

Uncovering in-vitro fertilization (IVF) patient and peer relationships:
A qualitative study on self-disclosure processes in a social support setting

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ABSTRACT

In Canada, the natural birth rate is declining in part because of delayed childbirth (Canada 2016). As a result of their decision to postpone parenthood and their increasing age, more couples are turning to assisted reproductive treatment (ART) including in-vitro fertilization (IVF) to conceive. The risk of IVF failure, the detrimental mental health outcomes (i.e. depression) associated with infertility, and the strain on physical, financial, spiritual, and emotional resources contribute to heightened stress for IVF patients, and compel them to identify and leverage psychosocial supports. Since the quality of social support individuals receive depends on the nature of communication they share with the receiver, it is important to consider how disclosure builds social support. Common social support channels such as spouses, family, friends, counsellors, and support groups and their associated communication patterns have already been explored in the fertility literature whereas processes integral to peer relationships, a support that women have signaled as promising, remain uncovered. It remains important to understand the nature of peer relationships in the context of infertility.

This dissertation explores how in-vitro fertilization (IVF) users approached their decision to disclose to a peer and carried out their communication. Guided by the Disclosure-Decision Making Model (DD-MM) it starts by showing how IVF patients assess their support needs, and peers as recipients before communication takes place. It then delineates how these women execute their communication with specific focus on the modalities of their process and the scope of the disclosures of fertility-related and non-fertility related information between them. A sample population of 23 first-time and recurring IVF patients were interviewed. Results show that prior to disclosing to a peer, women reflect on information about their condition and their personal support needs on the basis of the adequacy of their social circles and perceptions of stigma, the benefits and drawbacks of secrecy versus transparency, and their personal motivation

to leverage peer support. They also assess their peers, considering diverse pathways of connection as well as desirable peer traits which include IVF experience, other common ground and transparency. Relating to their communication, patients showed a distinct capacity to communicate with their peers and meet their support needs. The IVF patient-peer communication process is characterized through immediate disclosure transitions and backwards introductions, a solid mutual understanding when it comes to engagement and disengagement boundaries, a preference for digital communication via texting and instant messaging, and the coverage of a broad range of fertility topics in reciprocal conversations. The findings also show however that the majority of women choose to distance themselves and limit their conversations during the post embryo transfer waiting period and refrain from discussing pregnancy testing as a form of self- preservation.

IVF patients share a natural relationship with peers. This dissertation points to opportunities to facilitate patient-peer relationships and enhance the fertility-care experience overall by embracing: the transparency of patients, better coping resources for men, safe places to personally connect in clinic and support group settings, and roles for all IVF patients in social support regardless of their outcome. It also suggests that patient-peer support is a pragmatic and flexible support channel that when managed properly can respond to patients' personal disclosure and communication needs and preferences.

CHAPTER 1. INTRODUCTION

1.1 Understanding ART, Socio-demographics of Patients, Social Support and Communication

Natural birth rates are steadily declining in Canada and account for less than one third of the population growth (Canada, 2016). This trend may be caused in part by a rise in delayed childbirth due to “people placing a priority in establishing stable careers and homes in a fast-paced, competitive economy” (Weeks, 2011). While family building is in many ways a positive experience and rite of passage, many prospective parents seldom grasp the scope of challenges of trying to conceive in their late thirties and early forties (Weeks, 2011), and in particular those associated with fertility treatment.

1.1.1 *What is ART?*

When some couples have difficulty conceiving naturally, they turn to assisted reproductive treatment (ART) most commonly in the form of fertility enhancing drugs, intrauterine insemination (IUI) and in vitro fertilization (IVF) which has no guarantee of success (Canada, 2015). Fertility treatment primarily focuses on women as the patient given their unique reproductive outputs and the need for intrauterine procedures for each of its three stages; stimulation, monitoring, egg retrievals and embryo transfers. Male factor infertility is also quite common and beyond the provision of semen samples, some rare treatment protocols require invasive procedures for sperm extraction, or sensitive ultrasounds to test their reproductive systems (Kumar & Singh, 2015).

Traditionally fertility clinics approach ART with a biomedical lens by identifying the medical condition and applying the treatment protocol. The associated pressures and burdens of treatment are imposed on the woman (Cousineau et al., 2006) which heightens their stress.

Of the treatments, IVF is considered to be the most comprehensive and most stressful. On top of the stress of potential failure, IVF typically strains patient resources on a variety of levels,

including: the expensive cost of IVF which can be as high as twelve thousand dollars per treatment, the more invasive nature of the procedure (compared to the other treatments), and the large variety and volume of patient medications prescribed for each treatment phase (Bell, 2012; Cousineau & Domar, 2007). Given these stressors, Bell (2012) states that, “along with service users’ biomedical needs, there are important psychosocial support needs arising from their experiences of involuntary childlessness as well as their use of reproductive technology that warrant consideration” (p. 698).

1.1.2 *Characteristics of ART Users*

The Canada Community Health Survey reported that in 2009/2010 over 380,000 opposite sex couples in Canada sought medical help that year to start a family (Canada, 2015). It is known that for “those partners, reproductive difficulties extend beyond the health issues associated with the condition leaving individuals feeling stressed on variety of levels and uncertain about their romantic relationship” (Steuber & Solomon, 2012, p.4). While single, gay or lesbian people who use ART may also encounter challenges using fertility services, their experiences and reproductive concerns are seen as different from those who identify as part of a heterosexual couple (Grunberg et al., 2018). This can also be attributed to the societal expectations and norms placed on heterosexual couples to conceive and public attitudes towards childlessness (Koropatnick et al., 1993; Miall, 1985). Previous studies also indicate that married couples are five times more likely to resort to treatment than single women (Wilcox & Mosher, 1993), which suggests that couples are more motivated to find a solution to their inability to conceive than are single women.

The existing literature highlights the influence of other socio-demographics such as age, income and education on the ART experience, which are known to increase stress and call upon the need for psychosocial supports for ART users. We will now closely examine each one.

1.1.2.1 *Age*

To start there are trends that indicate that delayed childbirth is on the rise in Canada as a result of “people placing a priority in establishing stable careers and homes in a fast-paced, competitive economy” (Weeks, 2011). As a result, prospective parents seldom grasp the scope of challenges of trying to conceive in their late thirties and early forties (Weeks, 2011). These patterns are supported by research that indicates that the women who receive fertility treatment in North America are most often college graduates, aged 30 years and older, typically Caucasian, and earning high income high above poverty levels (Wilcox & Mosher, 1993; Inhorn & Birenbaum-Carmeli, 2008). Furthermore, fertility treatment is age restrictive. After the age of thirty-five fertility starts to change significantly. The likelihood and window of success gets narrower and narrower with as a woman advances in age and her egg supply diminishes and egg quality decreases (Pandey et al., 2014). While many clinics do not discriminate against age, egg reserve and quality are taken in to account by doctors prior to treatment and factor in to their recommendations on the pursuit of treatment and type of protocol. However the Ontario Government which now funds one round of IVF treatment has a cut-off of age forty-three for their program.

A study that examined fertility treatment outcomes in women of different age groups found that the live birth rate was highest among women in the youngest age group (fifty percent more likely to have a successful outcome) versus those aged forty and over (Pandey et al., 2014). The same study also found that the ratio of increased costs to the increased probability of live birth in women who were treated increased markedly in women over the age of 40 years (Pandey et al., 2014). In other words, the older the patient, the higher complexity and cost of their treatment and the more delicate their future pregnancy and delivery. These women are at likely candidates for the use of increased medications, the requirement of more ultrasounds, medical personnel, and a higher likelihood of at-risk pregnancy and c-section. Each of these scenarios comes with its own set of stressors. The most

obvious age-related stressor include a woman's biological clock which keeps going, making that window of opportunity smaller with the passage of time, bringing with it the question of whether or not they are treatable.

1.1.2.2 *Income and Education*

Research suggests that higher education (of 16 years or more) coupled with high-pressure, fast-paced jobs are linked with stress, infertility and IVF treatment (Hjollund et al., 1996; Wilcox & Mosher, 1993). For example, a study that examined socioeconomic disparities amongst infertility patients seeking care found that “nearly half of the patients, close to 5,000 patients had advanced degrees, at Master's, Doctoral, or Professional level” (Jain, 2006, p. 878). This finding parallels the trend of delayed childbirth for women who are focused on advancing their careers.

The average cost of an IVF procedure is expensive depending on where one lives it can be as high as twelve thousand dollars. As emphasized by Inhorn and Birenbaum-Cameli (2008) access to fertility treatments reflects class-based and other inequalities linked to insurance coverage and the ability to cover significant out of pocket costs, which means only a small proportion of the population who can afford treatment go through with it (p.179).

The World Health Organization (WHO), (2008) states that in countries “at all levels of income, health and illness follow a social gradient; the lower the socioeconomic position, the worse the health” (p.1). The WHO goes on to state that in “rich countries, low socioeconomic status (SES) means poor education, lack of amenities such as health insurance, unemployment”. SES is relevant to the experiences of couples facing infertility as it can pose challenges to seeking solutions to the problem. Across North America, fertility treatment is primarily privately delivered and a costly healthcare service. Wilcox and Mosher (1993) examined the uptake of infertility services in the United States and found that that overall the women who were “most likely to have obtained specialized services were white women of higher socioeconomic status, higher educational level, with

income 149 per cent above the poverty level (p. 125). Only a few of Canadian provinces partially fund IVF treatment or offer tax rebates for it; Ontario, Quebec, Manitoba and New Brunswick (Infertility Network, 2015).

Income is the resource that enables people to find solutions to conceive. Previous research states that low-income women and men face increasing difficulty in obtaining even the most basic evaluative services (Becker, 2000). While high-income earners have access to infertility treatment, that process still comes with a significant financial investment and a variety of social stressors regardless of the outcome. Raque-Bogdan & Hoffman (2015) found that patients can feel emotionally taxed and stigmatized amongst their cohorts for any host of reasons such as the lengths the couple had to go through to achieve a pregnancy, treatment failures, or the inability to achieve a second pregnancy after the first (secondary infertility) amongst others.

1.1.3 *Social Support and Communication*

1.1.3.1 *The Dualistic Nature of Infertility*

Starting a family is a natural and anticipated rite of passage for most heterosexual ?? couples, and societal norms suggest that couples should have and want to have children (Koropatnick et al. 1993; Miall, 1985). It is important to note that while infertility treatment is not a negative experience for all of its patients, it is nonetheless associated with variety of psychosocial issues that are known to take a toll on couples faced with this journey.

Given the expectations society imposes on individuals to become parents, infertility is viewed by many as a crisis, a “non-event transition”, and a stigmatizing situation which constitutes multiple layers of stress (Koropatnick et al., 1993). According to Allan (2007), infertility and its treatment is seen as a liminal experience, one associated with ambiguity, a grey zone. With no guarantee for success, it natural for patients to face a dichotomy of outcomes and a roller coaster of emotions. For example, seeking treatment at fertility clinics “offers biomedical explanations for

conditions and prescribes solutions, which offer a glimmer of hope for patients, in contrast with their negative experiences elsewhere” (Allan, 2007, p. 133) and affords patients reassurance and comfort in a safe space surrounded by peers. However, at the same time clinics also are “limited in their success rates and do not necessarily make all their patients mothers, and instead reinforce liminality creating a sense of limbo” (Allan, 2007, p. 133). This perception of a balancing act, gravitating towards optimism one day and towards hopelessness the next is not uncommon.

Imeson and McMurray (1996) document the “roller-coaster” nature of infertility in their phenomenological study of six couples’ experiences with the diagnosis and treatment. For one couple, the authors documented a sense of hope, marked by a sense of growing self-efficacy that came with increased knowledge about their situation alongside enhanced feelings of respect from medical professionals for their ongoing commitment to treatment and their increased ability to advocate for themselves through research and information gathering (Imeson & McMurray, 1996). Similarly, Cousineau and Domar (2007) credit modern women for taking charge of their fertility in order to “optimize her chances of conceiving, whether its through diet, meditation, acupuncture or positive thought”, they recognize that it is easy for women to revert to “feelings of failure when those efforts don’t result in a successful outcome” (p. 295). The majority of the other couples whom were interviewed by Imeson and McMurray (1996) identified with the challenging experiences such as “an endless hope-disappointment cycle, social isolation, life changes, and emotional distress” (p. 1014). Couples diagnosed with infertility and its treatment have cast light on a host of spin-off issues they face. Within the couple they experience changes such as mental health responses in the form of depression, anxiety, guilt, jealousy and anger (Imeson & McMurray, 1996, Cousineau & Domar, 2007).

Moving towards their extended family, it is not uncommon to feel pressure to conceive, judgement, or feel ostracized as a result of ethnic and religious beliefs about fertility (Missimer et al. 2011; Jain, 2006; Lampman & Dowling-Guyer, 1995). Finally many patients have offered insights on their broader social experiences which include strain on social networks, social comparison and acceptable norms (natural conception, biological parenting, carrying one's own child) can create stress for couples trying to conceive (Cousineau & Domar, 2006; Domar et al., 2000; Gibson & Myers, 2002; Nicols & Pace-Nichols, 2000; Peterson et al., 2006). Enduring such problems and personal perceptions of them impacts the heart and mind of the woman who, as the ART patient, is already enduring the unique female reproductive outputs to the infertility treatment.

1.1.3.2 *Psychosocial Support, Communication and Peers*

The psychosocial approach to the provision of healthcare refers to the intersection of social experiences and individual thought processes/behaviours that patients experience as a result of their condition and treatment (Makivic et al., 2016). Schmidt et al. (2005) state that “many infertility patients identify with the need for psychosocial support as a response to the stress of treatment” (p. 252). Infertility patients may establish beneficial support resources through communication in the form of self- disclosure. Self-disclosure establishes trust (Greene et al., 2006), alleviates stress (Kelly & McKillop, 1996), and reduces isolation (Martins et al., 2013). High and Steuber (2014) further emphasize that interpersonal verbal and non-verbal messages play a key role in the perception of support quality amongst infertility patients.

The infertility and social support literature offers extensive coverage of common psychosocial support directions and their associated communication dynamics for channels such as social isolation (Peterson et al., 2006), support groups (Domar et al., 2000), virtual (online) forums (Hinton et al., 2010), family and friends (High & Steuber, 2014), and counsellors (Bell, 2012). While any of these channels has the capacity to provide support, previous studies suggest

that support is not a one size fits all solution and is subjective (Bell, 2012). High and Steuber (2014) conducted a thorough examination of these channels and found that patients expressed a range of adequacy issues and shortcomings with each of them when it came to meeting their expectations. Another form of support that remains uncovered in the scholarly literature so far is peers. For example, High and Steuber (2014) did not assess the adequacy of peers which have been identified by other scholars as a valuable resource based on their ability to “offer genuine emotional and informational assistance stemming from their parallel journeys” (Bell, 2012, p. 705). Grunberg et al. (2018) also advocate for peer support for infertility patients in online settings. Dennis (2002) underscores the useful impact of peer support in a variety of stressful and related health experiences such as breastfeeding, post-partum depression, and breast cancer. Beyond peers being viewed as a satisfactory support and an enticing option, there are still many unanswered questions about the nature of communication in IVF patient-peer relationships. There remains a paucity of research illustrating the phenomenon of these relationships and how they function. The purpose of this qualitative study is to get a complete understanding of how patients approach their disclosure decisions at the outset of peer relationships, how they assess their situations and their peers as supports, and the modalities of their communication.

1.2 Overview of Research Goals and Questions

The main goal of this phenomenological study was to understand the disclosure communication processes between IVF patients and their peers. Using face- to-face interviews, it allowed the experiences of a sample of Ontario IVF patients to be shared with a focus on how these women reflect on their circumstances and their peers prior to disclosing, followed by how their communication actually unfolds -- the modalities and patterns they develop with peers – and the nature of their disclosure dynamics.

This dissertation is positioned in the interdisciplinary practice of population health, which incorporates a variety of schools of thought in to the research process (Borrego & Newswander, 2010). While the main tenets of this study stem from communication, it also incorporates principles from psychology, epidemiology and sociology. It also offers new insights into the social determinants of health, which focuses on how access to resources frames the lived health experiences of people (Friel et al., 2011). Through understanding how women undergoing IVF identify peers and disclose their journeys, a deeper understanding of how social relationships play a role in health experiences of a specific population is advanced.

The research objective that guided the literature review (Article 1, Chapter 2) was:

RO: *To understand the role of communication and self-disclosure amongst common social support channels.*

The main research question that guided this dissertation and emanated from the literature review manuscript is: *what are the communication processes that establish peer relationships for IVF patients?* The following subset of research questions guided the inquiry.

RQ 1: *What leads IVF patients to peer-based self-disclosure and social support?*

RQ 2: *How do IVF patients assess their peers for disclosure and social support?*

RQ 3: *How do IVF patients disclose their journeys and communicate with their peers?*

RQ 4: *What is the scope of fertility and non-fertility related disclosures between IVF patients and peers?*

Article 2 in Chapter 3 addresses the first two research questions and describes how IVF patients assess their support needs and peers as disclosure recipients. Article 3 in Chapter addresses the last two research questions and uncovers the disclosure and communication processes between IVF patients and peers. In the final chapter of this dissertation, Chapter 5, I will circle back to the primary research question by summarizing the communication processes between IVF patients and their peers as a whole.

1.3 Theoretical Framework

Self-disclosure plays an integral role for individuals as they establish psychosocial support. When individuals reveal personal information to each other, the process establishes trust and helps foster authentic, socially supportive relationships (Greene et al, 2006; Wu, 2009). Since this research focuses on the communication process between patients and peers as a whole and how they build social support, it was important that to consider more than one theory in order to encompass all elements of interest. With that in mind, Greene (2009)'s Disclosure Decision-Making Model (DD-MM) provided an overall sense of direction for the discussion guide as it pertained to communication modalities and a process structure. Social Penetration Theory (SPT) (Taylor & Altman, 1975) was used as a complimentary theory to better explain what drives the nature and content of patient self-disclosures.

1.3.1 *The Disclosure Decision-Making Model (DD-MM)*

The DD-MM explains the antecedent to the act of self-disclosure for individuals suffering from invisible health conditions. In other words, it focuses on how people plan and carry out their disclosure decisions. Greene (2009) summarizes this process according to three contemplation steps: information assessment (reflection on details specific to their journey), receiver assessment (reflection on disclosure recipient qualities) and disclosure efficacy (capacity to communicate). We used each step of this theory to guide us in the development of the interview protocol (Appendix 5) which is further discussed in the section 1.4.2.1 of this chapter.

1.3.2 *Social Penetration Theory (SPT)*

Taylor and Altman's (1975) Social Penetration Theory (SPT) compares the self-disclosure process to the layers of an onion, with the outer circles reflecting more superficial information that one could disclose about oneself and the inner circles reflecting more personal, private information that one may or may not choose to share with others. Through the lens of

SPT, information sharing can take on two dimensions; *breadth*, or the number and variety of topics discussed and its *depth*, or the degree of intimacy that guides this communication (Carpenter & Greene, 2016; Taylor & Altman, 1987).

1.4 Methodological Approach

1.4.1 *Methodology*

Since this research uncovered and described the lived peer support experiences of patients, it embraced a psychological phenomenological approach (Moustakas, 1994). It is a qualitative study that endeavoured to understand the self-disclosure process between IVF patients and peers and how these processes helped build psychosocial support by using one on one in-depth semi-structured interviews. The sample population was 23 first time or recurring Ontario IVF patients, who identified as peer- support users (relied on support from someone who also went through IVF) and lived in the Ottawa ($n=11$), Greater Toronto Areas ($n=9$), and a few rural towns ($n=3$).

1.4.2 *Data Collection*

Semi-structured interviews have proven an effective research tool in research on sensitive, fertility-related health topics for women that share parallels with this study. Interviews afford an opportunity for dialogue, a chance for participants to elaborate on their experiences and benefit from catharsis (Bute, 2009). For example, they have been used to uncover women's psychosocial support needs during assisted reproduction (Bell, 2012), to understand how women with polycystic ovary syndrome perceive support group intervention (Percy et al., 2009), and to document the role of the fertility clinic and perceptions of that environment through the eyes of patients (Allan, 2007).

By definition, semi-structured interviews are formal, require a protocol and sequence of set questions and also offer an opportunity for the interviewer to follow topical trajectories when appropriate and according to their discretion” (Cohen & Crabtree, 2006). Since understanding the peer support process for IVF patients is an emerging area of research, it was important to be able to understand the lived experience of the participants, through their own, individual voices. Using interviews allowed me to tap into each of these experiences, compare them, and get a complete understanding of how the self-disclosure process works. It was also critical to grasp these support dynamics from a “subjective point of view” (the perception of participants), and to give these women an “active role in attributing meaning to their experiences through interpretation” (Low, 2007, p. 75).

Two data collection tools carried out the methods for this study. The participant information form and the discussion guide can be found in Appendix 4.

1.4.2.1 *Theoretical Underpinning of Interview Questions*

The information assessment step of the DD-MM was reflected in the questions that covered topics such as perceptions disclosure experiences with other social circles, relevance, rationale for sharing or non-disclosure, and motivation for peer-based disclosure (Greene, 2009) and were designed to illustrate how patients reflect upon their personal situations prior to turning to peer for support. Receiver assessment questions focused on relational quality and anticipated response (Greene, 2009) and were crafted to show how patients assess and select their peers as disclosure recipients.

Disclosure contemplation aspects pertaining to information and receiver assessment steps is the focus of the article in Chapter 3, which outlines how individuals assess their situations and their peers prior to self-disclosure responding to research questions 1 and 2. Disclosure efficacy questions focused on communication mechanics and logistics (Greene, 2009) and the nature of

the information shared (Altman & Taylor, 1975), and were engineered to uncover the “how” and the “what” of patient to peer engagement. The elements of this step are the focus of the article in Chapter 4, that outlines how the disclosure and communication process between IVF patients and peers is carried out responding to research question 3.

With SPT in mind, we designed a question specifically asking patients to recall what types of fertility related information they shared with their peers and to what degree. We also asked women if they spoke of non-fertility related items with their peer support. We then used SPT as a framework through which to understand the breadth and depth of information IVF patients shared with their peers and what that told us about their relationships, responding to research question 4.

In recognition of my own lived journey in infertility and the importance of bracketing my experience, the discussion guide questions were reviewed by IVF patients and peer support users I know through infertility support and advocacy networks. Three women read the questions and offered feedback in order to ensure that they were appropriate, thought-provoking and complete before the discussion guide was finalized.

1.5 Ethical Considerations

1.5.1 *Emotional and Psychological Distress*

The main ethical issue this project had to contend with was the potential for emotional/psychological distress for participants as a result of disclosing one's condition and experience. This risk was mitigated and the well-being and comfort of participants was safeguarded at least five ways. To start, the Recruitment Letter and Consent Form (Appendices 2.3 & 2.4), included key features such as transparency regarding the study's purpose and an opt out option for participants (Creswell, 2013, p. 58). Second, data collection took place in a comfortable, private place for the participant devoid of “power imbalances and vested interests” (Creswell, 2013, p

58). Third, at the start of the interview, I established a degree of comfort with prospective participants by identifying with their struggle to conceive and positioning myself as a patient advocate. Participants reported that having that knowledge set their minds at ease and allowed them to feel open to sharing and discussing their journey further. Fourth, each participant was provided a list of free support services (Appendix 2.5) in different formats (online support and telehealth). Fifth, half-way through the interview I took a pause to check-in with the participant and ask how they were feeling, and encouraged them to have a short break (for water or a breath) if necessary.

1.5.2 Positionality of the Researcher

In any study, it is important to consider the viewpoint of the researcher in relation to the social and political context of the study especially as it pertains to the community, impacted organizations or participant groups (Rowe, 2014). The position the researcher assumes can have an impact anywhere in the research trajectory and has the potential for bias. Given my previous status as a patient, and the fact that I was undergoing IVF treatment during my time as a doctoral student, I positioned myself as a patient advocate and an “insider” of both my academic practice and the fertility patient community for purposes of this research (Rowe, 2014). I advertised myself as such in the recruitment posts (Appendix 2.1) and reminded participants of it during the interview. The intersectional identity I brought to this study helped set participants’ minds at ease, offered both parties an opportunity to use common language and terminology with little need for explanations and helped establish overall credibility with the population of interest.

While I closely identified with the sample population as an IVF patient, I was mindful of my status and privilege as doctoral student and a woman who had success becoming a mother and a variety of supports – social, financial and medical – and instead placed emphasis on our shared experiences of struggling to conceive in order to create a spirit of “collaboration” devoid

of “conflict” (Rowe, 2014). In order to keep questions and conversation objective and devoid of my personal experiences, at the outset of the interview I said I would be happy to offer participants any additional fertility insights after the formal discussion was over if they wished. I was also mindful of mitigating any bias I brought to the study by bracketing my experience. For example, I did not recruit or interview any patients while I myself was undergoing fertility treatment. Lastly, I kept detailed notes that clearly distinguished between my thoughts and those of the participants (Martin, 2009).

Being a patient who has navigated the system and a few clinics before was a benefit to the study in multiple ways. First, in addition to having access to support group forums, I also had existing relationships with fertility physicians and clinicians as a result of my previous volunteer work with Fertility Matters Canada. Dr. Kenneth Cadesky, Medical Director and Founding Partner of TRIO Fertility in Toronto, Dr. Sergey Moskovtsev, Clinician and Dr. Samantha Yee, Director of Psychosocial Research Program at Create Fertility Centre helped facilitate recruitment and graciously agreed to promote the project by allowing the research and recruitment to be advertised in their clinics and on their clinic webpages. The ability to recruit patients through social support groups and clinic channels was integral to the success of the recruitment process. Next, as previously mentioned, when patients realized that I could relate to their experience, they reported that this set their minds at ease. Finally, my passion for helping mothers-in-waiting comes from my lived experience. My knowledge of the process coupled with my own personal evolution through it was a constant source of inspiration to keep going through the dissertation work.

1.6 Reflexivity Statement

1.6.1 *Journey to the PhD*

As many other women can relate, when I look back at my thirties I see that infertility was a constant presence in my life that corresponds with my decisions regarding career path, settling down and delayed parenthood. For so many women, their professional trajectories evolve through and as a result of their motherhood milestones. I am not any different. My journey through infertility is one that was intertwined with my journey to a PhD. I started pursuing my graduate studies in health promotion topics and stigmatized health experiences as a mature student. I was in the middle of my Master's in Health Communication when we started trying to conceive (TTC). After a year of TTC we decided to get a medical opinion and were referred to a fertility centre for treatment and testing. I was diagnosed with low ovarian reserve. We started with intrauterine insemination and that did not work. We decided to move straight to IVF. At this point I was already relying on social support and learning about the treatment process and getting emotional guidance from an extended family member and another friend; women whom I looked up to as IVF alumni, and who had previously been transparent about their own journeys. One of them was successful in conceiving and the other unfortunately was not.

During the fall of 2013 we started our first cycle of IVF and ultrasounds showed limited progress with only two mature follicles. We were told to cancel. We went against the odds and the doctor's advice and said no, let's keep going. Clinicians were pleasantly surprised to find we were able to make two healthy embryos, and I was scheduled for a day 2 transfer and we put back both. One of our day 2 embryos hatched and I got pregnant. Our son Theodore Dennis was born shortly after I defended my Master's Thesis in the spring of 2014 and today he is 6 years old.

I continued my teaching and research experiences in health communication and interdisciplinary research during my time as a new mother. In addition to my Master's work where I engaged immigrant mothers' in conversations on mental health literacy, I had the privilege to carry out some special projects and initiatives: designing a seminar course in Communication focused on social determinants of health and service gaps for vulnerable populations, teaching several other courses in Communication, facilitating a World Café for youth (and their parents) in recovery at the Dave Smith Youth Treatment Centre and training fourth year students on discussion group facilitation, joining a team of researchers from the Faculties of Education and Psychology to pilot a mental health awareness program for students and teachers across Ontario and conducting focus groups as a patient advocate for the Ottawa Fertility Centre to get feedback on their patient experience. I thrived in face-to-face environments communicating with everyday people and giving them a forum to voice their diverse health experiences.

At this same time, my journey through infertility and interest in peer-based social support was just beginning. I learned from the forward thinking of my peers and wanted to offer the same support to women I knew who were struggling to build their own families. I started becoming more open about my experience with family and friends as a way of building what I referred to as ferti-literacy. I realized that there was still a lot of progress to be made in changing the perceptions of others, and that there were so many women who were coming to terms with their own needs for fertility treatment and social support. I grew to realize how common this struggle was. I started offering another friend peer support at a moment where secondary infertility was settling into our lives. At this time where I had so many unanswered questions about peer-based support and infertility and how and what other women were experiencing.

The second phase of my graduate work was inspired and I started my Doctorate in Population Health in the fall of 2015. An interdisciplinary program offered me valuable opportunities to expand my insights into the roles of social determinants of health in particular the role of social capital in health outcomes, strengthen and learn about diverse research approaches, learn about health interventions and apply new, complimentary and different lenses beyond communication to fertility and peer support such as psychology, social sciences, and epidemiology.

