

**Examining the Relationships Among Uncertainty, Control,
Emotionality, and Information Behavior in Patient
Experience During In-Vitro Fertilization Treatments**

by

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“Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom”

- Viktor E. Frankl, Man's Search for Meaning

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To My Father, In Loving Memory

*Thank you for always encouraging me to embrace my
curiosity and to do so with a kind heart*

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Abstract

Patients undergoing in-vitro fertility treatment (IVF) live challenging and complex lives. IVF is a highly demanding, high-stakes procedure involving an exacting self-administered medication regimen. The IVF experience is characterized by heightened emotionality, severe life disruptions, and physical and psychological difficulties. Additionally, it is marked by uncertainty; despite IVF's established safety, patients feel unsure about side effects and their chances, given IVF's perceived low success rate (4% to 40%). Nonetheless, patients typically achieve exemplary compliance, in striking contrast to what might be expected in theory, given the emotionality and difficulties that might undermine the self-control required. Although IVF patient experience studies have been performed, little is known about how patients actually experience the treatment day by day; i.e., how they navigate through these challenges, regulate their emotions, and manage their lives outside of the clinic. This study addresses the evolution of the patients' thinking and feeling and the psychological mechanisms by which certain behaviors are instigated and performed.

The study rests on data collected in in-depth semi-structured interviews conducted with 29 IVF patients, along with notes from extensive field observation. I used constructed grounded theory, which involves line-by-line coding and iterative comparison methods, to analyze my interview transcripts. My analysis of the interview data uses the appraisal theory framework, which emphasizes the interconnectedness of emotionality, cognition, actions, and treatment context.

Some important findings include:

1. the predominant behavioral driver was the desire for control, which provoked emotion episodes and prompted patients to engage in particular information behavior using *calibrated uncertainty*, a psychological mechanism driven by simultaneous seeking of

contradictory valences and varying levels of certainty in response to the desire for control and emotional needs at the moment.

2. patients experienced two different types of emotions, *immediate*, or those triggered directly by past or current events, and *anticipatory*, or those triggered by imagination of future events and states. The two types exhibited dissimilar trajectories and patterns of occurrence.
3. patients sought to regulate their emotions to stay within an optimal *self-constructed emotional range* and thus to preserve their well-being and persevere through the treatment. To do so, patients used *calibrated uncertainty* to appraise information that they acquired and thus to maintain emotional equilibrium. They also used both up- and down-regulation when they felt that they were falling out of their optimal *emotional range*.

The study has several important conclusions and implications, both for theory and for practice. One theoretical contribution is the demonstration that *immediate* and *anticipatory emotions* differ in their generation and effects and thus should be treated differently in discussions of emotional experience. For the practitioner, this implies that the design of patient support systems should reflect awareness of the different types of emotions that a patient is likely to be experiencing at given points.

A second contribution is the development of a profile of the appraisal dimensions or lenses (control, uncertainty, personal importance) that correspond to emotions of specific valences and intensities and shows how these interact and evolve to construct the emotional experience. While the profile may be specific to the IVF context, it could be extended to the study of emotionality in other types of experiences in high-uncertainty contexts. For the practitioner, it suggests that the design of information delivery systems, communication protocols, and caring interventions could benefit from this more nuanced understanding of patients' emotionality.

Chapter 1 – Introduction

This study is motivated by my general interest in behavioral science, user experience (UX), and product design and innovation management in the healthcare industry. Based on consumer-provider information asymmetries (i.e., the two have very different levels of knowledge and expertise), marketers and economists classify healthcare service as a credence good¹, meaning that consumers (i.e., patients), because of their lack of expert knowledge, are often unable to determine the quality and value/utility of the product (i.e., medical procedure and service) during, or even after, consumption. Unlike many other kinds of consumer products, credence goods (i.e., goods that consumers cannot evaluate because of lack of expertise) that do not perform as expected can lead to significant changes in emotions due to the possibility of significant adverse consequences, ranging from financial loss and physical discomfort to ill-health and even death. Patient experience, therefore, inherently features both uncertainty and emotionality and thus presents an especially interesting and rich research space for understanding human psychology and behavior, particularly on how uncertainty interplays with feelings and judgments, and interconnects with behaviors.

In this research, I use a UX framework, focusing specifically on the continuous interactions between patient-user and medical service-product, rather than the more commonly used surveys which capture patients' psychological/physiological state at one given point in time. This is because these kinds of iterative interactions are typical medical-care practice in that a patient usually stays in the care of one specific doctor or organization for an extended period. Moreover,

¹ Economists and marketers use the Search, Experience, Credence (SEC) classification of goods and services, which is based on the ease or difficulty with which consumers can evaluate or obtain information about a product. For example, education service is a credence good.

the study of continuous interactions between patient-user and medical service-product demonstrates how consumption of a credence product follows a different trajectory from the consumption of other products. Consumption of a credence good is by nature expertise and interaction driven and the consumption is a result of a dynamic interactive collaboration of provider and consumer.

Finally, yet importantly, because patient experience is known to be the critical link that bridges treatment and outcome, (Manary, Boulding, Staelin & Glickman 2013; Doyle, Lennox & Bell, 2013), a better understanding of the interaction between the treatment context and patient psychology and behaviors is needed. Such an understanding could lead to improvements in many important areas, such as in-patient management, adherence, and in the patient-centered care service delivery and technology design.

The purpose of this dissertation is twofold: (1) to reveal and explain unexamined aspects of the patients' daily experience while they are undergoing a high-stakes medical treatment and (2) to investigate the psychological mechanisms and processes patients use to form and shape their experience as they progress toward the treatment goal. The specific focus is on how in vitro fertilization (IVF) patients appraise their treatment progress, regulate their emotions, and overcome psychological obstacles, so that they can continue performing the challenging daily adherence tasks.

I chose IVF patient experience to explore this topic for two reasons:

1. The inherent emotionality and uncertainty of the medical context in general are not well understood, yet they are recognized as heightened in the IVF context.
2. The perseverance and exemplary adherence of IVF patients in the face of the unusual difficulties posed by IVF protocol are unexpected and striking, particularly considering the complex emotionality associated with the treatment.

1.1 The Heightened Uncertainty and Emotionality Characterizing the Context

Uncertainty is a pervasive condition in all healthcare service. Objectively speaking, uncertainty is inevitable, given the many questions our limited scientific knowledge cannot answer (e.g., why

does a treatment fail?), and the limitation of biotechnology (e.g., why is there no guarantee of 100% success for almost all medical procedures?). Such uncertainty, which we call objective uncertainty, derives from the incontrovertible fact that modern science has its limitations, sometimes greater and sometimes less, in diagnosing, treating, and preventing illness. We cannot be sure, in a strict sense, that in any medical treatment every single variable and process that can affect our biological conditions is always adequately observed and measured. Similarly, patients' experiential responses to the therapeutic regimen, including their physical sensations, symptoms, and side effects, may not in every case be attributable to identified causes. Essentially, no treatment outcome or prognosis is entirely predictable and definitively certain. Objective uncertainty permeates most healthcare contexts, and is shared, in varying degrees, by both physicians and patients.

