 57 minutes to one hour and 45 minutes. The average interview time was one hour and 26 minutes.

Demographic Questionnaire

Participants were also asked to complete a demographic questionnaire inquiring about factors such as age, ethnicity, cause of infertility, and partner status (Hammer, 2011). This approach to data collection was chosen as it allows for a clear depiction of sample characteristics and, therefore, increases transferability (Lincoln & Guba, 1985; Polit & Beck, 2017). The questions were crafted in a manner that promoted adequate data acquisition by providing various potential answers and the opportunity to elaborate (Appendix E).

Structuring Questions.

The answer options pertaining to participant age increased incrementally by five year periods with the final response category spanning all participants greater than 43 years of age. The provincial funding program's requirements restrict access to funded IVF to citizens under 43 years old and the responses were structured to reflect this criterion (GO, 2019).

The question inquiring about primary language use at home was based off of local census results; the top five languages utilized in the region were included in the questionnaire.

Participants were also provided with the option to specify an alternative language (Statistics Canada, 2012).

The provincial After-Tax Low-Income Measure (LIM-AT) can be calculated by dividing the after tax provincial household median in two (Statistics Canada, 2017b). Using this measure, families with a household income less than $37,143.50 are considered to be low-income (Statistics Canada, 2017b). After discussion with the thesis committee, it was decided that due to the sensitive nature of financial disclosure, that the LIM-AT would be rounded to $40,000 and all household incomes less than that value would be clustered together. Furthermore, all subsequent response ranges increased by increments of $40,000 with incomes greater than $160,000 clustered together.

Questions regarding level of education, ethnicity, and partner status were also included. The thesis committee brainstormed a list of potential responses based on perceptions of local culture, while ultimately providing the participants the freedom to specify their personal characteristics.

Four fertility-specific questions were also included in the questionnaire. These questions were developed in an attempt to increase the transferability of the study findings to other contexts with similar patient demographics and fertility histories. The process of screening these questions are further detailed below.

Sensitive Content Reflection.

The demographic questionnaire included four fertility-specific questions. These questions explore potential causes of infertility, number of reproductive losses experienced, types of fertility treatments previously used, and number of IVF cycles undergone by the participant, including the funded cycle. These questions were initially screened by the committee member

with expertise in fertility care to ensure that accurate language was being used. In an effort to maintain utmost respect for the participants, a third party who has experienced infertility and has had extensive experience working with individuals with infertility was consulted. The consultant provided feedback regarding the appropriateness of word choice and question structure. Based on the feedback acquired, minor changes were made prior to submission to the ethics board.

Data Analysis

Sandelowski (2000) claimed that "qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies" (p. 338); however, she later clarified that both qualitative content analysis and thematic analysis are routinely employed in qualitative description (Sandelowski, 2010). Qualitative content analysis is an approach used to deconstruct large bodies of narrative text into smaller, systematically organized codes and categories (Vaismoradi et al., 2013). This approach to data analysis is compatible with the research design, because it allows researchers to minimize interpretations, while subsequently exploring the intricacies of the data, including trends and relationships (Vaismoradi et al., 2013). Data analysis and collection occurred simultaneously, allowing the study to evolve in a cyclical manner (Adom et al., 2016). This process was inductive, meaning categories emerged based on patterns derived from the raw data rather than preconceived theories, which further reflects the constructivist nature of this study (Adom et al., 2016).

Conventional content analysis was used as it provides an appropriate depth of data exploration for the descriptive design without taking on an interpretive feel (Hsieh & Shannon, 2005). This method of analysis also supports the exploration of a phenomenon that is not well understood, such as the experiences of women who have suffered treatment failure or spontaneous abortion after a funded IVF cycle (Hsieh & Shannon, 2005). All of the data was

read multiple times and key concepts were identified (Hsieh & Shannon, 2005). Codes were developed reflecting the key concepts in the text and further sorted into subcategories (Hsieh & Shannon, 2005). Finally, the codes and categories were defined, and the findings were disclosed, including the relationships between the categories and subcategories (Hsieh & Shannon, 2005).

Analysis of Demographic Data

Nominal and categorical measurement was used to quantify the demographic data obtained from the questionnaire (Polit, 2010). Univariate descriptive statistics, such as ranges and percentages, were used to depict how certain participant features were represented within the sample (i.e. age range of the women) (Polit, 2010).

Rigour

Guba and Lincoln's (1994) five principles for developing trustworthiness in qualitative research were woven throughout the study design, including credibility, confirmability, dependability, transferability, and authenticity. As part of the requirements for the University of Ottawa's graduate-level nursing course titled "Advanced Nursing Practice in Primary Health Care" (NSG 5210), the researcher performed key informant interviews with a physician, nurse, administrator, and psychologist to gain an etic perspective of the population and setting during the time period spanning from January 1st, 2019 until April 17th, 2019. This approach supported the use of prolonged engagement and peer debriefing to enhance the credibility of the study by increasing the likelihood that the researcher has gained a thorough understanding of the phenomenon (Korstjens & Moser, 2018; Lincoln & Guba, 1985). Detailed field notes and audit trails highlighting decisional pathways and rationale for those choices were used to enhance the study's confirmability (Korstjens & Moser, 2018; Lincoln & Guba, 1985). The audit trail combined with verbatim quotations from the raw data were employed to support the study's

findings, in addition to enhancing the confirmability and dependability (Korstjens & Moser, 2018). The experiences of IVF and treatment failure or spontaneous abortion were described in great detail to ensure that an outsider is able to conceptualize the participants' expressed thoughts and experiences within this specific context (Korstjens & Moser, 2018). Furthermore, combining descriptive statistics with thick descriptions increased the transferability to other contexts (Hammer, 2011). Finally, various verbatim quotes from diverse participants were used to "fairly and faithfully show a range of realities" (Polit & Beck, 2017, p. 560), thus increasing the trustworthiness of the study by addressing the principle of authenticity.

Reflexivity

Reflexivity is another strategy employed in qualitative research to increase the rigor and integrity of the study (Dempsey et al., 2016; Etherington, 2004). During this process, the researcher actively uses critical reflection to document personal thought processes, ideas, and biases that could influence data collection and analysis (Hsieh & Shannon, 2005).

Throughout the research process, I employed several strategies to promote reflexivity and self-reflection. After each interview, I wrote a brief summary of the encounter and reflected on my personal interpretation of the interaction, often noting the general atmosphere and the participant's demeanour, as well as approaches used to build rapport and promote the exploration of the participant's experiences. I also provided contextual references and rationales for my methods of interviewing and described decisional pathways pertaining to the pursuit of certain lines of questioning. For example, in one reflection I explained how I was about to ask the participant about her experiences of grief after reproductive loss and the impact that her infertility journey had on her relationship with her partner when her family members arrived. Although the participant candidly explained the purpose of my visit and continued to discuss

topics that arose prior to their arrival, I chose not to pursue these questions in an effort to respect the participant's privacy and ensure that the responses that she offered would not be influenced by the presence of third-parties. She agreed to answer follow-up questions via e-mail and those personal topics were further discussed at a later date.

After each interview, I made a conscious effort to reflect on the main topics discussed, mentally noting the similarities and differences between the most recent interview and those done previously. I verbally synthesized the data to my thesis supervisor who identified key words and descriptive statements as I spoke. We then collaborated to create a list of potential categorizes based on the summary I had presented to her.

After we identified the emerging categories, I analyzed the first transcript and highlighted key quotes supporting those categories. I then proceeded to analyze the second and third interview transcripts. I noted three additional sets of data that I thought could potentially emerge into categories but recognized that the remaining transcripts needed to be analyzed before any further decisions could be made. After analyzing the initial three transcripts, I sent it to my thesis supervisor for review. When I received her feedback and approval, I created a general template with the categories that had already emerged and used it to guide the analysis of the other five interviews. I actively identified information that did not support the previously developed categories and sub-categories. After analyzing transcripts four through eight, I amalgamated the data, creating an independent document for each category that included a list of supporting quotations.

I then met with my thesis advisory committee. During that meeting I summarized the interview process and the preliminary analysis findings. The data collection and analysis process was found to be appropriate and feedback was received. I then went back to the data that did not

reflect the existing categories, analyzed the content, and developed an additional category. I also reorganized some of the existing categories to better represent the data. From there, I proceeded to write Chapter 4: Results.

As the study progressed, I continued to be vigilant in recognizing my role as the researcher and the subsequent impact that I have on the data. I made a concerted effort to keep detailed notes and provided context for all major decisions. I used the strategies described above to minimize personal projections or bias and mitigate any risks of misinterpreting the data.

Ethical Considerations

Prior to the initiation of this study, approval from the Research Ethics Board (REB) at the University of Ottawa was obtained (Appendix F). The participating support group did not have an ethics board; however, administrative approval was required prior to recruitment. Full disclosure of research activities and expected level of participation were provided to the participant, including, but not limited to the study purpose, description and duration, foreseeable risks, potential benefits, researcher's contact information, the voluntary nature of the study, and the right to withdraw at any time without consequence (Appendix G) (Government of Canada [GC], 2014). Participants signed an informed consent form indicating they voluntarily agree to participate in the study and be audio-recorded (Appendix H) (GC, 2014). A mutually agreed upon date, time, and location was chosen that promoted safety, comfort, and privacy for the interview (Elmir et al., 2011). Informed consent was obtained at the beginning of the interview. Following the interviews, the recordings were transcribed by the PI and stored on a password protected external hard drive that was locked in a filing cabinet in the PI's home office (GC, 2014). All direct identifiers, such as personal and organization names, were removed from the transcripts or changed to pseudonyms to de-identify the data through anonymization (Cavoukian

& El Emam, 2011). Physical copies of the data were kept in a locked drawer in Dr. Vandyk's office during the data collection period (University of Ottawa [UO], 2019). After the data collection period, the list of pseudonyms will be stored securely in the Centre for Research on Health and Nursing at the University of Ottawa separately from identifying information. In addition, all electronic and paper documents will be stored in the Centre for Research on Health and Nursing. This information will be safeguarded in the above stated manner indefinitely, but at minimum for the duration of the five-year data conservation period beginning after data collection (UO, 2019). The data will be kept indefinitely for the purpose of potentially performing secondary analysis in the future. This is in keeping with the consent obtained from participants, who have agreed to have their interview data used in the pursuit of a doctoral degree if the PI chooses to do so. At the point in which the potential for additional analysis is no longer required, the physical documents will be confidentially shredded, and the electronic data will be securely deleted. The external hard drive used for the purpose of this thesis only contains information pertaining to this research study. As such, the entire hard drive will be securely erased and set back to manufacturer's settings using the step-by-step instructions specifically designed for the device. These instructions can be found electronically on Seagate's website under the heading "How to Securely Erase Your Hard Drive".

Due to the sensitive nature of the topic, the interviewer offered a debriefing session to discuss emotional responses or concerns regarding the interview content and the process of re-experiencing the phenomenon through reflection (Dempsey et al., 2016). The interviewer is a registered nurse skilled in debriefing with experience in emergent situational crises. In addition, the participants were provided with written information regarding 24-hour telephone support

options, including the Mental Health Crisis Line, the Distress Centre of Ottawa Region, and Connex Ontario (GC, 2014; Dempsey et al., 2016).

Participants received a $25 prepaid VISA gift card in appreciation for their time, plus reimbursement of parking as applicable (Wellesley Institute [WI], 2018). This value is reflective of current trends in Ontario (WI, 2018). In addition, small food items, such as cookies, muffins, and water, were offered during the interviews as a token of appreciation (WI, 2018).