While the road to finishing my doctorate has not been easy, I am finding the silver lining in every challenge. From the time my doctorate began until last fall in 2019, we faced secondary infertility and went through six additional IVF treatments. Despite having consecutive failures due to my increased age and diminished ovarian reserve, I found strength in focusing on motherhood and our growing son, nurturing my spirit of inquiry in my dissertation work, and through the unconditional, constant, and kind support of another peer, Stephanie Côté. I would have never guessed that my former tennis opponent would become a close friend as a result of our shared fertility experiences.

Making a difference in the lives of other women became a guiding light for me, and kept me going on the dark days, and gave me the strength to accept the end of our own fertility journey, after receiving our last negative test result on September 16, 2019. Five days later I would have the honour of disseminating the preliminary findings of my doctoral research at the Canadian Andrology and Fertility Society Annual General Meeting in Ottawa. It was a defining moment on this path that I will never forget.

Today I wrap up my dissertation work in the middle of the world-wide pandemic COVID-19 while home-schooling our son. I am at peace in our socially distanced life with our small and happy family of three. Hindsight is 20/20. Now more than ever peer- based social

support matters for so many people facing a variety of challenges and who find themselves isolated from close relationships all around them.

1.7 Dissertation Overview

The next three chapters of this dissertation are standalone manuscripts. Chapter 2 is comprised of the first article that uncovers self-disclosure and social support in fertility-care using a psychosocial lens. Chapter 3 is the first part of the research study and depicts how IVF patients contemplate social support prior to self-disclosure through the assessment of their information and peers. Chapter 4 is the second part of the research study and breaks down disclosure between IVF patients according to two parts: the communication process and the scope of their disclosures. Chapter 5 wraps up this dissertation by with overarching conclusions. At the end of the dissertation, supplementary research material is organized in appendices: research ethics certificate (Appendix 1); recruitment and consent documents (Appendix 2), and the participant sampling frame (Appendix 3), and data collection tools (Appendix 4). Knowledge dissemination activities are also described (Appendix 5) alongside a list of abstracts from other academic works prepared during the thesis period (Appendix 6).

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Chapter 2. Article 1. LITERATURE REVIEW Overview

In this chapter I provide a rationale for focusing on psychosocial aspects to fertility-care and review the role of communication and disclosure in a broad range of support channels. The article starts by talking about the stigma of involuntary childlessness and social perceptions of fertility struggles. It then delineates and links the complimentary concepts of social support, disclosure and support adequacy before reviewing social support options (social isolation, spouses, family, friends, counsellors, support groups, online forums and peers) and examining the current literature on communication and disclosure within each one. Through that process I noted significant gaps in the literature when it comes to understanding ART patient-peer relationships and how they work. Given the importance of communication in sustaining adequate social support, I turn to the Disclosure Decision-Making Model (DD-MM) as a lens through which to explore opportunities to understand how ART patients engage their peers, laying the groundwork for the rest of this study.

I carried out this review by creating a centralized list of search terms and search combinations and then performing extensive searches with each potential one the library database. To start I used PubMed, Scholars' Portal and Google Scholar. As I kept reading I added new terms to search for, and added additional sources by consulting the references of articles of interest. When no new or relevant articles continued to appear on those lists I completed the process.

CHAPTER 2 - Article 1

Using a psychosocial lens to explore self-disclosure and social support in fertility-care: A review of the literature and call for future research

2.1 Abstract

Communication and social relationships frame the support outcomes for patients, and are tenets of the psychosocial approach to fertility-care. The purpose of this article is three-fold. First it underscores the value of using the psychosocial lens when it comes to patient needs in fertility-care. The article reviews the literature on the nature of stigma, the role of disclosure for patients, social support and the types of social support channels with an emphasis on disclosive communication used by women in fertility treatment to respond to stressors. Secondly, it uses the Disclosure Decision-Making Model (Greene, 2009), which describes how people communicate their health experiences, as a framework to explore the process of building social support. Thirdly, it points to significant gaps in the infertility research pertaining to patient-peer relationships. It calls for a research agenda that will uncover the disclosure process, the potential for future social support interventions, and the perceived social support outcomes that arise from patient to peer interaction in fertility-care.

Keywords: infertility, psychosocial, self-disclosure, social support, peer support, fertility, stigma, communication, disclosure decision-making.

2.2 Introduction

One in six Canadian couples experience infertility (Bushnik et al., 2015). Canadians are having fewer and fewer children as natural birth rates and fertility rates steadily decline in Canada (Canada, 2016). Some of this declining birthrate can be attributed to a rise in delayed childbirth, which can be explained in part due to “people placing a priority on establishing stable careers and homes in a fast-paced, competitive economy over child-rearing” (Weeks, 2011). The problem associated with this delay is that prospective parents seldom grasp the scope of medical and social challenges of trying to conceive in their late thirties and early forties (Weeks, 2011). When some couples have difficulty conceiving naturally, they turn to assisted reproductive treatment (ART), most commonly in the form of fertility enhancing drugs, intrauterine insemination (IUI) and in vitro fertilization (IVF) (Canada, 2012). However, as women enter their mid-late thirties and early forties, they are at higher risk for issues such as diminished ovarian reserve, poor egg- quality, or hormonal issues (Lindsay & Vitrikas, 2015). Male-factor infertility concerns that vary with age include abnormal sperm production with issues concerning morphology, speed, and volume (Lindsay & Vitrikas, 2015). Couples dealing with infertility also face significant risks for a multitude of personal and interpersonal stressors which can include anything from perceptions of infertility stigma, strained relational dynamics, and self-blame (Schmidt et al., 2005a).

Commonly, infertility clinics approach treatment with a biomedical lens (Cousineau et al., 2006) in the sense that medical teams identify the condition causing infertility and prescribe an intrauterine protocol. Given the nature of infertility treatment and its focus on reproductive inputs and outputs, it is common that women experience more stress as the main patient in the

course of treatment, compounded by the fact many treatment protocols are exclusively biomedical in nature (Cousineau et al., 2006).

Infertility and its treatment constitute a unique health struggle in several respects. Whereas other health treatments and options are often covered by public and private insurers, ART treatment is inconsistently covered across jurisdictions. It constitutes a significant personal financial investment for couples with an unpredictable outcome which makes it a stressful passage towards parenthood. It has been reported that out of 14,928 fresh IVF treatment cycles performed in clinics in Canada in 2013, the success rate was only 34% for women under 35 years old and 28% for women aged 35-39 years (CFAS, 2014). Of the ART treatments, IVF is considered to be the most taxing and demanding on patients. On top of the stress of potential failure, IVF typically strains patient resources on a variety of levels, including the cost of IVF, which can be as high as \$12,000 CDN per treatment in Canada, the more invasive nature of the procedure (compared to the other treatments), which requires egg retrievals and embryo transfers for the patient, the large variety and volume of patient medications prescribed for each of its stages (stimulation, egg retrieval, and embryo transfer), and fear of public judgement (Bell, 2012; Cousineau & Domar, 2007). Unlike other health conditions, infertility impacts the rite of passage for both parties in the couple. The condition and its treatment can leave individuals feeling a loss of control over their lives (i.e. coming to terms with involuntary childlessness) (Imeson & McMurray, 1996) and feeling individual blame for their role in the diagnosis (i.e. male-factor infertility and public image) (Steuber & Solomon, 2011). This can result in both spouses being left to their own devices to cope with the stress (Peterson et al., 2006)

Given these stressors, Bell (2012) states that, along with addressing biomedical needs (such as isolating the cause of infertility and an appropriate medical solution to the problem),

infertility treatment should tackle important psychosocial support needs (such as social acceptance and understanding) that women face as a result of their experience of involuntary childlessness and their use of reproductive technology. The high rates of infertility, the burdens of its treatment and individual and social perceptions of the condition constitute a serious public health problem that calls for more research on psychosocial support options with a view of providing a more holistic, patient-centred approach to care, one that focuses on emotional well-being (Macaluso et al., 2010).

The psychosocial approach to fertility-care reflects how social relationships “frame one’s infertility experience” (Schmidt et al., 2005a, p. 253). Socially supportive relationships include a wide range of social supports such as family, friends, psychologists and peers. Schmidt et al. (2005a) state that many infertility patients identify with the need for supportive relationships and outlets as they undergo the challenges and stressors of infertility and its treatment. Women suffering from infertility have been found to gravitate more deeply towards social support than men, who may prefer to distance themselves and find direct solutions to the problem (Peterson et al., 2006).

Some ART patients seek psychosocial support (communicating with others about the problem), from formal channels (service providers) or informal channels (family and friends) to cope with stress (Peterson et al., 2006; Bell, 2012). Specifically, ART patients are known to meet their psychosocial support needs through sharing their verbal and non-verbal messages with their channel(s) of choice (High & Steuber, 2014). Strategies include online forums (Hinton et al., 2010), counselling (Cousineau & Domar, 2007), support groups (Domar et al., 2000), talking with family, friends and peers (Bell, 2012), and social isolation (Hinton et al., 2010). In terms of the functional coping mechanisms, communication serves as a means to acquire psychosocial support. In the context of ART, it begins with the self-disclosure by a person

experiencing infertility of their private medical experience with a view towards leveraging the support channel (Slade et al., 2007). When individuals decide to share personal information with each other, the process establishes trust and helps foster authentic, socially supportive relationships (Greene et al., 2006; Wu, 2009) and lays the groundwork for sustained communication. Individual relationships conducive to psychosocial support are associated with self-disclosure and these relationships can alleviate stress (Kelly & McKillop, 1996), reduce isolation (Martins et al. 2012), and increase trust (Greene et al., 2006).

While family, friends and health care providers can provide psychosocial support, a study of patients' disclosure of their fertility journeys to others linked purposive and thoughtful disclosure to others in "similar situations" with an increased likelihood of reducing stigma and anxiety (Slade et al., 2007, p. 2316). Similarly, in her assessment of ART users' psychosocial needs, Bell (2012) found that women gravitated towards "other assisted-reproduction users" – peers – because of their ability to offer genuine emotional and informational supports based on their own personal journeys. This suggests that peers have the ability to offer unique benefits to IVF patients over and above conventional support resources.

The purpose of this article is to review current literature that addresses the role of communication in the psychosocial approach to fertility-care. It will do this in four ways. First, it starts with a synthesis of research on the psychosocial implications for individuals suffering from infertility including experiences of stigma and the benefits of social support. Second it will examine common social support channels for infertility patients and explore the role of communication and self-disclosure in yielding those supports. Third it will focus on the intrapersonal considerations individuals face when it comes to disclosing their health condition to others. It will do this by using the theoretical lens of the Disclosure-Decision Making Model (DD-MM) (Greene, 2009), which focuses on how individuals contemplate and evaluate

opportunities to share personal information. Finally, it will endeavour to set a research agenda that casts light on the quality and communication dynamics of IVF patient and peer relationships in the spirit of broadening public understanding of an unexplored and valuable psychosocial support channel for women suffering from infertility.

2.3 Review of the Literature

2.3.1 *The Psychosocial Dimensions of Infertility*

Approaches to infertility and its treatment are evolving beyond the diagnostic and prescriptive biomedical approach (Allan, 2007; Macaluso et al., 2010). There is a growing movement in fertility-care that embraces a more holistic outlook and the psychosocial dimensions of the condition and its treatment.

Parenthood is a social construct that suggests that starting a family is a natural and anticipated rite of passage for most couples, and societal norms suggest that couples should want to have children (Koropatnick et al., 1993; Miall, 1985). Given the expectations society imposes on individuals to become parents, infertility is viewed by many as a crisis, a “non-event transition”, and a stigmatizing situation which constitutes multiple layers of stress (Koropatnick et al., 1993). In the most extreme cases, particularly in scenarios where stress management is a challenge for infertile women, the levels of anxiety and depression they experience is comparable to women with cancer or heart issues (Domar et al., 1993).

There are many examples of psychosocial issues that women experience during their fertility journey. These include family challenges within the couple, such as gender and parenting roles, communication and interpersonal dynamics, self-blame and shame for the partner suffering the infertility diagnosis (Cousineau & Domar, 2007; Cwikel et al., 2004; Griel, 1997). For example, “modern women” commonly assume all responsibility for their fertility as demonstrated by their attempts to control their infertility treatment outcomes by using herbal

teas, acupuncture and yoga, and they may feel like failures when their added measures for a successful outcome do not come to fruition (Cousineau & Domar, 2006). These issues also exist within one's extended family and can include pressure to conceive, judgement, and religious and cultural beliefs about fertility. These challenges may be more pressing for minority women, as was underscored by Missmer et al. (2011), who found that IVF patients who identified as non-caucasian were "seven to 18 times more likely to be concerned about friends and family finding out about their infertility treatment compared with white women" (p. 1947).

In addition, broader social challenges such as cultural and stigmatizing perceptions within various ethnic communities (Jain, 2006; Missmer et al., 2011), strains on social networks (Lampman & Dowling Guyer, 1995), social comparison (Knobloch Westerick et al., 2016) and acceptable norms such as natural conception (Slade et al., 2007) can create stress for couples trying to conceive. This stress can be felt in the form of social judgement and feelings of inadequacy (Lampman & Dowling Guyer, 1995).

When couples face such problems and their own perceptions of them, this can impact the woman to a deeper degree, who, as the ART patient, is already enduring the reproductive outputs (steps such as stimulation, egg retrieval, and embryo transfer) of infertility treatment. These challenges are at the root of the infertility stigma and may explain why women call on psychosocial support channels to cope with these social stressors, on top of the other stressors (financial, physical, emotional) that they are already experiencing. Women's emotional stress within social relationships and their associated interactions has been reflected in the literature (Abbey, 2000; Remennick, 2000). For example, a couple experiencing infertility can find it painful or feel shame or other difficult emotions when they explain their treatment journeys to people with whom they interact (Bute, 2009).

2.3.2 *Infertility Stigma*

A stigma is defined as a negative sense of social difference from others, a perceived deviation from the norm, that deeply discredits and devalues the individual (Goffman, 1963). Martins et al. (2012) point out that while people with other stigmatized identities can guard their privacy, there is limited reprieve for couples facing infertility when people see they have not produced children. As Bute (2009) points out, the inquiring public can be very invasive when it comes to child-rearing questions, which sometimes leads women who are trying to conceive to feel hurt by what they perceive as insensitivity and stigmatized responses. For example, women might feel judged by others in a community for being childless or may perceive that their inclusion in various social circles is predicated upon having a child. Stigmatizing situations can compel individuals to avoid seeking social support, especially when one's self-esteem is at risk (Folkman et al., 1986). In other words, lower self-esteem as a result of judgement emanating from one's health experiences makes it harder to leverage social support resources. Examples of health experiences that commonly carry social judgment, the fear of potential stigma for patients, and less social support include mental illness (Abdullah & Brown, 2011), abortion (Cowan, 2017; Steinberg et al., 2016), substance-abuse (Birtel et al., 2017), HIV status (Lee et al., 2015), miscarriage (Bommaraju et al., 2016) and infertility (Slade et al., 2007).

Infertility stigma is difficult to escape and makes it difficult for individuals to disclose their fertility journey. Women are known to experience high degrees of “personalized stigma”, mainly in the form of how others will view and treat them (Steuber & Solomon, 2011). Lampman & Dowling-Guyer (1995) underscore how family get-togethers are often “reminders about one's infertility that typically lead to invasive family planning questions making it difficult for couples to decide how much to share” (p. 214). For example, couples who are trying to achieve pregnancy could face siblings and in-laws who themselves are building their families

with great ease, making their experience seem abnormal. Couples can also anticipate how their loved ones might react, given these people's preconceived notions and opinions, and thus sense that there is more risk than reward in sharing (Schmidt et al., 2005a). These concerns may force couples to make selective disclosure decisions when it comes to sharing information about their condition. Couples also share a sense of self-stigma and similar disclosure concerns as a result, and in cases where husbands experience more personalized stigma, couples disclose their journey less frequently in their various networks and remain protective of their public image (Steuber & Solomon, 2011).

Patients' self-stigma surrounding childlessness and infertility often compels women to be vigilant regarding the types of information they share. This can be "challenging because certain details have to be omitted from conversations at times, and in times of upset, other reasons might need to be found to explain the situation" (Bell, 2012, p. 701). Examples of the type of information that could be shared include topics such as the diagnosis, emotions and fears, the treatment protocol, and hopes for a child. The literature also states that patients are judicious when it comes to the "whom" -- the disclosure recipient -- in order to protect themselves from stigmatizing messages and questions (Bell, 2012). Disclosure recipients can include parents, friends, other couples, colleagues, neighbours, and acquaintances, but it is clear that the choice of recipient is influenced by perceptions of self-stigma and the benefit versus the cost of disclosing to this recipient (Bell, 2012).

In sum, according to Bell (2012), a perception and fear of negative communication patterns ends up imposing a "trade-off" for fertility patients, who may sacrifice social support by withholding information about their infertility (selective disclosure), with the end result being a limited circle of support. Depending on the situation, fertility patients may show varying degrees of openness versus discretion in relation to the disclosure content and disclosure recipients.

When patients sense stigma, decisions about “what” and “whom” to tell can become challenging, and may result in a guarded style of communication.

The stigmatizing nature of infertility and its isolating effects have been well documented in existing research. Common impacts include: seeking less social support from family and friends by “suspending” relationships or by putting them on hold and avoiding social gatherings (Slade et al., 2007); having to describe oneself as “voluntarily childless”, or being accused by others of being “too career focused” (Lampman & Dowling, 1995); receiving unsolicited and even offensive advice (Bute, 2009; Slade et al., 2007); and encountering inappropriate comments or jokes about sexual intimacy (Whiteford & Gonzalez, 1995). As a result, some couples might choose to retreat from their friendships during infertility treatment and resurface after they have positive news to share, or share nothing in the case of bad news. In the eyes of the patient, supports such as family, friends and colleagues may communicate and ask questions about their infertility with well-meaning intentions (Bute, 2009). However at the same time, many patients see that these supports have pre-existing attitudes about involuntary childlessness which factor in to their ability to help ease the burden of treatment (Lampman & Dowling, 1995).

One effect of the stigma associated with infertility is the choice of some patients to guard their treatment journey a secret (Slade et al., 2007). Secrecy for people with health conditions such as substance-abuse (Birtel et al., 2017), HIV status (Lee et al., 2015), and abortion and miscarriage (Bommaraju et al., 2016) has been well researched in the literature. This approach tends to have negative repercussions: keeping secrets has been linked to obsessive behaviours, heightened sensitivity, and higher stress (Folkman et al., 1986; Smart & Wegner, 2000). These challenges can give rise to social withdrawal, isolation, anxiety and depression, all of which impose an increased risk of IVF failure (Gibson & Myers, 2002; Miall, 1985; Peterson et al.,

2006; Slade et al., 2007; Whiteford & Gonzalez, 1995). Cousineau and Domar (2007) suggest that, in the case of recurring failed treatment cycles, it is not uncommon for IVF patients to report symptoms of depression, anxiety, anger, and isolation.

Slade et al. (2007), in their study of infertility patient perceptions of stigma, disclosure patterns, support and distress, echo concerns about transparency with family, friends and acquaintances, because of the unsolicited advice and counter-productive, devaluing and stigmatizing commentaries that openness sometimes brings. Specifically, these authors found that “consciousness of stigma and judgement leads patients towards a reduced disclosure of infertility to others” (Slade et al. 2007, p. 2309). This finding parallels that of Greene (2000) who found, generally speaking, that perception of stigma surrounding illness contributed to an unwillingness to disclose. In other words, stigma is a barrier to sharing information and help-seeking, which hinders an individual’s ability to leverage social support as a coping mechanism for their stress.

2.3.3 Social Support, Self-disclosure and Support Adequacy

2.3.3.1 Social Support

Relationships serve several social support functions such as models of desired health outcomes, reinforcers of positive behaviours, buffers of the effects of stress on health, and channels to other resources to cope with stress (Bartholomew et al., 2011). Social support is multi-dimensional in nature and touches an individual’s life on a variety of levels (Bartholomew et al., 2011). House (1981) developed a model of social support functions by describing distinct support actions and behaviour through which social support outcomes can be better understood. The main types of support as described by House (1981) are emotional (gestures of love, empathy, caring, and trust), instrumental (tangible aid and services that directly assist a person in need), informational (provision of education, advice, instruction and feedback) and appraisal

(feedback that is useful for self-evaluation purposes: constructive ideas, affirmation and social comparison), (Fakhraei & Lennox Terrion, 2017).

Heaney and Israel (2008) state that while support can be broken down on a conceptual basis, the constructs are inter-related. In other words, it is not uncommon that supportive relationships serve a variety or any combination of these support functions. These authors also contend that while social support always comes with kind and helpful intentions, “to what degree the support recipient experiences the support as helpful is variable, as negative perceptions and consequences to caring overtures have also been identified as important questions” (Heaney & Israel, 2008, p. 192). It is also significant to note that support is seen as a compelling force that can motivate the thought processes and actions of the receiver (Heaney & Israel, 2008). Since individual social support comes in the form of an interpersonal exchange, it is predicated by conditions such as caring, trust and respect (Heaney & Israel, 2008). Those conditions create a comfortable environment for disclosure, and help serve as a basis for supportive relationships.

Martins et al. (2012) found that infertile couples who rely on supportive relationships would always report healthier emotional outcomes than couples who cannot (p. 373). One of the main tenets of social support is to provide a safe environment conducive to open communication (Martins et al., 2012). However, this objective cannot be met in emotionally unsafe situations in which people feel uncomfortable, perceive stigma, and sense judgment – all of which can act as barriers to disclosure and exacerbate what is already a very difficult situation. The lack of a safe space to seek social support puts those individuals at risk for higher emotional discomfort and poorer outcomes.

2.3.3.2 *Self-disclosure.*

As an alternative to keeping infertility and its treatment a secret and experiencing its associated isolating effects, disclosive communication has the ability to cultivate social support. Self-disclosure is defined as a self-focused and interpersonal form of communication, the sharing of personal information between individuals, and a process that establishes trust and helps foster socially supportive relationships (Greene et al, 2006; Wu, 2009). Jouard (1971) framed it as a way for people to foster closeness and an act that requires courage because it requires sharing personal information and being authentic about oneself to another. That is, as stated by Rosenfeld (2000), it takes a “certain level of courage for an individual to be known and be perceived by others as one actually is” (p. 4).

The act of self-disclosure is multi-dimensional. On the individual level it encompasses a variety of introspective considerations – or reflections on engaging in disclosure – such as the benefits of being open versus closed, risks, rewards, personal feelings, breadth and depth, ideal qualities of the disclosure recipient, and the alternatives to disclosure (Rosenfeld, 2000). This introspective assessment is seen as a process that involves an evaluation of key criteria, including the information, the receiver, and the ability to share (Greene, 2009). On the interpersonal level, another process unfolds as a result of the ongoing communication: an exchange of supports between the individuals and the provision of tangible and intangible comforts that assist a person in need (Heaney & Israel, 2008).

Self-disclosure has been linked to a variety of benefits for people suffering from cancer (Hilton et al., 2009), alcoholism (Liu et al., 2017), pregnancy loss (Andalibi & Forte, 2018), mental health problems (Zhang, 2017), sexual abuse (Andalibi et al. 2018), and infertility (Martins et al., 2012). In these health-related situations, disclosure can reduce stress, guilt and associated psychological and physical problems for an individual and in turn offer “new insights

and perspectives on the secrets” (Kelly & McKillop, 1996, p. 454). In addition to the benefits above, connections fostered through self-disclosure matter because they have the ability to “develop one’s self-worth” in circumstances where the individual receives supportive responses from the disclosure recipient, ultimately benefitting mental health (Greene et al., 2006, p. 417).

In order to leverage social support, someone experiencing infertility must start by disclosing their condition. Martins et al. (2012) underscore that “when infertility is not disclosed to at least a close relationship, the beneficial effects of social support in managing stressors on personal and social levels cease to exist” (p. 371). In sum, self-disclosure of one’s infertility can lead to greater social support, resulting in greater psychological well-being.

It is also important to note that self-disclosure offers no guarantee of perceived social support. It is not unusual that in circumstances where couples disclose infertility to all close relationships, they may perceive low social support and a high incidence of stress (Martins et al., 2012, p. 372). That is, the people to whom infertility patients choose to turn in their time of need, as well as the perceptions, experiences and reactions of those people, have the ability to impact the quality of social support. For example, some couples have a difficult time navigating their disclosure decisions and managing their expectations of social support from people closest to them, especially when they are conflicted between “feeling the need to tell” and the anticipation of an unhelpful response (Martins et al., 2012). This suggests that disclosing one’s infertility experience to family members, friends, and colleagues offers no guarantee of reliable psychosocial support. This finding also offers an important takeaway by suggesting that individuals may be better served by looking beyond their typical everyday social networks to respond to their social support needs.

Steuber and High (2015) found that women suffering from infertility sought support using a variety of disclosure strategies including direct (face to face, live), third party (through

other people), incremental (starting off small in stages), humour (jokes), entrapment (leaving hints without having to share directly) and indirect media (revealing details through email or online messages). These authors concluded that infertility revelations made through direct disclosure was the only strategy that significantly corresponded with perceived support quality and was one of only two strategies, along with incremental disclosure that enhanced quality of life (Steuber & High, 2015, p. 1639). In other words, women suffering from infertility value the importance of authentic communication in leveraging desirable support outcomes.

2.3.3.3. *Support Adequacy.*

High and Steuber (2014), in their study of gaps between the supportive communication people desire and receive in the context of infertility, concluded that support adequacy is yielded by supportive communication (e.g. perceptions of empathic responses) and support quality (e.g. nature of social support provided). Participants in this study reported various inadequacies in the support they received from their spouses, family and friends, online sources, and medical professionals (High & Steuber, 2014). It was not uncommon that the women desired better emotional, network and tangible support from their spouses than they received or felt inundated by too much or inappropriate informational support from family and friends (High & Steuber, 2014, p. 168). A limitation of this study is that while it examined a variety of different social support channels, it did not assess the adequacy of peers. For similar reasons, Slade et al. (2007) echo a sentiment against “wide disclosure” of infertility with varied social circles, and suggest that, as an alternative, more thoughtful, purposeful disclosure to “others in similar situations may reduce the stigma and the level of anxiety” (p. 2316).

Meaningful self-disclosure builds authentic socially supportive relationships (Greene et al, 2006; Wu, 2009) and acts as a gateway through which to establish trust (Greene et al., 2006),

alleviate stress (Kelly & McKillop, 1996), and reduce isolation (Martins et al. 2012). Sometimes the absence of such outcomes and other support goals is best characterized as a gap between desired support, what a person really wants, and the support actually received by the individual (Xu & Burleson, 2001, p. 540). Support inadequacy describes this discrepancy whereas support adequacy describes the fulfillment of support objectives (Brock & Lawrence, 2009; Dehle et al., 2001).

In sum, one's potential to manage fertility-related stress through social supports is predicated by the decision of disclosing infertility (Martins et al., 2012, p. 371). In order to leverage social support there must be some degree of self-disclosure. Women suffering from infertility meet their social support needs through a variety of strategies such as social isolation, online forums, support groups, counselling, close relationships and peers. In the next section each social support resource and its links to self-disclosure will be more closely examined.

2.3.4 Support Strategies and Outcomes

2.3.4.1 Social Isolation

Some individuals and couples choose to cope with their infertility by retreating from their networks and cocooning themselves from social engagement (Peterson et al., 2006). In their study on gender differences in how men and women who are enduring IVF treatment deal with infertility stress, Peterson et al. (2006) found that women “proportionately engaged in a greater degree of escape/avoidance than men” (p. 2447). Women who are socially isolated before IVF are more distressed after its failure, pointing to the maladaptive nature of isolation (Litt et al., 1992). Social isolation is linked to exclusion in social circles of new mothers and couples with children or expectant parents and increased participation in online communities (Hinton et al., 2015; Raque-Bogdan & Hoffman, 2015), is sometimes self-inflicted (Raque-Bogdan &

Hoffman, 2015), and stigmatizing (Hinton et al., 2015). Poor long-term outcomes have been associated with social isolation, including depression (Lazarus & Folkman, 1984).

For individuals who perceive high levels of social support from close friends, keeping infertility a secret offers the benefit of privacy from distant, less trustworthy friends (Martins et al., 2012). In this sense, the risk for poor long-term outcomes as a result of social withdrawal and isolation is less threatening for these individuals. However, for individuals who encounter lower levels of support, the “decision to disclose infertility to less supportive people while guarding secrecy from distant sources” can cause heightened stress and anxiety (Martins et al., 2012, p. 383). The risks of isolation impact the patient on emotional and physical levels. From a mental health standpoint, isolation can intensify anxiety and heighten stress and depression (Slade et al. 2007). It is known that infertile women already have higher states of distress than their fertile counterparts (Domar et al., 2000) and isolation can heighten the magnitude of challenges facing these women and ultimately negatively impact the likelihood of success in treatment.