Patients can deliberately or unintentionally misconceive, magnify, transform, or distort the objective uncertainty because of their lack of expert knowledge and their emotionality. Lack of expert knowledge hinders patients' ability to correctly interpret information or situations. Moreover, a patient's subjective sense of uncertainty (i.e., subjective uncertainty) can be recursively influenced by emotionality. Research has well established that uncertainty can induce emotionality and that emotionality can further influence the subjective sense of uncertainty. According to emotion theory, uncertainty is one principal appraisal dimension that characterizes the emotions of anxiety, worry and hope (Smith & Ellsworth 1985).

The iterative nature of this emotion-driven loop of generating subjective uncertainty can, furthermore, affect patient-physician interactions as patients naturally turn to physicians to explain or resolve their uncertainty. Hence, ineffective communication or miscommunication often results from what might be called an "uncertainty gap" or the inability of each party to understand the uncertainty of the other. This gap results in further increase and/or complication of the patients' subjective uncertainty. It can also undermine patient-physician collaboration, and thus again, recursively increase the intricacy to a patient's subjective uncertainty and emotionality. Therefore, identifying and examining patients' subjective uncertainty is a more fruitful pursuit than examining the commonly shared objective uncertainty. Accordingly, this study focuses on the former.

Emotionality and subjective uncertainty are extraordinarily heightened for IVF because of the great personal significance of reversing infertility, coupled with the complexity of the treatment regimen. Most have experienced other treatments that failed. They turn to IVF as the last resort to have a biologically related child. However, this treatment has a greater than 50% probability of failure (i.e., the IVF success rate typically ranges from 4% to 40% depending on patient individual health condition and diagnosis). Despite a strong desire for success that may understandably drive patients to exert effort to reduce uncertainty as best they can, the objective uncertainty resulting from IVF's unpredictable, high-stakes nature, is not resolvable. Hence, undergoing IVF treatment means engaging in a potentially positive and life-changing, yet an indisputably fraught, perilous, and high-stakes venture, saturated with uncertainty and emotionality.

Furthermore, IVF, a multi-stage treatment mandating a demanding self-administered medical regimen, is complicated. Patients' sense of their own limited ability to fully understand or validate their understanding of the treatment, whether it relates to the compliance requirements, drug regimen, or treatment trajectory, can be intensified and elevated. This is because of the importance of the role played by the patients in following the rigid requirements of the regimen, which can result in an especially uncomfortable mental state of uncertainty and emotionality for them. Numerous studies report that IVF patients experience emotional distress, such as anxiety, anger, sadness and depression (Hahn et al. 2019; Hinton, Kurinczuk & Ziebland 2010), and regard IVF treatment as one of the most stressful experiences in their lives (Rooney & Domar, 2018;.Boivin & Gameiro, 2015; Rockliff et al., 2014).

1.2 Perseverance Through an Atypical Goal-Pursuit

IVF is taxing in all regards: financially, physically, emotionally, maritally and socially. Furthermore, IVF treatment has key features that correspond with well-identified major predictors for poor adherence, including complexity of treatment, demanding adherence, severe life disturbance, side effects, and psychological problems that may be ascribed to concerns about uncertain outcomes, emotionality, side effects, or patient-provider relationships (Bussell, Cha, Grant, Schwartz & Young 2017; Costa et al., 2015; Osterberg & Blaschke 2005). However, even

while experiencing the emotional rollercoaster, mood swings and psychological problems associated with the experience (Nicoloso-SantaBarbara, Busso, Moyer & Lobel 2018; Malina & Pooley, 2017; Gameiro, Boivin & Domar, 2013; Verhaak, Smeenk, Evers, Kremer, Kraaimaat & Braat 2006), IVF patients have demonstrated excellent adherence, despite the fact that in theory such emotional turmoil should almost certainly impair their ability to exercise self-control (Chester et al.,2016; Bernecker & Job, 2015; Baumeister & Tice, 2007).

Regardless of their backgrounds, medical and health conditions, and various treatment trajectories, exceedingly few patients voluntarily quit partway through². IVF patients exhibit not only unexpectedly dogged adherence, but also unorthodox behavioral and coping styles that run counter to what existing theory might lead us to expect (Greil, Slauson-Blevins & McQuillan, 2010; Hammarberg, Astbury & Baker 2001).

Obviously, a strong desire for a successful outcome - though the chance of success is arguably small in almost all cases - is a motivator. However, desire alone is not enough to explain IVF patients' perseverance and their exemplary observance of treatment protocols, nor does it provide an avenue toward suggestions for improvement of the patient experience. IVF patients evince an intriguing psychology and atypical behavior that no single theoretical framework sufficiently explains.

1.3 Research Objective, Scope and Questions

Most other studies investigate patients' adherence behaviors by asking "why don't they", focusing on patients' noncompliance factors and issues. In contrast, in this study I ask an equally, if not more intriguing question: "why DO they?", essentially addressing more substantive issues of pathways and patterns of how patients achieve compliance.

So I ask, how do patients undergoing IVF treatment process their perceptions and feelings and how do they act so that they can accomplish daily tasks and cope with their emotions in the face

² Anecdotally, the director of the clinic reports that he remembers only two patients who voluntarily quit during treatment from the study site between 2010 - 2018. This is significantly fewer than 1% of all IVF treatment cycles performed.

of psychological limbo and constant uncertainty (i.e., an unpredictable outcome, complex regimen, and burdensome life disturbances)? As I explore this question, the drivers and formation of patient volition, motivation, and emotionality for their behaviors and daily actions may be identified and illuminated, ultimately contributing to more effective guidance and support that may also be extended to patients with other medical conditions.

From a theoretical perspective, the question can be reframed as this: What are the psychological processes, mechanisms, or daily practices that people - in this case IVF patients - use to construct their emotional experience and enable themselves to persevere in pursuit of a goal and optimize their experience in situations when, because IVF treatment is a credence product, they are not able to monitor, appraise, predict or act in ways that ensure that they will reach the goal? This question may shed new light on traditional health behavior theories. Traditional health behavior theories (e.g., patient engagement, adherence), resting on a goal theory framework, are premised on an assertion of the certainty of a predictable outcome, to which a means-ends pathway can be planned, and effort can be monitored and motivated, all based on the direct and predictable one-to-one mean-ends correlation (e.g., weight loss plans).

Studies have argued, for example, for the crucial roles played by health education and patients' literacy, self-efficacy, and positive reinforcement. While such studies provide useful insights into addressing patient behavior, they are not applicable in an environment where the outcome is uncertain and the progress may be untraceable and fluid, such as most medical care contexts.

Once these fundamental and crucial questions regarding patient psychology are addressed, can we then abstract from the experience of IVF patients (i.e., the goal-seekers)? And then by learning how they experience their treatment, can we - the service providers, designers, marketers, and researchers - find ways to utilize this knowledge in the service of patients with similar challenging and high-stakes medical conditions?