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Chapter 4

Results

Results

In this chapter, I present the findings of the study, which explores the following research question: How do women who have suffered treatment failure or spontaneous abortion after funded in vitro fertilization cycles describe their experiences? First, the demographic details of the research sample are provided, including ethnicity, primary language, household income, education level, and partner status. Next, the experiences of using funded IVF are described through the use of eight categories (and six subcategories), which include: “Recognizing Something Is Wrong”, “Aging While Waiting” (“Uncertainty”), “Being Just a Number: Factory”, “Reacting to Others: Getting Bingo’d”, “Free, but Paying a High Cost” (“Physical Costs”, “Financial Costs”), “A Rollercoaster of Emotions” (“Greif”), “Shifting Relationships” (“Infertility’s Effect on Relationships”, “Disclosing”), and “Looking Ahead and Moving Forward”. Finally, the benefits and challenges of using the Ontario Fertility Program (OFP) to access funded IVF are summarized within a table below, as well as recommendations on how to improve the program as identified by the participants.

Demographic Data

All eight participants in this study self-identified as women, with ages that ranged from 28 to 43 years old. Seven of the participants indicated that their ethnicity was white or Caucasian and one participant identified her ethnic background as black or African American. All participants selected English as the primary language spoken at home; however, one individual indicated that she also spoke French in an equal capacity. All participants reported successfully completing some level of post-secondary education, including college diploma (n=2), bachelor’s degree (n=3), and master’s degree (n=3) (Table 3).

All participants, at the time of the interviews, were in long-term heterosexual relationships and cohabitated with their male partners. Six participants described their relationship status as married and two indicated that they were common-law. Three of the eight participants reported having one biological child. Five participants experienced primary infertility. The participants reported their annual household income, considering joint earnings with their partners. The household incomes ranged from $40,000 to greater than $160,000, with all participants earning more than $37,143.50, which is the provincial Low-Income Measure After-Taxes (Statistics Canada, 2017) (Table 3).

Table 3

Sociodemographic Characteristics of Participants

Characteristics	Participants (N=8)
Age *n* (years)	
28-32	1
33-37	3
38-43	4
Range	28-43
Ethnicity *n* (%)	
Black/ African American	1 (13%)
White/ Caucasian	7 (87%)
Highest Level of Education *n* (%)	
College diploma or certification	2 (25%)
Bachelor's degree	3 (37.5%)
Master's degree	3 (37.5%)
Partner Status *n* (%)	
Married	6 (75%)
Common-Law	2 (25%)
Household Income *n*, (%)	
$40,000-$80,000	2 (25%)
$80,000-$120,000	1 (13%)
$120,000-$160,000	3 (37%)
>$160,000	2 (25%)
Number of Children *n*, (%)	
0	5 (62%)
1	3 (38%)

Fertility Status

Female factor infertility (n=3) and unexplained infertility (n=3) were the two main reasons that the participants accessed the provincial fertility program. Less common reasons for accessing the program included male factor infertility (n=1), as well as a combination of both male and female factor infertility (n=1) (Table 4). As per eligibility criteria, all participants accessed the provincially funded IVF cycle, however three participants also used additional IVF cycles, with two of these participants having paid out-of-pocket for a subsequent IVF treatment after a failed funded cycle. Of the eight participants, three tried IVF exclusively. Two participants used both IVF and intrauterine insemination (IUI) in an effort to become pregnant. Three participants experienced one reproductive loss, half of the participants (n=4) experienced two reproductive losses, and one participant experienced more than two reproductive losses. The types of reproductive losses included treatment failures, miscarriages of single and twin gestations, as well as ectopic pregnancies.

Table 4

Reason for Accessing Funded Fertility Program

Reason for Accessing the Ontario Fertility Program	
Male factor infertility	1 (13%)
Female factor infertility	3 (37%)
Male and female factor infertility	1 (13%)
Unexplained infertility	3 (37%)

Recognizing Something Is Wrong

Each participant described a period of time, typically six months to a year, during which they consistently had unprotected sex without becoming pregnant: “So we started trying to conceive four years ago. I knew I had endometriosis, but I didn’t know how severe it was. We tried for a full year naturally.” (Mary) Participants became hyperaware of their menstrual cycles,

describing the feelings that accompanied their menses and the undeniable evidence that another month had passed without becoming pregnant: “Once you start thinking about it and noticing your ovulation patterns, it’s hard not to notice it and not know. Things become kind of more forced, but at a certain point you feel like there’s an issue or something.” (Sara) Participants were initially faced with uncertainty as they actively tried to conceive naturally without success and began to wonder why they were not becoming pregnant: “I’m young, relatively young, why isn’t this happening?” (Wellie) Despite trying naturally for varying durations of time, the inability to get pregnant forced participants to face the fact that there may be an underlying issue.

Feeling as though there was something “wrong” was a commonly shared experience, prompting the participants to seek primary health care services: “We had testing done just to see what was wrong with us.” (Raelynn) Participants who received an explanation for their infertility, experienced a sense of relief and their focus shifted to “fixing” the problem: “Bam! This is what’s wrong with you, now get it fixed. Except got it fixed and still nothing.” (Wellie) Meanwhile, participants diagnosed with unexplained infertility found the ambiguity frustrating and were often unaccepting of the diagnosis: “That’s what they said to me, ‘Oh it’s unexplained’. I’m like, ‘No, I’m not taking that it’s unexplained, there’s something wrong’.” (Abigail)

All participants decided to pursue IVF after enduring ongoing fertility challenges: “We got to the point where my age was increasing, we decided to try IVF because trying naturally for five years and not getting anywhere: no pregnancies, no miscarriages, nothing, was difficult.” (Raelynn) Whether these challenges were unexplained or resulting from an underlying condition: “They discovered through a sperm sample that there was actually no sperm …He said that our only option would be in vitro fertilization and a special type,” (Amy) the decision to pursue IVF

was made with the ever-present hope of having a child: “She did say that our best chance was with IVF.” (Skylar)

Aging While Waiting

The association between increasing age and the declining probability of conceiving naturally or with artificial reproductive treatments was widely discussed. As such, aging became the focus of many participant-healthcare provider interactions. Older participants found the use of terminology like, “advanced maternal age” and “geriatrics” to be offensive, sometimes acting as a barrier to accessing care: “A very big group of us are ‘geriatrics’. Come on, lets change that. Come on, please. It’s hard enough as it is then we have to deal with that kind of language.” (Francine) Conversely, younger participants felt that their concerns regarding their age were not taken seriously:

> “Thirty-one is young and 35 is not. There’s not a lot of time between that. It felt like there was a cavalier attitude towards my age, because you’re telling me I’m young and not to worry and at the same time you’re telling me I have to wait a year and then it ended up being more.” (Mary)

Participants were acutely aware of their advancing age, thus making the timely acquisition of fertility services, like IVF, a priority: “But because I’m old, it was kind of like we have to get you guys in there or start looking at something.” (Raelynn) Advancing maternal age became a source of stress and anxiety as the participants faced variable wait times: “From my perspective, it was panic. Time is ticking. We need to at least try [artificial reproductive treatments].” (Sara) Most participants waited over a year to access their funded IVF cycle, which they described as extensive given how increasing age is detrimental to fertility: “Regardless it would have been a year, because of access to the funding, so I do think it’s too long, because

some people don't choose that option until they're a little bit older." (Skylar) Further, several participants had to wait for the annual budget to renew in order to receive their funded IVF cycle, which was frustrating because external timelines dictated their access: "The secretary said, 'we've went through our funding, we can't get you in until the spring'; I was frustrated that we had to wait that long, because we had made the decision." (Amy)

Participants with underlying conditions that needed treatment or surgery to "correct" their reproductive organs before pursuing IVF also faced wait times associated with these interventions: "They can't go into [a funded IVF cycle] knowing that you can't do a fresh transfer. So they were like, 'You're going to have to have the polyp removed and it's going to be three to six months'." (Sara) Having to wait for these procedures was challenging for the participants, because of the uncertainty of when the treatment would take place and how it would impact the funded IVF cycle: "I was pretty depressed at that point; all of my friends that got the call were in the middle of their IVF cycles and I was just waiting, waiting for surgery." (Sara) Participants who required disease-specific interventions prior to obtaining IVF were faced with the harsh reality that their condition could worsen while they awaited care:

> "If I had been able to do it as soon as we were ready, we might have had different results. Having to wait meant that my endo got significantly worse, which meant that my ovaries were more damaged, which meant they couldn't produce healthy eggs." (Mary)

The progressive nature of these conditions caused fear that the disease would return in the post-operative period while they waited for their funded IVF cycle: "I was like, 'Imagine if we wait a month, they make me do the test, [the polyp] comes back and I have to do surgery again? Which could still happen now." (Sara)

Uncertainty

The participants explained how the process of waiting and aging was mired with feelings of uncertainty, unmet informational needs, and a pursuit for answers. Uncertainty was first felt when the participants waited for pending test results: "I didn't know if I had a polyp or not and I had to wait for a follow-up appointment to even get the referral for polyp surgery." (Sara) Sometimes, participants were aware that their test results were abnormal, but were not provided information or explanations until much later. This lack of information caused angst and heightened feelings of uncertainty:

> "The problem is at the ultrasound, because I'm such a Dr. Google, she had to go get another technician and the second she did that I was like 'what did she see that I'm not seeing'. So, I'm watching her click things and now I know what she was doing, but in the moment I didn't. In the moment, I'm like 'what's going on? What's in there? Is there a mass or tumour? Tumour, tumour, tumour', because that's where your brain goes. You get that momentary panic, because there's something and she's like 'there's just something complex about your ultrasound'. I said, 'well I had a c-section'. I am trying to make up reasons… I waited with the theory of 'complex' until I saw [the fertility doctor] and he told me what 'complex' meant…It was frustrating, because I knew there was something on my ultrasound that you're not telling me." (Wellie)

Uncertainty also coloured the egg retrieval, fertilization, and embryo transfer processes. With minimal information or healthcare support offered between egg retrieval and embryo transfer, the participants were left wondering whether their embryos were viable:

> "I can't remember how long it was, but the anticipation of waiting for them to call to see if any eggs were fertilized was hell. It felt so long. It was so stressful, because what if they don't take? What if I don't get any eggs out of it?" (Abigail)

The time-sensitive nature of embryo selection, which occurred immediately prior to transfer, left participants feeling rushed and anxious: "Having five minutes to weigh a medical decision that changes your life is not adequate." (Wellie) The uncertainty associated with unmet informational needs extended beyond the embryo transfer phase, with many participants stating they lacked the information required to make informed choices:

> "I was super anxious that anything I was going to do was going to affect implantation. They were pretty vague about that. They were like, 'Don't do too much exercise, you can do some but don't do too much; You don't have to rest, but don't go too hard'…That two week wait was very difficult." (Mary)

During the two week wait period post-transfer, participants found it difficult to deal with the uncertainty of whether or not they would become pregnant and often sought additional information: "…Then I was obsessed, because I kept looking up on my phone for early signs of pregnancy." (Abigail) Although advised not to do home testing during that period, the majority of participants admitted that they could not bear the unknown and took over-the-counter pregnancy tests: "You're not supposed to because it doesn't help apparently, but I couldn't. I just had to, especially when I started bleeding." (Mary) However, inconclusive home pregnancy tests perpetuated feelings of uncertainty: "I tested, and it was negative. I felt like it was negative, but then I used [a brand name pregnancy test] and it was positive." (Sara) For participants who developed bleeding, the inability to differentiate whether the cause was related to implantation or

menses magnified stress levels and highlighted the emotional toll that uncertainty can have on an individual: “I think the worst part was just not knowing.” (Sara)

This need for information in the wake of uncertainty was unwavering even after treatment failure or miscarriage. Each participant attended a follow-up appointment with their fertility doctor, many of them arriving with unanswered questions: “I had a list of questions for my follow-up when it failed, I had a very large list.” (Wellie) Participants hoped to have their questions answered and find the cause behind their unsuccessful attempt, however, they were often provided no concrete explanation: “There were no answers, because they don’t know. I understand that they can’t understand what’s going on in the womb, but there were no answers. Everything was still unexplained.” (Raelynn)

Being Just a Number: Factory

The participants described their impressions of IVF care, stating that it mimicked a factory’s production line: “At the fertility clinic, it feels like a bit of a factory.” (Mary) The nature of IVF care left some participants feeling like services were outcome-oriented rather than patient-specific: “It was frustrating because I never felt like their plan was to help us, it was more ‘let’s get you in, get IVF, and get you out’.” (Raelynn) This linear approach to care was said to dehumanize the experience of IVF and highlighted what participants perceived to be an assembly line designed to get women pregnant: “Then when you get into the system you realize that you’re just a number and there’s so many of us there. Nobody has extra compassion for your story, because everybody has a story.” (Francine)