2.3.4.2 Online Forums and Blogs

The virtual world encourages self-disclosure, particularly when it is easy to find many others who can relate through shared experiences in online forums (Hinton et al., 2010). Online forums have been noted meet the support needs of patients through the provision of factual and experiential information sharing, anonymity, emotional support, validation, a sense of empowerment, increased knowledge normalization and reassurance, and straightforward and timely accessibility (Hinton et al., 2010; Grunberg et al. 2018). However at the same time, they also have the potential to reinforce an alternate reality. For example, the transient nature of web-based discussion often results in fragmented discourse whereby people can drop in and out of communication, with little commitment for follow-up. Hinton et al. (2010) found that it was not uncommon for “online communities to remain virtual” (p. 438). Cousineau and Domar

(2007) summarize several concerns about online infertility supports including an inadequate quality of information, a common pattern between patients' reliance on internet forums and increased disregard for tangible supports, and higher distress levels amongst online support users versus multi-channel support users. Furthermore, Cousineau and Domar (2012) underscore the potential links between usage of online supports and the stress of fertility treatment, patients' psychological distress, and lower pregnancy rates.

Nevertheless, research on online forums and infertility suggests that they can be relevant because they allow patients to engage with other women who also suffer from infertility (Hinton et al., 2010). Grunberg et al. (2018) contend that there is appeal amongst fertility patients online peer support networks including the abilities to: access peer support on their smartphones, ask and answer questions, and have private one on one communication and had less interest for in-person meetings.

2.3.4.3 Support Groups

Infertility support groups are gatherings of peers who provide authentic insights for IVF patients and are usually professional or peer-led (Helgeson & Gottlieb, 2000). They can consist of any combination of talks by guest speakers, question and answer periods, and/or a group discussion (Percy et al., 2009). They are also unique in that they can meet a variety of support outputs across the four main categories (emotional, informational, instrumental, and social comparison) (Helgeson & Gottlieb, 2000; Percy et al., 2009).

Self-disclosure remains at one's discretion in support group settings. Percy et al. (2009) found that women suffering from polycystic ovarian syndrome and in a nurse-led peer support group were relieved that the groups did not "force self-disclosure" (p. 2050). This offers a degree of comfort and assurance to patients who may already have a heightened state of sensitivity.

Support groups offer several advantages for the IVF patient population. A randomized control study of the impact of group interventions on distress in infertile women found that women who participated in support groups showed significant psychological improvements in their paths towards parenthood over women who did not participate in these groups (Domar et al., 2000). Through a sharing atmosphere, peer support groups offer the benefits of drawing upon mutual experiences and vicarious learning, cognitive therapy, improved coping skills for patients, and practical help (Bell, 2012; Domar et al., 2000). In addition, support groups offer an opportunity to observe and adopt health-promoting behaviours through peer interaction (Domar et al., 2000).

While there are many benefits to support groups, support groups can also pose challenges (Bell, 2012). As time and treatment cycles progress, group dynamics can give rise to tensions based on successful (pregnant) and unsuccessful (not pregnant) outcomes experienced by different members of the group (Bell, 2012). Positive outcomes associated with support groups are sometimes viewed as temporary, as a result of a split between these patient subgroups and the eventual exit of expectant mothers (Bell, 2012). Furthermore, according to Bell (2012), participants found it hard to take conversations offline and also had privacy concerns about sharing a very personal experience in a wider group setting. This suggests that there is useful opportunity to understand these interactions beyond the support group setting. For example, individuals may behave and communicate differently in one on one interactions than they do in peer support group environments that are influenced by group dynamics and other constraints (Domar et al., 2000). The opportunities and limitations of peer support groups offer relevant insights into the value of peer-based support, and points to the potential strengths of individualized relationships between IVF patients.

2.3.4.4 *Counselling*

ART patients are typically faced with a choice when it comes to counselling. Some patients opt for in-house counselling provided by fertility clinics, while others prefer off-site sessions with a private therapist. Generally speaking, Bell (2012) recognizes the valuable impact of counselling with psychologists and social workers as the creation of a safe environment for “general emotional support”, “accepting involuntary childlessness”, “embryo issues” and “moving on” (p. 697). In other words, counselling can provide a place where patients feel understood, open to sharing, and free of judgement.

There are, however, unique limitations with in-house counselling from a self-disclosure perspective. First, it is not uncommon for patients to feel wary and circumspect about a clinic appointed therapist (Bell, 2012). Patients can be left with concerns about loyalty, objectivity, and trust and this can make it difficult to develop a meaningful relationship (Klein, 1989). Furthermore, these issues present challenges in terms of a comfortable self-disclosure experience. For example, engaging with a member of the clinic team raises questions about confidentiality for patients, thus heightening their stress and influencing their decisions about what to self-disclose and some women see their interactions with in-house counsellors as a “tick in the box” (Bell, 2012, p. 704).

Similar concerns about in-house counselling were underscored by Peterson et al. (2012), who question the viability of one stop shopping for infertility counselling and psychotherapy and the ability of in-house therapists to address issues related to treatment success rates, third-party reproduction choices, and issues related to stopping treatment. Interestingly, in her exploratory study of ART patients’ psychosocial support needs, Bell (2012) found that patients reported limiting their disclosure with counsellors and, when asked how they were doing, would simply say “fine” instead of delving deeper into their feelings in part due to perceptions that the clinic

had stretched capacity and resources and they felt guilty taking time away from other patients (Bell, 2012).

While providing support benefits, the alternative, off-site counselling, has its own set of disadvantages. It can be cost prohibitive for financially burdened patients, wait lists are long for a time-sensitive matter, and it is difficult to find therapists with adequate experience in infertility (Bell, 2012).

2.3.4.5 *Family, Friends and Acquaintances*

While having “close” people to talk to is a fundamental coping and support strategy for infertility patients (Schmidt et al., 2005a), it is not always straightforward. Bute (2009) examined how women talk about their infertility and how they handle requests for information. She found that many women experience a dichotomy in disclosure strategies and management of dialogue about their fertility struggles with family members, friends and acquaintances that manifests itself as a “disclosure dilemma” (Bute, 2009, p. 758). On the one hand, when people asked how women trying to conceive were doing with their infertility it was sometimes interpreted as “caring” and an “opportunity to talk” (Bute, 2009, p. 758). On the other hand, inquiries could also be seen as “insensitive, a threat to identity, an invasion of privacy, overbearing in nature and a reflection of larger societal beliefs about the motherhood mandate” (Bute, 2009, p. 758). Complex experiences like these, whereby the woman feels caught and torn between helpful and unhelpful perceptions of her condition, makes it difficult to navigate social relationships and access support.

Slade et al. (2007) found that greater disclosure of fertility problems was associated with higher distress and contend that once one’s infertility experience is common knowledge, one risks having it become a regular conversation topic with unpredictable timing in social situations and no “respite” from talking about it (p. 2315). Such developments have the potential to leave

individuals suffering from infertility to feel that they have lost control over their narrative and can lead to increased stress levels. Steuber and Solomon (2012) studied revelations amongst infertile couples and found that wives typically reveal more to their respective female circles than husbands to their respective male circles. Furthermore, it was not uncommon to see such levels of disclosure discrepancy amongst couples where one party would feel more comfortable being transparent than their non-disclosive counterpart (Steuber & Solomon, 2012).

Wide disclosure can also be a hindrance when it comes to the individual's needs for sensitivity and can also lead to a perception of low social support in close circles as a result of recipient responses such as insensitive remarks, unhelpful suggestions, and constant questions (Martins et al., 2012; Slade et al., 2007). It has been suggested that it may be in the patient's best interest to "disclose their infertility struggle to distant relationships, as an alternative especially when one experiences low levels of social support in their close relationships" (Martins, 2012, p. 383).

2.3.4.6 Peer Supports

One social support channel that has received less attention in the literature on the psychosocial aspects of infertility is patient-peer relationships. Peer support has been previously defined in the literature as the provision of assistance and encouragement by another individual who is equal (Dennis, 2002). In the healthcare setting, it follows that peer relationships are connections between individuals who have shared health experiences.

What is clear from some studies, however, is that patients may be interested in maintaining more personal contact with people who also used assisted reproduction services outside formal, restrictive settings (i.e. the fertility clinic, support groups) (Allan, 2007; Bell, 2012; Gibson & Myers, 2002). For example, Grunberg et al. (2018) found that a strong majority of infertility patients had a keen interest in online peer support channels. The current literature

identifies patient-peer relationships as a valuable, under-explored and under-utilized coping opportunity for women undergoing fertility treatment (Allan, 2007; Bell, 2012; Gibson & Myers, 2002). The patient-peer connection offers a variety of benefits to both parties in the relationship such as a chance to compare experiences, learn through observation of the other person, feel motivated about their capacity to solve their own problems, and have somebody available who cares and understands the nature of infertility and its treatment, in addition to the hopes and failures associated with it (Bell, 2012).

Bell (2012) found that when asked to reflect on the benefits of peer-based support groups, the majority of women interviewed in her study agreed that there “was no substitute for the lived experience of involuntary childlessness and use of assisted conception services” and that participants made a “clear distinction between the quality of connection and support from other women with shared experiences versus the quality of support they would gain from a counselor” (p. 705-6). Similarly, in a study on maternal perceptions of postpartum depression peer support, Dennis (2010) found that the majority of mothers had a positive experience with peer support and credited it with helping them maintain emotional well-being. In this example, telephone-based peer support helped mothers feel more socially connected and less isolated, improved the mothers’ access to health-care knowledge and resources, and increased the likelihood of healthy behaviours (Dennis, 2010, p. 567). Peers as psychosocial supports have the ability to offer special perspectives to IVF patients over and above conventional support resources, as well as the opportunity to complement IVF patients’ self-disclosure by casting light on their own experiences. However, beyond being described by infertility patients as ideal in meeting their needs, little else is known about what makes them a desirable social support channel and any associated shortcomings they might have.

In terms of where IVF patient-peer communication starts, it is known, on the one hand, that available environments for these women to connect, for example a clinic waiting room or support group, are viewed by some women as attractive and natural areas to engage with one another (Allan, 2007; Bell, 2012). On the other, these environments can be associated with typical norms and behaviours that include respect of one's privacy, which can act as barriers to potential peer connections (Allan, 2007; Bell, 2012). Given that clinics and support groups are bound by patient confidentiality and anonymity, asking for another patient's full name and phone number is seen as inappropriate in these settings. Allan (2007) also found that of the 15 participants in her study, whom she interviewed in a clinic waiting room, only 4 reported that they were comfortable to connect with someone that they met at the clinic. These women offered that these friendships began as an exchange of smiles, straightforward questions, encouraging responses, and graduated to phone conversations and interactions outside the clinic (Allan, 2007, p. 135). The other 11 participants in her study reported that they were less inclined to reach out to someone who was also facing infertility or disclose to another patient in the waiting room, especially because they were isolated and inexperienced at drawing upon peer support (Allan, 2007, p.135). For some people who are more extroverted, the challenge may be easy to overcome, but for the majority of others, breaking through barriers and engaging in conversation in such places can be a daunting task.

While the clinic waiting room may not be an optimal place for women to meet, Dennis (2003) indicates that there are several other ways that patients and peers can connect including one-to-one sessions, self-help/support groups, and on-line computer-mediated groups across diverse settings including homes, hospitals, clinics, schools, community centers and prisons (p. 325). However, it is still unclear how fertility patients connect in general and how they intersect outside of meeting in clinics and support groups. Understanding the various ways through which

fertility patients find each other, in addition to other logistical aspects of their self-disclosure and communication, could be useful for health promotion purposes.

An important, central outcome of social support is self-efficacy, defined as an individual's "beliefs about their personal ability to perform behaviours that bring about desired outcomes" (McAllister et al., 2008, p. 171). According to Bandura (1997), social modeling, or showing people that others in circumstances similar to their own can do something, plays an integral part in increasing one's self-efficacy and confidence in oneself. There is an existing body of research that emphasizes the ability of peers to serve as examples to patients and encourage healthy behaviours and actions in other health contexts such as smoking cessation (Ford et al., 2013), blood pressure control (Haidari et al., 2013), and weight loss (Aschbrenner et al., 2016).

Other impacts of peer-based social support interventions have been widely studied in other settings relevant to infertility. Dennis (2002), for example, notes the efficacy of peer support in both life-transitions and situations of chronic stress for diverse populations. Dennis points to the potential positive impact of peer support for grieving and loss, breastfeeding, post-partum depression and ongoing illnesses such as breast-cancer, diabetes and HIV. Peer support can make a positive difference in the lives of individuals by offering a coping mechanism to deal with the stressors of one's circumstances (Dennis, 2002). Similarly, Eckenrode and Hamilton (2000) contend that "mentors" and "advisors" -- individuals who have already been through a similar scenario -- have the ability to help motivate individuals who are in those situations. Another effective option is a "buddy intervention" whereby individuals who are experiencing a situation simultaneously provide support and encouragement to each other (Palmer, Baucom, & McBride, 2000). Buddy programs have been effective in weight loss and smoking cessation

programs (Heaney & Israel, 2008). These insights can offer a pertinent application in the fertility-care setting.

Infertility is a unique health condition as the inability to conceive is both a barrier to a rite of passage for adults and for many a repeated problem, a journey that does not necessarily end after a first success or attempt at treatment. For example, while many women can provide support to others based on their initial IVF experiences, often women endure secondary infertility and have to relive parts of the experience all over again to have a second or third child (Allan, 2007). Therefore, it is plausible that infertility patients have the capacity to play the role of both “mentor” and “buddy” in peer relationships. The potential for a duality of roles, a role-reversal between IVF patients and peers, has yet to be documented.

While it is clear that there is potential for social support in patient-peer relationships, there remains a paucity of literature on how and why they are so meaningful and adequate in the eyes of the IVF patients. In other words, how does their function make them a valuable source of social support? Therein lies an opportunity to understand the mechanics and capacities of these relationships: the role of self-disclosure in initiating them, the quality of these connections, the nature of their communication, the modalities that give rise to their initiation, and the outcomes for the individual of such a relationship. Given the importance of self-disclosure in the communication dynamics of IVF patient-peer relationships, the next section will explore the contemplative stages of disclosure through the theoretical lens of the Disclosure- Decision Making Model (Greene, 2009).

2.4 A Theoretical Perspective

2.4.1 *The Disclosure Decision-Making Model (DD-MM)*

People coping with invisible health conditions are faced with the challenge of managing their private health information and navigating decisions about sharing their ordeals with others

(Greene et al., 2012). For an infertile couple the outside world might remain completely oblivious to what is happening in their fertility journey. There is also a chance of feeling judged on a social level for being childless, in the case that the public perceives it as a selfish choice or abnormal (Lampman & Dowling-Guyer, 1995). Disclosure of a health condition becomes a difficult but critical choice in order to “facilitate access to social support” (Greene et al., 2012, p. 356). With this in mind, Greene (2009) developed The Disclosure Decision-Making Model (DD-MM), a framework that summarizes the self-disclosure planning process engaged in by people experiencing invisible health conditions. Specifically, the DD-MM breaks down how individuals make their decisions to divulge highly personal details about their diagnosis according to three contemplation steps: information assessment, receiver assessment and disclosure efficacy.

The first step of the DD-MM is the assessment of information that might be shared (relevant to a health condition) on the basis of potential rewards for sharing it versus the risks according to five key components: stigma, preparation, prognosis, symptoms, and relevance to others (Choi, 2016; Greene, 2009).

The first component, *stigma* is the most relevant to this paper since individuals’ perceptions of judgement and how others see their diagnosis can encumber their decision to disclose (Greene et al., 2012). For example, for couples suffering from infertility it is not uncommon to feel like they are competing with siblings and in-laws who are already having children (Lyngstad & Prskawetz, 2010). It is also known that people decide to share intimate information with someone with whom they establish liking and trust (Collins & Miller, 1994). Therefore, anticipating supportive versus stigmatizing responses from the people with whom they entrust their information factors in to the individual’s decision to disclose or not.

The second component, *preparation*, refers to how much the diagnosis was anticipated or, the opposite, a surprise (Greene et al., 2012). For example, some couples anticipate having to go

through ART treatment as a result of previous health conditions, such as patients who have endured cancer therapy. In this case, it might be easier to disclose information about infertility because it can be a form of catharsis and transparency and an opportunity to gain useful insights without feeling the burden of any blame for their condition.

The third component, *prognosis*, refers to the forecast of a disease or condition, whether it is treatable, chronic or terminal in addition to the uncertainty it brings with it (Greene et al., 2012). Infertility is a treatable condition; however, ART offers no guarantee of a baby at the end of its course. Treatments like IVF are a liminal experience that confront patients with high levels of ambiguity and feelings of limbo, which lead to stress, eventually becoming important considerations for patients' disclosure decisions (Allan, 2007). Given that infertility and its treatment are unpredictable and provided no guarantee of pregnancy, individuals are left having to navigate and balance not only their own expectations for success or failure, but those of others to whom they disclose.

The fourth component, *symptoms*, can include a wide range of indicators especially as one's condition (and its treatment) continue (Greene et al., 2012). In the case of infertility, these are for the most part invisible, but symptoms of IVF treatment can still be detected through any combination of indicators such as weight gain, mood changes, nausea, headaches, and a change in routine activities. However, these symptoms are not exclusive to IVF and they do present themselves for other conditions and treatments. In other words, people may not be able to pick up on one's fertility challenges without disclosure, and thus the decision to disclose depends in part on the individual's perceptions of how people view or are oblivious to their symptoms.

The final component, *relevance*, is how one views the appropriateness of the information they are sharing. Greene et al. (2012) contend that when an individual believes that their diagnosis matters to others, and perceives that a person has a direct or indirect connection to it

and an interest in knowing, they are more likely to disclose their condition. This is of particular interest to IVF patients and peers, given the ability of peers to be relevant, as a result of their shared experience.

According to the DD-MM, once disclosers have contemplated the information that they might share, they next think about the recipient of their disclosure on the basis of two criteria: relational quality and anticipated response. The first term refers to characteristics such as “close”, “supportive”, “trustworthiness”, “attachment” and “connectedness” that, when present, indicate a great potential for ideal relational quality (Derlega et al., 2002; Greene et al., 2006; Slade et al., 2007; Wu, 2009). The second term, anticipated response, refers to how individuals expect the disclosure recipient to respond. For example if the individual anticipates a negative remark in response to their revelation of their health condition, they will feel heightened risk and be reluctant to share.

Choi (2016) highlights how an anticipated response reflects patterns such as information regulation (controlling what gets shared), fear of judgement (concerns that the recipient’s impressions of the individual will change), the need for reciprocity (expecting that the recipient will identify with or share similar experiences), and the provision of support (receiving informational or emotional guidance). In her study that applied the DD-MM to understand how individuals plan to disclose nonvisible illness, Choi (2016) found that it was difficult to measure the significance of anticipated response on a retrospective basis (asking people to reflect on past disclosure circumstances) since these patterns of thought are very spontaneous and occur in the moment of disclosure-decision making. Nonetheless, the receiver assessment step allows us to understand how the disclosure recipient’s likely response to the discloser’s needs (such as understanding, support) is integral to the disclosure-decision making process.

Finally, once disclosers have considered the information and the recipient, they contemplate their own disclosure efficacy or, in other words, they “evaluate their capacity to disclose the information” (Choi, 2016, p. 1005). Disclosure efficacy is derived from Bandura’s (1977) self-efficacy and is a state whereby individuals feel confident in their ability to achieve desired behaviours and goals. According to Choi (2016), this last stage of the process “includes choosing the setting, timing, channel/mode, and message features” (p. 1005). Greene et al. (2006) state that the disclosure process can occur over any given time period whether it be a “single conversation, or a continued dialogue that takes place over days, weeks, months, and years” of a personal relationship (p. 417). Other personal choices that impact disclosure efficacy are linked to messaging and delivery such as “who to disclose to”, “what to disclose” “when and where disclosure occurs” and “how it happens” (Greene et al., 2006, p. 417).

The logistics of disclosure such as the “what”, “who”, “where”, “when” and “how” impact the quality of connection and support. According to Greene et al., (2006) these mechanics and potential for continued dialogue are determined by the nature of the initial exchange between the discloser and disclosure recipient, mainly the reaction of the person receiving the information. Continued disclosure and relationships are more likely when the recipient offers support, shows interest, shares their own experience, and asks questions (Greene et al., 2006, p. 417). Affirmative and validating responses can leave the discloser feeling hopeful about their decision to disclose and prospects for support. Choi (2016) found that when people felt more confident about revealing negative or stigmatized information, they were less likely to plan their disclosure (p. 1019). While pre-planning a disclosure gives the individual a certain sense of autonomy surrounding the disclosure process through information control, less pre-planning around disclosure of sensitive health conditions is linked to relief, catharsis and reciprocal sharing

(Greene et al., 2003). Ultimately such outcomes are associated with reduced stress and an increased opportunity to build supportive, significant relationships.

Greene (2009) uses this model to describe self-disclosure as a bi-directional and reciprocal experience. That is, as individuals get to know each other, mutual needs can be identified and trust builds, putting both parties in a position to offer and receive information. Reciprocity thus plays an important role in self-disclosure. Rosenfeld (2000) contends that mutual sharing establishes balance and comfort in the relationship. In a study of battered women's inclination to share their personal secret, the revelation of an experience of similar abuse by a friend, co-worker, relative or counsellor reduced barriers to their decision to disclose (Dieckmann, 2000). This suggests that peers, or people with whom an individual shares a health or life experience, are in an ideal position to act as a disclosure recipient, on the basis of their capacity to reciprocate with their own stories and insights and their ability to relate.

DD-MM offers a useful lens through which IVF patient and peer relationships can be understood. Breaking down components such as risk assessment, perception of the receiver and anticipation of response, and disclosure efficacy -- which includes the various facets of the communication such as how, when, why, for how long, where and what -- can help uncover self-disclosure patterns and their social support outcomes. This model has been tested in wide sample populations that identified with health conditions such as sexually transmitted infections, eating disorders, cancers, alcoholism, learning disorders, bipolar, diabetes, and Crohn's disease and who sought support from a variety of sources (family, friends, colleagues) (Choi, 2016) and more narrowly with carriers of the HBOC (hereditary breast and/or ovarian cancer) and BRCA (prostate, pancreatic and melanoma) gene mutation in the context of family planning decision-making (Dean & Rauscher, 2018). However, it remains unapplied in the context of infertility,

and thereby limits the fertility community's capacity to understand what drives women to disclose to peers and leverage their support, and how their communication process unfolds .

In one example of the application of the DD-MM, Dean and Rauscher (2018) explored how individuals approach disclosure about BRCA-related cancer risks and decision-making around family planning. These authors found that individuals develop nuanced ways to “simultaneously assess both the information they want to disclose and the person to whom they wish to disclose” (p. 2165). Dean and Rauscher (2018) also found that in situations where participants anticipated a risk for infertility based on a cancer diagnosis, they planned their disclosures from a proactive standpoint. Specifically, participants' disclosures to family members and friends were “driven by a desire to reduce uncertainty and seek more information to help themselves or their family members manage their risk, prevent cancer and learn more about their family planning options” (p. 2165). Dean and Rauscher's study not only speaks to the benefits of patient-peer disclosure and how it lends itself to social support, but also to the importance of applying the DD-MM in different realms where individuals are faced with an invisible health condition and ambiguity about their outcome, such as is the case with infertility and its treatment.

2.5 Directions for Future Research

It is critical to recognize that, in addition to the physical and medical burdens of care, patients are often confronted by powerful social perceptions of their condition and childlessness, which have the ability to influence their nature of their disclosure, communication, and social support outcomes during their journey. For example, many ART patients report a variety of stigmatizing circumstances as a result of being childless, which can include receiving unhelpful comments from family members or feeling excluded in neighbourhood circles bursting with children (Lampman & Dowling-Guyer, 1995). Like many others patients who endure trying

health circumstances, the needs of infertility patients for understanding and compassion compel them to pursue social support. While doctors, embryologists, nurses and sonographers are integral in the medical side of treatment, there is an existing body of research that attests to the role of counsellors, peer-support groups, family and friends, the internet, and peers in fulfilling the social support functions. Social support has the ability to help ART patients through emotional, informational, instrumental, and appraisal capacities. However, these functions cannot be fulfilled without self-disclosure.

While the nature, appeal and disclosure dynamics of distinct types of social support strategies such as social isolation, online forums and blogs, support groups, special programs, relationships with family, friends, and acquaintances for female infertility patients have already been thoroughly researched within infertility patient audiences (e.g. Bell, 2012; Helgeson & Gottlieb, 2000; Hinton et al., 2010; Peterson et al., 2006; Schmidt et al., 2005b), casting light on their benefits and drawbacks, there remain many questions about the communication patterns and social support outcomes specific to ART patient-peer relationships. We also contend that the male perspective of infertility alongside their rationale for their underuse of a variety of social support channels (Peterson et al., 2006) and preference for non-disclosure (Steuber & Solomon, 2012) is significant and for the most part unexplored in the current literature.

There is an existing body of research that espouses the positive nature of peer relationships by virtue of a “shared lived experience” (Bell, 2012); however little else is known about how these relationships start, the communication style and patterns of these relationships, how patients initiate interaction with each other, and how these relationships contribute to or detract from patient well-being. In the spirit of advancing psychosocial research in infertility and exploring the contributions of an untapped support resource for patients, we recommend that future research focus on the following two aspects of ART patient-peer relationships: their

complete disclosure and communication process including how they consider information, evaluate the recipient, and actually communicate, and their perceived social support outcomes, that is various forms of benefits and drawbacks these women bring to each other's lives.

2.5.1 ART Patient-Peer Disclosure Process

Understanding how patient-peer communication unfolds in the context of ART, specifically through the lens of the Disclosure Decision-Making Model, would help patients and clinics understand the unique nature of these relationships and provide greater understanding of their contributions to patient well-being and their drawbacks. We recommend that future studies break down this process in detail through application of the DD-MM. It is important to understand how these women:

- assess the information regarding their diagnosis and treatment – which includes how they perceive stigma of their condition, their prognosis, information specific to their journey and their treatment and its relevance to others, and the influencers of patient-peer communication. We note that while DD-MM offers a useful lens through which to understand how these women approach information sharing prior to disclosure, it may be beneficial for future research studies to identify additional complimentary theories with a view to understanding the nature of the content of communication between patients and peers. In other words, an examination of what details actually get shared.
- assess the receiver – which includes the capacity to develop a close relationship with the recipient, in addition to how and where infertility patients find other women with shared experience and the character traits of the women with shared experiences with whom patients engage and to whom they choose to disclose.

- consider their disclosure efficacy – which depicts the individual’s confidence that disclosure will produce meaningful outcomes and enhance both their relational quality and their ability to adopt healthy behaviours. More specifically, what outcomes for infertility patients can be specifically attributed to as a result of a peer relationship?
- plan and carry out their disclosure – according to Choi (2016) there is limited research available on how people plan and execute disclosure. More specifically, understanding the modalities (the means, frequency and antecedents) of ART patient-peer communication, how it happens and how relationships unfold would be important considerations in understanding this phenomenon.

2.5.2 *Perceived Social Support Outcomes*

It still remains to be understood how ART patients on the receiving end of social support from their peers perceive the outputs that emanate from their relationships and how they experience the relationship in general. Having ART patients elaborate on examples of support and self-efficacy outcomes of these relationships has a major role to play in the future of psychosocial approaches to patient care.

It would benefit the fertility community to better understand the tangible and intangible outputs that peers bring to the lives of patients according to the categories of social support types: informational, emotional, instrumental and appraisal (House, 1981). What remains to be explored is how ART patients view the capacity of their peers to fulfill these support functions and how the goals of social support are actually fulfilled or not. Charting how disclosure and fertility patient-peer relationships translate to support outcomes can play an important role in promoting more disclosure and more help-seeking for those suffering in isolation. A deeper

understanding of the overtures and gestures between patients and peers can clarify what makes these relationships so unique and worthwhile compared to other types of support.

Secondly, it is unknown how peer-based social support enhances the self-efficacy of ART patients. Current evidence points to the ability of peer-support groups for patients to encourage healthy actions and outcomes in infertility such as improved coping skills, practical help, and vicarious learning (Domar et al., 2000). However, a deeper interpretation of how individualized, peer-based relationships encourage specific healthy actions and behaviours is required.

2.6 Conclusion

This review advocates for a continued and improved focus on psychosocial research as a complement to the biomedical advances to infertility-care. It casts light on key highlights emerging from the literature on the nature of stigma, the role of self-disclosure for patients, social support functions and the common types of social support strategies. It addresses the role of communication in leveraging social support by dissecting the Disclosure Decision-Making Model. Finally, it suggests new directions in social support research with a goal of better understanding patient-peer relationships in the context of infertility. Going forward, it is important to understand infertility patients from an enhanced holistic viewpoint. A detailed understanding of why these women credit peer relationships as an ideal support channel is still required. There is ample opportunity to expand future research and provide a platform for the voices of infertility patients in the spirit of elaborating on patient-peer relationships, their processes and the nature of self-disclosure within them, discovering new social support interventions and documenting the impacts of these relationships on the lives and journeys of women.