In conclusion, my research objective is to understand IVF patients' emotional experience and investigate how IVF patients maintain perseverance and exemplary adherence throughout the treatment. Specifically, I focus on how patients appraise their treatment progress and regulate their emotions so that they can continue performing challenging daily adherence tasks to complete the

treatment and maintain their mental wellbeing. These emphases are based on my fieldwork and pilot study where I learned that because of IVF's high-stakes nature, patients had already resolved or made accommodations for many other factors when making the decision to partake the treatment, such as their religious/spiritual backgrounds, values, financial concerns, biological conditions, medical literacy, and individual relationships and socialization with friends and family. Therefore, while those factors may certainly affect patients' experiences with the treatment, they are not the focus of this investigation.

1.3.1 Insufficient Studies of Patient Experience

Despite its obvious importance, patient experience has not been extensively or well-studied. Traditional scholarship in patient experience has primarily focused on two limited methods: 1) studying patients' outward, expressed behaviors while using a service or undergoing a medical procedure in a clinic, or 2) measuring patient satisfaction, and reaction toward a medical procedure, product, and/or service.

These investigations typically involve the use of surveys, structured interviews or standardized scale measurements in which patients are asked to provide feedback concerning their attitudes, and impressions about their treatment services. While these individual studies cover multiple topics, they typically represent a small facet of patients' overall experiences, discounting the breadth (i.e., the whole spectra of various components and aspects of interactions and situations) and depth of experiences (i.e., how the experiences evolve throughout the continuum of care). Hence, the root causes of problems are often insufficiently addressed. Furthermore, such limited scope approaches overlook patients' behaviors outside of the clinic, which, for many treatment regimens, usually comprise the majority of their experience. Lastly, and most important, this approach misses or even dismisses a patient's mentation and psychology, and their evolution during treatment, without which we cannot efficiently address underlying factors affecting their behaviors.

In addition, the fragmented, quantitative measuring approaches used to date have other limitations. Data abstracted from narrowly-focused aspects of a service, typically at fixed time points using

surveys, structured interviews or standardized scale measurements, presume that a patient's experience is static and disconnected, thus often failing to provide the essential view of a complete picture of patient's experience.

Patient experience, like any other human behavior study, must be studied holistically and evaluated comprehensively; we must account for a *lived* experience, that is not only the integration of inner and outer lives, (i.e., thoughts, feelings, and behaviors), but also its dynamic and evolving progression.

This study therefore emphasizes exploratory perspectives to thoroughly uncover the entirety of patient experience, particularly concerning their psychological processes. Thus, I have chosen to use an open-ended, inductive approach to conduct my investigation through in-depth interviews and field observations guided by grounded theory methodology. Furthermore, because this study aims to identify general patterns of how patients process information and appraise clinical encounters that often have highly emotionally charged consequences, goal theory and emotion theory, particularly cognitive appraisal theory, were chosen as the two main areas of scholarship referred to for this study. Goal theory informs goal-attainment processes, while cognitive appraisal theory provides a useful framework to understand psychological process.

1.3.2 Research Questions

I take an integrated user experience approach to address three research questions. My goal is to investigate and describe crucial elements of the IVF patients experience: the construction, the trajectory, and the patterns and pathways of patient actions, interactions, cognitions, and emotions within the treatment context. Specifically, the questions this study addresses are:

1. How do patients manage and perform treatment tasks daily to maintain their well beings and to perform adherence throughout the treatment?

This question encompasses all of the patient's activities and a lived life within their situated social world during treatment, so I will pay attention to characterizing both the patients'

outward, expressed conduct and activities and also the intangible and implicit (psychological and cultural) contextual changes (i.e., situatedness). For example, I will report on not only how they structure and acquire support to accommodate treatment requirements, but also on their subjective views, preconceived assumptions, and evaluation of the circumstances they are in.

2. How are the patient's reflections, motivations, cognitions, and emotions formulated during different stages of the treatment process and how do they evolve?

This question aims to uncover the underlying psychological mechanisms, such as how patients set their goals and expectations, and monitor their progress toward accomplishing their daily tasks through different treatment stages. For example, I will report on not only the routine tasks, such as how they perform daily injections, but also on their concerns, and feelings about and evaluation of self-injection.

3. How do patients' interactions with providers help them to construct the experience?

This question addresses multiple aspects of patient-provider interactions and clinic encounters. For example, I will explore and track patients' interpretations of and responses to doctors' remarks and lab reports; I will seek an understanding of their rationales and drivers for their assessment and actions. Moreover, I will examine how a better understanding of these interactions and psychological insights might help improve patients' experience and guide the development of interventions that lead to a better practice.

4. How can the knowledge that has been generated be communicated to both IVF patients and the medical staff in such a way that treatments and the treatment experiences can be ameliorated? What are the design implications for better service delivery and technology innovation?

These questions showcase the high practical relevance of the study objectives. I aim to make the findings generated by the theory usable for practical application. For example, with the end of improving the patient-provider relationship, I will inquire how patients address their treatment concerns. I will also investigate how they perform information searches and report further on emerging patterns, regularity, and frameworks. Moreover, I will transform these insights into design guidelines for patient education and for communication protocols and technology.

Chapter 2 - Background and Study Context

This chapter is composed of three sections. I will first provide some general background about In Vitro Fertilization (IVF) treatment including an overview of the treatment regimen and the patient experience. Following that, I will describe the study context, introducing the study site and the details of its administration, the available services, and the actual delivery of IVF service (e.g., pretesting, consent, and treatment regimen milestones). Finally, I will focus on my research methods. I will explain the rationale for the choice of the method including my data collection and analysis methods and report my recruitment and analysis procedures in detail.

2.1 Treatment Overview

2.1.1 IVF Treatment: A Complex, Multiple-Step Procedure

Infertility is generally considered a chronic and complex condition with varying and possibly unidentifiable causes resulting from potentially unidentifiable medical disorders. IVF is an acute therapy - also the most technologically advanced intervention and the last resort - for people with fertility concerns who desire to have a biological child.

IVF treatment involves stimulating the patient's ovaries to produce numerous egg cells (oocytes) through hormone therapy, retrieving the oocytes from the patient's ovaries, and fertilizing them with the donor's sperm (generally, from the patient's spouse or partner) in the lab. After fertilization, the fertilized egg (embryo) is delicately transferred into the patient's uterus; a successful procedure will ultimately lead to pregnancy and the birth of a child.

The average IVF treatment cycle requires patients to take 10 or more different kinds of hormone-altering medications in different delivery forms, such as oral ingestion, intramuscular injection, or vaginal suppository, and to undergo medical procedures such as oocyte retrieval and embryo transfer. It is a complicated, multiple-step process. Pretreatment/pretesting is a prerequisite of IVF. It typically starts with the administration of birth control pills and several diagnostic tests and procedures during one or two menstrual cycles. In conjunction with pre-treatment, a typical IVF treatment cycle lasts approximately 6 - 8 weeks with a defined time span. Physicians monitor patients closely and extensively to prescribe therapies and adjust dosages accurately in response to minute hormonal changes. The accuracy of the therapies coupled with rigorous monitoring and patient adherence are all mandatory for treatment success. The treatment cycle concludes with a pregnancy test, which is typically binary, positive or negative.