Participants described their interactions with healthcare providers as clinical in nature and devoid of emotion: “There are no warm and fuzzies, no cuddly and I totally understand that. I’m sure the nurses and doctors have to be a little emotionally detached because they do this every

day, but we don't." (Raelynn) They attributed this dispassionate approach to the routineness of these situations for the healthcare providers: "At that point he knew he had a plan, he had a protocol, because for him, he's seen it a thousand times; for me, I barely know your office, let alone your staff, let alone anything." (Wellie) The healthcare teams' lack of displayed emotion throughout the process reflected the participants impressions that they were just another number:

> "…they have dead eyes. I hate to say that. The nurses were wonderful. The doctors were very much like, 'On to the next. We will do what we can. We are trying to help you all', but they're not emotionally invested." (Francine)

Some participants felt that the healthcare providers' preoccupation with treatment outcomes was not conducive to developing personal relationships: "They care [about] the outcome, but it's so medical [that] it doesn't feel like there's any sort of personal relationship." (Mary)

Similarly, the, participants described how the physical environment of the clinics, specifically the crowded waiting rooms, reflected a sense of mass production akin to a factory setting: "Everyone is just shoved in this room and there's not enough seating in the waiting room. You feel like you're just in some sort of factory." (Mary) As treatment continued without success, participants began to associate the physical environment of the clinic with negative feelings: "I said, 'I don't want to see this place'. It was traumatic for me to just come back in here, to just come back in this building." (Amy) Once in their appointments, the participants felt rushed: "I didn't find it overwhelming, it's just that you wait a few months to get that appointment then you're in and out really quickly. They kind of rush you through…" (Sara), which left them feeling like "…just another number." (Abigail)

Reacting to Others: "Getting Bingo'd"

The participants discussed the comments that they endured from friends, family members, co-workers, and acquaintances. Being on the receiving end of comments like, "When are you having kids?" was a universally shared experience. In one way or another, participants faced invasive and often insensitive comments pertaining to their fertility and endured events that further highlighted their inability to become pregnant, like baby showers and pregnancy announcements. One participant explained that within the fertility community this phenomenon is referred to as "getting bingo'd." (Sara)

When reflecting on their own actions prior to facing fertility challenges, some participants admitted asking these same questions: "Before, I never thought about it when I used to ask people, but now I'm so conscious about it because everybody has a story." (Abigail) Only one of the eight participants was unbothered by these types of questions: "I think for me, the reason it doesn't upset me is because I know it's coming from a good place in people. Nobody is saying things maliciously to me. That's why it doesn't bother me. I just say 'thanks'." (Mary) However, this same participant later explained that she was subjected to "…lots of advice that's super unhelpful. The worst thing is that people tell you to just relax and stop worrying and it'll happen if it's meant to happen." (Mary)

Initially, when confronted with these comments, participants chose to provide reasons for why they were not getting pregnant, like "we still want to travel and enjoy being married," (Abigail) rather than discuss their infertility. Although most participants kept their fertility status private in the past, some indicated that they now openly discuss their struggles and use these instances as opportunities to educate the inquirer on infertility: "For that brief second in time, they actually register that maybe I shouldn't have asked that question and that is all I want to get

out of the conversation" (Raelynn) and "Most people asked a lot of follow up questions after those comments, which I felt was always constructive." (Francine) While the majority of the participants described receiving these comments from family and friends, one participant received "insensitive comments" (Francine) from healthcare providers as well. She clearly recounted how her doctor told her (on Mother's Day), "'Your ovaries are ridiculously high in your body' He was like, 'You can try naturally, but there's nothing anybody can do for you, we're not going to be able to do IVF.' He told me that on Mother's Day" (Francine). These remarks were not uncommon with "…nurses, assistants, techs, and residents making off handed comments" (Francine) about the participants' fertility.

Pregnancy announcements and baby showers were particularly challenging for the participants because of the comments about their fertility by others: "I hate baby showers… I don't like the 'oh you're next'." (Raelynn) Most of the participants found these situations challenging and chose to avoid them: "I only go if you're my best friend or you mean a lot to me. That's my rule about baby showers now." (Skylar) Although the participants reported that baby showers acted as reminders of their inability to conceive, they also provided an opportunity for some participants to focus on the happiness of others: "Now I've decided that instead of hiding in the corner, I'm going to put all my energy into throwing an amazing baby shower." (Wellie) And while it was possible for many of the participants to be genuinely happy for others who experienced pregnancy-related joy, this did not eliminate their heartache of not being able to conceive: "…I'm happy for her, but I'm still ruined for myself." (Raelynn) Despite sharing in the happiness of pregnant friends and family members, sustained infertility also led the participants to experience periods of "bitterness" (Wellie) towards pregnant women, baby showers, and

announcements: “Once I realized my turn wasn’t coming then there was some resentment.” (Mary)

Several participants employed measures to decrease their exposure to these types of messages: “I literally didn’t go on social media for a good six months to almost a year, because of that reason. It felt like every time I went on, there was a baby announcement.” (Abigail) When they could not avoid being around other pregnant women, the participants often felt angry, resentful, and jealous: “I was surrounded by all these pregnant girls…I had that constant reminder. It was so hard. I literally would cry all the time, because I’m like ‘why them and not me?’” (Abigail) For some, harbouring these negative emotions towards others also triggered feelings of guilt: “I was angry at the woman who was pregnant. I hadn’t really experienced that before. Before that, I felt guilty about being angry.” (Mary) As their personal fertility journeys progressed, participants indicated that they began to accept that others’ pregnancies had no impact on their ability to conceive: “You tend to get a little bit jealous sometimes, but then you bring it back to ‘that person who got pregnant has nothing to do with you not getting pregnant’”(Skylar) thus decreasing feelings of resentment towards pregnant women.

Free, but Paying a High Cost

The participants dismissed the view that IVF is “free” when accessed through the publicly funded program, because of the various ways in which the process was physically and financially taxing.

Physical Costs

Several aspects of the funded IVF cycle took a physical toll on the participants. The act of administering medication was very difficult for participants who feared needles:

> "I have a phobia of needles, which I didn't really fully understand how bad it was until I was faced with having to put needles in my stomach four times a day. I don't think I could have done it myself." (Mary)

Piercing the skin with a needle was deemed to be physically daunting: "To puncture your skin, it's a little harder than you think. Also, you know it's coming. You can't look away, you have to watch what you're doing, so that was hard." (Wellie) The blood tests required for cycle monitoring were also taxing on the participants: "The blood tests are endless, if you're scared of needles don't be infertile." (Skylar) The injections and blood draws were not only painful but left physical evidence of the procedures: "As time progresses there are only so many spots on my belly that don't have bruises." (Raelynn)

In addition to the marks left at the injection and blood draw sites, some participants were forced to deal with adverse medication effects: "Well it definitely makes you tired." (Sara) Participants recognized that the medications were intended to chemically and physically alter their natural biology to increase their chances of experiencing a successful IVF cycle: "I thought I was just tired, but that's what it was from, your body is creating mass surges of hormones right now and needs a little bit of a break." (Raelynn) Optimizing fertility by chemically altering hormone levels was often done at the physical expense of the participants:

> "Those were by far the worst shots of this whole thing. Well my husband had to do it and it had to go into the top of your thigh at the back here. [Indicates to buttock region]. They're painful. With me, they caused wicked mood swings. I was very depressed. I actually stopped doing the progesterone." (Amy)

The tests required to monitor these changes during the various stages of IVF left participants feeling physically and emotionally drained: "Then when you get home you're just exhausted;

emotionally exhausted and physically too, because you just underwent an ultrasound and bloodwork." (Amy)

Medication administration was demanding, with the participants being acutely aware that the fertility medications not only significantly impacted the body's physical and chemical composition, but also affected IVF outcomes:

> "I was melting down in front of our piano with all our drug regimen in front of me, trying to clean things and keep things sterile and not mess it up, because if I mess it up then there goes all of our chances. That is a lot of pressure. That is a significant amount of pressure; they do not prepare you for that mental capacity of pressure." (Wellie)

The fear of making a medication error weighed heavily on the participants because they recognized that improper administration could ruin their chances of becoming pregnant: "It's still very overwhelming, because you're like 'Oh my God, what if I don't do it right? Is it going to affect something? What if I do it wrong?'" (Abigail) Participants became fixated with the timing of medication administration, recognizing the importance of giving the drugs at the prescribed intervals: "I put 17 alarms for each injection." (Skylar) Medication storage was also a preoccupation for participants who feared that improper handling would negatively affect the drug's integrity and effectiveness: "I feel like I was more paranoid: should they both be in the fridge or should they both not be in the fridge?" (Sara) Medication administration, testing, and interventions associated with IVF caused substantial physical pain, impacted the participants' thought processes, and highlighted how funded IVF is not free in a physical sense.

Financial Costs

The participants were grateful for the opportunity to undergo a funded cycle, especially those who would not have been able to access IVF otherwise. However, most participants were

not fully aware of the out-of-pocket costs associated with the funded IVF cycle: “There was a bit of a surprise to see the cost involved with the free funding.” (Raelynn) The notion that the OFP offers free IVF negates the fact that the funding does not include the cost of fertility medications, which typically ranged from $6,000 to $9,000.

The lack of medication coverage was identified as a challenge faced by those using the OFP: “The fact the medications aren’t covered [is a problem], because that’s a huge amount of money for most people…We were shocked by how much the medication cost.” (Mary) In an attempt to cover the cost of the fertility medications and alleviate the associated financial stress, some participants were forced to make both short and long term sacrifices, like taking on a second job or giving up vacation time: “So I went and said, ‘I will permanently give up eight days of vacation to have fertility benefits added to the package’.” (Wellie) These measures highlight the financial challenges faced by participants undergoing funded IVF and the sacrifices associated with the pursuit of parenthood. The economic burden of fertility medications was widely acknowledged; even participants with extensive drug coverage recognized the economic strain that medication costs posed for people without benefits: “I remember calling my husband crying, like ‘I feel so blessed, but at the same time I feel so bad and guilty, because a lot of women don’t have coverage’.” (Abigail)

Several participants sought professional mental health services throughout their fertility journey, which came with additional out-of-pocket fees. Although some participants found the publicly offered free support options to be beneficial, others felt that the environment was not conducive to their wellbeing, which led them to turn to costly professional services: “I stopped going to the support group, because it ended up becoming a bitchfest.” (Abigail)

Travel, by land and air, was another factor that increased the financial cost of accessing provincially funded IVF. Despite taking measures to mitigate the cost of travel, several participants were faced with substantial travel-related costs: “Sometimes when my husband would come, we would stay at the hotel down the street that has a medical rate.” (Francine) Participants who lived within close proximity of the clinics were also faced with travel expenses: “That’s another expense too, I was always having to uber to the clinic from my house, because I don’t have time to drive there, drive home, and then walk to work.” (Sara) From the medications and mental health services to travel expenses, it was widely acknowledged that the funded IVF cycle was not free.