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Chapter 3: Article 2. **IVF/PATIENT PEER SUPPORT STUDY PART 1 Overview**

In the first part of my research study, I examine how in-vitro fertilization (IVF) users approach their decision to disclose to a peer and this investigation forms the basis of Article #2. This article starts with a short review of the literature focusing on the concepts of support adequacy and stigma, both of which contribute to the disclosure decision-making process. It then reviews the first two stages of the Disclosure-Decision Making Model (DD-MM), information assessment and receiver assessment, as a lens to uncovering how patients perceive their circumstances and their peers as recipients and support providers. Next, the methodology describes the recruitment process which yielded a sample population of 23 first-time and recurring IVF patients and describes the subsequent one on one interviews. Finally the analysis brings forth results showing that prior to disclosing to a peer, women reflect on information about their condition and their personal support needs on the basis of the adequacy of their social circles and perceptions of stigma, the benefits and drawbacks of secrecy versus transparency, and their personal motivation to leverage peer support. The results also illustrate the process through which these women assess their peers. This includes consideration of points of connection as well as desirable peer traits which include IVF experience, other common ground and transparency. The article concludes by summarizing the process and suggesting opportunities to facilitate patient-peer relationships and enhance the fertility-care experience overall.

CHAPTER 3 - ARTICLE 2

Contemplating social support: IVF patients' assessment of their information and peers prior to self-disclosure

3.1 Abstract

Assisted reproductive treatment (ART) imposes emotional, financial, physical, and marital stresses on women as patients who are compelled to leverage social supports, which requires self-disclosure. This present study explores how in-vitro fertilization (IVF) users approach their decision to disclose to a peer. Using the Disclosure-Decision Making Model (DD-MM) as a lens, it uncovers how patients reconcile their support needs alongside peers as disclosure recipients and support providers. A sample population of 23 first-time and recurring IVF patients were interviewed. Results show that prior to disclosing to a peer, women reflect on information about their condition and their personal support needs on the basis of the adequacy of their social circles and perceptions of stigma, the benefits and drawbacks of secrecy versus transparency, and their personal motivation to leverage peer support. They also assess their peers, considering diverse pathways of connection as well as desirable peer traits which include IVF experience, other common ground and transparency. IVF patients naturally gravitate towards peers and this study points to opportunities to facilitate patient-peer relationships and enhance the fertility-care experience overall through: the transparency of patients, better coping resources for men, safe places to personally connect in clinic and support group settings, roles for all IVF patients in social support regardless of their outcome.

Keywords: *infertility, self-disclosure, disclosure decision-making, information assessment, receiver assessment, social support, peer support, communication,*

3.2 Introduction and Literature Review

The trend of delayed parenthood is growing, with natural birth rates steadily declining in Canada and accounting for less than one-third of population growth (Canada, 2014) and sixteen percent of Canadian couples facing this hurdle of infertility (Canada, 2012). Many individuals put an emphasis on continued education and employment stability before getting married and building a family (Weeks, 2011). These prospective parents seldom grasp the scope of reproductive health and social challenges of trying to conceive later in life (Lindsay & Vitrikas, 2015; Weeks, 2011) and many find themselves going through assisted reproductive treatment (ART).

ART comes in the form of fertility enhancing drugs, intrauterine insemination (IUI) and in vitro fertilization (IVF) which is known to be the most taxing on the patient with no guarantee of success (Bushnik et al., 2012). IVF comes with additional strains including: the expense of IVF which can cost as much as CA\$12,000 per treatment, the more invasive nature of the procedure (egg retrievals and embryo transfers for the patient), and the large variety and volume of patient medications prescribed for each of its stages (stimulation, egg retrieval, and embryo transfer) (Bell, 2012; Cousineau & Domar, 2007). It is not uncommon for couples undergoing ART to be oblivious to their potential needs for social support as a result of risks to emotional well-being and mental health (Boivin et al., 1999) and to be left in a period of marital adjustment (Peterson et al., 2006). Stressful aspects to infertility and its treatment can leave both female patients and their male partners feeling vulnerable, isolated, highly emotional, anxious and depressed during a delicate time for them both in their personal development and spousal relationships (Domar et al. 1993; Greil et al. 2010; Imeson & McMurray, 1996; Malik & Coulson, 2008) making it a serious health concern.

Women are found to be in greater distress than their partners when confronted with the crisis of infertility (Pasch et al., 2004; Beaurepaire, 1994) and report using more coping strategies than men do (Beaurepaire, 1994, Pasch et al., 2004) including help-seeking through social supports such as spouses, family and friends (Peterson et al., 2006). While disclosure and communication within these outlets have been known to yield support, more often they have been associated with risks of stigma which can be more detrimental to an infertility patient's mental health (Slade et al., 2007). As an alternative, Slade et al. (2007) suggest that sharing with others in "similar situations" is an ideal support option that has a high likelihood for promoting patient well-being (Slade et al., 2007). Beyond peers being viewed as a satisfactory support (Bell, 2012), there are still many unanswered questions about patient-peer relationships in the context of infertility. While it is important to expand upon research on the male experience of infertility and its treatment, given that women bear the physical burden and emotional stressors of this condition as the primary patient, it is important to start by understanding peer support more closely from their perspective. The purpose of this qualitative study is to delve deeper into IVF patient-peer relationship process by casting light on how female patients approach their disclosure decisions at the outset of peer relationships and assess their situations and their peers as supports.

3.2.1 *Socially Supportive Relationships*

Social relationships, supports and communication are an important part of infertility-care that can influence women's journeys in response to the stressors they are experiencing (Cousineau et al., 2006). Communication and disclosure of private medical experiences leads to social support, and support requires ongoing communication (Slade et al. 2007, Martins et al., 2013). Meaningful self-disclosure builds authentic supportive relationships (Greene et al, 2006;

Wu, 2009) and acts as a gateway through which to establish trust (Greene et al., 2006), alleviate stress (Kelly & McKillop, 1996), and reduce isolation (Martins et al. 2013). The provision of social support that can take on a variety of forms: informational (education, advice, instruction and feedback), emotional (gestures of love, empathy, caring, and trust), and instrumental levels (House, 1981), instrumental (tangible aid and services); and appraisal (constructive ideas, affirmation and social comparison) (Fakhraei & Lennox Terrion, 2017).

3.2.2 *Support Adequacy, Stigma and Disclosure*

The absence of such outputs and other support goals is best characterized as a gap between desired support -- what a person really wants -- and the support actually received by the individual (Xu & Burleson, 2001, p. 540). Support adequacy is a term used to describe a sense of fulfillment of support objectives by an individual or dissatisfaction with unmet support needs (Brock & Lawrence, 2009; Dehle et al., 2001). High and Steuber (2014) found that women undergoing fertility treatment consistently reported gaps in the support they received. For example, they desired better emotional and tangible support from their spouses and often felt inundated by too much or inappropriate informational support from family and friends (High & Steuber, 2014, p. 168). Bell (2012) found that women gravitated towards “other assisted-reproduction users” – peers – because there was no substitute for the lived experience of involuntary childlessness and use of assisted conception services” (p. 705).

Stigma around health conditions contributes to an unwillingness to disclose and hinders one’s capacity to share information and leverage social support in order to cope with stress (Greene, 2000; Slade et al, 2007). Since self-disclosure is inherently risky, before people disclose personal aspects of their life they carry out some important groundwork. A variety of considerations such as the costs and benefits of transparency versus secrecy, the risks and

rewards of disclosure, and the qualities of the disclosure recipient ruminate in the minds of the individual prior to sharing (Rosenfeld, 2000).

3.3 Theoretical Framework and Research Questions

Greene's (2009) Disclosure Decision-Making Model (DD-MM) summarizes the process through which individuals with invisible health conditions plan their revelations according to three contemplation steps: (1) information assessment, (2) receiver assessment and (3) disclosure efficacy. The first two steps serve as a useful lens through which to understand how IVF patients consider their respective situations and peers prior to self-disclosure.

3.3.1 *Information Assessment*

Assessment of information refers to reflection on what might be shared on the basis of potential rewards for sharing it based on five key components: (1) the degree to which an individual anticipates supportive versus *stigmatizing* responses from the people with whom they entrust their information, (2) how much the individual was prepared for diagnosis, (3) the *prognosis* of the disease or condition and whether it is treatable, chronic or terminal in addition to the uncertainty it imposes, (4) the range of *symptoms* as indicators of one's condition (and its treatment), and (5) how one views the *relevance* of the information they are sharing (Greene et al., 2012). Since the scope of this study focuses on women with shared lived experiences in fertility, the stigma, symptoms and relevance components of this contemplation step factor more prominently than the other two (preparation and prognosis). For example, another person with lived experience in IVF may be more intuitive when it comes to the symptom of childlessness in other people. Furthermore, IVF patients are sensitive and attune to the presence or absence of stigma in their various social interactions. It is important to understand to what degree their history with infertility stigma compels them to leverage peer support.

3.3.2 *Receiver Assessment*

This step describes how the individual reflects on characteristics of the recipient with whom they will share their experience on the basis of two criteria: relational quality and anticipated response. When it comes to relational quality, the presence or absence of characteristics such as “close”, “supportive”, “trustworthiness”, “connectedness”, and “attachment” come into question (Derlega et al., 2002; Greene et al., 2006; Slade et al., 2007; Wu, 2009). A discloser thinks about how much the prospective recipient’s qualities match the ideal traits of the desired relationship. Anticipated response refers to how individuals expect the disclosure recipient to respond. It reflects individual thought patterns such as controlling what gets shared, fear of judgement, the need for reciprocity, and the provision of support (Choi, 2016).

3.3.3 *Research Questions*

These two steps of the DD-MM led us to develop the following research questions to guide the discussions with IVF patients.

RQ 1: *What leads IVF patients to peer-based self-disclosure and social support?*

RQ 2: *How do IVF patients assess their peers for disclosure and social support?*

3.4 Method

One-on-one interviews were conducted with 23 women who identified as current or recent IVF patients and users of peer-based social support – assistance from another woman with whom they share the IVF experience in common, in order to reveal how these women consider their information and their peers prior to self-disclosure. The following paragraphs describe (a) the recruitment process (b) participant characteristics (c) data collection tools and (d) how I approached data analysis and maintained the integrity of the results.

3.4.1 *Recruitment*

Once I received ethics clearance from the University, participants were recruited from clinics and online support groups. Recruitment ads were posted online using websites, blogs, and Facebook forums. Purposeful and snowball sampling were used to recruit IVF patients. The former approach allowed us to select current IVF patients on the basis that they identified as peer-support users during Phase One. Connecting to the women who have bought in to peer support and learning about their experiences provided a fuller understanding of the phenomenon of interest in this study (Creswell, 2013). Snowball sampling helped grow the sample size, given that this population is sometimes hard-to-reach. Specifically, the sample size was expanded through participant referrals that were offered at interview completion, a technique widely used in research on sensitive health topics and shared health experiences (Hendricks & Blanken, 1992, Momartin et al., 2003) during Phase Two. Patient confidentiality required participants to self-select and initiate contact with me before confirming eligibility.

Recruitment began December 2018, and continued until data saturation was reached in July, 2019 by which point “no new information or themes were observed in the data”, (Guest, Bunce, & Johnson, 2006, p. 59). A total of 29 women expressed interest in the study and met the eligibility criteria and 79 per cent of these women participated for a total of 23 participants. According to Guest, Bruce and Johnson (2006) it is not uncommon to reach data saturation after the first twelve interviews, however it remained a priority to get as robust a sample population as possible.

Table 1 offers a breakdown of recruitment numbers by source. 17 women were recruited during Phase One online. Phase Two was an ongoing process of referrals from existing participants yielding another 6 women.

Table 1. Recruitment Breakdown by Sample Source.

Source	Phase	Number of Participants
Online support group (social media)	1	9
Clinic social media & advertising	1	8
Participant referral	2	6

3.4.2 *Participants*

Women who had undergone treatment in Ottawa and the Greater Toronto Area (GTA), were recruited yielding samples of 11 and 12 women respectively. Table 2 on the next page breaks down the sample in terms age, residence, treatment location, number of IVF treatments and children. The majority of the women (14 participants) had only completed a single IVF cycle. The remaining 9 women identified as recurring patients. At the time of the interview, 11 women had at least one child (three of whom identified with secondary infertility), 12 women had 0 children (half of whom were already expecting their first child) and the rest of the women ($n=6$) were not pregnant.

Table 2. Interview Participants.

Alias	Age	City of Residence	Treatment Location	Number of IVF Treatments	Number of Children
1. Caroline	34	Ottawa	Ottawa	1	1
2. Ali	36	Ottawa	Toronto	4	0
3. Leanne	32	Ottawa	Ottawa	1	0
4. Heidi	33	Ottawa	Toronto	1	0
5. Melissa	39	Ottawa	Ottawa	1	1
6. Nancy	37	Ottawa	Ottawa	1	0
7. Rachel	32	Ottawa	Ottawa	1	0
8. Carly	33	Ottawa	Ottawa	2	1
9. Sandra	33	GTA	Toronto	1	0
10. Reena	34	GTA	Toronto	1	0
11. Tracy	32	GTA	Toronto	1	4
12. Taylor	33	rural	Toronto	1	1
13. Jenny	34	Ottawa	Ottawa	3	0
14. Lauren	37	Ottawa	Toronto	2	0
15. Nora	36	rural	Toronto	2	0
16. Cathy	37	GTA	Toronto	3	1
17. Esther	35	GTA	Toronto	1	0
18. Lindsey	28	GTA	Toronto	1	0
19. Clara	29	Ottawa	Toronto	3	1
20. Mary	37	GTA	Toronto	1	1
21. Daniella	36	GTA	N/A	5	1
22. Siobhan	42	rural	Toronto	4	1
23. Aisha	38	GTA	Toronto	1	2

Table 3 on the next page breaks down other participant characteristics. All of the women identified as heterosexual and in a relationship. Women in same-sex relationships did not respond to the recruitment methods, which is expanded upon further in the limitation section. The average age was 35, and the majority had at least an undergraduate degree, identified as English, and reported a household income of \$125,000 and up ($n=15$), supporting the epidemiology on common users of ART (Inhorn & Birenbaum-Carmeli, 2008; Wilcox & Mosher, 1993). A variety of fertility diagnoses was evenly represented across the sample by a minimum of 3 women except for the two conditions of recurring miscarriages and hypo hypo which were experienced by fewer than 3 women.

Table 3. Other Participant Characteristics

Characteristic	Data	
Age	28-42 years ($M= 34.7$, $SD 3.17$)	
Marital Status	all participants were married, common-law or in a relationship	
Sexual Orientation	all participants were heterosexual	
Origin -Ethnicity ¹	North America - Canadian	15
	North American – American	1
	Asia – South Asian – Punjabi	2
	Asia – South Asian - South Asian origins	1
	Europe- English	1
	Europe- French	1
	Europe – Scottish	1
	South America - undisclosed	1
Highest Level of Education	graduate degree	7
	professional degree	3
	undergraduate studies	11
	high school	2
Occupation	Lawyer, marketing management, fundraising and not-for-profit, entrepreneur/ business owner, general manager, part-time professor, health therapist, early childhood educator, teacher, social worker, scientist, graduate student, media sales, finance/ investment banking, government agency manager, nurse, nutritionist and lab technician.	
Household Income	\$125,000 and up	15
	\$88,000 to \$125,000	4
	\$62,000 to \$88,000	4
Number of Current Pregnancies	9	
Diagnoses	The most frequent diagnosis was unexplained infertility ($n=6$). Followed by polycystic ovarian syndrome ($n=3$), endometriosis ($n=3$), male factor ($n=3$) and low ovarian reserve ($n=3$). Additional diagnoses included cancer related infertility ($n=2$), a history of previous miscarriages & related complications ($n=2$) and hypothalamic hypogonadism ($n=1$).	

3.4.3 Data Collection

Since understanding the peer support process for IVF patients is an emerging area of research, it was important to be able to understand the lived experience of the participants through their own voice. After closely examining the literature on qualitative methods and

¹ Ethnicity data was based on categorizations from List of Ethnic Origins – Statistics Canada 2016: <https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TV=402936>

infertility, I felt confident that using interviews was the best way to grasp a sensitive health experience. For example, an alternative, conducting a focus group on this support topic had too many similarities to a peer led support group, presented confidentiality issues and the risk for participant bias and group think. Offering women a chance to elaborate on their journeys in an open forum offers the benefits of catharsis for participants (Bute, 2009). Interviews have been used before in research on the psychosocial aspects of fertility-care including areas such as needs assessment (Bell, 2012), perceptions of group interventions (Percy et al. 2009), and communication and information sharing with social circles (Bute, 2009).

Various interview locations were offered to participants and selected at their discretion: a private office on campus, a quiet coffee-shop, video-conferencing via Skype, or the home of the participant. In the instrument development phase, the discussion guide was previewed by three different IVF patients and peer-support users known to me through my personal networks in order ensure participant comfort level and validate the discussion guide that ultimately featured 10 open-ended questions. Participants were asked to review the consent form which outlined the study's purpose and offered an opt out option for participants. Depending on the location, participants were either treated to coffee or given a ten dollar gift card for Starbucks. Interviews lasted between 45-60 minutes and were tape-recorded.

The interview protocol featured 10 open-ended questions that uncovered a variety of aspects of the IVF patient/peer relationship. These questions were developed through a combination of inputs based on the literature, my own knowledge of the IVF process, as well as many conversations with other IVF patients known to me through community networks. The discussion guide questions were reviewed by three other women to ensure that questions were appropriate, thought-provoking and complete before it was finalized. The following questions pertained to the information assessment step of the DD-MM:

- *Who are your social circles? Have you ever kept your infertility experience a secret within these circles? Please explain your rationale.*
- *What factors compelled you to self-disclose your infertility experience to your IVF peer?*

The information assessment step of the DD-MM is reflected in these questions through the coverage of topics such as disclosure experiences with other social circles, rationale for sharing or non-disclosure, and motivation for peer-based disclosure (Greene, 2009).

The following questions pertained to receiver assessment step of the DD-MM:

- *Who is your IVF peer and what made them an appropriate choice for you?*
Please tell me about this person and the process through which you found each other.

Receiver assessment questions focused on anticipated response (Greene, 2009) by asking about peer selection steps and pathways and desirable peer qualities.

3.4.4 *Data Analysis and Validity*

All of the one on one interviews were digitally recorded with permission and transcribed verbatim no more than three days after each interview. During the transcription process, I read my notes simultaneously while listening to the audio files in order to avoid transcription errors. In order to safeguard the anonymity of the participants, pseudonyms were immediately created for each participant. After transcription was complete, I reread the data sets and reconciled them with my written notes in conjunction with the audio file in order to confirm that participants' experiences were properly captured as they were communicated.

I started developing a preliminary codebook based on "tentative codes" and the questions that were asked (Creswell, 2013, p. 184). As the datasets grew and upon reviewing the transcripts in their entirety after data saturation was reached, I started expanding the categories. The transcripts and codebook were then reviewed by my supervisor in order to establish reliability and affirm the meaning of each code. NVivo (v.8) software was used to carry out the coding and data analysis

processes and interview transcripts were uploaded in the system. Following the recommendations of Strauss and Corbin (1990, 1998) a three-phase (open, axial and selective) coding approach was followed.

To start, in the open coding phase, “distinct categories” of information emanating from the data files (Creswell, 2013; Strauss and Corbin, 1990) were applied to the sections of the transcripts which corresponded to the theoretical underpinning: needs and recipient assessment (to represent how patients reconciled their personal situations and prospective peers) and communication process (to represent the nature of the information shared and the modalities specific to carrying out disclosures) discussed in a separate manuscript. I substantiated each category by looking for other instances that echoed similar sentiments and continued this process through the research until no “new information” was available. Each category was then “dimensionalized” (Creswell, 2013) and broken down into a series of child nodes (sub-themes) in order to capture the information and receiver assessment steps of the disclosure decision making process for IVF patients. Next, during the axial coding phase, categories of information were linked together and connections were made. Finally, during the selective coding phase, the codes that were the most relevant to the research questions were selected, and connections to other key codes were refined to ultimately tell the story of how IVF patients approach their disclosure decisions with a view to leveraging social support from their peers.

In order to maintain the trustworthiness and accuracy of the data I took multiple measures in addition to the time for self-reflection whenever the opportunity presented itself during each stage of the research process (Bute, 2009; Lincoln & Guba, 1985). Tactics included detailed notes on the recruitment process and how each participant learned about the research, written notes taken during the data collection, and detailed coding maps to document the code development process.

It is important to note that qualitative findings are dependent on the viewpoint of the researcher (Taylor & Bogdan, 1998). Following the recommendations of Bute (2009), I was mindful of my positionality and engaged in self-reflection throughout the data collection and analysis, in order to ensure that “my own assumptions and interpretations were informing but not clouding my understanding of women’s recollections” (p. 756). To this end, a journal and detailed notes helped me bracket my experience, knowledge and perceptions. These combined measures give me confidence in affirming that I have properly captured how IVF patients assess their information and their peers prior to self-disclosure.

3.5 Results

3.5.1 *Personal Needs and Information Assessment*

Participants assessed their own situation and the information in question on the basis of risks and rewards, stigma, and their rationale for opening up to a peer. The following sub-themes cast light on important aspects IVF patients take into when deciding to divulge their journey: (1) social circles, (2) open or closed approach, and (3) personal motivation to find a peer.

3.5.1.1 *An Inventory of Social Circles*

Participants associated various social settings with a perception of stigma and perceptions of judgement, exclusion, discomfort and inadequacy. The most common situation was receiving unhelpful comments. Fourteen participants were able to recall counterproductive messages from ranging from condescending advice, baseless and dubious recommendations on sex and conception, pity, and self-centred feedback that displayed limited empathy and understanding.

Other suggestions included sleep positions, nutritional advice, and recommendations to stop dancing, see a psychic and healing crystals. Clara thought back to a comment made by a friend on how much money she and her husband were spending when they “didn’t have much”.

Melissa was devastated when a friend told her that the baby was not meant to be and could have been born with disabling conditions.

“She told me it wasn’t in the cards. For me it was like losing the dream all over again.”

Melissa

Participants identified with an onslaught of questions when they recalled telling family and friends about fertility struggles. Several spoke of general questions such as “do you have children?” or “when are you two starting a family?” and which would eventually evolve into more probing questions such as “are you pregnant?”, “do you have any news?”, “how does it work?”, “when will you know?”, and “how do you feel?”. Leanne talked about feeling a need to over-explain herself as well as emotional exhaustion from retelling the story and reliving the pain. Mary echoed this sentiment with the following reflection.

“Having the whole background conversation piece was taxing, especially when certain people couldn’t really relate. How could I have that conversation when they don’t understand?”

Mary

Seven participants identified their misinformed parents and siblings starting families before them with ease as sources of stress. These women sensed competition within their extended families and insensitivity toward their experience, and felt resentful as a result. Two separate responses reflected the pain of watching family members conceive naturally and focused on “feeling broken”. Comments received from family such as “our baby can sense that you don’t have children”, and a participant’s experience of a sibling’s pregnancy news capture this pain.

“when my sister called me from overseas to tell me she was pregnant again I had to cut the call short because I was ready to cry”

Caroline

While unintentional, and partly as a result of the other parties having limited knowledge on infertility, the impact was still the same for these women. Jenny sums up the response of her sister-in-law who was self-focused on her own pregnancy:

“Hers was the first pregnancy in the family and it was awful. She even went so far as to asking me for ideas on how to tell people her news when she knew what I was going through”.

Jenny

On a similar note, Carly also recalled a sibling and their spouse announcing conception. Her in-laws were astonished that Carly and her husband “could not be happy for them” and invalidated her infertility diagnosis those words. When Carly finally did conceive they “washed out her ordeal” as if it never happened.

Participants recalled sensing pregnancies as an omnipresent force and feeling bombarded by triggers. Whether it was at work, in the neighbourhood, as a result of cultural expectations and sensing competition in places of worship, stinging social media baby announcements on Facebook and Instagram and other children’s milestone celebrations such as baby showers, christenings, and birthdays, these reminders had the same impact. Sandra’s voice captures this type of narrative.

“When our treatment failed and I sent regrets to my friend’s toddler’s birthday. She got angry with me and made it about herself. It compelled me to isolate from other occasions with families, kids and expectant mothers.”

Sandra

3.5.1.2 Open Versus a Closed Approach

Participants were asked if they kept their infertility a secret within social circles and why. All but three responded to this prompt and those who did answer were divided on the costs versus the benefits of secrecy almost right down the middle. Eleven women associated transparency of their condition in social circles with risks and costs and preferred to keep their infertility and treatment a secret.

“I don’t need ten thousand people to rely on. I just new a few good friends. I’ve tried talking to other friends and they aren’t as supportive and never follow-up. They don’t understand so I prefer keeping to myself. I had one friend question why I was doing it more than once. I also kept subsequent rounds of IVF a secret. The more failures the more questions and it’s painful to relive again and again.”

Clara

Some were concerned about social perception in the case of non-success, and anticipated constant questions and the need to over explain, felt shame and embarrassment and wanted to maintain control over their situation by being able to escape. Responses also spoke of regret for being so open, looking stupid if doesn't work, feeling pressure to talk, over-explaining, and a perception that "nobody understands so why bother".

"We started off by telling people that we may not want to have kids. We were guarded. We wanted to avoid lots of questions."

Cathy

Five patients were not transparent about their condition and treatment due to the wishes of their husbands. In these circumstances male-factor infertility played a role in the diagnosis or male partners were very sensitive to strong perceptions of norms in their cultures.

"My husband didn't want to burden our social circle with our sadness whereas I saw that they could offer support. It distanced me from that group because it made me feel I had to lie"

Heidi

Nine women were transparent with people in their social circles about their infertility condition and IVF treatment. Collectively these participants associated revealing their journey with advantages such as catharsis, the potential to gain support, the opportunity to promote infertility literacy, increase knowledge on the subject, and combat stigma, and the chance to help others.

"I never kept it a secret. If I feel close to someone I am open. It makes me feel better and allows me to process feelings. Being open makes me feel less alone instead of carrying a burden."

Taylor

Three women going through recurring treatment talked about a vacillating disclosure strategy. At the start of their very first cycles they were optimistic and open about their journey but ultimately faced disappointment. Non-success the first time brought a burden of "letting others down" or "too many questions". These women decided to keep their future treatments confidential in their social circles, which gave them "control" over their journey.

“I regretted being so open. I was naïve thinking it would work. I had to keep answering questions. It bothered me that I couldn’t control timing and that I was forced to justify things.”
Norah

Strategies also evolved the opposite way, from keeping it secret or only telling a couple of people to being more open with a variety of people. Three women talked about a period of growth personally, and a sense of confidence on the course of their treatment. These approaches attest to another side of the disclosure dilemmas that these women face:

“We kept it secret from almost everybody at first. As it looked more hopeful, we started to open up a little more.”
Daniella

3.5.1.3 Personal Motivation to Find a Peer

Eleven women talked about needing someone close to them who understood infertility and the nature of IVF, aside from their husbands. These women echoed concerns about having only their partner to talk to about their fertility journey such as: overwhelming them, risks of fertility fixation in a marriage and heightened marital stress. These ruminations included phrases such as “he doesn’t understand my fears”, “he doesn’t like details nor does he care for them”, and “mine complains that’s all we talk about”. The quality of support that Aisha described receiving from her husband summarizes it succinctly.

“Since I went through the treatments, he didn’t realize how much emotional support was required. He could not identify or connect with what I was feeling or going through.”
Aisha

Three women said that their husbands backed up their decision to rely on peer support.

“It helped my husband too since he doesn’t like obsessing about the details.”
Siobhan

The personal motivation to connect with a peer was very similar for all of the women and was reflected in the following support needs: a strong comfort level, mutual understanding, unconditional support, and support inadequacy from spouses, family and friends. In the voices of participants: “I needed someone who was more supportive than my family”, “I wanted to hold

on to someone else's success", "I wanted someone to console me", "I needed reassurances and to be able to cry and laugh with someone", "who else could I talk about my uterine lining with?", and "it's super motivating to be as honest and raw as possible".

"My friends did not understand the ins and outs. I needed to find someone that got it and who could answer the questions about the treatment, doctors, ups and downs."

Sandra

3.5.2 Disclosure Recipient Assessment

When asked to discuss the person that they had chosen to disclose to, participants recounted how they found each other and described their selected "peer" and their rationale for choosing them as a support. These results are captured under the following themes: (1) pathways to peer support and (2) disclosure recipient traits.

3.5.2.1 Pathways to Finding a Peer Support

Women described different means by which they intersected with their prospective peers and identified opportunities to leverage social support. Table 4 summarizes the pathways that facilitated IVF patient-peer relationships.

Table 4. Pathways to Peer Support.

Pathway	Number of Mentions
existing friend	6
online support group	4
Workplace	4
friend of a friend	3
run-in in clinic waiting room	2
neighborhood/community	2
family member	1
infertility community event	1

Most women relied on an existing friend for peer support and the support process made these friendships stronger. Melissa described her peer support as "one of my dear friends, with

whom I now have a strengthened and unique bond.” Reena described a schoolmate and how she renewed their friendship many years later.