2.1.2 Stages and Milestones

IVF treatment involves three clearly defined sequential stages: 1) the stimulation stage for follicle development, 2) the retrieval and fertilization stage, and 3) the early pregnancy support stage. Each stage presents its own unique challenges and specific treatment goals. The stimulation stage focuses on follicle development, beginning with³ the start of the treatment and ending with egg retrieval. It aims to produce a greater quantity of larger sized follicles than in an unmedicated menstrual cycle, and, after the use of a “trigger shot” to finalize oocyte maturation, it culminates with the retrieval of oocytes. The duration of this stage is typically eight to sixteen days, depending on the patient’s physiological response.

³ The three stages and goals described here are defined in accordance with the clinical perspective; as will become clear in subsequent chapters, from the point of view of the patients, the procedure is divided into two stages: pre-embryo implantation (i.e., stimulation and fertilization) and post-embryo transfer (waiting). This is an important discrepancy of perception, since the patients’ emotionality differs strikingly in the pre- and post-embryo transfer periods.

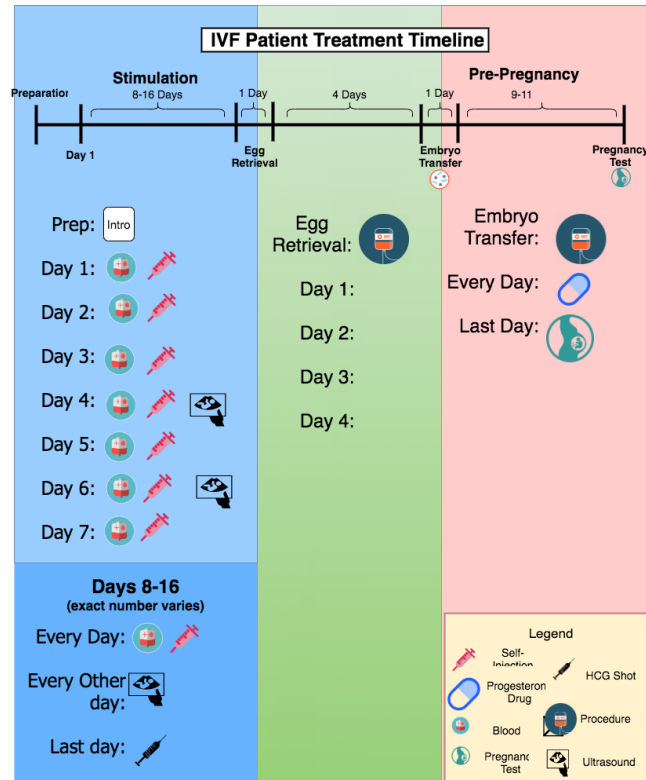


Figure 1. IVF Patient Treatment Timeline

The retrieval and fertilization stage begins with egg retrieval and ends with an embryo transfer procedure. The aims for this stage are threefold: 1) to extract and preserve the maximum number of mature oocytes from the ovaries; 2) to combine eggs and sperm in the assisted reproductive technology lab to create embryos; and 3) to implant the optimal number (generally, one or two) of high-quality embryo(s) into the uterus. The duration for this stage is between 2 and 6 days, depending on the clinic.

Upon completion of a successful embryo transfer, the stage of early pregnancy hormone support begins. It ends with a pregnancy blood test that reveals the treatment outcome. The focus is to administer hormone medicine to produce a uterine condition that is favorable for the growth of the embryo(s). The duration of this stage, prior to the pregnancy test, is typically nine to eleven days. After the pregnancy test, a follow-up consultation is scheduled if the test result is negative. Otherwise, if the test is positive, and a subsequent test shows an appropriate increase in the pregnancy hormone level, an ultrasound examination to confirm fetal cardiac motion is arranged to confirm the treatment success. Either of these concludes the treatment cycle.

2.1.3 Affiliated IVF Therapies

Additional IVF procedures, which may be incorporated in the basic IVF treatment plan, include preimplantation genetic diagnosis/screening (PGD/PGS) and intracytoplasmic sperm injection (ICSI) [Ref]. The IVF treatment may also involve treating patients' male partners to improve sperm production and quality, or it may involve addressing a variety of other infertility abnormalities such as damaged or occluded fallopian tubes.

2.2 Patient Experience - Demanding Regimen and Stressors

2.2.1 Sharp Learning Curve

Because IVF is a complex therapy with various treatment concerns at each stage, it presents a unique and difficult challenge for patients. The demands of treatment adherence coupled with a relatively short treatment duration create a sharp learning curve for them. IVF typically requires patients to perform extensive self-administration of medicines that are closely monitored throughout the regimen. Most medications required for IVF are administered through injection. Patients must; 1) acquire self-injection skills (or arrange for someone to perform them); 2) learn about the drug labels and the instructions; 3) ensure reception of daily messaging from the clinic about maintaining or adjusting medicine and/or dosage as needed; and 4) keep track of the supplies, manage refills, and ensure timely prescription refills or delivery. The frequency of administration of medications varies throughout the treatment cycle, ranging from 1 to 4 times daily. The meticulous timing of medication administration is imperative; patients must perform injections and take medicines with the right dosage in a specified narrow window of time (e.g., between 7 and 9 PM) daily over several weeks. The accuracy of the prescribed therapies, their administration, and the monitoring times are all mandatory to maximize treatment success.

2.2.2 Extensive and Unpredictable Schedule

Physicians monitor patients daily during the stimulation stage; this requires patients to have regular visits to the clinic, including daily or every-other-day visits (typically, for either blood draws and/or ultrasounds) for two to three consecutive weeks. After the embryo transfer procedure, there are typically no required appointments until the pregnancy test.

Even more demanding, several crucial visits cannot be scheduled at the outset, because their timing depends on the unfolding progression of the treatment. For example, the date of the egg retrieval, a procedure that requires the patient and potentially her partner to take a day off from normal activity, is not known until the afternoon two days prior. Patients must, then, accommodate appointment(s) for their egg retrieval days, embryo transfer, and/or any contingencies, as their physiological responses to medications can vary for each treatment cycle.

Because it is routine for sedation or anesthesia to be used for the egg retrieval procedure, it is recommended that patients avoid normal activities such as work or school on that day. A consultation for anesthesia and procedural preparation beforehand is also arranged. Moreover, patients must perform a self-administered ovulation inducing hormone (hCG) injection within 24-26 hours before the scheduled egg retrieval appointment. On top of that, the donor's sperm must be collected, delivered, preserved, and prepared for the fertilization.

The tentative embryo transfer schedule will be confirmed after a successful fertilization takes place; it is scheduled either 3 or 5 days after the egg retrieval but may not be confirmed until the morning of the procedure after confirming embryo development. Also, for both egg retrieval and embryo transfer procedures, patients are required to make transportation arrangements. Most patients find it difficult to accommodate such an intense, frequent, rigid–yet unpredictable and impromptu–schedule.

2.2.3. Side Effects, Physical Discomfort and Risks

Bruises and soreness often occur at the injection sites. Moreover, common side effects include mild abdominal bloating, mild cramping, breast tenderness, mood swings, weight gain, constipation, diarrhea, nausea, vomiting, insomnia, headaches, hot flashes, and ovarian hyperstimulation syndrome (OHSS) (The Patient Education Website of the American Society for Reproductive Medicine [SART], 2020).