A Rollercoaster of Emotions

The emotional responses elicited by undergoing a funded IVF cycle and subsequently suffering a reproductive loss varied between participants and changed as IVF treatments progressed. Regardless, the experiences were described as emotionally taxing: “The emotional toll, you cannot prepare anybody for that.” (Francine) The pursuit of parenthood and the subsequent process of undergoing funded IVF was described as: “This emotional rollercoaster that you’re going on, because you just want it to work so bad.” (Abigail)

Several participants depicted events that left them feeling excited: “There were no negative feelings about anything, we just had come to terms that this was what we were doing, and we were just excited to see if it was a three day or five day call.” (Raelynn) The anticipation of having the embryo retrieval, fertilization, and transfer offered an opportunity to feel happy as well: “I went to work after [the transfer]. I came, sat at this desk, and I worked. I rubbed my stomach, I talked to myself like a crazy person, and I felt good.” (Wellie) Some participants were so hopeful that they did not acknowledge the potential for treatment failure or spontaneous

abortion: “Even though I always knew that it was very possible and probably likely that it wouldn’t work, I hadn’t accepted it. Really in my heart, I thought it was going to work.” (Mary) As time progressed, the excitement and anticipation that was initially described by the participants evolved into stress and anxiety: “Going to appointments was more stressful for me.” (Skylar) The exciting and hopeful aspects of accessing funded IVF became overshadowed by the negative emotional effects of the experience, which were more prominently discussed by the participants: “It’s just this cloud that is constantly covering every aspect of your life; you can’t get out from under it.” (Francine)

Participants openly acknowledged how experiencing a reproductive loss after funded IVF effected their emotional state: “I was an emotional wreck at that point… I was processing the loss.” (Skylar) Some participants used words like anger, depression, and fear, to describe their emotional experiences: “When it didn’t work, there were so many emotions. I was angry. Mostly angry. I was very sad. I was shocked.” (Mary) Other participants detailed emotionally provoking events instead of attributing specific feelings to their experiences:

> “I bought a shirt that said, ‘big sister’ that I kept tucked in my drawer to put on my daughter to tell my husband, which is still tucked in my drawer. Just knowing that I’ll never get to use it. We’re starting to feel like we’re never going to get to use it.” (Wellie)

Regardless of how the stories were conveyed, most participants described dealing with a complexity of emotions that developed in response to challenges and hardships faced throughout their fertility journey: “It always starts with the sheer depression and angst and devastation. ‘This is just not for me. How can I do this?’ I always wanted [children], my husband would have been fine.” (Francine) Anger was a very commonly discussed emotional response to treatment failure and miscarriage after funded IVF: “I was angry when I got my period. I was like, ‘It didn’t

fucking work." (Wellie) Witnessing expectant mothers engaging in unhealthy habits and learning of women who became pregnant unintentionally were experiences that infuriated the participants. It was difficult for these participants to accept that someone could become pregnant inadvertently when they faced tremendous obstacles: "You've got to be fucking kidding me, you're 40 years old and you accidentally get pregnant? I've been trying for years." (Raelynn) Responding amicably to the news that someone conceived with no intentional effort was challenging for the participants: "Having to keep my composure as she told me that this was a child that she didn't want was very difficult." (Wellie) Furthermore, witnessing pregnant women participate in activities that are known to be harmful to a fetus, like smoking, was described as anger-provoking: "It made me really angry, because you're potentially damaging this wonderful miracle that you have inside you." (Amy)

Grief

Within this category, grief emerged as a central idea. Some participants were quite clear when identifying their grief reactions and used grief-related terminology: "You do go through grief." (Abigail) However, various other terms were also used to describe emotional reactions, like sadness and depression: "I was so sad after. I went into a huge depression for a while." (Abigail)

Participants frequently reported feeling sad or depressed; these feelings of sadness were all consuming: "I'd wake up sad. I'd go to bed sad. I'd cry all the time. I just couldn't get out of this hole, this black hole." (Abigail) After experiencing a reproductive loss, one participant's emotional wellbeing declined so significantly that when she finally became pregnant again, she no longer wished to pursue parenthood:

> "I was in the depths of despair. I didn't want it. I didn't want to be pregnant. Below it all was worry… I had crazy mood swings and I was depressed and all that. I had major depression and anxiety that summer." (Amy)

Participants expressed a longstanding desire to become parents. For some, motherhood became part of their identity and being unable to fulfil that aspect of themselves resulted in a grief reaction:

> "I've wanted to be a mom for as long as I can remember. Like being five, I was talking about what my kids were going to do when I grew up. It's a piece of my identity. Having to renegotiate that was a big part of the grieving process." (Mary)

Participants not only mourned part of their self-identity, but also grieved the loss of being able to conceive as traditionally dictated by human nature: "That was tough to hear that news and to find out that we're not going to conceive a child naturally. There was grieving that happened there for sure." (Amy) Facing a reality that challenged the participants' preconceived ideas about their family unit evoked a cycle of negative emotions, including grief:

> "After every setback came intense feelings of grief and I would cycle through denial, despair, hopelessness, and then acceptance, which was helped by making a plan. But then there was always an undercurrent of grief that would hit me at any time- when a friend told me she was pregnant, when watching a tv show, when thinking about my husband not getting the chance to be the great dad I knew he would be." (Francine)

IVF was typically seen as a means to address infertility and ultimately offered participants hope when other methods of conception failed. For some participants, IVF was their only chance of becoming parents, so experiencing a reproductive loss after funded IVF reiterated the death of an opportunity to become parents and destroyed that hopefulness: "Even though we

didn't lose any baby after IVF, that hit me harder I think than anything else. That was the hope. That was like 'Ok, if all else fails then you're going to do IVF' then it failed." (Skylar) For many, the grieving process involved mourning an envisioned child, the child that they had dreamed of and yearned for:

> "It's like you're grieving a child that never existed, but it still feels like a death, because I imagined this baby my whole life. I could picture it so clearly in my head. I felt like I already had a connection to this baby and then the baby died." (Mary)

Learning that a pregnancy was no longer viable signalled the start of the grieving process for some participants: "I think the grieving period started at that ultrasound when they said that they had arrested." (Amy)

Although grief was a prominent participant experience, it is important to note that it was not universal. One of the eight participants outwardly stated that she did not identify with the grieving process: "I was just sad that it didn't work. Through the whole IVF process, I never got a sense of grieving." (Raelynn) She went on to explain that after she had her funded IVF cycle, she conceived naturally and subsequently experienced a miscarriage that resulted in grief: "After the miscarriage, that's when I checked in to what grief was really, but not through this [IVF] process." (Raelynn) Interestingly, this participant felt that her failed IVF attempt redirected her towards methods that were in line with her personal values: "It helped us go back to the route that we would have normally gone to had this funding not been available." (Raelynn) Another participant also reported that she did not feel like she was grieving following her failed embryo transfer, but surmised that the context of her infertility and hopefulness of conceiving a biological child using her remaining frozen embryos prevented her from entering a grief period: "I don't think I am at the point yet that I've had to grieve, 'Oh ok, it's not happening naturally

now we're going to have to do adoption'." (Sara) Although these two participants did not experience grief in the wake of treatment failure, most participants shared reflections that depicted a grieving process.

Shifting Relationships

Infertility's Effect on Relationships

Although some participants felt that the strength of their partner relationships was unchanged, infertility and IVF posed challenges for both parties:

> "I think on our lives it has. It's been really hard, but as far as our relationship goes… It's been really hard on him, because of all the extra he's had to do and the emotional support. I think we're still very strong." (Mary)

Shifts within the partner relationship were more common than not in the wake of infertility and the subsequent pursuit of funded IVF treatments. The participants who felt that their relationship ultimately changed for the better, typically worked through hardships and challenges: "I feel like we are a lot better and stronger now than we ever were before…We had issues and problems before that had always been there, but now they're so much better because we've really worked on it." (Abigail)

For most participants, the mounting stress of experiencing infertility and subsequent IVF treatments placed a strain on their partner relationships:

> "It's very difficult on the marriage. It was very difficult for us. He is supportive, it's just the pressure that mounts on you. You just can't get around it no matter how strong your relationship is, no matter how supportive you are." (Francine)

The partner relationship became burdened by fertility-related concerns, which occasionally caused disagreements: "There were definitely frustrations. There were fights or arguments."

(Sara) The participants' attitudes towards their partners sometimes changed when they felt that their partner's actions were not conducive to conceiving, and this led to resentment and blaming:

> "You know, if you drank less and if you ate better, you know, we wouldn't be in this problem. I didn't really voice that to him, because I didn't want to make him feel crappier than he felt. There was some blaming going on in my mind." (Amy)

The participants' approaches to dealing with fertility challenges, like reproductive losses, were often incongruent with their partners' coping mechanisms, creating instability within the relationship that was not previously there:

> "My husband and I weren't necessarily on good terms; it's not that we weren't on good terms, but we were just not on the same page. He was processing the loss. I was processing the loss. We process very differently." (Skylar)

Several participants also felt that their infertility detrimentally effected the sexual aspects of their intimate partner relationships. Despite pursuing IVF, most participants continued to try to conceive naturally in parallel. While participants felt that their partners were mostly supportive, many admitted that their relationships became strained when the focus of their sexual activities changed from gratification to reproduction:

> "You lose your closeness. You lose, I don't know if it's like the passion, because you're not really making love anymore. You're just having sex, 'ok this is when I'm ovulating, this is when we have sex'. It's not meaningful anymore." (Abigail)

Sex became less appealing for participants who felt that the underlying intention of conceiving took away the sense of spontaneity: "You don't feel like engaging as much with your partner, because it's forced." (Sara) Participants attributed their lack of sexual desire to the feeling that intimacy was forced, which was also perpetuated by an ongoing awareness of ovulation and

periods of optimal fertility: “It’s thinly veiled why I don’t want to touch you then all of a sudden I’m like ‘hey baby!’” (Francine)

In addition to changes within partner relationships, the participants described altered relationships with parents, other family members, and friends. With parents, these were primarily driven by the financial burden associated with the participant’s infertility and IVF treatments. Despite being financially stable and capable of paying for additional self-funded IVF cycles independently, some of the participants’ parents readily offered to pay for additional treatments:

> “We had the money if we wanted to do it again. If we really wanted to do it again, we would have. And my parents are great, they said ‘If you want to do it again and don’t have the money, we will give it to you so you can try it again’.” (Raelynn)

In doing so, the participants described how their parents reverted to previous relationship roles in which they provided support and security through financial means: “My parents were really supportive and were like, ‘We’ll help you pay for it if you need to do it now’.” (Sara) With friends, participants explained how they were sometimes excluded from social events because of their childlessness:

> “All of your friends have kids and they’re getting together and they’re not inviting you, because they’re all going out to the [kid’s concert] and of course you don’t want to go to the [kid’s concert], but the idea of social isolation is huge.” (Mary)

The participants spoke about how their social relationships waned as friends became parents and they remained childless. Participants believed that their friends were unsure of how to manage these social situation and consequently chose not to invite them: “We would get excluded and that sort of thing. I think that was part of it, they didn’t know how I would react” (Amy)

Disclosing

The participants explained how they decided whether or not they would disclose information about their fertility status to their family and friends. The decision to share their experiences with someone was largely based on their perceptions of the existing relationship and whether they believed the person would be compassionate: "My closest friends, only obviously when I felt comfortable and to who I felt would be supportive. You wouldn't believe how many people have gone through fertility treatment when you start telling people." (Skylar) Participants chose not to disclose information about their infertility or treatment to people they felt would not react well because these interactions were detrimental to their own wellbeing:

> "I knew that telling them that I am infertile would mean having to have a lot longer conversation to still be at the exact same place I would be if I had not told them, because they wouldn't understand or grasp it… this would be more work for me and I needed to prioritize myself in that moment." (Wellie)

Sometimes, participants shared information but set boundaries regarding what they were willing to discuss: "I think my girlfriends, I just sent a text saying, 'It didn't work, and I don't want to talk about it'." (Raelynn) Even participants who openly discussed their stories within broad social circles set boundaries that limited the type of disclosure: "I'm very open – I wouldn't say on Facebook –but anyone who knew me in person knew what I was going through." (Francine)

Participants most often chose to share their personal stories with people who had gone through similar experiences because these individuals were more understanding of their situation and offered support: "I talk to people online or people that I know that are going through the same thing." (Sara) Different from others, one participant shared her experiences widely regardless of how she believed people would be received. She opted to do this because she felt a

responsibility to be open about her infertility and took the opportunity to promote fertility awareness: “And I feel a responsibility to be open as well, because I know that is not as easy for all women to talk about it and I feel like I can do that, so I want to do it.” (Mary)

Looking Ahead and Moving Forward

The participants explained how an integral part of the experience with IVF and pregnancy loss was planning: “So basically that was the other support strategy we had, we always had a plan and had ‘ok, what’s the next step?’ We were always looking at what to do next.” (Francine) Thinking prospectively and mentally preparing for the future helped the participants deal with adversity throughout their fertility journeys:

> “I was already prepared for the next step to tell you the truth. I knew in the back of my mind. Once she said it, it kind of confirmed what I already kind of knew. I was like, ‘Can we do IVF next month again?’ I was ready to just do it again. I was kind of in that mindset.” (Skylar)

Looking ahead and creating a plan of action was a universally shared approach to moving forward after experiencing treatment failure or spontaneous abortion after funded IVF: “I had to have plan a, b, c, d, e, f, g.” (Mary)

Participants either planned to give themselves time to decide how to move forward or planned to pursue parenthood through other means. Half of the participants reported how they initially planned on adopting if they were unable to have a child naturally or through the use of IVF, but those plans changed: “Originally, we had always said that we were only going to do the funded cycle; if it didn’t work then we would look at adoption, but then we kind of got scared by adoption.” (Wellie) After identifying various challenges with the adoption process, all of the participants who considered adopting decided against it: “I’ve heard that adoption is really

complicated and it's very expensive. I think if it was super easy, I'd maybe take that route over this one." (Sara) The cost and complexity of going through adoption was a deterrent for one participant (Sara). The inability to pursue IVF in parallel to adoption, the fear of a biological mother surrendering a child then later rescinding, and a lack of available adoptees were other reasons cited for not pursuing adoption.