“we went to college together. She was honest about her journey and finally had twins through IVF. I wasn’t at the same stage when she lived it but I went back to her once I was diagnosed”
Reena

Four women felt comfortable pursuing a peer friendship outside of an online support group and another benefited from attending an infertility community event and meeting a peer.

At least two women overcame barriers to connect with their peer at their clinic:

“When a mutual friend suggested I meet her friend, and then coincidentally, I saw her in the waiting room it was so easy for to pick up a conversation.”
Siobhan

Given that infertility is an invisible health condition, many women experience kind overtures of their peers who took notice and showed sensitivity toward the symptoms they were experiencing. For example, in Leanne’s journey, her neighbour, a mother of an only child, noticed she did not have children and was non-judgemental about her circumstances. As soon as they started talking about Leanne’s desire to have children, her neighbour revealed that her son was an IVF baby. Nancy had a similar experience where her neighbour picked-up on what she and her husband were going through.

“my neighbour is my peer’s sister and she understood my struggle and offered to connect us”.
Nancy

3.5.2.2 Disclosure Recipient Traits

When asked what they looked for in a peer, the most common and desirable peer traits were: (1) shared IVF experience, (2) common ground in other aspects of life, and (3) a path to friendship paved by transparency.

3.5.2.2.1. *Shared IVF experience.* It is a given that the eligibility criteria for this study sought women who relied on other women who had also gone through IVF. Nonetheless the women

were still given an opportunity expand upon the IVF qualities of their peer in more rigorous detail. In other words, they were asked to elaborate on what made these women special in their eyes, beyond meeting the single criterion of having IVF in common. Half the women emphasized the importance of their peer having “already gone through the process”. It made these women “relatable” and “empathic”, and established a comfort level between them. Four of these women emphasized the positivity that a successful model emanated and credited these living examples for giving them “faith” and “something to hold on to”:

“She is an IVF success story. It worked for her and she was able to have another child without IVF. It’s an amazing story that inspires me.”

Reena

Eight women talked about how the IVF struggles and non-success of their peers was also a form of reassurance. The knowledge that these women “understood the hardships of IVF”, “the rollercoaster of emotions”, had other related struggles such as “miscarriages, or abortions due to abnormalities”, and were still strong in the face of such adversities was inspiring to the participants. IVF failures also positioned the participants to provide reciprocal support to their peers in the case of continued treatment.

“My peer was an example of strength. After repeated miscarriages and IVF failures she gave birth through surrogacy.”

Aisha

“When I shared I had negative results from my subsequent IVF, it increased my ability to provide support to her. All of a sudden we were in the same boat.”

Cathy

Heidi expressed an opinion that women who only had successful outcomes in treatment were incapable of providing support since “*part of their brain turns off the horrible journey they went through.*” She suggested that women who had failures were even more deserving of a happy ending and any eventual success. Heidi’s peer was a woman who had a few failed IVF cycles at the time they connected and who was in continued treatment:

Having someone who doesn't know their outcome is important, it makes them easy to relate to. As opposed to someone who has already had their miracle, which makes it a fantasy."

Heidi

Specific IVF- related details also attracted participants to their peers. These answers reflected precise components of treatment such as "same doctor", "same clinic", "concurrent treatment", or "diagnoses". It helped that their peer knew the dynamics of the same clinic or were going through treatment synchronously. Nine of the women saw it as a benefit that treatment schedules with their peer were closely matched, offering them a support who could relate to the demands, stressors, appointments, balancing work, the ups and downs and offer insights. Some answers talked about how meaningful it was that "IVF was the front line of both of their lives," to have someone on the same "boat," or "path."

"I told my peer about my clinic in Toronto and she switched. We ended up going through our stimulation phases at the same clinic simultaneously. It was hilarious keeping each other company and being in the waiting room together."

Heidi

"We were the same age, similar pace of the journey approaching it at the same time as newbies. We could obsess about it together."

Siobhan

Some patients shared a similar cause of infertility. Cathy described sharing a "unique bond" with her peer since both of their husbands had survived cancer, a major factor in these couples' fertility diagnoses. Nancy also voiced that kind of sentiment for her condition:

"We had low fertilization when we did IVF. It was comforting to know that I could find someone who was in a same diagnostic situation"

Nancy

3.5.2.2.2 *Common ground in other aspects of life.* Fourteen women agreed that sharing common ground with their peer outside of fertility was a desirable quality in their prospective peer and helped nurture a stronger bond of friendship. Answers in this category included mentions such as

“working together,” “being close in age,” “shared interests,” “shared life experiences,” and “common professions”.

Some women were the same ages, sisters-in-law, or colleagues, they shared similar levels of education or professional pursuits, and they had similar lifestyle interests such as fitness or meditation. Caroline saw this as a foundation for friendship:

“We started talking our similar professional goals as colleagues. Then we moved on to fertility. She cheered me on and supported me unconditionally.”

3.5.2.2.3 *Path to support paved by transparency.* Eleven women spoke about an initial fertility revelation by their peer before they experienced infertility themselves which made them feel reassured in sharing their own ordeal. Five women spoke about a pattern of retrospective transparency. They were initially on the receiving end of hearing about struggles of fertility and oblivious to the fact that they too might eventually face that same struggle. Reena described herself a “bystander to the journey of her friend and ignorant when it came to infertility.” Years later, this story remained etched in Reena’s mind when she received her diagnosis, and gravitated to her old friend. Taylor also spoke about a similar situation. Her boss had gone through IVF years ago and was open from the beginning. She spoke of this as signal and an invitation for future support, a safe passage way to getting the help that she needed.

“When I started going through it I knew I could mention to her. It was a major benefit not having to keep things hidden. In addition to working together we were able to cultivate a friendship.”
Taylor

3.6 Discussion

3.6.1 Theoretical Implications

Broadly speaking, this study offers a new application of the DD-MM in the context of peer support and fertility-care. The information and recipient assessment steps provided a valuable lens through which we were able to understand how patients contemplate their situations and

their prospective peers as supports prior to disclosure. As it relates to information assessment, stigma, symptoms and relevance components clearly factored into patients' decisions to disclose to a peer. Pertaining to recipient assessment, participants reflected upon their peers on the basis of relational quality and anticipated response by talking about the qualities of their peers in two distinct categories: shared IVF experience and common ground in other aspects of life. While the findings of this study for the most part support and advance the information assessment and recipient assessment steps of the DD-MM there is room to elaborate and improve upon this theory. We contend that how individuals perceive the costs and benefits of secrecy and transparency should factor in to the information and recipient assessment components more concretely.

In the next few paragraphs we discuss the importance of core findings in specific detail while making links with the scientific literature with a focus on the following areas: the influence of stigma, secrecy versus transparency, adequacy of existing supports, pathways to peer support and personal fit, before wrapping up with practical implications for care and limitations and directions for future research.

When participants were asked to describe their social experiences they freely and automatically made correlations with stigma and reflected upon inadequate support patterns that develop with family and friends. This parallels the findings of High and Steuber (2014), who established how a lack of supportive communication leads to insufficient support quality. The findings validate key components of the first decision making step identified in the DD-MM: information assessment. The experiences evaluating their respective situations and decision to share according to their perceptions of stigmatizing responses (Greene, 2009) from various recipients played an important role in their decision to disclose to a peer.

The inability of people to understand or associate participants' symptoms of infertility and the likelihood of negative responses in social circles decreases the likelihood of disclosure or continued disclosure. This parallels the "symptoms" component of information assessment whereby Greene (2009) states that the means by which individuals pick up on the perceptions of others pertaining to their symptoms matters in disclosure patterns they adopt. Patients identified tendencies in their social circles that have been underscored in the previous literature such as offering unsolicited and offensive advice (Bute, 2009; Slade et al., 2007) or making inappropriate comments or jokes about sexual intimacy (Whiteford & Gonzalez, 1995).

Participants related to the experience emphasized by Bute (2009): "progressively more invasive" inquiries from social circles that left them feeling conflicted and compelled to make difficult decisions on how much private information to share, and feeling vulnerable to stigma and its impacts (p.757). Situations like these heighten sensitivity for individuals suffering from infertility, inhibiting their desire to disclose, leaving them to experience lower social support and higher distress (Slade et al., 2007).

Participants struggled with their decision to keep their condition secret or be open and for some, their initial decision was never static and subject to change. This supports the disclosure dilemma for fertility patients described by Bute (2009). The majority of women opted to keep their experience secret, mirroring the notions of Bute (2009), who found that it is common for women to associate asking as "insensitive", "a threat to identity", and "a reflection of societal expectations" (p. 758-9). Some women spoke about their decision to keep their condition secret because of the wishes of their partner which left them feeling torn, isolated, stressed and facing risk of depression. This parallels previous findings on coping and disclosure differences between men and women when dealing with infertility (Peterson et al., 2006; Steuber & Solomon, 2012). In other health situations such as breast cancer, as conditions worsen, beyond their family, some

women guard their prognosis a secret (Henderson et al., 2002). This tendency was not uncommon amongst this sample, especially in the cases of ongoing treatment and no success with pregnancy.

Women saw value in being transparent about their condition in terms of help-seeking and enhancing others' and their own knowledge of ART. It was an opportunity to answer questions, receive support and educate others. Bute (2009) concurs that being asked questions for some women is viewed as an expression of care. Women alternated their strategies on secrecy and transparency depending on their stage, how they gauged their support needs, and how they reconciled the relevance of the information regarding their condition with the information recipient (Greene, 2009). This dichotomy in approaches is not uncommon for infertility patients who perceive a double-edged sword: stress keeping it a secret within close friends when high social support is perceived, stress with too much disclosure to all close relationships when low social support is perceived (Martins et al., 2013). In sum, participants wanted to access social support and maintain their well-being, yet they were concerned about stigma, stress, and strained relationships, thus leading them to hide their condition. Women's abilities to straddle both sides of secrecy and transparency and evolve according to their personal needs shows us that these women were never stuck in their decisions and adept at using variable disclosure strategies. When the information recipient was no longer their family, friends, colleagues and acquaintances but a prospective peer, they sensed that the information regarding their condition mattered and could be validated (Greene, 2009), and their open disclosure strategy reflected that.

Women were dissatisfied with the quality of support they received from their husbands and had unresolved support needs. This finding parallels the work of Pasch et al. (2004) who report that women and men approach communication and marital adjustment differently in the face of infertility: females place a higher emphasis on child-rearing, are more involved in the

mechanics of baby-making, have a greater need to talk about their baby desires , and experience a greater loss of self-esteem. It is unsurprising that women felt dissatisfied with the spousal support at the same time that they reported dilemmas in terms of navigating privacy boundaries with their spouse on infertility (Steuber & Solomon, 2012). The need to find a close source of social support outside of their marital relationships oriented women towards peer support.

Many women decided to conceal their treatment from other social circles as a result of stigmatizing responses on childlessness and infertility in general. Participants were especially sensitive to triggers and reminders of childlessness such as omnipresent pregnancies amongst their friends. Making an effort to avoid baby and pregnancy-related situations (such as showers and birthday parties) entirely has been underscored as a common coping mechanism for women but one that brings higher stress (Schmidt et al., 2005). The tendency of patients to reconcile their social circles and unmet support needs prior to self-disclosure is substantiated through the DD-MM, and the first step of the disclosure process, “information assessment” and its final component, relevance. According to Greene et al. (2012), the individual contemplates “how much the information that they are sharing matters” and the “quality of connection of a person to the information” when making the decision to disclose or not.

The majority of participants in this study indicated that they relied on existing friends as a peer support for their IVF journey. Bell (2012), found that while “close friends” were a common source of support for patients, the experience infertility sometimes “eroded usual sources of support for participants”, and left patients feeling like “a burden” or “embarrassed to disclose” (p. 700). Our current study builds upon this notion, with the finding that when women go to an existing friend who shares the IVF journey with them, it has a meaningful advantage. The other responses shared in relation to the place of connection encompass online support groups, workplaces, friend of a friend, the clinic waiting room, the community, a family

member, and an infertility community event. There is no single window through which women draw on peer support as shown through the capacity of participants to identify appropriate peers in variety of contexts. An essential element for each point of connection was a degree of transparency that set a tone of trust for sharing and disclosure, echoing the findings of Choi (2016). Appropriate disclosure recipients and peers can be found anywhere at any time and certain women feel naturally inclined to explore such opportunities when they arise.

Available fertility-centric environments for these women to connect such as a clinic waiting room or a support group are dichotomous. Some women see them as attractive and natural areas to engage while others see them as restrictive and associated with typical norms and behaviours including privacy boundaries, which can impede peer to peer connections (Allan, 2007; Bell, 2012).

It is noteworthy that work colleagues and neighbours who had also experienced infertility were sensitive to the symptoms and circumstances facing IVF patients based on their own personal connection with ART. This could be attributed to the fact that these people would see each other with higher frequency and as such have a unique window into their personal lives. For example, some participants had to take time off work for IVF treatment, and others moved in to family neighbourhoods as childless couples with the expectation of having children. These peers showed a clear ability to steer around these conversations softly and open a gate towards support.

It is clear that shared IVF experience was essential in the assessment of peers as disclosure recipients. It made peers trustworthy and empathic in the eyes of participants (Greene et al., 2006). The women elaborated on what aspects of their peers IVF journeys resonated with them most. Over half of the respondents identified IVF success as an ideal trait that offered inspiration, and at least a third talked about the how IVF struggles and non-success irrespective

of previous success was equally valuable and reassuring. Women gravitated towards other women who understood the ambiguous nature of IVF and the dichotomy of success and failure, which Allan (2007) suggests is common for most women who endure multiple treatments and secondary infertility. Several women emphasized how helpful it was that they shared deeper aspects of IVF in common which foreshadowed a capacity for reciprocity, which has been underscored in the previous literature as an important factor in disclosure-decision making (Choi, 2016).

Participants showed no strong preference for only successful or only unsuccessful peers as supports. On a stand-alone basis, IVF experience is not enough to make for an ideal disclosure recipient. The ability to relate to their peer through other parallel paths such as education, choice of career, or lifestyle interests offered reassurance in the form of someone who understood their circumstances. There are clear links between patient and peer similarities and the epidemiology of infertility which highlights the risks of delayed childbirth as a result of graduate education, career focus and high-pressure jobs (Hjollund et al., 1996; Jain, 2006; Wilcox & Mosher, 1993).

The prevalence of transparency as a criteria supports the findings of Choi (2016), who underscores expectations of reciprocity when individuals are in the second step of the disclosure decision making process, evaluating the receiver. For IVF patients, the previous transparent examples that their peers offered also served as a reassurance, and a signal for future support. When individuals consider the receiver, the expectation that the recipient can identify or share similar experiences weighs heavily in the disclosure process (Choi, 2016). Transparency served as a gateway to establish a degree of “trustworthiness” which factors into high relational quality (Derlega et al., 2002; Greene et al., 2006).

3.6.2 *Practical Implications for Care*

Patients showed that they had a remarkable ability to assess themselves and their situation which led them to gravitate naturally to peers. Just as these women knew how to nuance their communication and non-communication to suit their comfort levels, these relationships were never forced. With a view to helping more women benefit from this type of social support we identify opportunities to facilitate the patient-peer relationships and fertility-care in clinical, social and community settings:

3.6.2.1 *Transparency Begets Transparency*

As more couples face infertility and gain access to treatment, it is important for fertility-care providers to educate both women and men on the benefits and drawbacks of disclosure and opportunities for peer support. We underscore the importance of patients embracing the opportunity to talk about their experience unconditionally. Starting the conversation does not necessarily guarantee instant support; however, for many participants it set a good example and charted a path with an open door that they eventually walked through at the opportune time. For example, patients remembered past conversations, and friends introduced friends. We contend that this finding can apply broadly to other health journeys such as miscarriages, addiction recovery, smoking cessation and cancer.

It also remains equally important to engage multi-generations from baby boomers, new couples, millennials, and professionals in conversations to enhance awareness so that collectively everyone contributes to improved reproductive health, pregnancy outcomes, and enhanced well-being (Barron, 2013a).

3.6.2.2 *Need for Male Fertility Literacy Resources*

Patient dissatisfaction with the adequacy of support they received from their husbands was profound. Women expressed a clear need to be heard and understood by their male partners and

that men were ill-equipped to provide support. While peers were seen by participants to be a great alternative channel, there is still a need to strengthen the quality of support within the couple. Clinics and support services might start by moving beyond the patient-centred female focus and offer support tools and options to men to enhance their fertility literacy (Barron, 2013b) by addressing their perceptions of fertility stigma and helping them reconstitute barriers of masculinity.

3.6.2.3 Establish Fertility Friendly Environments

While many patients are adept at finding places to connect with peers, others can benefit from opportunities paved by the fertility community. Safe communication zones in waiting rooms could provide patients an opportunity to talk to one another at their discretion. These spots could be in designated areas of the waiting room, offer refreshments for patients, and designed as comfortable, engaging environments. Peer support groups and fertility community events can also be designed to encourage personalized connections between patients.

3.6.2.4 Role for All Patients

The wide variety of treatment experiences of peers, irrespective of success or non-success and stage of treatment (in treatment or past it), positioned these women to provide meaningful support to peers. Patients are interested in connecting with women who can reciprocate through perspective, validation, and affirmation stemming from their own lived experience. Future peer support strategies (whether they be facilitated by clinics, community organizations, support groups, counsellors, or people themselves) must be inclusive and emphasize that there is a role to play for all patients regardless of their outcome, or whether or not they are beyond fertility treatment.

3.6.3 *Limitations and Directions for Future Research*

This study marked a start to understanding how IVF patients lay the groundwork in pursuit of peer relationships. However there remain numerous avenues for future research in this area.

3.6.3.1 *Sample Population Diversity*

Sensitive health situations are often lived as secret experiences, resulting in hard-to-reach populations (Faugier & Sargeant, 1997) and there were audiences that may be more susceptible to stigma and isolation who were unrepresented in this study. First, while the sample was made up of all heterosexual women this was not by design. However it is known that there are differences in types of social stressors for ART patients who have a fertility diagnosis and other individuals who identify as ART users and who cannot conceive without (Grunberg et al. 2018). In other words, many individuals in same-sex relationship do not necessarily suffer from a fertility problem, and have no choice but to use ART in order to reproduce their own children.

Second, the majority of the participants identified as Canadians and fewer than five women identified as ethnic minorities. For some women infertility issues are exacerbated by cultural expectations and the stigma they experience within their families (Missmer et al. 2011; Hasanpoor-Azghdy et al. 2015). Given that cultures and their associated norms are very different, studies that focus in cultural stigma and fertility would have to offer a specific focus on targeted ethnic groups which was beyond the scope of this study.

Future studies on peer support and infertility should recruit and engage more diverse patients such as childless patients, non-users of peer support, more patients from rural areas, members of the LGBTQ community, a wider-range of ethnicities and lower-income women. Future studies would benefit from finding additional sampling sources that representative of higher numbers of more diverse populations. While this study was inclusive to everyone, diverse

parameters were not explicitly sought out during the recruitment process given that IVF patients can be difficult to engage. For example, recruitment calls could be refined to mention infertile people using IVF or people using IVF.

3.6.3.2 *Sample Selection Bias*

There was an over-representation of women ($n=17$) who were pregnant at the time of the interview, or who already had a live birth post IVF which has the potential to bias the findings since it remains unknown to what extent pregnancy achievement motivated participation or impacted the capacity of these women to remember parts of their experiences. This does not suggest that their struggles and social support experiences matter less. The goal of this study was to understand how the patients who rely on peer support communicate. Every participant offered useful insights irrespective of their journey and ultimately a baseline through which the peer communication processes for other subsets of patient populations can be compared. While history and memory may sometimes influence an individual's recollection and emotional perspective of it, it is important to note that the women in this sample who had children already were still IVF patients, reliving the infertility treatment all over again through secondary infertility. In addition, IVF was still a recent experience for these women with no noteworthy difference in the time that elapsed since treatment for women with children and those without. Future studies however should be mindful of the potential for recall bias amongst pregnant and post-partum participants (Bryant et al. 1989) and recruit women at the start of their fertility journey.

3.6.3.3 *Generalizability*

Generalizability was not an aim or possibility with this study as it was designed. However it does give us enough information about IVF patients peer communication that could feed into future quantitative research designs. Instead, by describing a phenomenon in

exhaustive detail this study offers what Lincoln and Guba (1985) call transferability. Future research should evaluate to what degree the same experiences are applicable to other people in social support settings and larger subsets of the ART patient population.

3.7 Conclusion

This study allowed the voices of IVF patients to be heard and illuminated key considerations these women make in their pursuit of peer-based support: the adequacy of spousal, familial and other social relationships, calculations of secrecy versus transparency, and the prominence of their own support needs. When it comes to peer selection, the following elements helped patients in the process: diverse points of connection, mutual experience in IVF, other common ground, and existing examples of transparency. Therein lies an opportunity for women to empower each other through the spirit of sharing their experiences and take comfort with the knowledge that there is someone else out there who has also gone down that same road. There is also an integral role for the greater fertility community to play, with clinics, support-groups, and online forums fostering more personalized patient-peer connections that can give rise to the uptake of supportive relationships amongst all ART patients.

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Chapter 4: Article 3. IVF/PATIENT PEER SUPPORT STUDY PART 2 Overview

In the second part of my research study, I examine how in-vitro fertilization (IVF) patients carry out their communication with their peers. The article starts with a short review of the literature that focuses on peer support and the roles of supportive communication and disclosure that build social support. It then reviews the last stage of the Disclosure-Decision Making Model (DD-MM), disclosure efficacy, as a lens for the study with a view to outlining the communication process between IVF patients and peers. A second complimentary theory, Social Penetration Theory (SPT), that draws connections between the significance of disclosure content and the stages of relationships, is also described. Next, the methodology describes the recruitment process which yielded a sample population of 23 first-time and recurring IVF patients and describes their subsequent one on one interviews. Finally the analysis brings forth results illustrating the strong capacity of these women to disclose information to their peers and meet their support needs through immediate disclosure transitions and backwards introductions, a solid mutual understanding when it comes to engagement and disengagement boundaries, a preference for digital communication via texting and instant messaging, and the broad range of fertility topics covered in their reciprocal conversations. It also points to a notable gap in these relationships characterized by distance during the post embryo transfer waiting period. It concludes by suggesting that future support strategies in fertility-care and beyond should frame patient-peer support as a pragmatic channel that adapts to patients' personal disclosure and communication preferences.

Chapter 4 - Article #3

Building social support: Disclosure and communication processes between IVF patients and peers

CHAPTER 4 – ARTICLE 3

4.1 Abstract

Fertility patients have alluded to the potential of peers to provide meaningful social support on the basis of their ability to relate through shared experience. Meaningful social support requires supportive and quality communication in the form of self-disclosure of private experiences. This study explored the IVF patient and peer disclosure process. It explored how IVF patients communicate with one another and the scope of the disclosures of fertility-related and non-fertility related information between them. Using the Disclosure- Decision Making Model (DD-MM) and Social Penetration Theory (SPT) as a theoretical framework and taking a qualitative phenomenological approach, this study reports on interviews with 23 first-time and recurring IVF patients. Results showed IVF patients have a strong capacity to disclose information to their peers and meet their support needs through immediate disclosure transitions and backwards introductions, a solid mutual understanding when it comes to engagement and disengagement boundaries, a preference for digital communication via texting and instant messaging, and the disclosure of a broad range of fertility topics in their reciprocal conversations. Many women reported distancing themselves from their peers during the post embryo transfer waiting period and a lack of sharing aspects of their personal lives beyond issues related to fertility. Future support strategies in fertility-care and beyond should frame patient-peer support as a pragmatic channel that adapts to patients' personal disclosure and communication preferences.

Keywords: infertility, self-disclosure process, peer support, disclosure efficacy, social penetration.

4.2 Introduction and Literature Review

For many couples, starting a family is not a natural rite of passage. This situation manifests itself through any variety of stressful consequences such as stigma in social circles, personal anguish, the cost and availability of assisted reproductive treatment (ART) and medications (IVF being the most expensive), marital stress, loss of control, and strain on the patient's body (Cousineau & Domar, 2007). Given the unique reproductive outputs of treatment, women bear these burdens more than their spouses (Cousineau et al., 2006) and are left to find coping mechanisms. Many women turn to social support through interpersonal communication and self-disclosure (Steuber & High, 2015). Men suffering from infertility have also been known to rely on social support but to a lesser degree than their female counterparts (Beaurepaire, 1994, Pasch et al., 2004). According to Bell (2012) male partners' support needs often go unrecognized and uninitiated.

The current literature offers extensive coverage of common social support channels for infertility patients including spouses, extended family members, counsellors and friends and recognizes their ability to provide informal support (Bell, 2012; Schmidt et al., 2005; High & Steuber, 2014). However at the same time, patients have expressed their perceptions of how "involuntary childlessness erodes usual support channels" for example in circumstances where "family and friends were having children with ease" (Bell, 2012, p. 700). In fact, patients have associated these typical support channels with support inadequacy in infertility. For example, women reported feeling inundated by too much or inappropriate communication from family and friends in the form of unhelpful and unsolicited advice (High & Steuber, 2014, p. 168). As a result, patients have reported a desire for better emotional, informational and tangible support emanating from their perceptions of a gap between their support needs and the actual support

they receive (High & Steuber, 2014). Another support channel that remains uncovered in the infertility, support and adequacy literature is peers.

4.2.1 Peer Support

Peers have been known to provide support on the basis of sharing the same lived, health experience and similar characteristics as the person seeking help in a variety of health circumstances (Dennis, 2003). Through an examination of patient support groups, Bell (2012) suggests that women suffering from infertility gravitate towards other assisted-reproduction users, because there is no better substitute for support than someone with a shared journey, who can offer a point of comparison of experiences, and the opportunity to learn through observation. However, peer interaction can inundate patients with other people's problems or leave women dwelling on negativities (Bell, 2012). Peer support has helped women in related contexts, such as postpartum depression (source), breast cancer (source) and breast-feeding (source) and motivated a variety of healthy outcomes: self-care and the maintenance of emotional well-being, the development of sense of connection and decreased isolation, access to health information and resources and the adoption of healthy behaviours (Dennis, 2010; Forster et al. 2019; Pistrang et al. 1999). However outside of this cursory overview little is known about how peer-support in this context works. Furthermore, what is known is mainly a result of research on the nature of peer-based infertility support groups which has an entirely different dynamic than one on one relationships.

4.2.2 Communication and Self-Disclosure

Establishing authentic peer support requires communication of private experiences and regular sharing (Slade et al., 2007; Wu, 2009). Disclosure acts as a gateway through which to establish trust (Greene et al., 2006), alleviate stress (Kelly & McKillop, 1996), and reduce isolation (Martins et al., 2013). It is not uncommon for patients to have perceptions of stigma

surrounding their personal infertility disclosures, which leads them to forgo social support (Bell, 2012). Martins et al. (2013) found that when “fertility patients perceived opportunities for desirable social support but kept their diagnosis a secret, women experienced higher amounts of social and personal stress” (p. 371). Slade et al. (2007) echo the sentiment against “wide disclosure” of infertility with varied social circles, and suggest that, as an alternative, more thoughtful, purposeful disclosure to “others in similar situations may reduce the stigma and the level of anxiety” (p. 2316).

High and Steuber (2014) found that supportive communication- verbal and non-verbal messages played a role in the perception of support quality amongst infertility patients. In a subsequent study they report that direct disclosure was the only communication approach that significantly corresponded with perceived support quality and, along with incremental disclosure, one of only two strategies that enhanced quality of life (Steuber & High, 2015, p. 1639).

When it comes to disclosure, infertility patients have been found to share frequently, reveal sensitive information, let their defenses down and disclose highly intimate details in environments such as online blogs (Knoll & Bronstein, 2013). Whether they communicate to the same degree and in the same manner with peers remains unknown. According to Grunberg et al. (2018) fertility patients expressed strong preferences for an online peer support network and were enticed by features such as: the ability to access peer support on their smartphones, ask and answer questions, and have private one on one communication. A limitation of this study was its conditional nature that was not based on actual experiences. Instead it had patients imagine ideal online peer support situations and it solely focused on virtual connections. The scope of the current literature on peer support in infertility shows a paucity of research in this area, and limited knowledge on the nature of patient-peer communication process.

A study on how breast cancer patients perceived styles of peer communication showed that highly empathic peer conversations were viewed as helpful and credible and that peer abilities to listen and relate through their mutual experiences mattered (Pitstrang et al., 1999). On the flip side, when peers overwhelmed recipients with their experience and knowledge, and displayed poor listening, they were viewed as weak supports (Pitstrang et al., 1999). There is a call for innovative social support and disclosure research people suffering from illness that offers robust options for patients and avoids limiting participants to certain types of talk or relationships (Donovan-Kicken et al., 2011)

Given the integral role that communication plays in establishing social support, a broader understanding of peer relationships for female fertility patients is abridged without a complete picture of the communication mechanics that lay its foundation. We recognize that it is also important explore the peer support processes for men suffering from infertility. However given the toll of treatment on the woman, their tendency to rely on supports more heavily, and the signals women have made towards peer-based support in infertility (Bell, 2012), we felt it was important to begin by understanding peer support from their experience. Illustrating how this type of support works amongst women as the primary patient can ultimately increase uptake and awareness of an alternative social support channel for both women and men.