Signs and symptoms of OHSS include severe abdominal pain, bloating, fever, rapid weight gain, and shortness of breath. Although OHSS is rare, occurring in fewer than 1% of patients (The Patient Education Website of the American Society for Reproductive Medicine [SART], 2017), patients are alerted to that risk and to warning signs before treatment begins, because the condition can lead to serious health concerns and so patients may need to be treated for it immediately.

IVF procedures, particularly egg retrieval and embryo transfer, carry the risks associated with minimally invasive medical procedure (RESOLVE: The National Infertility Association [RESOLVE] 2020) Potential complications include bleeding, infection, constipation, and damage to the bowel, bladder, and blood vessels; patients may also experience cramping, spotting, soreness and discomfort in the vaginal area after the procedure (The Patient Education Website of the American Society for Reproductive Medicine [SART], 2020).

Although all these side effects may last days or even linger beyond the treatment, IVF is considered in general a safe treatment. Nevertheless, these physical effects may carry enormous significance for the patients. For example, patients may wonder whether these physical sensations are signs of long-term damage.

2.2.4 High Cost

Stress resulting from infertility can be intensified by IVF treatment since the therapy is costly and strenuous in numerous aspects (time, effort, and resources). The major barriers for patients considering IVF are financial affordability and treatment stress. As for expense, IVF costs

between \$10,000 and \$35,000 per treatment cycle; the actual costs are difficult to determine because clinics vary in regard to their services, protocols, technologies, and charges (Resolve™, 2020). Currently only 15 states have laws requiring insurance coverage for infertility treatments (Resolve™, 2020); and even when coverage is provided it rarely covers 100% of the costs.

2.2.5 Critical Uncertainty: Suboptimal Success Rates and Risks

IVF's current success rates are perceived as too low by almost all patients, considering the amount of money, effort, energy, and time they are investing in the procedure. The rates vary depending on the patient's age and physical condition, from a low of 9% for patients over 40 years of age to a high of 40% for patients under 25 years of age with mild infertility factors ("The Society for Assisted Reproductive Technology [SART] (2020)) These percentages are considerably lower than most patients would hope for; on average, patients undergo more than one treatment cycle to achieve pregnancy.

Research suggests that use of IVF increases the chance of a multiple pregnancy and the associated risks of carrying multiples, such as prematurity and a low birth weight (The Patient Education Website of the American Society for Reproductive Medicine [SART], (2020). The rates of miscarriage are also higher; however, this may be attributed in part to the advanced maternal age of many IVF patients. By the same token, it is uncertain whether babies conceived through IVF bear slightly higher risks of birth defects, and whether they may be more prone to have long-term health problems resulting from the treatment itself. More research is needed, as well, to determine possible long-term adverse effects on the patients' health, such as development of ovarian tumors, though the available data suggests no increase in cancer from these treatments (Sergentanis 2014; Klip et al., 2001).

Not only is the success of treatment not guaranteed, as discussed above, but most often, when treatment fails to produce pregnancy, the reasons are unknown. Deciding on whether and when to undergo another IVF treatment can be an extremely difficult decision, particularly after several failed treatments. As patients puzzle about the cause of the failure, they now become hyper-aware that not only success, but also failure can result from the treatment.

2.2.6 More Uncertainty - Unpredictable Daily Trajectory and Compounding Stressors

The success of treatment is cumulative, progressing through achievement and completion of each stage. Important decisions are required from patients to direct the treatment progression. These decisions include how many embryos to transfer, what to do with extra embryo(s) (e.g., store in cryopreservation for later use, discard, or donate to research studies or to other couples), how to deal with the potential complications associated with multiple pregnancy, and in some cases whether or not to use donor sperm, eggs or a gestational carrier. This decision-making can be extremely challenging, not only because of its high-impact nature, but also because of the aforementioned uncertainty and unpredictable risks.

In some cases the treatment cycle can be cut short, or cancelled for many reasons, such as the patient's having retrieval of too few (or no) eggs, failure of the eggs to fertilize, failure of the embryos to develop normally, the patient's unexpected physical reactions to drugs, or signs of or concerns for developing OHSS. Cancellation of a treatment cycle can occur at any point in the cycle. Often, physicians make the recommendation based on a poor prognosis. However, the final decision to halt the treatment is primarily left up to the patient and her partner. Making such an unfortunate, and often unexpected and painful decision under intense time pressure can be excruciatingly difficult.

As discussed above, the demanding regimen, unpredictable scheduling, invasive medical procedures, financial burden, side effects, risk concerns, and uncertainties are all stressors patients face while undergoing treatment. These are further compounded by concerns of inadequate social support and relationships, privacy and work concerns, the difficulties of the experience are far beyond what most patients might have anticipated and certainly beyond what they might have hoped for.

2.3 Study Context

While all IVF clinics in the United States offer similar core technologies and procedures - there are commonalities in many key aspects - there are variations in how they deliver services, based on factors such as individual organization's priority and general service protocols, personnel structures, and available resources. Thus, here I detail the practices of the study site in the delivery of service and management of patients below.

2.3.1 The Study Site

This study was conducted within a reproductive endocrinology and fertility clinic at a major research university hospital. It is located inconspicuously at an end corner of the satellite office complex of the university hospital within the vicinity of a popular shopping mall. Although the fertility clinic is a subsidiary of the Obstetrics and Gynecology (OBGYN) department and works closely with it, the clinic was moved to the current location - discrete, away from the other OBGYN clinics, and somewhat disguised as a medical center - in consideration of the fertility patients' feelings. Fertility patients suffer from fertility stigma and have privacy concerns (Finamore et al.,2007). It is also felt that fertility patients do not want to see any pregnant women and/or anything that reminds them of their reproductive challenges.

With its own ultrasound and embryology labs and full-time staff, the clinic provides comprehensive assisted reproductive technologies and services including intrauterine insemination (IUI), IVF, ICSI, and additional therapies such as pre-implantation genetic testing (PGT). At the time of the study, the clinic's staff included eight physicians, four embryologists, and three IVF nurses, who played the primary roles of the IVF team during the time of this study. All physicians, including one urologist who specializes in treating male patients, and three nurses see patients at all stages and conditions and make the treatment and care decisions jointly. Because it is a teaching hospital, rotating residents and interns may also participate in patients' care under the attending physicians' supervision. Unless specially arranged, a patient most likely encounters different physicians in different visits during one treatment cycle.

The clinic also has two social workers and one insurance and financial specialist on site, providing free psychological consultations and hosting a monthly peer-support meeting, helping patients understand their insurance coverage, and making payment plans, respectively.