The pursuit of parenthood continued for most participants, with many planning to undergo further fertility interventions. These interventions included partaking in subsequent IVF treatments, using donor biological products, accessing treatments at international clinics, and reverting to natural methods as an exclusive means of attempting to conceive. Regardless of the chosen path, the participants shared a commonality in that each had developed a plan moving forward.

Benefits, Challenges, and Recommendations

Throughout the interviews, participants discussed the benefits of the OFP, as well as the challenges that they faced during their fertility journeys. Participants drew on their experiences, offering recommendations for improving the provincial program. The participants' reflections on the OFP were described within the context of five elements. The table below provides a summary of these benefits, challenges, and recommendations (Table 5).

Table 5

Participant-Identified Benefits, Challenges, and Recommendations

	Benefits	**Challenges**	**Recommendations**
Financial Coverage	-Financial support minimized overall burden. -Increased access to fertility treatment.	Not applicable.	-Expand coverage for additional services. -Offer larger tax incentives. -Coverage for two IVF cycles.

	-Improved acceptance of seeking fertility care.		-Ensure sustainability of the program.
Availability of Program	-Universal access broadened treatment seeking population. -Increased access to advanced fertility services. -Increased likelihood of having a child. -Offered hope to participants. -Reassurance of having tried IVF.	-Limited number of clinics. -Requires frequent travel to appointments.	-Develop satellite clinics. -Normalize mental health care. -Coverage for mental health services. -Advertise resources.
Communication	Not applicable.	-Difficulty communicating with care providers.	-Address informational needs. -Limit points of contact. -Operationalize patient feedback.
Wait Times	Not applicable.	-Extensive waitlists.	-Encourage early enlistment in OFP. -Educate the general public on the OFP.
Appeal Process	Not applicable.	-Disparity in publicly and privately funded IVF rules. -Prohibition of multi-embryo transfers. -Lack of patient-centered approaches.	-Eliminate universal rules. -Address cases individually. -Improve appeal processes.

References

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Chapter 5

Discussion

Discussion

In this chapter, I provide a summary of the findings and discuss three key considerations: 1) grieving a reproductive loss; 2) Blenner's theory; and 3) getting bingo'd. I also offer implications for practice, policy, education, and research resulting from the study, identify the strengths and limitations of the work, and provide a conclusion.

Summary of the Findings

The purpose of this Master's thesis was to gain insight into the experiences of women who suffered treatment failure or spontaneous abortion after funded IVF. Sandelowski's (2000, 2010) descriptive design was employed to study this phenomenon. Convenience sampling resulted in a sample of eight primarily English-speaking, well-educated women of mid- to high-income households who fall within an age range that spans 15 years. Through the inductive process of qualitative content analysis, eight categories (and six subcategories) describing the participants' experiences were formed: Recognizing Something Is Wrong, Aging While Waiting (Uncertainty), Being Just a Number: Factory, Reacting to Others: Getting Bingo'd, Free, but Paying a High Cost (Physical Costs, Financial Costs), A Rollercoaster of Emotions (Grief), Shifting Relationships (Infertility's Effect of Relationships, Disclosing), and Looking Ahead and Moving Forward.

The participants' experiences with funded IVF and subsequent pregnancy loss began with the recognition that something was wrong and feeling like they needed to fix the problem affecting their capacity to conceive. The effects of waiting (for diagnosis, treatment, appointments, information) and the passage of time on their age and fertility was worrisome for participants, and they described a range of emotions felt in response to their fertility journeys that reflected hopefulness, anticipation, uncertainty, anxiety, and anger. The beneficial and

detrimental effects of infertility on their intimate partner relationships, as well as changes within their friendships and family relations were apparent, and the participants spoke to the ways in which they made their decisions to disclose information about their fertility status to family, friends, and the general public.

The physically taxing nature of undergoing funded IVF was described, including the act of administering injectable medications and the subsequent effects on their bodies, as well as the ever-present fear of improperly storing their drugs or making a medication error that would affect their chances at a viable pregnancy. The costs associated with fertility medications, travel to appointments, and additional health services, like counselling, were noteworthy, contradicting the notion that funded IVF was free. In the wake of a reproductive loss following funded IVF, participants planned to pursue parenthood through other means, like natural conception and additional IVF treatments. Finally, participants identified the benefits and challenges that they faced while using the OFP (Ontario Fertility Program). In light of these experiences, they offered recommendations to improve the overall program. These recommendations were related to aspects of financial coverage, availability of the program, communication, wait times, and appeal processes.

Key Finding One: Grieving A Reproductive Loss

Grief in the wake of infertility and reproductive loss is not a new concept, but the process of grieving treatment failure or spontaneous abortion within the context of *funded* IVF extends this body of knowledge. A reproductive loss, like treatment failure or spontaneous abortion, is experienced similarly to the death of a loved one (Brier, 2008). The notion that infertility and reproductive loss evokes a sense of grief is well documented (Harris & Daniluk, 2010; James &

Singh, 2018; Lukse & Vacc, 1999), and is congruent with the experiences expressed by the study participants, which speak to grief and IVF, as well as complex losses.

Grief and IVF

Lee and colleagues (2010) explored the experiences of women post-IVF failure, discovering that grief was central to the overall experience. Grief was also a prominent emotional response described by the participants of my study following treatment failure and spontaneous abortion during funded IVF cycles. This suggests that grief is tied to the experience of reproductive loss, regardless of the context in which the treatments were accessed (i.e. privately or publicly funded).

Over three decades ago Greenfeld et al. (1988) reported that advancements in IVF technology fostered unrealistic expectations for successful outcomes. By undergoing IVF treatment, patients developed a strong attachment to an anticipated pregnancy, which heightened their expectations for success (Greenfeld et al., 1988). Around the same time, Blenner (1990) reported that feelings of hope and determination within the infertility journey lead to a "selective perception" regarding treatment outcomes and a "strong discounting of negative information" (p.155). Similarly, despite being told that a successful pregnancy and live birth are not guaranteed when using IVF, the participants in my study recognized that their hopefulness prevented them from accepting treatment failure or spontaneous abortion as a potential outcome.

Having unrealistically high expectations negatively affects an individual's ability to cope in the wake of a reproductive loss (Peddie et al., 2005). According to Peddie and colleagues (2005), difficulty coping occurs because initial hopefulness quickly evolves into a sense of despair with ongoing unsuccessful IVF treatments. Reinforcing realistic expectations and recognizing when women are at risk for impaired or unproductive coping should be part of all

fertility care, regardless of funding. However, it is possible that the "one IVF cycle per lifetime policy" of the OFP perpetuated a more pronounced grief reaction because participants relied more heavily on the success of this one opportunity.

Complex Losses

Infertility presents a complex web of associated losses, including loss of having a biological child, loss of an envisioned child, and loss of the parenting experience (Conway & Valentine, 1988; Thorn, 2009). Within my study, the reality of not being able to conceive naturally marked the participants' first experience with grief during their fertility journey. The inability to conceive naturally and the subsequent realization that biological reproduction would require assistive measures, weighed heavily on the participants and sparked a sense of grief. In Thorn's (2009) study, she reported that loss and grief occur in varying stages, noting that one of the phases involves the "failure to conceive spontaneously" (p.50).

Sustained infertility despite concerted efforts to conceive marked the start of another phase in which the participants came to grieve the loss of an envisioned child. This notion of the loss of the envisioned child is often discussed within the context of disability, where the inability to produce a healthy child can result in the mother experiencing feelings of inadequacy and failure (Hugger 2009; Walter & McCoyd, 2009). Interestingly, this feeling as though something was wrong with them was a notable experience in my study, specifically during the period when participants were actively trying to conceive naturally. This notion of being "inadequate" is often embodied by the infertile woman. They interpret their inability to conceive naturally as being a personal defect, which damages the part of their identity that is tied to fulfilling the role of motherhood (Loftus & Namaste, 2011).

Infertility forces an individual to renegotiate their self-perception, which can cause an identity crisis for women who must assimilate their envisioned self as a mother with their infertility diagnosis (Kikendall, 1994; Thorn, 2009). Motherhood is a central component of self-identity for many women; thus, infertility threatens one's self-concept and what it means to be a woman on a personal level (Loftus & Namaste, 2011; Thorn, 2009). Participants in my study also reported grieving a lost part of themselves; the portion of their identity tied to motherhood.

Interestingly, Kerr (1999) reported that industrialized societies are more accepting of childlessness, which would suggest that the socially-induced pressure to fulfill the role of being a mother would be lessened for women living in an environment like Ontario. Ontario, as an industrialized province whose economy hinges on industrial development while also supporting high birth rates, fits this description (Cranston-Reimer, 2019; Kaur & Ricciardelli, 2017). However, research exploring this phenomenon, reports that in pronatalist regions, especially those where fertility services are subsidized, a woman's identity tends to be centered around motherhood (Greil et al., 2011). The findings of my study begin to provide some insight into the conflicting evidence explaining the interplay between societal values and identity formation for women. They suggest that, despite an increasing acceptance of childlessness from a social standpoint, fertility and motherhood continue to be instrumental in the development of a woman's identity, and that infertile women who have experienced a reproductive loss are susceptible to grieving the portion of their self-identity that is tied to a mothering role.

Key Finding Two: Blenner's Theory

I selected Blenner's (1990) Stage Theory of Passage Through Infertility to inform my theoretical thinking on this topic because it has been cited in publications exploring infertility.

Considering the findings through this lens, reveals several similarities between the theoretical explanation and the participants' lived realities.

Blenner (1990) describes the initial phase: Dawning of Awareness, as the pre-diagnosis period in which the couple actively tries to conceive naturally without success, recognizing the potential of having infertility. The category: Recognizing Something Is Wrong focuses on the participants' struggles to conceive and the path that ultimately led them to seek fertility services, reflecting this dawning of awareness described by Blenner (1990). It is interesting that 30 years after Blenner's (1990) study, this finding continues to be pertinent to the participants' experiences. Based on the findings of this study and Blenner's (1990) study, it is important to note that the initial stages of discovering one's infertility, and the subsequent decision to pursue fertility services, transcends time and crosses the barrier between public (i.e. funded) and private care.