4.3 Theoretical Frameworks and Objectives

4.3.1 Disclosure Decision-Making Model (DD-MM)

Greene's (2009) DD-MM summarizes how people suffering from invisible health conditions share their ordeal. Specifically, it identifies three contemplation steps used prior to disclosure: information assessment, receiver assessment and disclosure efficacy. Since the goal of this study is to understand the disclosure and communication processes specific to patient-peer relationships, we focus on the final contemplation stage.

Disclosure efficacy describes how individuals reflect upon and assess their ability to communicate the information (Choi, 2016, p. 1005) and is linked to self-efficacy, a concept developed by Bandura (1977) that refers to one's confidence in their ability to achieve desired outcomes. Features of relevance include the setting, timing, channel/mode and message features (Choi, 2016, p. 1005). Other cogitations that impact disclosure efficacy are linked to messaging and delivery such as "what to disclose," "when and where disclosure occurs," and "how it happens" (Greene et al., 2006, p. 417).

4.3.2 *Objective 1*

Using the final step of the DD-MM, disclosure efficacy, as a lens, our first objective was to uncover the self-disclosure and communication patterns between IVF patients and peers by examining the following aspects to their process:

- approach to self-disclosure
- types of information exchanged
- modes of communication
- frequency and timing of communication
- prompts and boundaries influencing communication

4.3.3 *Social Penetration Theory (SPT)*

As we designed the study it became clearer that there was an element that remain uncovered by the DD-MM. While it was thorough in its explanations of the contemplation considerations and communication functions, mainly the act of disclosure, it was missing a theoretical element that covered the content of actual disclosure itself. Bearing this mind, we turned to a complimentary theory to address this gap. Taylor and Altman's (1975) SPT compares the self-disclosure process to the layers of an onion, with the outer circles reflecting more superficial information that one could disclose about oneself and the inner circles reflecting more personal, private information.

Specifically, their model examines the progression of a relationship and familiarity from the peripheral public layers (basic information such as name, residence, job, interests) to the more personal, deeper levels (personal ordeals, health struggles, inner-self). Intimate details of one's health experiences lie in the "individual's core self which is made up of layers that include spiritual values, deep fears, hopes, goals, fantasies, and secrets and an individual's most private information" (Carpenter & Greene, 2016, p. 1).

Taylor and Altman (1975) also point to the importance of trust in the relationship, since the disclosure of personal information is risky. They suggest that measured and gradual self-disclosure as people get to know each other can foster trust, while divulging highly personal details too quickly can come with repercussions such as judgement, constant questions, and insensitive remarks. They suggest that trust and self-disclosure are interdependent; trust grows as disclosures are met with supportive responses, and that greater trust leads to more intimate disclosures.

The exchange of information can be described according to its *breadth*, or the number and variety of topics discussed and its *depth*, or the degree of intimacy that guides this communication (Carpenter & Greene, 2016; Taylor & Altman, 1987). As a compliment to breadth and depth, close relationships embrace reciprocity, which suggests that when one party shares something, the recipient is expected to disclose something at the same level of intimacy, in the spirit of maintaining a balanced relationship (Carpenter & Greene, 2016). It is very common for the discloser to think about the information recipient on basis of their ability to reciprocate (Choi, 2016), and peers offer a unique advantage by virtue of their similar experiences.

The process of getting to know someone takes place through four stages of social penetration which include orientation (general pleasantries, testing the waters, getting to know

someone), exploratory affective exchange (information moves beyond superficial, people start to get a bit more comfortable), affective exchange (deep inner layers get shared and private information gets revealed) and stable exchange (a wide span of topics, most intimate information, continuous disclosure characterized by honesty, spontaneity and openness) (Carpenter & Greene, 2016; Taylor & Altman, 1987).

4.3.4 *Objective 2*

Our secondary objective was to understand the nature of social penetration between IVF patients and peers by understanding the scope fertility and non-fertility related disclosures.

4.4 Method

Interviews were carried out with 23 women who identified as IVF patients and peer support users in order to delineate the interpersonal communication processes these women engage in for social support purposes. The following paragraphs describe (a) the recruitment process (b) participant characteristics (c) data collection tools and (d) how I approached data analysis and maintained the integrity of the results.

4.4.1 *Recruitment*

A blend of purposeful and snowball sampling were used to recruit current IVF patients with lived experience using peer support in order to cast light on this phenomenon. Once I received University ethics approval for my project, recruitment started. Purposeful sampling started in Phase One using online clinic webpages and Facebook support groups. Snowball sampling was a useful complimentary method that allowed us to expand the sample size of a hard-to-reach population through referrals which were done at the end of each interview in Phase Two (Hendricks & Blanken, 1992, Momartin et al., 2003) Patient confidentiality required participants to self-select and initiate contact with me before confirming eligibility.

Recruitment began December 2018, and continued until data saturation was reached in July, 2019 by which point “no new information or themes were observed in the data” (Guest, Bunce, & Johnson, 2006, p. 59). By this stage I noticed patterns of repetition in the answers and recurring themes which left me feeling satisfied that there were enough examples through to illustrate the IVF patient-peer support phenomenon and its stages in a meaningful way. A total of 29 women expressed interest in the study and met the eligibility criteria and 79 per cent of these women participated for a total of 23 participants.

Table 1 offers a breakdown of recruitment numbers by source. Online support group page posts yielded the most participants, and clinic social media page posts and website entries and participant referrals were also an effective recruitment tool. The first group of 17 women was recruited during Phase One using digital means (Facebook pages, blogs and websites). Phase Two was an ongoing recruitment process of referrals from existing participants resulting in an additional 6 women.

Table 1. Recruitment Breakdown by Sample Source.

Source	Phase	Number of Participants
Online support group (social media)	1	9
Clinic social media & advertising	1	8
Participant referral	2	6

4.4.2 *Participants*

Table 2 on the next page breaks down the sample which represented women who underwent treatment in two major urban centres (Greater Toronto Area and Ottawa) and a majority of first- time IVF patients for a total of 14 women. The remaining 9 women identified as recurring patients undergoing multiple cycles. At the time of the interview, 11 women had at least one child (three of whom identified with the experience of secondary infertility), 12

women had 0 children (half of whom were already expecting their first child) and the rest of the women ($n=6$) were not pregnant.

Table 2. Interview Participants.

Alias	Age	City of Residence	Treatment Location	Number of IVF Treatments	Number of Children
1. Caroline	34	Ottawa	Ottawa	1	1
2. Ali	36	Ottawa	Toronto	4	0
3. Leanne	32	Ottawa	Ottawa	1	0
4. Heidi	33	Ottawa	Toronto	1	0
5. Melissa	39	Ottawa	Ottawa	1	1
6. Nancy	37	Ottawa	Ottawa	1	0
7. Rachel	32	Ottawa	Ottawa	1	0
8. Carly	33	Ottawa	Ottawa	2	1
9. Sandra	33	GTA	Toronto	1	0
10. Reena	34	GTA	Toronto	1	0
11. Tracy	32	GTA	Toronto	1	4
12. Taylor	33	rural	Toronto	1	1
13. Jenny	34	Ottawa	Ottawa	3	0
14. Lauren	37	Ottawa	Toronto	2	0
15. Norah	36	rural	Toronto	2	0
16. Cathy	37	GTA	Toronto	3	1
17. Esther	35	GTA	Toronto	1	0
18. Lindsey	28	GTA	Toronto	1	0
19. Clara	29	Ottawa	Toronto	3	1
20. Mary	37	GTA	Toronto	1	1
21. Daniella	36	GTA	N/A	5	1
22. Siobhan	42	rural	Toronto	4	1
23. Aisha	38	GTA	Toronto	1	2

Table 3 on the next page summarizes other participant characteristics and demographics such as sexual orientation, relationship status, level of education, ethnicity and diagnosis.

Table 3. Other Participant Characteristics

Characteristic	Data	
Age	28-42 years ($M= 34.7$, $SD 3.17$)	
Marital Status	all participants were married, common-law or in a relationship	
Sexual Orientation	all participants were heterosexual	
Origin -Ethnicity ²	North America - Canadian	15
	North American – American	1
	Asia – South Asian – Punjabi	2
	Asia – South Asian - South Asian origins	1
	Europe- English	1
	Europe- French	1
	Europe – Scottish	1
	South America - undisclosed	1
Highest Level of Education	graduate degree	7
	professional degree	3
	undergraduate studies	11
	high school	2
Occupation	Lawyer, marketing management, fundraising and not-for-profit, entrepreneur/ business owner, general manager, part-time professor, health therapist, early childhood educator, teacher, social worker, scientist, graduate student, media sales, finance/ investment banking, government agency manager, nurse, nutritionist and lab technician.	
Household Income	\$125,000 and up	15
	\$88,000 to \$125,000	4
	\$62,000 to \$88,000	4
Number of Current Pregnancies	9	
Diagnoses	The most frequent diagnosis was unexplained infertility ($n=6$). Followed by polycystic ovarian syndrome ($n=3$), endometriosis ($n=3$), male factor ($n=3$) and low ovarian reserve ($n=3$). Additional diagnoses included cancer related infertility ($n=2$), a history of previous miscarriages & related complications ($n=2$) and hypothalamic hypogonadism ($n=1$).	

4.4.3 Data Collection

² Ethnicity data was based on categorizations from List of Ethnic Origins – Statistics Canada 2016: <https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TV=402936>

Semi-structured interviews are widely seen as an appropriate method for research on sensitive issues and an ideal way to get a window into the health and social experiences of vulnerable people while offering an opportunity for catharsis for these participants (Bute, 2009). Interviews have proven an effective tool in research on fertility-related health topics for patients that share parallels with the study including women's psychosocial support needs during ART (Bell, 2012), perceptions of support group interventions (Percy et al., 2009) and fertility clinic environments (Allan, 2007), and how infertility patients handle requests for information about their journey (Bute, 2009).

The interview location was kept flexible and selected at the discretion of participants (e.g. a private office at the University of Ottawa, a quiet coffee-shop, video- conferencing via Skype, or the home of the participant). Interviews lasted between 45-60 minutes and were tape-recorded. The interview protocol featured 10 open-ended questions that uncovered a variety of aspects of the IVF patient/peer relationship. These questions were developed through a combination of inputs based on the literature, my own knowledge of the IVF process, as well as many conversations with other IVF patients known to me through community networks. The discussion guide questions were read by three IVF patient reviewers (including one first-time patient, one recurring patient with no history of success, and one patient in a same-sex relationship) to ensure that questions were appropriate, thought-provoking and complete before it was finalized. The following questions pertained to disclosure efficacy and the communication process between these participants and their peers:

- *How do you depict your relationship? Is it reciprocal or one way? Please explain how you each approach self-disclosure.*
- *How did you get acquainted the very first time? How quickly did you move in to your conversations about IVF?*

- *When do you feel the need to communicate with your IVF peer? Can you identify conditions that compel you to talk? Can you identify conditions that compel you to avoid communication?*
- *How do you most often connect? Virtually? By text? In-person on the telephone or face to face? And how is dialogue initiated?*
- *How frequently do you connect?*
Weekly? Multiple times a week? monthly? Every couple of months?
- *Is there a time that you do not connect?*
- *Is there anything else you can think of that influences your communication and decision to engage?*

Collectively these questions focused on how the communication process unfolds or, in other words, on the mechanics and logistics of the patient to peer communication (Greene, 2009). Questions explored topics such as the nature of communication, communication channels, frequency, prompts, and barriers to disclosure.

Pertaining to the scope of disclosures between patients and peers, prior to finalizing the discussion guide, one of the IVF patient reviewers suggested that a list should be provided to help participants recall topics they touched upon. I worked closely with my supervisor to generate a list of possible topics based on literature and this feedback. Building off of subjects IVF patients tend to communicate about with their spouse (treatment plans, treatment outcomes, treatment perspectives, emotional aspects and marital aspects) (Steuber & Solomon, 2012) we formulated the following question with a list of topics below.

Please identify from this list which topics you talk about with your IVF peer and how much you talk about it.

- *Information about a clinic, clinic experience overall, a specific doctor*
- *Nature of a treatment protocol -*
- *Your diagnosis, how many IVF attempts, other treatments*
- *How to use various medications and perform injections*

- *Financial questions, advice, burden*
- *Marital adjustment -*
- *Family acceptance, social pressures and strain*
- *Emotional adjustment Treatment milestones and measures*
 - *Retrieval day*
 - *Number of follicles*
 - *Number of eggs retrieved, number mature*
 - *Number of embryos , Quality of the embryos*
 - *Transfer day*
 - *Number of frozen embryos*
- *Pregnancy achieved?*
 - *symptoms of success*
 - *symptoms of non-success*
 - *advice on early self-testing*
 - *advice on blood testing*
 - *result*
 - *next steps after pregnancy or failed attempt*
- *Do you speak about anything else IVF related?*
- *Do you talk about other things unrelated to IVF? Can you give me some examples?*

SPT suggests that the content and types of information shared between parties indicates the closeness of a relationship. With this premise in mind, as a whole, this question focused on the types of topics participants covered with their peers with the goal of showing how intimately and how frequently these women shared information and the nature and proximity of their connection.

4.4.4. *Data Analysis and Validity*

In order to capture the fresh experience of each interview, transcription took place no more than three days after the completion of the interview. I relied on reading my notes synchronously while playing the audio files in order to ensure that the data captured was accurate. Pseudonyms were immediately created for each participant in order to protect their confidentiality and anonymity. After transcription was complete, the data sets were then reread and were reconciled with my written

notes in conjunction with the audio file in order to confirm that participants' experiences were captured as they were communicated.

I started developing a preliminary codebook based on “tentative codes” and the questions that were asked (Creswell, 2013, p. 184). As the datasets grew and I reviewed the transcripts in their entirety after data saturation was reached, I started expanding the categories. The transcripts and codebook were then reviewed by my supervisor in order to establish reliability and to affirm the meaning of each code. NVivo (v.8) software was used to carry out the coding and data analysis processes and interview transcripts were uploaded in the system. Following the recommendations of Strauss and Corbin (1990, 1998) a three-phase (open, axial and selective) coding approach was followed.

To start, in the open coding phase, “distinct categories” of information emanating from the data files (Creswell, 2013; Strauss and Corbin, 1990) were applied to the sections of the transcripts which corresponded to the theoretical underpinning: disclosure efficacy (to represent the nature of the information shared and the modalities specific to carrying out the communication process). I substantiated each category by looking for other instances that echoed similar sentiments and continued this process through the research until no “new information” was available. Each category was then “dimensionalized” (Creswell, 2013) or broken down into a series of child nodes (sub-themes) in order to capture disclosure efficacy step of the disclosure decision making process for IVF patients. Next, during the axial coding phase, categories of information were linked together and connections were made. Finally, during the selective coding phase, the codes that were the most relevant to the research questions were selected, and connections to other key codes were refined to ultimately illustrate the complete process through which IVF patients and their peers communicate. In order to illustrate the nature of information shared and how frequently

these women broached these topics, this data was tracked with simple binary yes or no answers, and descriptors such as a lot, somewhat or not at all.

In order to maintain the trustworthiness and integrity of the data I took multiple measures in addition to the time for self-reflection whenever the opportunity presented itself during each stage of the research process (Bute, 2009; Lincoln & Guba, 1985). This included detailed notes on the recruitment process and how each participant learned about the research, written notes taken during the data collection, and detailed coding maps to document the code development process.

It is important to note that qualitative findings are dependent on the viewpoint of the researcher (Taylor & Bogdan, 1998). Recognizing my own positionality as the researcher, I followed the recommendations of Bute (2009) and engaged in self-reflection throughout the data collection and analysis, in order to ensure that “my own assumptions and interpretations were informing but not clouding my understanding of women’s recollections” (p. 756). I kept a journal that I started from the time I began the interviews and kept my notes focused on the participants’ experiences irrespective of my own knowledge of infertility. These combined measures give me confidence in affirming that I have put forth accurate and reasonable descriptions of the disclosure and communication process between IVF patients and their peers.

4.5 Results

Part 1: How the IVF Patient-Peer Communication Process Unfolds

4.5.1 *Self-Disclosure Patterns*

Participants were asked to describe how they moved into their conversations about IVF, the nature of the discussions and continued disclosures of their infertility journey. Fifteen women described their initiation into fertility disclosures with their peers as “immediate” or “smooth” transitions. Responses that included mentions such as immediate, quick transition, instantaneous,

no sugar-coating were coded under this category. In the words of Lindsay “no small talk, time is money.” In her experience, it was refreshing that somebody else could relate to the constraints of treatment, and how to balance with all other aspects of life. It was clear that the ability to just get right into the fertility topics of interest provided an unwavering degree of comfort for many patients. Another common response that depicted the initial fertility conversation was “backwards,” or the experience of sharing highly personal information before small talk or superficial pleasantries. Five women described this pattern and included references to “reverse introduction”, “backwards introduction”, and “we move backwards to other aspects in our lives after talking about our IVF concerns”, and most memorably:

“when the first thing you talk about with this person is your vagina, there is no going backwards.”

Jenny

Ongoing communication between the women was described in three different forms. Firstly, 12 women described a form of “reciprocity” whereby both parties equally shared aspects of their journeys and took turns depending on who was in treatment. It is important to note that in these circumstances, both patient and peer were in ongoing treatment. Taylor notes that because they already shared so much in common, being able to share such intimate details on a reciprocal and regular basis with her peer “made her experiences feel validated.” Heidi described a sort of mutual understanding of openness and transparency whereby “they would offer each other the same amount of information and in the same level of detail.”

Six women talked about an “initial reciprocity” that transitioned to “a one-sided dynamic” based on personal timing and preferences of the women. Some peers graduated or moved on from their fertility journeys – either through a successful pregnancy or abandoning treatment -- and were viewed as “alumni” mentors at the same time that this relationship was unfolding. Jenny’s experience offers an example. For her, support became one-sided once her

peer became pregnant. Despite the pregnancy, she was still able to rely on her friend for the support she needed.

Five women spoke of a “one-sided dynamic” that had them on the receiving end of support without the requirement for them to reciprocate as their peer supports were well past fertility treatment at the start of these relationships. When her peer, who happened to be her sister-in-law, was trying to have kids, Tracy played the role of “uninformed onlooker” totally oblivious to the fact that her family member was suffering from infertility. However when it came time for Tracy herself to go through IVF, her peer offered her the support she needed after disclosing that she, too, had been through the process. Caroline had a similar experience, whereby her peer was well past IVF and finding alternatives to infertility but still there for her. Nonetheless, participants still offered a type of reciprocal support to their peers, but for the new and different chapters these women were living after moving on from ART which included other challenges related to family building such as adoption or illness such as cancer treatment.

4.5.2 *Facets of Communication*

The patient-peer communication process was broken down in to three topics areas: (1) descriptions of communication prompts and boundaries (2) the frequency of conversations, and (3) preferred modes of communication.

4.5.2.1 *Prompts and Boundaries*

Eighteen women replied that “treatment milestones”, “highlights”, and “decision-points” compelled them to initiate contact with and engage their peer. At these junctures, peer-based social support was positively associated with “information gathering stages,” “unconditional support,” and “regular check-ins” for all of these women. Clara described her motivation to communicate with her peer in a straightforward way:

“IVF was the front line of both of our lives as we lived it together. I reached out when treatment was starting, always when something important was happening, and when triggers popped up.”

Clara

Four women spoke about the post-transfer waiting period -- the two-week wait until pregnancy test -- as an opportunity to communicate and get through an excruciatingly “nerve-racking” stretch of time. However, five women saw the two-week wait in an opposite way, as a reason to maintain boundaries and a period of retreat. Their motivation to isolate during this time was reflected in a variety of statements: “there was nothing left to talk about,” “loss of control at that point,” and “being on eggshells.” Siobhan, who went through multiple IVF treatments, transfers and surrogacy, talked about her approach to the two-week wait:

“I had so many miscarriages already. There was nothing to talk about in terms of the two week wait so we didn’t. I was on egg shells at that time”

Siobhan

Siobhan’s message captures the feelings of uncertainty and ambiguity that for a few women led pregnancy topics to become off limits as time went on and non-successes became the norm.

Other barriers to communication included the period of time immediately after experiencing a loss or failure and one-sided success, whereby one of the parties in the peer relationship experienced pregnancy and the other did not. Five women identified with the need to have alone time to process poor results, failed treatment or miscarriage. They would eventually come around to communicating with their peer, but on their own terms. These women talked about “feeling down” and the “need to be alone.” In this regard, Aisha credits her peer for her high level of emotional intelligence. Her peer showed great sensitivity in “reading” her mood and “knowing when space was necessary”. Aisha recalls something her peer said to her after her first unsuccessful embryo transfer:

“I know you must feel inundated. I am thinking of you I just want to give you some space.”

Aisha

Caroline also identified with feelings of depression after her first failed frozen embryo

transfer and needing time to get over her outcome before reengaging in communication with her peer. Eventually, when she became pregnant following a subsequent treatment she also waited before disclosing to her peer. This time it was out of sensitivity to her peer who had never experienced success with IVF. Melissa found herself in a similar situation, which had its blessings and but also some challenges. She and her peer were two weeks apart during their respective treatment cycles. Melissa had already received the news that she was pregnant when she learned that her peer's transfer had failed. She put disclosure of her news on hold and "withheld updates temporarily" to spare her peer. As a result, she was also "initiating conversation less," "limiting the scope of various topics" and felt it wasn't "really an honest conversation." These women said they eventually overcame the temporary communication hiatus with time and that they always felt that they could come back and continue to receive and offer support when they were ready, no matter what the outcome.

"Communicating after my second transfer and my positive pregnancy test, I waited longer than I should because I didn't want to hurt her. I texted her and asked for her updates first because I didn't want to hit her out of left field with my news."

Caroline

4.5.2.2 Frequency of Communication

"we connected on a daily basis and consistently shared milestones in treatment as they happened".

Heidi

Next, six women said they would connect a minimum of four times a week or more. Five women said they connected one or two times a week. The remaining four women said they communicated about only a few times a month.

Regardless of how frequently they connected, participants expressed that they were getting the amount of time they needed and that their communication frequency matched their preferences. Furthermore, it was clear that peer support had a unique capacity to be tailored to individual expectations when it came to communication style overall.

“I reach out to my peer when I feel my needs to be listened to haven’t been met elsewhere. That when I share with her. Usually it we talk three or four times a month and that’s convenient for me.”

Cathy

On a related note Reena expressed satisfaction about how her peer was really there for her at the start of her treatment cycles when she really needed support the most.

“when something was coming up I knew she was there for me”

Reena

4.5.2.3 Modes of Communication

Participants were asked to identify which modes of communication they used to connect.

For the most part, many of the women used multiple channels and hybrid approaches to reach their peers. Four of the women seldom spoke in person (on the phone or face-to-face) with their peer and opted to keep communication entirely virtual, especially in cases of long distance supports.

“I haven’t seen or spoken my peer live for a few years. Facebook messenger works just fine for us”.

Lauren

“I met my peer online through a forum and we communicate mostly by text. We only facetime a couple of times a year.”

Jenny

The most popular mode of communication for patients and their peers was text messaging, referred to by eleven women.

“text messages were easy to handle and compartmentalize, whereas sometimes face to face communication became over the top.”

Esther

Sometimes text messaging was seen as “instantaneous” and other times it offered a chance to share and for the other party to reflect and write back when possible. On a similar level, Facebook Messenger received a high number of mentions by eight women.

Ten women recalled connecting with their peer in person, however this was not a regular occurrence nor a necessity. Heidi spoke of a rare opportunity she had to personally connect with her peer face to face whom she had met virtually. Both women were in concurrent treatment at the same clinic and drove to Toronto together for their cycle monitoring on their first “blind date.” Heidi recounted that “spending four hours in the car with someone I didn’t know allowed us to get closer.” On a similar note, two participants described live phone conversations as the odd call, a periodic happening during what was a stressful and overwhelming time. Some women emailed the “odd time” if they were sharing “detailed information and lengthy attachments.”

Part 2: Scope of Disclosures

4.5.3 *Topics of Discussion*

Participants were asked to select fertility-related topics of conversation from the list of 10 possibilities and indicate how much and to what extent they touched upon each of them by indicating a lot, somewhat or not at all.

The topic that patients and peers touched upon the most was treatment milestones, which was discussed by the majority of the participants, $n=17$, in exhaustive detail. These women discussed their results with their peers, including outcomes from ultrasound monitoring during stimulation, egg retrieval, embryo grading and transfer day, and some discussed their specific results with a view to getting feedback on treatment decisions.

“I liked sharing all my treatment information with my peer because she was always researching the meaning of the result and finding evidence to help guide my choices.”

Norah

For Daniella, while she shared a great amount of detail with her peer, sometimes she found herself being circumspect with offering information.

“We went through IVF pretty much at the same time which made disclosing challenging at times. If someone has success before you, you are in a predicament. But the silver lining is

that you share the same philosophy, knowing it's a sensitive topic you don't tell the person right away. Our retrievals were close together so we spared each other the exact details"

Daniella

One woman described a strategy she had with her peer that maintained focus on general aspects of treatment milestones such as retrieval day, sperm count and number of embryos without delving deeper in to more concrete specifics like the number of eggs retrieved and the number of mature embryos and embryo quality.

"I became afraid of bringing up details of my results because I had a fear of having abnormal outcomes. I didn't want my fear confirmed."

Hayley

Two other common topics women touched with regular frequency but to a lesser degree than treatment milestones were clinic details and emotional adjustment. At least 15 women talked about their clinics and compared notes on the quality of care. Discussion on clinics included many touchpoints such as doctors, nurses, ultrasound techniques, patient communication, quality of embryology lab, services offered, empathy and treatment costs.

For a few of the women, their discussions on clinics prompted them to switch to their peer's fertility centre.

"Through our chats about clinics my peer taught me how to advocate for myself and get what I want. It led me to change clinics and get a second opinion in Toronto at her clinic."

Ali

Emotional adjustment was another topic embraced by at least 13 women. The capacity they shared with their peer to receive validation through all of the highs and lows of their mutual experiences helped these women feel comfortable, at ease and normalized.

"Being able to share my feelings makes me feel normal, knowing that other people go through and that I'm not alone. It could be a lot worse and this relationship gave me hope. I'm hopeful but realistic that I could still be in the same position."

Rachel

It is remarkable that pregnancy achievement, which included the two-week wait, testing and results, showed discrepancies in how much it was discussed. Only nine women identified it as a topic they touched upon a lot. The rest of the women touched upon it a little.

Given that the goal of IVF is to achieve pregnancy, participants were probed further on the reason for discussing post transfer details to a lesser degree. Patients who felt optimistic about the likelihood of success or positive about treatment overall were comfortable talking about pregnancy testing, results and next steps unconditionally. Norah's experience serves as an example of a support where no detail was left untouched during the lead up to transfer and then the two- take week wait.

"We would talk around negative pregnancy tests, take screenshots of the results and share deep information about milestones. My husband didn't even understand what embryo grades meant – but she understood IVF language."

Norah

Reena recounted receiving fun messages and jokes from her peer that would keep her smiling and her mindset positive while she was waiting for her pregnancy test.

Conversely, several participants voiced a personal discomfort and a decision to avoid the topic when it came to talking about pregnancy achievement. The members of this group rationalized their decision to disengage from conversations about it through reasoning that included: "a need for personal space," "low desire to go there based on a record of subsequent non-successes," "being on egg shells," "nothing left to talk about," "a loss of control over the results," and "being too close in their respective retrievals and wanting to be sensitive to the possibility of one-sided success." For Aisha, her peer support was there to provide more insights through the actual process where decision points really mattered:

"We didn't talk about pregnancy. I had less control at that point. It was more about the science and getting caught up in the milestone details and procedures and all the unknowns."

Aisha

Jenny, who had been through multiple treatments and failures, concurred with feelings

of awkwardness. For her a pattern was starting to prevail:

“The first IVF we talked about pregnancy achievement a lot. As time progressed she had successes and I didn’t and my ability to discuss it became limited. I could only talk briefly.”

Jenny

Other topics that participants recounted that they touched upon with their peers, but with a lesser frequency of air time included treatment protocol, diagnosis, medication and injections, financial questions, marital adjustment and family/social acceptance.

Participants also recalled some uneasiness in terms of getting inundated with advice by their peers and expressed some regret for revealing too much information. Four women talked about their feelings of bombardment and incompetence: “at times it was like my way or the highway”, “controlled”, “too much unsolicited advice”, “guilt for not listening to them”, “feelings of ignorance and stupidity”, and “I felt like I wasn’t doing enough”. The perspective of one participants described it metaphorically:

“It made me research more, but that puts me in an Alice in Wonderland kind of hole. And then I get overwhelmed, and am hard on myself when I didn’t do what she suggested.”