Like other fertility clinics, this site serves patients who are voluntarily undergoing treatment because they, for the most part, see IVF as a last resort to have their own biological child. The clinic performed about 150-200 IVF treatment cycles per year during the time of the initial study from 2013 to 2016; about half of them were for returning IVF patients. The state where the clinic is located does not mandate insurance coverage for infertility treatment. At the time of the study, the cost for a basic IVF treatment is approximately \$11,500 not including fees for any pre-testing, additional therapies, and services such as ICSI, PGT, or fees for processing and storage of frozen embryos. Since 2016 the IVF caseload has roughly doubled to nearly 400 treatment cycles, attributed in part to the dramatically increasing infertility insurance coverage from employers including the university, the major employer in the city where the clinic is located. The university insurance now pays \$20,000 per lifetime for infertility treatment, which approximately covers most of the cost of one IVF treatment cycle.

2.3.2 IVF Service Delivery Protocol:

Upon receiving an IVF treatment recommendation, patients are scheduled to meet with an IVF nurse and are given an information packet. The nurse concisely introduces the topics contained in the information packet and encourages the patients to read through the packet and to schedule an *intake meeting* with the nurse team. The intake meeting is meant for patients to officially commit to the treatment and receive patient education for the treatment. The information packet contains a 24-page consent form entailing the legal, ethical, and administrative compliance of the IVF treatment, its fee schedules, insurance codes, contacts of local and specialty pharmacies that carry IVF medicines, and a list of resources including the contact information of the clinic's social workers, a schedule for the clinic sponsored patient support group, and the web address of Resolve™, the online site hosted by the National Infertility Association.

2.3.3 Prerequisites: Complete Pretests, Fill Prescriptions, and Set a Start Day

Once the intake meeting is scheduled, there is a set of tasks for the patient and the clinic to complete, either simultaneously or sequentially, prior to the meeting. The goal is to construct a customized treatment plan with a treatment calendar including a start day for the patient. To achieve this, patients are required to coordinate not only with the clinic, but all arrangements must be synchronized with their individual physiological rhythms, and their work and personal schedules, as well as with the clinic's service and operational timetables.

The clinic's tasks include: prescribing pre-tests if applicable; finalizing treatment protocols; validating and sending prescriptions to the pharmacy that the patients choose; coordinating a treatment start day with the patient and the care team; and finally generating a tentative treatment calendar.

The patients' tasks include: making arrangements to complete and/or update all required pre-tests; checking with insurance and/or making financial arrangements; identifying a specialty pharmacy that both the clinic and insurance can work with; ensuring timely reception of medication for the treatment; assessing work and/or personal schedules to accommodate the treatment activities; making arrangements for them; and coordinating a start date.

2.3.4 Intake Meeting: Patient's Consent and Patient Education

The intake meeting takes place after a treatment calendar is established; it is hosted by an IVF nurse and typically lasts 2 hours. The patients are invited to bring along their partner or family members, and additionally, to bring their prescribed medicines and syringes.

In the intake meeting, the nurse delivers in a two-hour dose an overwhelming amount of information that pertains to a major desire of a patient's life. The main items on the meeting agenda are 1) to obtain the patient's consent and confirm the logistics for the treatment; 2) to educate patients in necessary self-administered medication skills and tools including how to use the treatment calendar, manage prescription refills, and perform self-injection.

The nurse needs to ensure two main documents, the consent form, and the treatment calendar, are completed and reviewed by the patient. The nurse walks the patient through the consent form page by page while acquiring patient's signatures as needed. The 24-page legally termed consent form includes topics such as treatment risks and benefits, procedure, and extensive side effect details, as well as the patients' financial obligations.

The nurse stresses that most side effects are tolerable and mild. Patients are advised to use a hot/cold pad, avoid strenuous activities, and resume their regular activities. Although ovarian hyperstimulation and some potentially dangerous complications may arise, the chances of their occurrence are extremely rare. Nevertheless, patients are warned that if they have fever, shortness of breath, or other signs indicating hyperstimulation or another life-threatening condition, they need to contact the clinic immediately or call 911. Furthermore, acknowledging potential difficult emotions that the patients may experience, the nurse advise patients to remain "cautiously optimistic". So, the nurses' approach in this meeting serves to minimize the patients' upcoming distress, both physically and emotionally, while also alerting her to life-threatening possibilities and regulating her emotions.

After obtaining consent, the nurse moves on to the treatment calendar. The 2-page treatment calendar is formatted as a typical calendar layout with tentative daily medication in abbreviation and dosages, and anticipated appointments and procedures. The selected pharmacy, the clinic's operation, and communication protocols such as hours, contact information, and responsible personnel are also listed on the calendar. The nurse provides an overview, introduces the regimen, medicines, and administration techniques, and points out all the milestones, contingencies, and reminders on the calendar. The nurse emphasizes that patients must follow this calendar with the utmost care, but also be adaptable enough to anticipate changes while complying strictly to the clinic's operation and communication protocols and schedules.

The nurse concludes the meeting by introducing various drug labels and different syringes by going over the medications that patients bring in, and teaching patients injection techniques. Under the nurse's guidance, the patient uses a small vial of sterile water to prepare a syringe and gives a shot on a Styrofoam model. The patient's partner also gets to practice the HCG injection (one-

time ovulation-inducing HCG hormone medicine required prior to egg retrieval procedure) using saline solution and gives a shot to the patient under the nurse's supervision.

2.3.5 Compliance Requirements: Rigidity and Flexibility

The regimen is both demanding and impromptu; both the importance of precision and rigidity and the tentative, circumstantial nature of the treatment calendar are highlighted. This poses significant challenges for patients. Diligence, amenability, as well as good judgement are all required to accommodate the regimen and confront treatment uncertainty.

Instances of rigidity and precision are manifested through the time and effort required by an unyielding and extemporaneous schedule, meticulous and laborious medicine regimen, and an arduous and elaborate regimen administration

2.3.6 An Unyielding and Extemporaneous Schedule

The appointment schedule is intense, with both hardline characteristics and impromptu elements, particularly for the first part of the treatment cycle that typically lasts 2-3 weeks.

There are typically no required appointments during the latter part of the treatment cycle which most likely last for approximately 2 weeks until the administration of the pregnancy blood test. Sometimes patients may be requested to repeat the blood test if the result is inconclusive. Depending on the test result, either a follow-up consultation for patients with a negative result, or an ultrasound examination of fetal heartbeat for patients with a positive result, is scheduled. One of these steps concludes the treatment cycle with a typical duration between 24- 36 days.

Required appointments consist of approximately 8 - 16 consecutive daily visits for blood draw, a clinic appointment every other day for ultrasound examination (4 - 7 in all) , and 2 extemporaneous procedural visits (one for egg retrieval and one for embryo transfer), which are typically scheduled 1-2 days beforehand, contingent upon the patient's development.

Patients must punctually attend all required appointments at the times scheduled by the clinic. For the blood draw, patients must come in before 9:00 am every morning. This schedule allows the lab to process the tests in time for the physicians to review and make medication adjustments, if needed. The starting point and the number of appointments for ultrasound examination are contingent upon the individual patient's response to the stimulation drug and the treatment protocol used. The timing for egg retrieval and embryo transfer appointments are also unpredictable; it is case-by-case and cycle-by-cycle, dependent upon the patient's development with each cycle. The meetings are confirmed one to two days beforehand; a minimum of 2 hours time for each procedural visit is required. Deeming the procedures to be both physically and emotionally demanding, most patients take a whole day off for recovery.