In the phase: Facing a New Reality, Blenner (1990) describes how the infertile partner experiences feelings of guilt. In my study, three participants experienced female factor infertility, one participant's partner was diagnosed with male factor infertility, one participant described both male and female factor infertility, and three participants' infertility remained unexplained. Interestingly, the participants who were deemed to be the infertile partner, did not express these feelings of guilt. Instead, participants who had infertile partners (male factor infertility) appeared to blame their partner, specifically when the cause of infertility was thought to be associated with lifestyle choices. It may be that the timing of my study influenced the participants' perceptions and awareness of their guilt, because I did not capture their experiences at the time when they learned of their infertility. However, casting blame and the triggers perpetuating this behaviour are important to understand, because women who place blame on their infertile partners are more

likely to report depressive symptoms (Peloquin et al., 2018) and experience greater distress (Mendola et al., 1990). Within my study, participants who blamed their inability to conceive on their partners' lifestyle choices also reported increased conflict within the intimate partner relationship. This finding is unsurprising because when women cast blame onto their infertile partners, both parties tend to report lower relationship satisfaction (Peloquin et al., 2018). As a qualitative study, I cannot comment on the relationship between these two factors, however future work is needed to explore the effect of blaming on the experiences of infertility.

In Blenner's (1990) three phases: Having Hope and Determination, Intensifying Treatments, and Spiralling Down, immense hopefulness and anticipation evolves into disappointment, frustration, and exasperation. These findings were reflected in my study as the category A Rollercoaster of Emotions emerged. Interestingly, Benyamini et al. (2005) used the term "rollercoaster" (p.279) to describe the experiences of women with infertility, citing Blenner's (1990) publication as a reference. Blenner (1990) describes emotional responses to infertility and subsequent treatments, depicting a linear passage from stage to stage. However, participants in my study did not exclusively transition from "highs" to "lows" throughout their journey, often experiencing these emotions cyclically. The linearity of Blenner's theory was criticized by Gerrity (2001), who recognized that participants may spend varying amounts of time in each phase or, alternatively, not experience every stage. Although the findings of my study reflect some of these phases described by Blenner (1990), the cyclical process and notion that not all stages are experienced was also a finding of my study. This is noteworthy because it draws attention to the intricacies of the individualized experiences within the broader shared experience of infertility and fertility treatments.

The final two phases of Blenner's (1990) theory: Quitting and Moving Out and Shifting the Focus, centre around the decision to terminate treatments and the subsequent "peaceful resignation" (p.158) where couples shift their attention away from fertility to focus on other important aspects of life. None of the participants in my study discussed their experiences with these phases. Instead, fertility continued to be a fundamental aspect of the participants' lives, as was described through the category Looking Ahead and Moving Forward. It is possible that had the participants' been older or more removed from their reproductive losses, the change in focus described by Blenner (1990) may have been evident within the findings.

Key Finding Three: Getting Bingo'd

Women who experienced a reproductive loss after funded IVF reported "getting bingo'd", a term used by participants in my study to describe being exposed to insensitive comments regarding their fertility. Although this idea of getting bingo'd is not yet widely discussed in academia, informal platforms like Reddit and personal blogs present a vast collection of stories from individuals who have been bingo'd. Hintz and Brown (2020) authored the only study I could find pertaining to this notion of getting bingo'd. They explored the narratives of Reddit users to gain an understanding of the meaning creation behind getting bingo'd within the context of voluntary childlessness (Hintz & Brown, 2020). Hintz and Brown (2020) discovered that reproductive normativity was central to the experience of voluntary childlessness and getting bingo'd. Similarly, the participants in my study were often subjected to comments that reflected the notion that reproduction was a "normal" part of life. The findings of Hintz and Brown's (2020) study and my study illustrate how common it is for infertile women to be on the receiving end of such comments despite the lack of formal research.

Participants in my study also found it challenging to deal with pregnancy announcements and baby showers. Avoiding baby-related events is not a new concept for women with infertility; in fact, this behaviour has been documented in the associated body of literature for decades (e.g., Harris, 2017; Parry, 2004; Valentine, 1986). Several of my study participants took steps to prevent exposure to these types of messages by declining to attend baby showers and limiting their social media use. Given that women in the childbearing age group (18-44 years) are more likely to use social media than women of other ages (Clement, 2020), it is important to recognize that women with infertility often wish to avoid fertility-related content online, despite social media use being a central aspect of life for many women aged 18 to 44 years old.

Sormunen and colleagues (2020) discovered that women in the infertile community often seek information and social support on social media. Similarly, participants in my study described their use of social media and online forums to access information and peer support. Avoiding social media for fear of encountering pregnancy or baby announcements is challenging when it is through these platforms that they connect with other women who shared similar experiences. One study that surveyed women seeking fertility treatments in Ontario and Quebec found that 90% were interested in accessing peer support through online means (Grunberg et al., 2018). Although the research about this is sparse, it is logical to assume that increasing use of social media for peer support and information, may also increase the likelihood of exposure to fertility-related content on the same platforms. As such, it is important to consider the benefits and consequences of using social media as a means of accessing information and peer support within the context of getting bingo'd and reproductive loss.

Garnering an understanding of getting bingo'd can lend insight into communication strategies for those supporting infertile individuals and bring attention to the effects of getting

bingo'd on their well-being. It is also important to recognize the implications of getting bingo'd on social media, because women who have experienced a reproductive loss in the wake of funded IVF actively try to avoid pregnancy and birth announcements, while concurrently pursuing information and support on the same platforms. This finding creates the foundation for further exploration of the influence of social media on experiences of infertility, peer support, and the provision of information.

Implications for Nursing

The findings of this study shed light on the experiences of women who lived through reproductive loss following funded IVF. While the funded aspect of the phenomenon of interest was apparent in their shared stories, the implications provided below are transferable to other populations who have used IVF and experienced subsequent reproductive loss. The aspects of the participants' experiences pertaining to artificial reproductive treatments and pregnancy loss outside the context of funded IVF are reflected in the literature as described above in Key Finding One and Key Finding Two. In light of the study findings, nursing implications are discussed within the following spheres: clinical care, education, policy, and research.

Clinical Care

It is vital that patients feel that their fertility-related needs are acknowledged and valued. Participants in my study believed that healthcare providers who are exposed to these situations on a regular basis were "desensitized". Similar findings emerged from Kitzman's (2016) study where the participants perceived some of the providers as callous and lacking empathy. Understanding this perception is important because it can make patients feel that their experiences and mental health needs are not appreciated, like participants in Kitzman's (2016) study who felt that they were "…left alone to process the loss" (p.5). Ensuring incorporation of

psychosocial care into routine appointments is necessary when providing a comprehensive approach to offering fertility care. This approach is shown to diminish stress, improve patient well-being, and increase access and referral to appropriate mental health services (Gamerio et al., 2015).

Although participants received training, medication storage and self-administration was found to be one of the most stressful aspects of the IVF journey for women who had suffered treatment failure or spontaneous abortion following IVF. Introducing the concept of medication administration early in the journey may help participants conceptualize the process and become more comfortable with the idea of self-administration. Ensuring that professional advice is readily available to participants during the medication administration phase would also address feelings of uncertainty regarding this part of the process. Finally, offering virtual support for medication administration, to the small subset of women who are deeply uncomfortable with doing their own injections, would ease the burden of IVF treatments. Wosik and colleagues (2020) examined virtual care during COVID-19, discovering that video visits were a feasible and sustainable method of ensuring the continuity of outpatient care for patients with access to reliable internet. As such, nurses could offer virtual support through video conferencing during the medication administration phase, by assisting patients with needle landmarking, answering medication storage questions, and addressing side effects that may arise.

Education

Within the realm of fertility care nurses are responsible for delivering devastating news to patients, like disclosing that an embryo has arrested or that a pregnancy is no longer viable. From an educational perspective, the findings of this study highlight the need to equip nurses with the communication skills required to convey information to patients in an empathetic manner that

also addresses informational needs. This is crucial as unmet information needs were found to perpetuate feelings of uncertainty, and participants often perceived healthcare interactions to be cold in nature. Developing the communication skills required for such situations allows for the clear, accurate conveyance of information in a sensitive manner (Downe et al., 2013; Redshaw et al., 2014). Furthermore, learning about reproductive loss and grief, as well as the needs of the families, offers the opportunity to gain an understanding of the patient experience and provide individualized support (Stillbirth and Neonatal Death's Charity, 2016). The Stillbirth and Neonatal Death Charity's (2016**)** guidelines for professionals, details holistic, inclusive care that focuses on loss, grief, communication, and staff training. In addition to the nurses at the fertility clinics and obstetrical departments, emergency room nurses providing care to patients who have suffered treatment failure or spontaneous abortion after IVF may also benefit from training, specifically focusing on the Emergency Department Best Practice Suggestions developed by the Pregnancy and Infant Loss Network at Sunnybrook (2020). Women experiencing this phenomenon often seek emergency services for various acute presentations, like vaginal bleeding related to a spontaneous abortion, post-abortion infections caused by retained products of conception, and mental health crisis evoked by a reproductive loss. Delivering bad news and caring for bereaved families can be difficult, but training can increase staff confidence and subsequently reduce stress in such situations (Kenworthy & Kirkham, 2011).

Through the nursing diploma program (Registered Practical Nurse) and Bachelor of Science in Nursing degree (Registered Nurse), nursing students learn the foundational knowledge, skills, and judgment required to provide safe, patient-centered nursing care across a range of specialities, including maternal-child health and mental health. Content that speaks to reproductive loss could be incorporated into several courses within these programs. For example,

in addition to the traditional content offered in the maternal health course, case studies exploring the emotional effects of treatment failure and spontaneous abortion after IVF and the associated coping strategies, could be examined within the mental health course. In an effort to promote continuity in learning, students could also spend time at a fertility clinic as part of their maternity or community placements. This approach would ensure that students have the theoretical and practical experience to provide holistic care to women who have experienced a reproductive loss in the wake of IVF.

Policy

The OFP covers the cost of the IVF procedure itself, however the associated medications are paid for out of pocket by the patient. One of the main recommendations that participants offered for improving this program was expanding the OFP's coverage. Participants suggested adding more fertility services, larger tax incentives, and two funded IVF cycles. Winsor et al. (2020) surveyed OFP users who echoed these recommendations, suggesting medication coverage and funding for more than one cycle. Similarly, Jrade's (2016) unpublished work focused on Ontarians with infertility during the implementation of the OFP. This study explored the experiences of infertile Arab immigrant women, who felt that policy changes that supported the coverage of medication costs and enabled families to access more resources would improve the program (Jrade, 2016).

Undergoing IVF and subsequently suffering a reproductive loss was described as being an emotional rollercoaster. Counselling has proven to be helpful for individuals undergoing emotionally-charged situations, specifically in the short-term (Bower et al., 2011). Interestingly, Emery and colleagues (2003) found that 86% of couples who underwent pre-IVF counselling reported that it was helpful, despite never intending to do counselling prior to the study.

Meanwhile, of those couples who had intended to do pre-IVF counselling, 96% stated that the counselling was helpful, highlighting the benefits of pre-IVF counselling for all treatment seeking couples (Emery et al., 2003). Normalizing universal mental health services in fertility care may lessen the associated societal stigma, promote mental health, and benefit individuals who would not have sought these services independently. The Ontario government recently announced their plan to introduce the Roadmap to Wellness: A Plan to Build Ontario's Mental Health and Addiction System (Government of Ontario [GO], 2020). This plan was designed to address the fragmentation and challenges stemming from the current system using a four-pillar model: improving quality, expanding existing services, using innovative solutions to address gaps in care, and improving overall accessibility (GO, 2020). As the provincial plan is rolled out, it may be possible to offer an intake appointment and subsidize universally accessible care for individuals who have suffered treatment failure and pregnancy loss following IVF.

The universal set of rules that governs the OFP were perceived as being disadvantageous by many of the study participants who compared the program to the privileges afforded to people accessing self-funded treatments; individuals who pay out-of-pocket for IVF treatments are able to transfer more than one embryo at a time and participate in a freeze-all cycle. This is important because the women in my study who used the provincially funded program felt that they did not have the same rights as women who accessed IVF using personal means. Eliminating the universal rules and evaluating cases on an individual basis may increase the program's inclusivity and minimize perceptions of bias. Furthermore, streamlining the appeal process for patients who wish to challenge the current regulations would also help address the concerns voiced by my study participants.