Leanne

One woman’s negative experience with her peer talked about the pitfalls of too much information sharing and associated it with a lack of limits and a growing sense of competition.

“I started off feeling slightly better, then I felt compared to too much. I felt controlled. Compared to her I felt awful. Why compare yourself to a woman when you are in this together? I felt imposed upon because there were no boundaries in this relationship”

Hayley

Three women spoke of some mild regret from oversharing private details of their lives. They expressed concerns such as “some stuff can’t be taken back”, “it could be used against me at work”, and “admitting failures was hard”.

Finally, participants were asked if they talked about other things unrelated to IVF and fertility. The majority of the women, a total of 16, said they briefly touched upon other aspects of their daily lives including husbands, jobs, exercise routines, homes, moves, leisure and nutrition

but to a lesser extent. It is compelling to note that 10 women mentioned that IVF was “dominant”, “most prevalent”, and “pressing” when compared to all other topics. Seven women said they exclusively spoke about IVF.

“Sometimes we try talking about other things like the neighbourhood, community stuff and work but fertility topics dominate our conversations.”

Nancy

4.6 Discussion

4.6.1. Theoretical Implications

Overall, the exploration of the third and final step of the DD-MM, disclosure efficacy, offered us a thorough window into this phenomenon and advanced the components of this step. Communication was prompted by treatment milestones and a sense of telepathy whereby women reported the ability of their peer to read their minds and sense the moments when support or privacy was needed the most, happened frequently and took place for the most part virtually via text and messenger. However our findings also cast new light on this theory by highlighting an opportunity to build upon disclosure efficacy in terms of “how” the transition to very first disclosure actually unfolds. For example, women in this study talked about patterns of immediacy and backwards introductions in addition to reciprocity when they were asked to describe their first conversations. Since the nature of these introductions was indicative of the style of relationship and rapport they developed, we maintain that is useful to capture the different types of initial disclosures in this model. Furthermore, we suggest that the style of disclosure may vary according to the recipient.

We also found that there was a gap in the DD-MM pertaining to “what” actually gets shared. This compelled us to use a complimentary theory, SPT, in order to explore the breadth and depth of fertility related topics with a view to uncovering the nature of the penetration and engagement between these women. The variety and depth of the topics shared showed a close

affective exchange. However for many relationships this progression would stagnate and stall, failing to move towards a stable exchange characterized by sharing intimate information.

In the following paragraphs, self-disclosure patterns, prompts and boundaries, frequency and mode of communication, and topics of discussion with supporting links from the literature will be discussed more closely before concluding with practical implications for care alongside limitations and directions for future research.

Starting with self-disclosure patterns, for all patients, it was straightforward and easy to connect in conversation with their peers. This was marked through their natural ability to transition straight to the details of their journeys with no hesitation and without reserve. It was also commonly reported that women would start by immediately disclosing highly personal information related to aspects of their treatment, a backwards introduction which is a rare occurrence amongst strangers, who usually begin disclosure with impersonal and superficial topics. This approach was very similar to the “direct disclosure strategy”, outlined by Steuber and High (2015), that correlates with quality support and positive life outcomes. These findings speak to special ability of peers to provide support and affirm the importance for ART patients of another’s lived experience of childlessness and treatment (Bell, 2012). These women had a unique level of trust and were comfortable starting their communication at the core of their very private health experience instead of through their peripheral public shell (Altman & Taylor, 1975). Many women did not know the rest of the details of their peer’s personal life and that did not matter.

The other important self-disclosure pattern between patients and peer was reciprocity, which could take on three different forms or combinations: reciprocity, reciprocity to a one-sided dynamic, and a one-sided dynamic. The majority of patients in our sample population relied on peers who were also going through treatment at the same time and described their support

process as entirely reciprocal as they took turns sharing milestones and mindsets. The second, smaller group of participants talked about a natural progression through a relationship that started off with balanced sharing but grew to one-sided once one of the women was at the end of her treatment journey. The third and smallest group described a complete one-sided dynamic whereby peers relied on women who had done IVF in the past and were in a different chapter of their lives.

While these three patterns of continued communication are different, they still share an essential ingredient of reciprocity, just at contrasting levels, depending on the stage of fertility-treatment and family-building for each party. Communication patterns between IVF patients and peers gravitate towards different ends of the spectrum depending on where each party is at in the process. The ability of peers to offer some degree of reciprocal disclosure by identifying through their respective fertility experiences, regardless of where they are at reinforces previous findings underscored in the literature (Choi, 2016; Greene, 2009).

Prompts and boundaries findings showed that more than two thirds of the women felt inclined to engage with their peer at their various “treatment milestone” stages. Participants leveraged benefits talking through treatment milestones with someone who understood the significance of the decisions and treatment progression. The opportunity for peer emotional assistance, appraisal and affirmation through their own experiences motivated patients to continue to communicate and disclose, a finding that is consistent with the social support literature (Bartholomew et al., 2011; Percy et al., 2009).

Patients unanimously agreed that peers have a special power to anticipate their needs and had a firm grasp on when support was needed or when space was in order. There were moments when participants described a need for boundaries to avoid feeling overwhelmed, which parallels the findings of Pistrang et al. (1999). It is significant that while the majority of the women would

communicate regularly in the lead up to the egg retrieval, boundaries would gradually grow during the two-week wait following the embryo transfer stage. Space during this time period offered patients a chance to process their results, come to terms with things in the case of non-success, and come up with a communication strategy sensitive to their own needs and those of their peer.

Patients were confident with their communication strategy as shown through their choices of prompts and boundaries. Patients' ability to select and manage the timing, message features, when and where disclosure happened with ease reflects a strong capacity to contemplate disclosure efficacy according to the DD-MM (Choi, 2016 ; Greene et al., 2006).

Frequency and modes of communication responses contend that at least one third of participants had constant needs for peer contact and gained benefits from consistent and regular communication. This finding reflects the constant, growing, and changing demands of treatment that patients are faced with and the impacts it has on their daily lives (Cousineau & Domar, 2007). Regardless of how much they were in contact, the frequency of patient-peer communication was mutually understood for many women and personalized according to their circumstances. Women who were in treatment at the same time or after one another, would reach out to each other on a very similar basis, and the unconditional nature of this support made communicating very straightforward and natural. This finding provides evidence that supports previous findings that attest to the unique bond these women share and the rare lived understanding that peers can offer ART users (Bell, 2012).

Given that IVF patient-peer communication was seen by many as a “continued conversation,” it is not surprising that the majority of participants showed a strong preference for text and Facebook Messenger as a mode of communication that allowed respective stories to

unravel and “pick up where they left off.” This supports previous findings that show strong ART patient preferences to access online peer support through mobile technology and private messaging rather than through face to face channels (Grunberg et al., 2018). Our results also contend that face to face conversations were for the most part sporadic, given how busy people’s professional and personal lives were already, even without the added demand of treatment, and in some cases, patients started off their supportive relationships entirely online. Grunberg et al. (2018) found that the opportunity to move to face to face interaction from online peer support had some appeal amongst infertility patients but it was not seen as a necessity. It is also significant that patient peer communication through phone conversations and email was more limited.

Our analysis on topics of discussion posits that patients and peers communicate on a breadth of private fertility-related topics. SPT theory suggests that this behaviour requires a certain level of trust and intimacy (Taylor & Altman, 1975). For the entire sample population, almost every discussion item from the list of possible topics was covered in patient-peer discussions including: treatment protocol, diagnosis/IVF attempts, medication and injections, financial questions, marital adjustment, family and social acceptance, emotional adjustment, treatment milestones, and pregnancy achievement just in varying degrees. It was clear there was a build-up to deeper fertility disclosures echoing an incremental approach as highlighted in previous studies on disclosure in general (Steuber & High, 2015). Patients were satisfied by the level of balance they shared with their peers when it came to mutual, reciprocal disclosure. This finding is supported by previous research that suggests as a discloser’s expectations for reciprocity are met, continued communication and information sharing grows (Choi, 2016; Carpenter & Greene, 2016).

Conversation surrounding treatment milestones and clinic information received the greatest amount of coverage in patient-peer discussions. Our findings show how information sharing on these topics has the ability to influence future health behaviour and actions that patients take. In some cases, women sought insight and guidance about other fertility clinics for second opinions and ended up taking that advice while others shared stories and compared experiences about the same clinic. It is also compelling to see that sharing details around treatment milestones helped inform patients and their subsequent decisions. While this can certainly be of benefit to women, there is also the risk with regards to the quality, accuracy and authenticity of the information being shared. This finding advances the work of Dennis (2014) who advocates for comprehensive training of peer supports that includes increasing their knowledge base with regards to health information.

However, there was a drop in the amount of time spent for the two most intense aspects of treatment: treatment milestones leading up to egg retrieval and the post embryo transfer waiting period, a trend that warrants further examination. It was ironic that pregnancy achievement is the single most important aspect of treatment and yet it was considered to be beyond boundaries of conversation in many cases. The vulnerabilities facing women undergoing IVF treatment have already been well documented in the literature (Bell, 2012; Cousineau & Domar, 2007) and the post-transfer waiting period is a time when women who are awaiting their reproductive outcome are known to have higher levels of psychological stress, anxiety and depression (Atwani et al. 2019). Patients were more inclined to stay private during this period and distance themselves from their support. These women reported comfortable and reassured by their peer's ability to understand and avoid pressuring them which has been previously documented in other health settings such as breast cancer (Pistrang et al., 1999). While isolation served as a useful temporary strategy, its detrimental impacts on well-being

cannot be overlooked (Cohen, 2004). Our findings suggest that more research is still needed to understand patients' specific support needs and expectations during this very sensitive post-transfer time period and how those needs can be properly addressed.

The topics of information were also associated with drawbacks of peer support for the participants who voiced some of the pitfalls they experienced by being too transparent. These women were mainly concerned with feelings of being over-saturated with information, controlled and risk of comparison and competition. These challenges have been well-documented in research on peer-led support groups (Bell 2012; Domar et al., 2000) and clearly transcend group settings. However at the same time we posit that most women with shared journeys are adept at establishing their own communication style that responds to each party's sensitivities. It is therefore important that patients and peers continue to be mindful of boundaries and communicate their respective needs when it comes to the provision of support.

It was clear that fertility-related topics dominated the communication between IVF patients and their peers ($n=9$) and that while they touched upon other topics of conversation such as their families, careers, homes and exercise, the scope of that engagement was narrow and brief. The women experienced an affective exchange of disclosures by sharing private information but not every relationship gravitated towards a stable exchange characterized by talking about a variety of topics ($n=16$) and sharing the most intimate secrets such as pregnancy achievement ($n=13$). On a related note, these women saw their friendships as pragmatic and not necessarily deep which is corroborated by the lack of stable exchange. These results parallel the logic of social penetration explained in previous studies (Carpenter & Greene, 2016; Taylor & Altman, 1987).

The manner through which these women approached information sharing suggests that while these relationships are valuable, they serve a practical and personal purpose and are there

to fulfill a support need at a specific point in time. For a few women, sharing too much information immediately came with repercussions including regret and feeling overwhelmed with advice, a phenomenon that Taylor and Altman (1987) highlight in their work on social penetration. It is not uncommon that sometimes when relationships become too intimate too quickly parties can suffer more negative and undesired support consequences, as a result of the absence of growing trust incrementally. In other words the immediate open book approach did not necessarily work for all participants. However it was clear in most cases that the need for support through one's fertility journey eclipsed the usual need for small talk which is prevalent in other relationships, as evidenced by the outset of peer support which was described for many as a "backwards introduction."

4.6.2 Practical Implications for Care

4.6.2.1 One of a Kind Support.

Patients and peers share a unique and natural ability to read each other in ways that no other supports can. Women were comfortable with backwards introductions and direct transitions to their fertility conversations. Participants were also confident in selecting their peer and choosing their timing, message content and managing their needs for privacy, and they reported a strong capacity to understand mutual expectations when it comes to disclosure and support. For example, participants and their peers were adept at balancing both their desires for engagement with those of solitude without facing any setbacks in their relationship. Patients and peers also benefitted from finding their own opportunities to get to know their peer and a rhythm for their support in a non-prescriptive way. The same could apply for any other sensitive health and life experience such as grieving and loss, divorce, coping with mental illness or weight management. By virtue of their shared experience, peers have lived through similar sensitivities themselves.

4.6.2.2 One Size Doesn't Fit All.

Peer supportive relationships can be creative and take on variety of forms. In today's fast-paced world, and given the constraints and pressures of treatment, it is common for women to prefer sharing a virtual connection and communication through text and Facebook Messenger. In-person communication was never a requirement and transcended geographical boundaries and took place long-distance. Patients and peers should feel free to connect regardless of wherever they may live and work and be open to the opportunity for support however it presents itself. This finding can also be applied in other invisible health settings.

4.6.2.3 Establish a Connection Beyond Fertility.

The backwards introductions between patients and peers and their strong tendency to delve straight to the deep details emphasized the clear support needs of IVF patients who had a desire to get immediate insight during stressful circumstances. The communication patterns showed that peers played a pragmatic role in the lives of IVF patient. Even though they sometimes touched upon aspects of their lives outside of treatment, those moments were limited. If patients are interested in pursuing a lasting relationship, stronger bonds and sense of familiarity should be prioritized through the communication of other interests outside of fertility treatment. The same holds true for any other health experience that has compelled those undergoing it to leverage peer support.

4.6.2.4 Understanding Specific Support Needs Post-transfer.

IVF patients gravitate towards solitude during their two-week wait and avoid disclosing details surrounding pregnancy testing as a form of emotional protection oblivious to the negative impacts of isolation on their well-being. All channels of social support including doctors, family members, support groups, online fora, psychologists and peers must recognize these sensitivities around this time period and tailor support approaches accordingly.

4.6.3 *Limitations and Directions for Future Research*

This study marked a start by understanding the disclosure and communication processes between IVF patients and peers, however it is not without its limitations.

Future studies should endeavour to recruit more diverse populations who experience the psychosocial aspects to infertility differently reflecting social determinants such as socioeconomic levels, ethnicity, geography (rural residents) in addition to sexuality that have been previously identified in fertility research (Wilcox & Mosher, 1993; Becker, 2000). Some women are more susceptible to social isolation than others and may have challenges when it comes to communicating and establishing support. While the initial goal of this study was to recruit women from the Ottawa and Toronto regions given my existing relationships with clinics and sample sources in those areas, the study attracted the attention of women from a few rural parts of the province. In order to ensure a robust sample and diverse perspectives, these three women were deemed eligible to participate. Future studies should endeavour to interview more patients who live in rural settings who may be more prone to social isolation. In addition, 75 per cent of the women (n=17) either had already had a live birth post IVF or were pregnant at the time of the interview. The potential for bias and to what degree pregnancy achievement motivated their participation is unknown. Nonetheless, regardless of an existing child, many of these mothers were dealing with secondary infertility, with recent and upcoming IVF treatments in their prognosis. Subsequent studies on peer support tendencies should attempt to focus on first-time IVF patients around the same point in treatment.

It was clear that some women felt the need to put up boundaries in situations of non-success impacting their communication. Future studies should account for disclosure differences between successful and unsuccessful patients. Furthermore, given the post-transfer waiting

period is one of liminality for fertility patients, subsequent studies should address the support needs of women at this most vulnerable juncture.

It was also evident from the results that some women sustained peer relationships through virtual communication channels such as messenger and text-messaging. In situations where individuals have not met their peer in person, it would be valuable to understand the impact of using such platforms on the communication and quality of support received.

As principal researcher for this project and a former IVF patient myself, it is important to consider any bias I may have brought to the study, which I mitigated by bracketing my own experience. Questions were kept objective and devoid of my personal experiences and detailed notes were kept in order to clearly distinguish between my thoughts and those of the participants (Martin, 2009).

Finally, the findings of this qualitative study were informed through the perspectives of a small group of IVF patients. While understanding the communication approaches of IVF patients who use peer support was an important place to begin, it would be useful to apply and verify these findings through quantitative survey measures.

Infertility and its treatment focus on the woman since they bear the burden of the treatment (Cousineau et al. 2006) which yields scientific literature that typically focuses on females. Studies should explore male perceptions social support in infertility and their own needs when it comes to stress and coping.

IVF patient-peer support should be explored using other innovative methods such as dyad interviews for patients and peers to compare their perspectives, longitudinal approaches that could assess the course of the friendship post IVF treatment, and quantitative approaches that measure the relationship between patient-peer relationships and stress, anxiety and depression.

4.7 Conclusion

IVF patients have a strong capacity in disclosing information and a natural ability to communicate with their peers with a view to building social support. Upon securing a peer connection, patients immediately transition to sharing intimate fertility treatment details. This action is described as a rare, backwards introduction that serves patients' immediate support needs. They also have a mutual understanding when it comes to boundaries, illustrated through their ability to engage or disengage freely in addition to their frequency of communication which was regular and consistent. Patients showed an overwhelming preference for digital modes of communication such as text and instant messaging that prompted a continued conversation, responded to their needs for convenient communication in difficult and fluctuating circumstances, and fulfilled their desire to have compartmentalized, non-invasive engagement. Understanding these facets of patient-peer communication offers functional insights that are useful for the fertility-care community and healthcare sector as a whole that can ultimately help promote and increase the uptake of a valuable social support channel.

When it comes to the scope of information sharing related to fertility-care, patients and peers covered a broad range of topics and deep level of detail characterized by a sense of reciprocity which made the women feel comfortable and validated. It was also clear however that women did not necessarily share everything and can sometimes feel burdened by oversharing. Many participants felt a need to safeguard their privacy during their two-week wait, by not broaching the topic of pregnancy testing and results particularly in the case of failed treatment, a choice that was respected and understood by their peers. It is incumbent upon future support strategies and promotion efforts in fertility-care to frame peer support strategies as a useful tool that responds to a very practical need at a specific point of time while also casting light on the benefits of sharing information according to one's comfort levels and talking about other

interests. Peer support is a social support channel that adapts to the preferred disclosure and communication of the patient.

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CHAPTER 5– CONCLUSIONS

CHAPTER 5 - CONCLUSIONS

5.1 Summary of major findings

The overarching goal of this study was to uncover self-disclosure processes between IVF patients and peers and explore how these processes help build psychosocial support. Data collection was designed to illustrate how IVF patients assess their support needs and peers prior to self-disclosure and how social support is built through the disclosure and communication processes these women share.

The findings of the first article set the stage for a study on self-disclosure processes between IVF patients and peers by providing a robust literature review. It underpins the importance of a psychosocial approach to fertility-care with an emphasis on the role of interpersonal communication, self-disclosure and support adequacy in leveraging social support. It offers a thorough review of common social support mechanisms, casts light on how disclosive communication functions within each one and points to a gap in the literature on peer support in fertility treatment. Then it explores the merits of using DD-MM in order to uncover how ART patients build social support with their peers.

The results of the second article provide an understanding of how IVF patients assess information regarding their situations and their peers as disclosure recipients before leveraging peer support. Participants described an inventory of their social circles in groups such as family, friends, and colleagues and reconciled the ability of these people to provide social support, which was ultimately marked by inadequacies. This inadequacy of social support was exhibited by the detail participants offered pertaining to their decisions surrounding secrecy and transparency. They showed an ability to navigate between being open or staying guarded, gravitating towards being open when they sensed a personal fit with a peer. Diverse pathways such as existing friends, online peer support groups, workplaces, clinic waiting rooms, neighbourhoods, and

friends of friends led these women to find their peer support. Their supportive relationships were predicated by distinct experiences in IVF such as success stories and struggles, to sharing other parts in common such as clinics and doctors. Sharing other common ground outside of IVF helped solidify many of these relationships, whether it was a shared workplace, similar career paths, or educational background.

The results of the third article offer an important and new contribution to the scholarly literature, a more thorough understanding of the disclosure and communication processes specific to IVF patients and their peers. From a disclosure efficacy perspective, the support process between these women can be described as intuitive and pragmatic. This was exhibited by immediate disclosure transitions and backwards introductions, a solid mutual understanding when it comes to engagement and disengagement boundaries, a preference for communication mediated by texting and instant messaging (in many cases transcending geographical boundaries), and the coverage of a broad range of fertility topics in their reciprocal conversations. Our findings also underscore the mutual understandings between women with shared IVF experiences when it came to boundaries with regards to information sharing. It was not uncommon for participants to insulate themselves during the post embryo transfer waiting period and refrain from discussing pregnancy testing as a form of self-preservation. There were also instances whereby participants described feeling saturated with information offered and feedback overload by their peers. The breadth and depth of their social penetration illustrated a deep level of affective exchange as shown through the nature of private information they shared. However, not every relationship gravitated towards a stable exchange characterized by talking about a variety of topics and sharing the most intimate secrets such as pregnancy achievement. Some participants reported that they needed time to process results, particularly in the case of a negative pregnancy test. This shows that irrespective of their peer's lived experience and ability

to relate to this circumstance, IVF patients place an emphasis on information regulation at this sensitive time.

5.2 Reflections on DD-MM and SPT in Understanding the Peer Support Process

Overall, the DD-MM served as a useful model to inspire the research questions and craft the discussion guide for the interviews in the spirit of understanding the role of communication in social support processes. First, information assessment points of contemplation such as stigma, symptoms and relevance (Greene, 2009) were congruent and clearly present in IVF patients' pre-consideration of peer-based social support. The remaining two parts, preparation and prognosis, factored less in to the equation. For example, IVF patients disclosed to their peers unconditionally, with no foresight to any future success or non-success with their prognosis. Preparation was also less relevant. This could be attributed to the fact that fertility diagnoses are in a constant state of flux as a result of elapsed time and treatment peaks and valleys. For the participants in this study, it was impossible to know what to expect.

Second, receiver assessment components such as information regulation, fear of judgment, the need for reciprocity and the provision of support (Greene, 2009) clearly came in to play as participants reflected upon and made their choice in a peer as a disclosure recipient. Knowledge of their shared IVF experience, common ground and the transparent examples of peers gave patients confidence in their peer's abilities to reciprocate and validate their journey, allow these women to feel understood and accepted, encourage a wealth of information sharing between them as opposed to others, and offer support.

Finally, disclosure efficacy considerations of individuals offered us a window through which to understand how IVF patients and peers disclose and communicate, and illustrated the natural and pragmatic communication process through which these women engage. Its application was useful in understanding almost everything related to the communication process

between the participants and their peers: the initial disclosure approach of IVF patients, their modes of communication, the frequency and timing of their conversations and finally prompts and boundaries. The only element that was left outstanding was the types of information that get exchanged, which had our research team integrate a secondary, complimentary theory, social penetration theory (SPT; Altman & Taylor, 1975), to interpret the breadth and depth of their disclosures. Specifically, SPT offered another important lens through which we examined the meaning behind the information patients offered their peers, and what it said about the nature of their relationships.

5.3 Limitations

We would be remiss without highlighting three limitations of this study. In order of their emergence, they include the recruitment method, the sample population, and the potential bias imposed by the chosen method of one on one interviews.

The first limitation of this study concerns the recruitment method and sample pool. Since patient confidentiality and ethics stipulated that participants (IVF patients who identified as peer-support users) had to self-select for the study, some women may have been overly enthusiastic in their participation, as it required follow-up and follow-through on their part. On this point, it is important to note that 75 per cent of the women ($n=17$) either had already had a live birth post IVF or were pregnant at the time of the interview. The potential for bias and to what degree pregnancy achievement motivated their participation is unknown. Nonetheless, regardless of an existing child, many of these mothers were dealing with secondary infertility, with recent and upcoming IVF treatments in their prognosis. Subsequent studies on peer support tendencies should attempt to focus on first-time IVF patients around the same point in treatment.

Furthermore, though recruiting from online infertility support groups was fruitful and offered a diversity of fertility experience, it did not necessarily offer diverse sample

demographics. Despite best efforts to have an inclusive call for participation, there was an under-representation of minority ethnic groups and visible minorities, lower income groups, and lesbian women. These populations are often marginalized in their health experiences and more prone to social isolation (Missmer et al., 2011). It would also be useful for emerging studies to find innovative avenues to reach these women, as many might be less inclined to use an online support group (Hinton et al., 2010; Grunberg et al., 2018). Engaging more diverse individuals on their perceptions of social support and peers in the context of infertility remains a priority for future research.

Second, the sample population of IVF patient peer-support users was highly educated. Ninety-one per-cent of the participants had at minimum an undergraduate or college degree, and thirty per-cent had graduate degrees. This is not surprising given the epidemiological trends associated with infertility and its treatment that indicate higher levels of education and income amongst patients (Inhorn & Birenbaum- Carmeli, 2008; Wilcox & Mosher, 1993). The participants' capacity to understand social support was certainly a benefit to the discussion; however it could also have been a factor in their communication and perspectives pertaining to peer-based social support. It remains unknown how other women of more varied backgrounds communicate with their peers. As more diverse populations gain access to funded IVF treatment in the province of Ontario, it would be useful to understand how and if they leverage peer-based social support as a coping mechanism to deal with the stressors of treatment.

Finally, qualitative studies in the areas of infertility, stress and coping can be prone to social desirability bias in circumstances like one on one interviews. Infertile patients have an interest in portraying themselves and their experiences in a positive and optimistic light, especially when they might feel their selection for treatment depends on having a balanced outlook (Stanton et al., 1991, p.51). Methods used to reduce social desirability bias in this study included conducting

this research as a patient advocate who understood the perspectives of patients paving the way for an open and honest dialogue, and offering the choice of research environments where participants felt the most comfortable, and removed from the influences of clinics and devoid of power imbalances. In addition to that, questions were carefully worded and the roles of study participants were carefully defined according to recommended approaches in the literature (Latkin et al., 2017).

5.4 Implications for Advancement of Peer-Based Social support in the Context of Fertility

By offering clear insights into the patient perspective and communicational aspects of the experience of peer support, this study offers a variety of implications that can help advance the uptake and awareness of peer-based social support in fertility-care settings. Firstly, it offers patients and clinicians, counsellors, and audiences beyond the realm of fertility such as family and friends an understanding of the lived experiences of IVF patients, especially pertaining to challenges such as support gaps within social circles, navigating openness versus secrecy, and inadequate support from male partners. Collectively these struggles gravitate women towards peer support, however that does not absolve any of these parties from their role in combatting the fertility stigma. These women benefited from the transparent examples of their peers. In order for the peer support to grow, new cohorts of patients must feel comfortable in their ability to disclose information about their condition, free from judgement. Everybody knows somebody struggling with infertility, and it would be a benefit for society as a whole to see increased awareness around ferti-literacy. There is potential for government to also take a leadership role in this dialogue, given that the province of Ontario has maintained funding for ART treatment.

Secondly it shows patients and clinicians that the opportunities through which women can leverage peer support are omnipresent, especially for women who are inclined to look for it. For example, our findings show that patient-peer connections are already happening in

workplaces and clinic waiting rooms. While patients do have concerns about privacy and norms when it comes to these environments, they nevertheless maintain interest in engaging with women they encounter. While carving out a pathway to support requires the open mind of the patient, clear communication and leadership on terms of engagement and what is appropriate would provide more meaningful connection opportunities to other patients who otherwise may not have had the chance and require support the most. Whether it be at treatment information sessions or in safe communication zones in the waiting room, parameters could be developed to make this opportunity for support a win-win for everyone.

Thirdly this study gives patients and clinicians a detailed account of why patients feel that there is “no substitute for the kind of support they receive from a peer” (Bell, 2012) while still recognizing that peer support is not necessarily a panacea. It offers a window into specific aspects of peer IVF experiences that patients find so appealing at the same time that it casts light on some of the drawbacks of peer support. The findings show that success and non-success of peers are equally enticing in the eyes of patients, as is sharing similar treatment schedules, leveraging the support of an IVF alumni who have moved on from treatment, and attending the same clinic. IVF alone is not enough to connect patients with supportive peers, and some common ground other than IVF makes the support bond that much stronger. This tells the fertility-care community at-large that there is a role for every woman who has experienced ART to play in the support process irrespective of their treatment outcome. Most importantly it gives fertility audiences a thorough breakdown of how ART patient-peer support works in terms of communication dynamics. It positions peer support as a pragmatic solution for women in need that can offer immediate insight and that can be tailored to her comfort levels with regards to information regulation, prompts and boundaries, and modes and frequency of communication.

It points to opportunities for care providers and patients to do better particularly when it comes to information sharing, which requires nuance and depends on the receiver. Some participants voiced discomfort as a result of divulging too much and expressed regret alongside a need for boundaries. Other women talked about feeling overwhelmed and saturated with too much advice. Finally, a couple of women spoke about an awkwardness and a sense of competition that grew as treatment journeys and relationships progressed. It is also important to underscore a pattern. During the two week wait post transfer, when women are the most vulnerable and need support, they showed a tendency tend to shield themselves from any interaction even with their peer.