2.3.7 Meticulous and Laborious Self-Administered Medicine Regimen

Throughout the treatment, patients must adhere to meticulous timing requirements for self-administered daily medicine which, along with different sizes of syringes, filled a file-size box (18in X 18in X16in) from their specifically designated pharmacy. The timing for taking injectable stimulating hormone medicine is between 7:00 to 9:00 pm. In addition, 3 Progesterone suppositories must be taken approximately eight hours apart from each other during the pre-pregnancy support stage. By the same token, once the egg retrieval time is set, the one-time egg-releasing inducing hCG hormone injection must be performed by the patient/partner within an *exact* window of time between 24 to 26 hours before the procedure.

Not only its timing, but accuracy in dosage and efficiency in tracking the medication supply and managing refills, are required. Patients must diligently take inventory and be able to plan effectively; it is the patients' responsibility to ensure that they have the needed medicines at hand throughout their treatments. When a refill is needed, patients must be proficient in making necessary arrangements with all parties, the clinic, the pharmacy, the insurance, and the delivery company, to ensure they obtain the needed medication in a timely manner. In other words, they bear responsibility for a process they do not control. At the same time, they are likely to be overwhelmed by the uncertainty of the outcome and its importance to them.

2.3.8 Arduous and Elaborated Regimen Administration and Contingency

2.3.8.1 Information Exchange, Feedback, and Compliance

Information exchange between the patient and the clinic is intense and vigorous. Once their treatment begins, patients must check in daily during the time between 1:00 pm to 6:00 pm to receive up-to-date feedback from the clinic with updates on potential changes in medication or dosage for their daily medication/injection. The clinic determines whether the patient's medication or dosage requires adjustment based on her physiological response to the treatment; patients must promptly and effectively adhere to such adjustments and administer their regimens accordingly.

Patients also receive information in the form of lab results and ultrasound reports as they progress through treatment. Physicians use these reports manage treatment trajectory. Lab results from daily blood draws provide patients with daily reports on their varying hormonal levels; these reports are also reviewed rigorously by the physician team to monitor patients' progress. Ultrasound reports inform patients about their follicle development and number and size of eggs; the updates on their general physical status are also noted. For the patient, this flood of readings may be beyond their ability to interpret or comprehend fully. However, they are inevitably drawn to try to track, make sense of the reports, and desire to have control over their treatment trajectory. Furthermore, although the clinic provides patients with their up-to-date conditions until completions of the embryo transfer; this does not curb patient's restless attentiveness to seek out other information to validate or support their interpretation or make predictions about generally unpredictable treatment trajectory and outcome.

Prior to embryo transfer, patients are informed - possibly immediately - about the quality of the embryos through a graded report based on which patients grant the decision to the physician regarding the number of embryos to transfer and/or put in storage. Patients are often required to make these decisions in a prudent and prompt manner in the face of newly received information regarding the changes or development of their condition. Although they may contemplate this decision for a while, playing out various scenarios in advance, it is still nerve-wracking because the significance of this decision to their outcome and their lack of confidence in their ability to

make a sound decision (e.g. don't know how to optimize the chances considering all factors such as the quality of their embryo and their uterus condition for the implantation)

The pregnancy blood test takes place at the clinic, at which time all the efforts and stress that patients undergo come to a climax. The resulting information consists of an HCG hormone level reading and a positive or negative sign of pregnancy. It is delivered by an on-duty physician or nurse via a phone call and an email message within 48 hours after the blood draw. The clinic discourages patients taking at home pregnancy tests beforehand because the hormonal drugs injected in them may lead to false positive or negative test results. However, it is very tempting - and many patients take it - because waiting for the clinic's pregnancy blood test can be agonizing.

Finally, in addition to understanding feedback and complying with new instructions promptly and effectively, the patient must perform assorted tasks proficiently and coordinate with others to manage the regimen. For example, the egg retrieval schedule is often confirmed less than 3 days in advance. Once it is confirmed, the patient must 1) make personal and work arrangements to ensure her availability for the procedure and recuperation, 2) meet the procedure requirements such as delivering sperm collection, confirming the anesthesia application, ensuring payment, and transportation arrangement from/to the clinic, while tending to her physical needs for the optimal condition for the procedure.

Chapter 3 - Literature Review

From its inception in 1978, IVF treatment has been regarded as a highly specialized, complex, and high stakes treatment; it is the last resort for infertility patients who want to have a biological child. Over the last four decades the predominant focus of the scholarship related to IVF has been on continuous advancement of the biomedical technology and improvement of interventional therapies for treatment outcome (see e.g., Niederberger et. al 2018; Broekmans et.al 2006; Mastenbroek et. al 2007; Hendriks et al. 2007; Virro, Larson-Cook & Evenson, 2004; Griesinger, G., Venetiset.et. al. 2008; Sunkara et al 2011; Pelinck et al 2002). Significantly less literature addresses other important topics such as medical ethics, legality, political and cultural concerns associated with the treatment (see e.g., Gurmankin, Sisti & Caplan 2003; DeLair 2000; Savulescu et. al 2015; Robertson 2001; Ross & Moll 2020). The patient experience, what is more, is vastly understudied.

3.1 IVF Patient Experience

From early on, the prevalent focus of research on the IVF patient's experience has been the complexity of the psychosocial experience. This complexity is largely treated as a product of stress and negative emotions, which come from several sources: the demanding regimen, the low odds of success, and the effects of the hormonal drugs, coupled with the social stress associated with infertility (Peterson, Sejbaek, Pirritano & Schmidt, 2014; Kee, Jung & Lee, 2000; Greil, Slauson-Blevins & McQuillan, 2010). The patients' emotion episodes have been of great interest to researchers because of their practical implications; research has confirmed that the emotional burden is the primary reason for the patients to withdraw from and discontinue the treatment (Olivius et al., 2004; Verberg et al., 2008; Verhaak et al., 2010; Gameiro, Boivin, Peronace &

Verhaak, 2012). Many studies, in addition to this, suggest that emotional distress may potentially have adverse effects on the treatment outcome (Haimovici et al. 2018; Maroufizadeh, Navid, Omani-Samani & Amini, P. (2019; Miller et al., 2019). Investigations of the IVF patient's experience, moreover, has shown that patients are in great need of psychosocial support, which is also a great concern of the medical providers in attempting to create optimal patient experience (Boivin et al., 2012; Verhaak et al., 2007; Gourounti 2012)

The bodies of current literature on IVF patients' experience can be divided broadly into two categories: 1) investigations focused on emotionality, and 2) studies proposing and evaluating various kinds of psychosocial intervention or caring therapy.