Research

Certain elements of reproductive loss and IVF have been studied, like depression and anxiety post-IVF failure (Milazzo et al., 2016), but the subjective experiences of women who have lived through this phenomenon, as described in personal stories, has rarely been explored using a holistic lens. In light of the findings of this study, it is apparent that reproductive loss in the wake of IVF effects the romantic partner relationship; however, the partner perspective was not the focus of this study. It would be beneficial to pursue research that speaks to the partner perspective of reproductive loss, because it can offer further insight into the partner relationship and relationship dynamics during fertility treatments. Arya and Dibb (2016) set out to explore the experiences of infertility treatment "from the perspective of men" (p.242), recognizing that this field is understudied. Despite their research on the "male perspective" (p.242), Arya and Dibb (2016) identified several topics pertaining to fertility that require further research, including the psychological effects of treatment on men. This is interesting considering the emotional response to reproductive loss in the wake of IVF was a finding in my study.

Although all participants in my study were in heterosexual relationships, it is also important to consider that some women undergoing IVF cycles have same-sex partners. After a search of the literature, I did not identify any studies that focused on the experience of same-sex partners and reproductive loss in the wake of IVF. As a result, future research focusing on the experiences of same-sex couples who experience treatment failure or spontaneous abortion after using IVF is recommended.

In the current body of literature, studies pertaining to nurses and reproductive loss tend to focus on the effects of nursing care on the patient who is experiencing the phenomenon (e.g., Ozan & Okumus, 2017). Hutti and colleagues (2016) offer insight into the experiences of nurses

who care for women after fetal loss, however it was difficult to find articles that explore the subjective experiences of nurses providing IVF care, specifically in the wake of a reproductive loss. Due to this research gap, it is difficult to determine if the nurses are aware of the obstacles faced by their patients and whether they are capable of supporting their patients across the continuum spanning pre-treatment to post-IVF failure. Research exploring the experiences of nurses will provide insight into their perceptions of the program, capacity to provide care to this population, and the professional challenges that they face. It would be beneficial to research the impact that caring for this population has on the nurses, focusing on compassion fatigue as previously suggested by Hutti et al. (2016).

Strengths

Topics explored within the context of nursing research often focus on personal matters that are considered to be sensitive in nature (Enosh & Buchbinder, 2005). Elmir et al. (2011) reflected on the works of Cowles (1988) and Sieber and Stanley (1988) "to define a sensitive topic as one having the potential to cause physical, emotional or psychological distress to participants or the researcher" (p. 12). In light of this definition, infertility and reproductive losses are sensitive research topics.

Shirmohammadi and colleagues (2018) reported that safeguarding the participants' confidentiality and privacy, as well as obtaining informed consent, were critical ethical considerations in sexual health research. Those ethical considerations were key features on the ethics application that I submitted for my study, which included the review and approval of consent forms and the measures implemented to ensure confidentiality (i.e. allowing participants to choose their pseudonyms). Ethical considerations were cornerstone to my study with confidentiality and the wellbeing of the participants being of utmost importance. The approaches

that I described above align with the recommendations found within the current body of literature pertaining to sensitive interviewing in qualitative research (Dempsey et al., 2016). Interestingly, participants became more comfortable disclosing their experiences and spoke freely when they were assured that their privacy would be protected and that the names of care providers and loved ones would be omitted. It was critical to the success of my study to ensure the participants felt comfortable discussing the sensitive topic, because it promoted the disclosure of detailed, authentic experiences (Elmir et al., 2011; Speziale & Carpenter, 1999).

In-person interviews are often considered to be the best approach to collecting data on sensitive topics (Elmir et al., 2011). In-person interviews enable the researcher to build rapport with the participant and ultimately create a comfortable environment (Karnieli-Miller et al., 2009; Liamputtong, 2007). Much like in Elmir and colleagues (2011) study, I initiated conversations with participants before the interviews using email or telephone, introducing myself, and explaining the premise of the study. In Elmir et al.'s (2011) study and my study, the researcher and participants collaboratively chose a convenient, private location to meet that ensured the safety and comfort of both parties. This approach was also recommended by Dempsey and colleagues (2016), who developed a framework that outlines the essential elements of qualitative interviewing. I inquired about dietary concerns prior to the meeting to ensure that suitable refreshments would be available for the participants, demonstrating an appreciation for the participants' time and enhancing the comfort of the experience (Dempsey et al., 2016). Some participants offered to provide refreshments for the interview, which I believe was in part because most interviews were hosted at the participants' homes and that the participants wanted to demonstrate an appreciation for the researcher taking an interest in this understudied phenomenon.

In keeping with Sammut Scerri et al.'s (2012) advice, debriefing was completed after each interview as discussing personal experiences evoked an emotional reaction in some of my study participants. Debriefing acted as a means of supporting the participant as they regulated their emotions and returned to a resting state (Sammut Scerri et al., 2012). Although all participants appeared to be in a stable emotional state as I concluded the interviews, mental health resources were given to the participants. Debriefing and offering support services is recommended when conducting sensitive research as it creates a positive closure to the experience (Dempsey et al., 2016). My study participants felt grateful for the opportunity to share their experiences and expressed a hopefulness that this research would positively impact others who suffered treatment failure or spontaneous abortion following funded IVF.

Debriefing is a key component of sensitive interviewing for both the participant and the researcher (Campbell et al., 2009; Dempsey et al., 2016; Melville & Hincks, 2016). As the researcher, I kept detailed logs of my perceptions of the interactions, including mine and the participants' emotional reactions, potential biases, and decisional pathways pertaining to lines of questioning. The literature suggests that reflexive journaling helps novice researchers work through unanswered questions that emerge throughout the interview process and ultimately support the researcher's personal growth (Meyer & Willis, 2019). I took this approach to ensure that my personal preconceptions were not imposed on the data without realizing the extent to which journaling was helping me improve my interview skills and identify emerging categories. I also frequently met with my thesis supervisor to discuss the interview process and preliminary findings. Practicing reflexivity, as described above, is a strength of this study, because it maintains a level of objectivity towards the data and further supports the credibility of the study

by reflecting truthful depictions of the participants' experiences (Dempsey et al., 2016; Etherington, 2004).

Limitations

The phenomenon, the experiences of women who have suffered treatment failure or spontaneous abortion following funded IVF, focused specifically on female Ontarians who accessed the provincially funded program. Consequently, the findings may not be transferable to other settings; however, the extensive detail provided by the participants and the overall richness of the data allows readers to gain an understanding of the context surrounding the findings and offers the opportunity to apply them to similar situations. Further, while the sample size was adequate to support the analysis process, and was congruent with the estimated pre-study range, it was small. This was in part due to the cessation of recruitment efforts through the support group meetings due to COVID-19 restrictions and the withdrawal of a participant who was not comfortable doing a phone interview in lieu of face-to-face. Regardless of the sample size, information redundancy was evident by the second last transcript analyzed.

All of the participants in this study were self-selecting. This is a potential limitation because those who volunteer to discuss their experiences may have viewpoints or personal characteristics that differ from the individuals that opt not to participate. The sample was also relatively homogenous in that the women were financially stable, in committed partner relationships, and well educated. The experiences may have varied had the women been single, of lower socioeconomic status, or less educated. For example, women living below the low-income measure after taxes may describe different experiences than women of the demographic of the participants, because of the more obvious affect of the cost of medications on their finances. In addition, the participants were recruited from the support group and associated

Facebook group. This method of recruitment limited the sample to individuals with access to these resources, which again may result in a non-representative sample within the larger population.

Conclusion

Since the inception of Ontario's fertility program in 2015, the experiences of women who have suffered treatment failure or spontaneous abortion following funded IVF have not been formally explored through research. Although subjective experiences promote the holistic conceptualization of the phenomenon by offering insight into the nuances of reproductive loss and IVF, these experiences have been overlooked in favour of objective findings like IVF success rates. Through storytelling, the participants described the emotional nature of reproductive loss and IVF, the physical and fiscal costs of accessing treatment and the effects of infertility on personal relationships.

The study findings provide valuable insight into how women who have suffered a reproductive loss following funded IVF perceive their experiences within the context of relationships, patient-provider interactions, and intrapersonal emotional responses. Participants described the challenges they faced during their fertility journeys, and also provided recommendations related to financial coverage, availability of the program, communication, wait times, and appeal processes. In light of the findings, further research is needed to explore the phenomenon from the perspective of partners and nurses, as well as the implications associated with the use of social media for peer support post-IVF failure. While appreciating the complex nature of the phenomenon, experiencing reproductive loss after funded IVF, nurses and health care leaders should consider the mental, physical, and social implications and address the needs of the treatment seeking population by taking a holistic approach to care and program planning.

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Appendix A

Glossary of Fertility Related Terms

Artificial Reproductive Technology (ART): Procedures that involve handling human biological products, like sperm, oocytes, and embryos, outside of the human body with the intention of establishing a pregnancy; includes in vitro fertilization, embryo transfers, egg and embryo donations, embryo freezing and surrogacy

Grief: An emotional reaction inflicted by a loss that is often characterized by sadness, emotional stress, and mourning

Infertility: The inability to conceive despite frequent, unprotected vaginal sex over the span of one year

In vitro Fertilization (IVF): The process of external fertilization of the egg with sperm and the subsequent embryo transfer into the uterus

Reproductive Loss: Any voluntary or involuntary absence of innate reproductive functioning or the propagation of the life cycle, which spans pre-conception to the post-partum period and includes infertility, spontaneous abortion, and treatment failure; also encompasses the loss of an envisioned child

Spontaneous Abortion: The unplanned loss of a clinical pregnancy before 20 weeks of gestational age

Treatment Failure: The absence of a live birth; the insertion of an embryo into the uterus via in vitro fertilization and the subsequent failure to produce an ongoing clinical pregnancy as indicated by the identification of a fetal heartbeat on ultrasound, which typically occurs prior to 12-weeks gestation

Appendix B

Funded In Vitro Fertilization Cycle

Although variations in care may exist based on individual patient characteristics, a typical in vitro fertilization cycle offered within the Ontario Fertility Program includes the following:

- One harvest of eggs following a natural or medication-induced ovulation cycle.
- Insemination of the retrieved eggs using laboratory technology.
- Transfer of viable embryos into the uterus- typically one embryo at a time.
- Intracytoplasmic sperm injections, assisted hatching, embryo freezing, and thawing are included in the funded cycle, if required.

The medication used to stimulate egg production is not covered by the Ontario Fertility Program although it is often required within the funded cycle. The cost associated with storing the embryos is also not covered within the funded in vitro fertilization cycle.