5.5 Implications for Promoting Peer-Based Social Support in Non-Fertility Contexts

Infertility is an invisible health condition like so many others. In the current context and post-pandemic world social support is more important than ever: Social support experiences matter for all patients -- those who have been afflicted by the coronavirus, those afflicted by other ailments who have not received the medical attention they require due to the pandemic and the delay and shut down of routine medical procedures, and entire communities who are being forced to social distance and isolate within their immediate households. Thus, the results of this study serve as a reminder about how patients dealing with stigmatized and invisible health conditions often perceive support gaps from the people closest to them. Whatever the condition that one may be facing, there is a role for family and friends to play through educating themselves.

The findings also reinforce that patients help reduce stigma and leverage the benefits of support when they adopt an open approach to whichever condition they are facing even if support is not immediately or readily available. Transparency marks disclosure recipients, and keeps conversation and cycles of support moving. For example, pertaining to COVID-19, the full disclosure of patients and people who are awaiting test results on details such as prognosis,

symptoms and history of social contacts impacts support. It offers those individuals the support they need to get through a difficult time, and it supports the public by offering them valuable information about their potential to contract the disease.

Our findings also suggest that is natural for patients to find comfort in secrecy and self-preservation when it comes to sensitive aspects of their condition. Instead of enabling further isolating behaviour, particularly during a pandemic, it is important to create comfortable, safe communication zones, especially whereby people who are dealing with COVID-19 do not feel discriminated against. Our findings also confirm that, by virtue of their shared health experience, peers have the ability to validate the experiences of other patients, reciprocate with information sharing, and understand the patient's needs and sensitivities when it comes to communication engagement or disengagement.

This study shows that patient-peer relationships can be mediated through a variety of channels and thus can overcome barriers such as physical and social distance. Text messages and platforms such a Messenger make connections straightforward and people do not necessarily require an initial physical meeting to kickstart support.

Finally this study suggests that patients and peers who are interested in pursuing a longer and fuller relationship should place some priority on getting to know one another beyond their shared health experience. While this kind of relationship is not the goal of all patients, some individuals may benefit engaging with their peer on a variety of levels.

5.6 Methodological contributions

This research experience offers two distinct methodological contributions: insights into how to conduct research on shared health experience and juxtapose positionality by a patient advocate, and a best practice pertaining to carrying out one on one interviews on sensitive health topics.

My positionality as a patient advocate (based on my own patient experiences and my volunteer work) in fertility research offered me the unique advantage of access to fertility clinics and support group networks for recruitment purposes, both of which helped us attain a reasonable participation rate and sample size. It also helped build a level of trust and rapport with participants before, during and after the interview which I may not have had otherwise, and which was extremely important given the sensitive nature of infertility. After the interviews, patients mentioned that the experience felt cathartic, and like a form of support in itself. Finally, as a patient advocate I was mindful to bracket my own lived experience. I did this by clearly stating the terms of engagement, that the interview was there for participants to elaborate on their own journeys, and only offering them perspectives based on my journey after they were done answering formal questions, and only when asked to do so.

It was important for this study to conduct the research in a comfortable environment devoid of imbalances, such as fertility clinics, that could have been detrimental to the well-being of participants. While many of the interviews were conducted in an office space at the University of Ottawa, it was essential to maintain flexibility for interview locations. For example, some women lived in Toronto, which required planned trips and the use of a quiet coffee shop or, in some cases Skype, whereas others felt more comfortable in their own home and not speaking in public, or had newborn infant sleep schedules to work around. Offering this flexibility helped ensure their participation and no attrition of willing subjects.

5.7 Reflections on population health

The social determinants of health are the economic and social conditions that influence the health of people and communities and that are shaped by the distribution of money, power, and resources that people have (World Health Organization, 2008). This approach to health suggests that improving lived experiences in areas that include social support improves the

health of populations (Friel et al., 2011, p. 865). This study offered insights into how peer support works for women suffering from infertility in Ontario. It is recognized that the majority of the participants had access to financial, professional, and educational resources but nonetheless still needed support and guidance from someone who understood their journey. The current reality of IVF is that most patients come from high income and educational brackets (Inhorn & Birenbaum-Carmeli, 2008). Nonetheless, their journeys and openness in sharing their experiences help pave the way for more vulnerable populations who face even harder struggles in fertility; lower-income earners, new immigrants with a lack of social networks, LGBTQ individuals, and rural residents are known to face any number of challenges in seeking healthcare services and supports (Centers for Disease Control and Prevention, 2013).

Now that a more fulsome understanding of patient peer supportive communication exists in fertility, future research must turn to more diverse perspectives and offer them a voice, especially as government funded treatment has started to change the landscape in which individuals and families get access to treatment.

Borrego and Newswander (2010) view interdisciplinarity as an approach to research which focuses on individual intellectual processes while synthesizing and bringing together concepts from multiple disciplines. As a member of the interdisciplinary PhD programme in Population Health, it was a privilege to converge knowledge and consider infertility, and other health conditions and experiences, from a variety of standpoints -- psychology, humanities, communication, health sciences, medicine, epidemiology, geography and sociology -- as it was to learn from a variety of scholars in those fields, both at the University of Ottawa and beyond.

5.8 Overall conclusion

This research has given me a life-changing opportunity to hear the voices of IVF patients and get insights into how they contemplate and build peer-based social support. Listening to their stories has been a privilege. This interpretation of the results substantiates why women gravitate towards peer support in response to the stressors of IVF treatment and offers a fulsome view of how IVF patients disclose information to their peers.

This research provides a start to understanding peer-based support in infertility which, until this point, had been largely uncovered in the literature. It was limited with respect to its sample population that represented a majority of successful IVF patients, who were highly educated and had high household income thresholds.

The first article cast light on the value of understanding peer support through the lens of the DD-MM and application of its information assessment, receiver assessment and disclosure efficacy steps and their contemplation criteria. It also points to opportunities to more closely demonstrate the tangible and intangible outputs that peers bring to the lives of patients according to categories of social support and discover how peer-based social support influences self-efficacy outcomes for ART patients.

The second article illustrates the key factors that IVF patients contemplate regarding their condition and situation prior to leveraging peer support. Participants considered the adequacy of spousal, familiar and other social relationships, weighed out the costs and benefits of secrecy versus transparency, and reflected on their own support needs. This article also details how IVF patients go about selecting their peers by uncovering diverse pathways of connection and emphasized the importance of mutual experience in IVF, the previous examples their peers set with their own IVF transparency and other common ground outside of IVF.

The third article suggests that IVF patients and their peers share a unique capacity to disclose and communicate between themselves. This was depicted by immediate and backwards introductions whereby women offer private information first. In addition, patients and peers exhibited a mutual understanding for boundaries when it came to the decision to engage or disengage and the frequency of their communication. Furthermore, patients reported a strong preference for virtual modes of chat such as text and instant messaging that stimulated continued, convenient and compartmentalized communication. It offers an account for a broad range of topics that patients touch upon with their peers on a reciprocal basis. It also points to a tendency of women to safeguard their privacy during the two-week wait post embryo transfer and to isolate themselves from support. While this may be functional in some respects, it remains a priority to understand how the support needs of women can be better fulfilled at that time. Finally, it suggests some drawbacks in information sharing, such as the burden of oversharing and the threat of competition between the peers.

Future research avenues can use these findings to build upon questions that explore diverse perspectives of disclosure and peer support. Research driven by patient advocates has an important role to play in ensuring all individuals have a voice and opportunity to share their journey, and accomplishing meaningful change when it comes to broadening perspectives of infertility and its treatment.

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APPENDICES

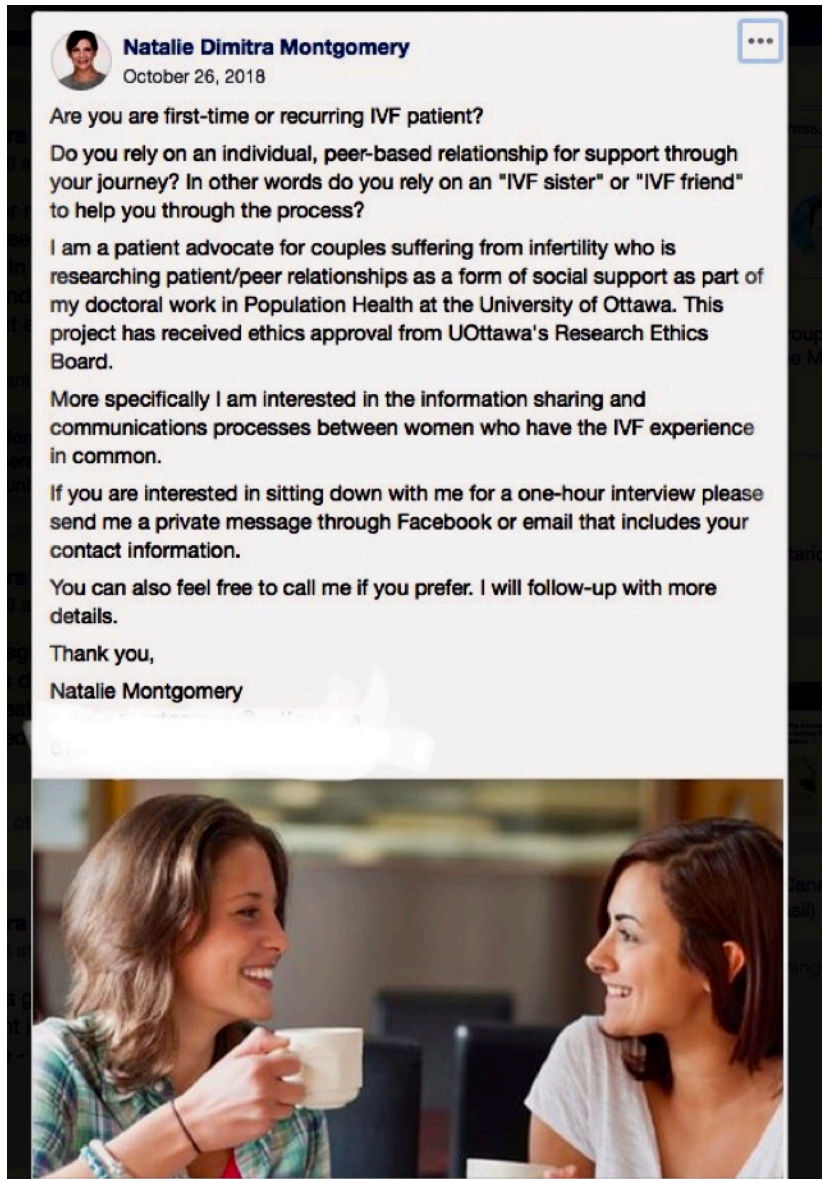
Appendix 1. Ethics Approval

A1.1 Ethics approval from Ethics Review Board, University of Ottawa

Université d'Ottawa Bureau d'éthique et d'intégrité de la recherche		University of Ottawa Office of Research Ethics and Integrity	
26/10/2018			
CERTIFICAT D'APPROBATION ÉTHIQUE CERTIFICATE OF ETHICS APPROVAL			
Numéro du dossier / Ethics File Number		H-08-18-973	
Titre du projet / Project Title		The quality and communication dynamics of IVF patient and peer relationships: Self disclosure, psychosocial support and intervention opportunities.	
Type de projet / Project Type		Thèse de doctorat / Doctoral thesis	
Statut du projet / Project Status		Approuvé / Approved	
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)		26/10/2018	
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)		25/10/2019	
Équipe de recherche / Research Team			
Chercheur / Researcher	Affiliation	Role	
Natalie Dimitra MONTGOMERY	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Chercheur Principal / Principal Investigator	
Jenepher LENNOX-TERRION	Département de communication / Department of Communication	Superviseur / Supervisor	
Conditions spéciales ou commentaires / Special conditions or comments			

Appendix 2. Recruitment and Consent

A2.1 Social Media Post





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

University of Ottawa
Faculty of Health Sciences
Interdisciplinary School of
Health Sciences

Understanding the Communication Patterns between IVF Patients and Peers

Are you a first-time or recurring IVF patient?

Do you **rely on an individual, peer-based relationship for support** through your journey? In other words **do you have an "IVF friend" or an "IVF sister" whom you turn to meet your various needs?**

I am a patient advocate for infertility patients who is researching patient/peer social support as part of my doctoral work in Population Health at the University of Ottawa. This project has received approval from UOttawa's Ethics Board.

I am interested in the communication process **between women who have the IVF experience in common.**

This study offers unique benefits to IVF patients. Through this work I hope to advocate for more women to rely on each other for much needed support. After the interviews, a few months from now, there will be an opportunity for participants to attend a community-building fertility social that will include dinner and a guest speaker.

If you are interested in sitting down with me for a friendly one-hour interview please send me a message by email that includes your contact information. By all means feel free to call me if prefer! I will follow-up with more details.

I can be reached at:



uOttawa

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

University of Ottawa
Faculty of Health Sciences
Interdisciplinary School of
Health Sciences

STUDY: IVF Patient and Peer Relationships

Recruitment Letter

Dear Registrant,

I am a Doctoral Candidate in Population Health, Departments of Health Sciences and Communication, University of Ottawa and I am conducting research on the role of self-disclosure in building social support for in-vitro fertilization (IVF) patients and peers. More specifically I want to understand how sharing personal information about one's treatment journey influences the quality and communication dynamics of IVF patient and peer relationships. You have been contacted with permission from the University's Research Ethics Board because you have identified yourself as an IVF user.

I hope that you are interested in contributing to this study. Your feedback could make a difference in the social support experiences of other IVF patients.

I would like to invite you to participate in a one on one, in-person interview. Since the goal of this research project is to understand the experience of IVF patients who use peer support, prior to confirming your participation, I require confirmation that you:

- are a first time or recurring IVF user
- live in Ontario - Toronto or Ottawa
- share a social connection with another woman who has also gone through IVF treatment

The interview will be one hour long. Examples of the kinds of questions you will be asked include: *How do you feel your experience has impacted your relationships with others in your various social circles? Please describe how sharing your infertility journey with your "IVF peer" makes you feel. Has your relationship motivated different actions and behaviours in yourself that you can identify?* The interviews will be conducted in English only.

In order to ensure your comfort, convenience and a level of open discussion in an ideal, private environment, I am asking that we conduct the interview at a neutral university campus location to be specified upon confirmation. We can set up a meeting time at your discretion, and I remain flexible in terms of time of day.

☎ 613-562-5800 (2983)
📠 613-562-5632

25 Université / University
Ottawa ON K1N 6N5 Canada
www.uOttawa.ca

A2.3 Recruitment Letter cont.

You will be given a gift card as an incentive for your participation in this research project. The nature of the questions is general and based on your experiences and poses minimal risk to you, as a research participant. The questions will also be provided to you at least 48 hours in advance of the interview.

The answers that you provide in the discussion will be tape-recorded and, later, transcribed and printed. Your answers will be treated as confidential, and therefore will be kept in a secure area. Once the data from the completed discussions have been transcribed, any information that could identify you, the individual - for example, your name – will be omitted and will not be used in any of the analyses or subsequent reports or published articles.

I hope you will agree to participate in this study. This is a chance to be part of research that could promote the use of peers as social supports for IVF patients on their treatment journeys and shed light on an untapped coping resource for the stressors of treatment.

After reading this letter, if you remain interested in participating in the interview, please contact me by reply to my email at XXXX@uottawa.ca so that I can confirm your participation. Please let me know the best way to remain in contact you.

Sincerely,

|
Natalie Dimitra Montgomery



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

University of Ottawa
Faculty of Health Sciences
Interdisciplinary School of
Health Sciences

Consent Form

Title of the Study: The quality and communication dynamics of IVF patient and peer relationships: Self-disclosure, psychosocial support and intervention opportunities.

Principal Researcher: Natalie Dimitra Montgomery

Supervisor: Jeneffer Lennox Terrior
jlennox@uottawa.ca
613.562.5800 x 2517

Invitation to Participate: I have been invited to participate in a doctoral thesis research project on in-vitro fertilization patients and peer-based social support that is being conducted by Natalie Montgomery. Natalie is a Doctoral Candidate in the Department of Health Sciences at the University of Ottawa and can be contacted at the coordinates above. As a Graduate student, she is required to conduct research as part of the requirements for a PhD in Population Health. It is being conducted under the supervision of Jeneffer Lennox Terrior who can also be contacted at the coordinates above.

Purpose of the Study: The purpose of this study is to understand the quality and communication dynamics of relationships between IVF patients and peers. It will involve a one on one interview about the communication dynamics between IVF patients and peers. This research study will use my answers to illustrate the IVF patient-peer process in greater detail.

Participation: My participation consists of:

○ **Phase 1 :**

being part of a 60-minute (maximum) one on one interview facilitated by Natalie Montgomery at location of my discretion.

With the option of participating in :

○ **Phase 2:**

participating in an evening, follow-up, and voluntary focus group / peer-based social support intervention that runs 2.5 hours in a few months time. I understand that this is not a mandatory component to my participation.

☎ 613-562-5800 (2983)
📠 613-562-5632

25 Université / University
Ottawa ON K1N 6N5 Canada
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Risks and Discomforts of Participation: Participation in this study requires at least 1 hour of my time to participate in the initial Phase 1 interview.

There is a risk for emotional discomfort such as anxiety and regret for disclosing personal and my couples' perspectives and experiences in infertility which some people see as very private.

In order to mitigate any such risk, I will be given the names and phone numbers of support lines in case I feel the need to contact them.

Benefits of Participation: Benefits include contributing to an important discussion on the value of peer-based social support for IVF patients, promoting the use of an untapped social support channel for the IVF community at large, and encouraging wider social acceptance of a stigmatized health experience.

Confidentiality: I have been assured that my anonymity will be protected. I will chose a pseudonym (alternate name) if I wish for all references made to my feedback. I understand that all names will be removed from the data and if necessary, any identifying stories or circumstances will be slightly altered to protect my confidentiality.

I will not be identifiable in publications or presentations but may be directly quoted from the discussion in publications or in presentations. Only the researchers will have access to the raw data and anonymity in publications and presentations will be preserved. Discussion audio-tapes and transcripts will be kept in the locked office of the researcher's supervisor. I know that the confidentiality of the data will be protected by ensuring that all data from the interview is stored in password protected computer files.

I am also aware that efforts will be made to remove all identifying features from interview transcripts before they undergo group analysis so that my answers will not be identifiable.

Compensation: Tokens of appreciation for interview participants include a \$10 gift card for Starbucks. Compensation will still be given if participants decide to withdraw from the study.

Voluntary Participation: Participation in this research is completely voluntary. I am free to choose to participate or not to participate in this research study. If I agree to participate in this study, I may choose to withdraw your participation at any time. I may also refuse to answer any specific questions. If I choose to withdraw, the principal researcher will obtain my permission to use the information up until the time of withdrawal.

Consent to Participate in Research

I understand that I am being asked to participate in a research study on the role of self-disclosure in IVF patient and peer relationships.

I have read and understood this Consent Form. All my questions at this time have been answered to my satisfaction.

A2.4 Consent Form cont.

If I have any further questions about the study, I may contact the researcher or her supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: ethics@uottawa.ca

I voluntarily agree to participate in this study.

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

Participant's signature:

Date:

Researcher's signature:

Date:

A2.5 Support Services Listing

Infertility Support Resources Listing

+		
Name	Website	Phone Number
The Ottawa Distress Centre	https://www.dcottawa.on.ca	613.238.3311
The Toronto Distress Centre	https://www.torontodistresscentre.com	416.408.4357
Fertility Matters – Ontario Support Group Listing	http://fertilitymatters.ca/directory/categories/ontario	1 800 263- 2929
Infertility Network (information, support resources)	https://www.infertilitynetwork.org	
Infertility Support Group Ottawa and the Valley (online support forum)	Can be accessed through Facebook	

Appendix 3. Sampling Frame

A3.1 Interview Participants

Count	Alias	City of Residence	Source
1	Aisha	GTA	snowball
2	Ali	Ottawa	online support group
3	Carly	Ottawa	online support group
4	Caroline	Ottawa	online support group
5	Cathy	GTA	snowball
6	Clara	Ottawa	online support group
7	Daniella	GTA	snowball
8	Esther	GTA	clinic
9	Heidi	Ottawa	online support group
10	Jenny	Ottawa	clinic
11	Lauren	Ottawa	clinic
12	Leanne	Ottawa	online support group
13	Lindsey	GTA	clinic
14	Mary	GTA	snowball
15	Melissa	Ottawa	online support group
16	Nancy	Ottawa	online support group
17	Nora	rural	snowball
18	Rachel	Ottawa	snowball
19	Reena	GTA	online support group
20	Sandra	GTA	clinic
21	Siobhan	rural	clinic
22	Taylor	rural	clinic
23	Tracy	GTA	clinic

Appendix 4. Data Collection Tools

A4.1 Participant Information Form

Please tell us about yourself:

Age:	City of Residence:		
Relationship Status:	Heterosexual	Same Sex	
Children:	YES	if YES how many? ____	NO
Number of years spent trying to conceive before turning to treatment? _____			
Number of IVF treatments: _____			
Other infertility treatments received? _____			
Have you received OHIP funded treatment ? YES NO			
What city are your undergoing treatment in? _____			
Occupation: _____			
Please circle your highest level of education completed:			
1. High school	2. Undergraduate Degree	3. Professional Degree	
4. Master's degree	5. Doctoral degree		
Please circle your Annual household income:			
Under \$40,000	\$40,000 - \$62,000	\$62,000-\$88,000	\$88,000 - \$125,000
\$125,000 and up			

The central theme of this interview is “self-disclosure”.

“Self-disclosure” is the sharing of personal information between individuals, and a process that establishes trust and helps foster authentic, socially supportive relationships

1. *Can you tell me about your infertility journey?*

2. *Who are your social circles?*

Have you ever kept your infertility experience a secret within these social circles? Please describe your rationale

3. *In the pre-screening selection process for this study, you indicated that rely on peer-based social support, that is, you share at least one connection with another woman who has also gone through IVF treatment. For purposes of this interview we will call this your “IVF peer”. Is that ok with you?*

*Who is this person and what made them an appropriate choice for you?
Please tell me about this person and the process through which you found each other.*

4. *Please identify from this list which topics you talk about with your IVF peer and how much you talk about it.*

Information about a clinic, clinic experience overall, a specific doctor

Nature of a treatment protocol -

Your diagnosis, how many IVF attempts, other treatments

How to use various medications and perform injections

Financial questions, advice, burden

Marital adjustment -

Family acceptance, social pressures and strain

Emotional adjustment

Treatment milestones and measures

- *Retrieval day*
- *Number of follicles*
- *Number of eggs retrieved, number mature*
- *Number of embryos , Quality of the embryos*
- *Transfer day*
- *Number of frozen embryos*

Pregnancy achieved?

- *symptoms of success*
- *symptoms of non-success*
- *advice on early self-testing*
- *advice on blood testing*
- *result*
- *next steps after pregnancy or failed attempt*

Do you speak about anything else IVF related?

Do you talk about other things unrelated to IVF? Can you give me some examples?

5. For this question, **self-disclosure** is defined as :

A self-focused form of communication, the sharing of personal information between individuals, and a process that establishes trust and helps foster authentic, socially supportive relationships.

What factors compelled you to self-disclose your own infertility experience to your “IVF peer”?

How do you depict your relationship - is it reciprocal? One-way? Please explain how you each approach disclosing aspects of your infertility journey.

6. For this question, **support** is defined as

- **emotional** - provision of love, empathy, caring, and trust
- **informational** - the provision of education, advice, instruction and feedback
- **appraisal**- provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison.
- **instrumental**- provision of tangible aid and services that directly assist a person in need.

7. Please describe how sharing your infertility journey with your “IVF peer” makes you feel.

Do you have any regret about anything you have disclosed?

8. *The goal of this next question is to understand the communication style you share with your “IVF peer”.*

- a) *When do you feel the need to communicate with your IVF peer? Can you identify conditions that compel you to talk? Can you identify conditions that compel you to avoid communication?*
- b) *How do you most often connect? Virtually? By text? In-person on the telephone or face to face? And how is dialogue initiated?*
- c) *How frequently do you connect?*

Weekly? Multiple times a week? monthly? Every couple of months?

Is there a time that you do not connect?

- d) *Is there anything else you can think of that influences your communication and decision to engage?*

9. *Has your relationship motivated different actions and behaviours in yourself that you can identify? Please explain.*

10. *Name at least two benefits that you leverage from your communication with your “IVF peer*

Name at least two drawbacks you have encountered from your communication “IVF peer

Closing Comments:

Further Sampling:

In order to get a robust sample of informants who share this experience, I was wondering if you can think of a friend who is also going through IVF that you might refer me to for another interview. This can be anyone you think may be appropriate, but not your IVF peer.

If yes, please ask them if they are comfortable with the idea before exchanging my coordinates with them. The introduction could be facilitated via email, social media on Facebook, or telephone, whatever they prefer.

Do you know of anyone?

If yes can you tell me about the nature of your relationship?

Appendix 5. Knowledge Dissemination Activities

A5.1 Oral presentation, Waypoint Mental Health Conference

Montgomery, N.D. (2018, May). *Building Psychosocial Support Through Self-Disclosure: Understanding the Quality of IVF Patient and Peer Relationships*. Waypoint Research Institute 6th Annual Conference: Momentum Research Realized, May 14-16, 2018 in Barrie Ontario.

A5.2 Oral Presentation, Canadian Fertility & Andrology Society, Annual General Meeting

Montgomery, N.D.* & Terrion, J. Lennox (2019, September). *Understanding the self-disclosure process of infertility between IVF patients and peers: Facets of their communication. Oral Communication, Basic Science*. CFAS 2019 65th Annual Meeting. It Takes a Village to Create an Embryo. Canadian Andrology and Fertility Society, September 19-21, 2019 in Ottawa, Ontario.

Appendix 6. Abstracts of Select Other Academic Works Prepared During the Thesis Period

A6.1 *Immigrant Mother and Teacher Perspectives of Mental Health Literacy and Responses Towards School Mental Health Initiatives.*

Department of Child and Family Studies, University of South Florida

29th Annual Research and Policy Conference: Child, Adolescent, and Young Adult Behavioural Health, March 16, 2016 in Tampa, Florida.

Two studies demonstrating the needs of diverse audiences in mental health promotion will be disseminated; a qualitative study on the impressions of new immigrant mothers on mental health promotion for adolescents; and a mixed methods study implicating teachers and students on the delivery through the evaluation of a mental health program. The objective is to understand the perspectives of the variety of people with integral roles in mental health promotion, using a group exercise and discussion. This presentation endeavours to enhance participants' capacity to identify the unique needs of diverse audiences implicated in school health promotion in addition to foster an exchange of insights on the sensitivities and challenges in school health promotion programs.

A6.2 **Montgomery, N.D.* & Lennox Terrion, Jenepher** (2016). Tensions Along the Path Towards Mental Health Literacy for New Immigrant Mothers: Perspectives on Mental Health and Mental Illness. *International Journal of Mental Health Promotion*, 18(2), 83-94. DOI:10.1080/14623730.2016.1154480

This study explored how mothers approach their own mental health literacy and that of their teenage children. The research used focus groups and questions based on the messaging of a community-based mental health awareness program called 'Talking about Mental Illness' (TAMI) to investigate the nature of mental health perceptions and attitudes of new immigrant mothers and illustrate how the program's messaging can contribute to or build upon their levels of mental health literacy. A qualitative thematic assessment of the knowledge and perceptions of the study participants, all recent immigrants to Canada from India, Bangladesh, Iran, and Romania within the last three years and mothers of high school students, was undertaken. The findings show that participants appreciate the importance of fostering mental health understanding and discussion with their children at the same time that they encounter obstacles to the advancement of their mental health literacy.

- A6.3 Bergen, N.*, Hudani, A., Khan, S., **Montgomery, N.D.**, & O'Sullivan, T. (2020). Establishing writing groups for students in interdisciplinary doctoral programs. *Palgrave Communications*, 6, 1-6. <https://doi.org/10.1057/s41599-020-0395-6>

Academic writing capabilities are a cornerstone of success in doctoral programs, yet prove to be a point of anxiety and apprehension for many students. Providing support for academic writing within interdisciplinary programs poses special considerations, as students in these programs are called upon to transcend single disciplinary perspectives to address a central area of research, and to integrate multiple different disciplinary perspectives that may be conflicting or overlapping. When treated as a social practice, writing can serve as a common interest that draws doctoral students to convene and develop in their learning. This article describes the development of a student writing group in an interdisciplinary doctoral program, considering how the characteristics and activities of the group create an environment that enables and encourages enhanced interdisciplinary learning. The article argues that, when delivered successfully, student writing groups have the potential to strengthen student writing skills and outputs, as well as deepen interdisciplinary learning. Drawing from Lattuca's four aspects of interdisciplinary learning (relational, mediated, transformative and situated), the article illustrates ways that the writing group helped to promote each aspect of learning and benefit the overall student experience in the program. Reflecting on these experiences, the authors propose six practical considerations for establishing writing groups in interdisciplinary programs: vision and purpose; dedicated time and space; institutional support; readings or educational material; socialization opportunities; and shared responsibility. Administrators, students, faculty members and support staff involved in the delivery of interdisciplinary doctoral programs are called upon to consider the introduction and/or strengthening of writing groups for the purpose of enhanced interdisciplinary learning.