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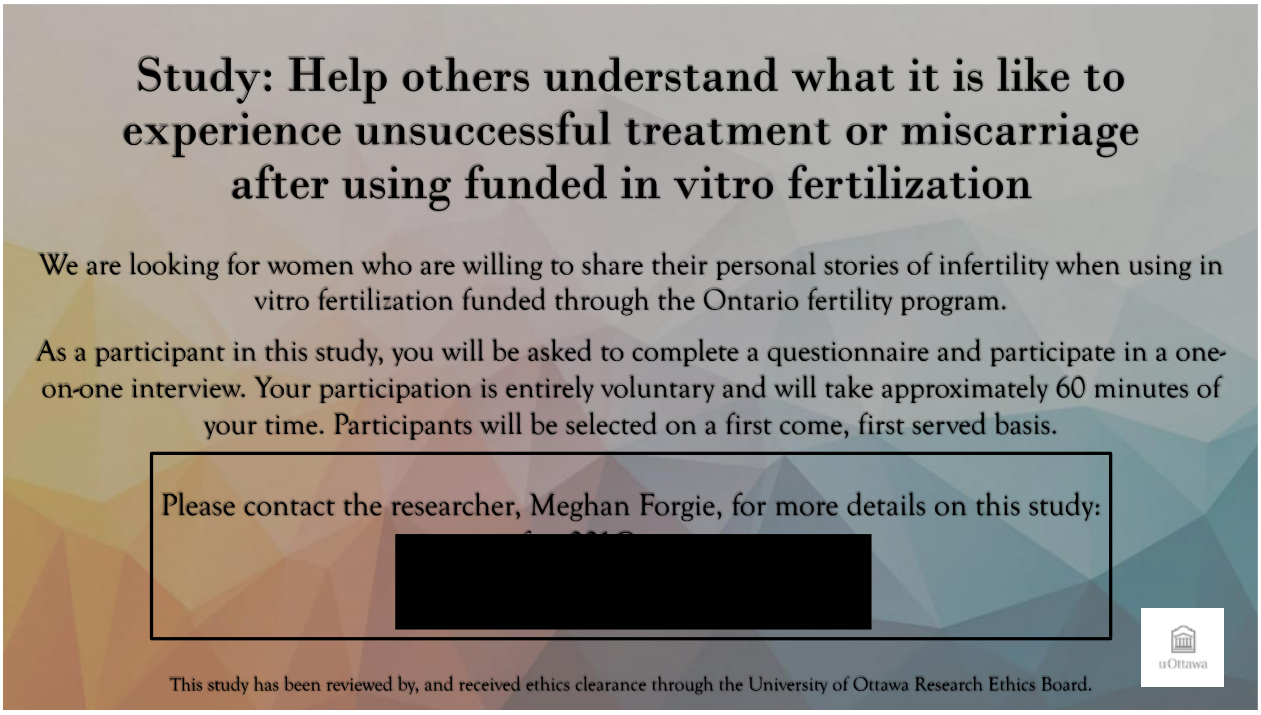
Appendix C

Participant Recruitment Poster



Appendix D

Semi-Structured Interview Guide

Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief

Plan: five to seven questions or investigative statements with additional probes to gain more in-depth data (i.e. How did you feel when that happened?).

1) Tell me about your fertility journey prior to accessing this program.
    a. Prompts may include timelines, personal perceptions, emotional reactions etc.

2) Tell me about when you found out that you and/or your partner were infertile. (If applicable)
    a. Prompts may include: "How did that make you feel?"

3) Tell me about your experience of undergoing funded in vitro fertilization.
    a. Prompts may include processes, benefits, and challenges.

4) Tell me what it was like when you realized that your funded in vitro fertilization was unsuccessful.
    a. Prompts may include emotional reactions, physical symptoms, psychological symptoms, duration of symptoms, experiences of grief.

5) What is your plan moving forward?

6) How do you think the fertility program impacted your fertility journey?

7) What have been the biggest benefits and challenges of using the provincially funded fertility program for in vitro fertilization?

Appendix E

Participant Demographic Questionnaire

Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief

Please indicate your response by placing an "x" in the corresponding box (i.e. ☒ Female).

1) What is your age?

☐ 18-22 years old
☐ 23-27 years old
☐ 28-32 years old
☐ 33-37 years old
☐ 38-43 years old
☐ >43 years old

2) Which of the following ethnicities do you identify with?

☐ Black/ African American
☐ White/ Caucasian
☐ Aboriginal or First Nations
☐ Hispanic or Latino
☐ Asian or Pacific Islander
☐ Middle Eastern
☐ Other (Please specify: _____)

3) Which language do you primarily use at home?

☐ English
☐ French
☐ Arabic
☐ Spanish
☐ Chinese
☐ Other (Please specify: _____)

4) What is your partner status?

☐ Single, never married
☐ Married
☐ Common-law
☐ Divorced
☐ Widowed
☐ Other (Please specify: _____)

5) What is your highest level of education?

☐ Some high school education
☐ High school diploma
☐ College diploma or certification
☐ Bachelor's degree
☐ Professional degree (i.e. Law, Medicine)
☐ Master's degree
☐ Doctorate degree
☐ Other (Please specify: _____)

6) What is your annual household income?

☐ Less than $40, 000
☐ $40, 000- $80, 000
☐ $80, 000- $120, 000
☐ $120, 000- $160, 000
☐ > $160, 000

7) Why are you accessing this program?

☐ Male factor infertility
☐ Female factor infertility
☐ Male and female factor infertility
☐ Unexplained infertility
☐ Other (Please specify: _____)

8) How many reproductive losses have you experienced? (i.e. miscarriage, unsuccessful IVF)

Please specify: _____

9) Please indicate which of the following fertility treatments you have used (select all that apply):

☐ Hormone therapy or medication regimens (i.e. natural conception with ovarian stimulation)

☐ Intrauterine insemination

☐ In vitro fertilization

☐ Other (Please specify: _____)

10) How many in vitro fertilization cycles (egg retrieval and embryo transfer) have you undergone, including both provincially funded and privately funded cycles?

Please specify: _____

Appendix F

Research Ethics Board Certificate

20/12/2019

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

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE I CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-11-19-4938
Titre du projet / Project Title	Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	20/12/2019
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	19/12/2020

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Meghan FORGIE	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Amanda VANDYK	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Wendy PETERSON	École des sciences infirmières / School of Nursing	Autre / Other

Conditions spéciales ou commentaires / Special conditions or comments

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

Appendix G

Study Information Letter

uOttawa

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

Study Information Letter

Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief

You are invited to participate in a research study exploring the experiences of women who have suffered a reproductive loss (i.e. unsuccessful embryo transfer, miscarriage) following a funded in vitro fertilization cycle. You are being invited to join this study, because you have valuable stories that could provide insight into these experiences. This study is being conducted by second year graduate student, Meghan Forgie, under the supervision of Dr. Amanda Vandyk of the School of Nursing at the University of Ottawa.

This study is being done because there is limited research exploring women's experiences of infertility, reproductive loss, and grief after using cycle-limited funding. New nursing knowledge, standards of care, and a platform for patient advocacy may be supported by looking into personal experiences, program outcomes, and the population needs in this study.

Taking part in this study is voluntary. Your decision to participate or not participate in this study will not affect your fertility care. You are free to withdraw from the study at any time without penalty. We expect to invite five to 12 women to participate on a first-come, first-served basis. There will be the option to be placed on a waitlist as well.

As a participant in this study, you will be asked to complete a questionnaire and participate in a one-on-one interview during which you will be asked about your infertility journey. Your participation would take approximately 60 minutes of your time.

All information gathered from the surveys and interviews will be kept strictly confidential. The electronic data collected will be stored securely on a password protected external hard drive that will be kept in a locked filing cabinet in the principle investigator, Meghan Forgie's, home office. Hard copies of the data will be stored securely in a locked cabinet in the thesis supervisor, Dr. Vandyk's, office at the University of Ottawa. After the completion of the research study, the data will be kept indefinitely for the purpose of secondary analysis, but at minimum for a five year conservation period. When the data is no longer needed for further analysis, they will be confidentially destroyed.

☎ 613 562-5473
613 562-5443

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uOttawa

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

You may or may not directly benefit from the study. However, your input and perspective would be of tremendous value to us. In recognition of your time and effort, you will be given a $25 pre-paid VISA gift card. The risks of participating in this study may include emotional discomfort as you reflect on your experiences and share your story. You are free to withdraw from the study at any time, choose to skip questions, and take breaks throughout the interview. You will be offered an optional debriefing session following the interview and will be advised of additional resources for support.

Prior to the interview, you will be given the opportunity to ask questions and then will be asked to sign a form indicating that you consent to participating in the study.

This study has been reviewed by, and received ethics clearance through the University of Ottawa's Research Ethics Board.

Please feel free to contact the principle investigator, Meghan Forgie, at _____ if you have any questions about the study.

☎ 613 562-5473
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Appendix H

Participant Consent Form

uOttawa

Université d'Ottawa
Faculté des sciences de la santé
École des sciences infirmières

University of Ottawa
Faculty of Health Sciences
School of Nursing

Title of Study: Exploring Women's Experiences of Infertility, Reproductive Loss, and Grief

I am invited to participate in the abovementioned research study conducted by Meghan Forgie under the supervision of Dr. Vandyk.

Researcher:
Meghan Forgie BScN, MScN (C)
Graduate Student, School of Nursing, University of Ottawa
[E-mail]

Supervisor:
Dr. Amanda Vandyk BScN, MScN, Ph. D.
Professor, School of Nursing, University of Ottawa
[Telephone]; [Email]

Purpose: I recognize that the purpose of this study is to understand the lived experiences of women who suffered a reproductive loss (i.e. unsuccessful embryo transfer, miscarriage) during funded in vitro fertilization treatments.

Participation: My participation will consist of one interview and one questionnaire that will last approximately 60 minutes, during which I will discuss my experience with infertility. The interview will be scheduled at a time and location that is convenient to me. I know that the interview will be tape recorded to allow the researcher to review the content. In the event that the researcher requires clarification of my transcript, I may participate in a 10-20 minute telephone discussion, if I choose to.

Risks: My participation in this study will entail that I volunteer very personal information, which may result in an emotional response, including, but not limited to anger, sadness, hopelessness, or grief. I have received assurance from the researcher that every effort will be made to minimize these risks, by allowing me to choose not to answer questions that make me feel uncomfortable and granting me the ability to take breaks or terminate the interview at any time without consequence. I know that I can participate in a debriefing session with the interviewer to discuss my emotional responses or concerns following the interview. I am aware of additional mental health resources available to me, including the Mental Health Crisis Line (613-722-6914 or 1-866-281-2911), the Distress Centre of Ottawa Region (613-238-3311), and Connex Ontario (1-866-531-2600).

Benefits: My participation in this study may have potential benefits. I will be given the opportunity to share my infertility journey with someone who is genuinely interested in my story. I will contribute to the advancement of knowledge by providing insight into the experiences of individuals who use in vitro fertilization and experience a reproductive loss. I recognize that other researchers and healthcare providers may benefit from the information generated through this study, which could positively impact care. I know that this research has the potential to help others experiencing infertility in the future.

☎ 613 562-5473
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451 Smyth
Ottawa ON K1H 8M5 Canada

www.uOttawa.ca

Modified from Stacey, D. (2019). Invitation to participate in a course project consent form. Retrieved from https://uottawa.brightspace.com/d2l/le/content/111475/Home

Confidentiality and Anonymity: I have received assurance from the researcher that the information I share will remain strictly confidential. I understand that the contents will be used for this Master's thesis project (THM 7999). I also understand that the information I share may also be used in the future for the researcher's doctoral dissertation (THD 9999), secondary research, and subsequent publications (_____ initial here). I understand that my confidentiality will be protected through the safe storage of research data. Anonymity will be protected through the use of pseudonyms and the omission of identifying information.

Conservation of data: The electronic data collected will be stored securely on a password protected external hard drive that will be kept in a locked filing cabinet in Meghan Forgie's home office. All hardcopies will be stored in a locked cabinet in Dr. Vandyk's office at the University of Ottawa. Only members of the research team will have access to the data. This information will be stored securely at the Centre for Research on Health and Nursing at the University of Ottawa indefinitely. When the data is no longer required for further analysis the physical copies will be confidentially shredded and the electronic data will be securely deleted.

Compensation: I understand that I will receive a $25 pre-paid VISA gift card in appreciation of my time, as well as reimbursement of parking fees. If I choose to withdraw from the study, I will still receive this compensation. I will also be offered small food items, like coffee, tea, or muffins, during the interview as a token of appreciation.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I may withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, I can indicate whether the information I have provided may or may not be used by the researcher.

Acceptance: I have read this consent form and had my questions answered.
I, _____*(Name of participant),* agree to participate in the above research study conducted by _____*(name of researcher)* of the School of Nursing at the University of Ottawa under the supervision of Dr. Amanda Vandyk RN, PhD. I understand that by accepting to participate I am in no way waiving my right to withdraw from the study.

If I have any questions about the study, I may contact the researcher and/or supervisor using the contact information mentioned above.

If I have any ethical concerns regarding my participation in this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, 550 Cumberland Street, Room 154, (613) 562-5387 or ethics@uottawa.ca.

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: _____ Date: _____
(Signature)

Researcher's signature: _____Date: _____
(Signature)

Modified from Stacey, D. (2019). Invitation to participate in a course project consent form. Retrieved from https://uottawa.brightspace.com/d2l/le/content/111475/Home