In the first category, previous research has well established that IVF patients suffer from a variety of negative emotions and mood swings. These negative emotions include anxiety, fear, anger, burn-out, depletion, sadness, and depression. (see, e.g., Pasch 2002; Peterson 2006; Wright et al., 1991; Rapoport-Hubschman et al., 2009; Greil, Slauson-Blevins & McQuillan, 2010) Some earlier studies, additionally, reported that patients experienced common and harmful feelings revolving around having infertility problems, such as shame, guilt, helplessness, loss of self-esteem and isolation (Wright et al., 1991; Edelman & Connolly, 2000; Peterson et al., 2014; Rockliff et al., 2014). Although the negative emotions have been identified and studied, this research, typically, has involved one-time measurement of their intensity and has treated single emotions in isolation rather than in combination. More critically, there has been little exploration or description of the mood swings that have been observed in most patients (Suthersan, Kennedy, & Chapman, 2011; Gourounti et al. 2012) but which are commonly attributed to the effects of hormones. These previous studies on emotionality, which underscored merely negative emotions, appear to take -- though mostly inexplicitly -- a static view of the emotional experience in various stages of the treatment (Ockhuijsen et al., 2014;). A dynamic view and an exploration of the interactions between the emotions and between the emotions and the stimuli in the environment is lacking, particularly within theoretical frameworks of emotionality and appraisal.

In the second category of the patient experience literature, the studies have emphasized proposing, comparing, and assessing different caring therapies or coping practices. They have largely focused on several therapeutic approaches: positive reappraisal-based therapy; encouragement of

distracting, distancing, or redirecting activities; and mindfulness and imagery. These are often grouped together under the term cognitive behavior therapy.

Clearly, the basic premise of all these therapies is that, for the reasons enumerated above, the patients suffer as a result of experiencing negative emotions and that the psychosocial support thus should aim to target these negative emotions by eradicating or suppressing them and elevating the positive emotions (Czamanski-Cohen, et al. 2019, 2016; Domar et. al 2011; Lord & Robertson, 2005). This assumption is supported not only by the conventional wisdom that patients should ‘feel good’ and not worry but also by the scholarship in positive psychology, which asserts that fostering positive attitudes toward future states (i.e., encouraging optimism) will help patients feel more motivated to preserve their current well-being and hence exercise better self-control (Seligman 2003; Chakhssi, Kraiss, Sommers-Spijkerman & Bohlmeijer, 2018). While some studies suggest that these approaches can be helpful, particularly in lowering anxiety at specific points, others have concluded that the effects are minimal (Domar 2011; Peterson, 2011; Rockliff 2014).

The body of literature in goal theory also suggests indirectly that patient experience can be considered, at first glance, as a goal-directed endeavor because patients undergo the treatment to achieve a specific goal -- the desired outcome of becoming pregnant. IVF patients have demonstrated, furthermore, excellent adherence, despite the heightened negative emotionality, in theory, would impair their ability to exercise self-control (Baumeister, Vohs & Tice, 2007). Although goal theory has much to contribute⁴, particularly in explaining the motivation for patients’ strong desire for gaining a sense of control, its emphasis on action planning, initiation and action control does not readily fit the IVF context (Bagozzi & Dholakia 1999). The goal of IVF is atypical; the perseverance patients exhibit in the face of great uncertainty and heightened emotionality is a striking feature of the IVF patient experience. The patients’ pursuit of the goal is in many ways quite unorthodox. Examining the interplay of emotions, certainty, and the struggle for control is crucial for understanding the patients’ experience, and these are not the focus of goal-theory research.

⁴ For example, the discussion of goal-oriented emotion in Bagozzi 1999 is relevant but is situated in a practical goal-seeking that does not share many features with the IVF experience

In brief, with regard to IVF patient experience, the literature has focused primarily on negative emotions and their effect on patient satisfaction and motivation to continue the treatment. While cognitive behavioral therapy seems to result in some benefits, it has focused primarily on handling negative emotions. While many negative emotions have been identified, little research has gone beyond the drug effects and difficult treatment requirements to find reasons and investigate emotion episodes. Overall, we have limited understanding of patients' emotionality, which is central to the IVF experience. Few studies have investigated mood swings or the emotional roller coaster. If we are to effectively construct better coping support for IVF patients, we must address unanswered questions regarding the interrelations among emotionality, their thoughts, their actions and behaviors, and the specific treatment context. Such questions are the province of appraisal theory, which will be discussed in the next section.

3.2 Appraisal Theory as a Lens for Explaining Experience

IVF patients explain their experience in terms of the emotions it generated; thus, a look at the literature on the nature of emotions and the processes involved in their production is central to the examination of that experience. Researchers on emotion, in general, agree that emotion is an internal phenomenon that can be, but is not always, observed through the person's physiological changes, facial expression, and self-reported feelings and psychological state (Niedenthal & Ric, 2017). Rather than a fixed state, emotion is regarded as a continuous, fluid, and multidimensional process (Ellsworth, 2013; Fontaine, Scherer, Roesch & Ellsworth, 2007). Emotion has an adaptive function and thus is vital to human evolution (Smith & Lazarus, 1990; Nesse & Ellsworth, 2009; Oatley & Johnson-Laird, 2014).

The study of emotion prior to the middle of the last century reflected a primary interest in how physiological changes relate to particular emotions, rather than how cognition might play a critical role in generating emotions or how one emotion can be qualitatively differentiated from others on the basis of non-physiological factors (Reisenzein, R. 2006; Lazarus, 1966). Thinking and feeling, however, are intimately and recursively related (Smith & Lazarus 1990; Ellsworth & Scherer 2003; Oatley & Johnson-Laird 2014). Cognition is inextricably bound up with emotion, which is the

dominant driver of most meaningful decisions in life (Lerner, Li, Valdesolo & Kassam 2015; Keltner et al. 2014; Lazarus 1991; Scherer & Ekman 1984). Appraisal theory, which takes as a basic premise that emotions are adaptive and that the relationship between stimulus and action is mediated by cognition, was proposed to better explain the role of emotion in human experience (see e.g., Lazarus 1966; Scherer, 1984; Smith & Ellsworth, 1985; Roseman, 1984; Frijda 1986; Oatley & Johnson-Laird, 1987; Ortony, Clore & Collins, 1990; Roseman & Smith 2001; Moors, Ellsworth, Scherer & Frijda, 2013); appraisal theory is thus highly relevant to the exploration of a complex and extended emotional experience such as IVF .

Appraisal theory, in general, contends that emotions are elicited by evaluations, or appraisals, of events and situations, rather than by the events and situations themselves (see e.g., Lazarus 1966; Scherer, 1984; Smith & Ellsworth, 1985; Roseman, 1984; Frijda 1986; Oatley & Johnson-Laird, 1987; Ortony, Clore & Collins, 1990; Roseman & Smith 2001; Ellsworth 2013; Moors, Ellsworth, Scherer & Frijda, 2013). Magda Arnold (1960) and Richard Lazarus (1966) pioneered the concept of appraisal's central role in producing emotion and formulated the basics of the theory (Arnold 1960; Lazarus 1966). Their essential contention, now widely accepted, was that the potential effect of a situation or encounter on a person's well-being was the focus of the appraisal. What scholars, following Arnold, understood as the appraisal process is a person's perception, evaluation and knowledge, both conscious or subconscious, in response to a stimulus (see e.g., Lazarus 1966; Scherer, 1984; Smith & Ellsworth, 1985; Roseman, 1984; Frijda 1986; Oatley & Johnson-Laird, 1987; Ortony, Clore & Collins, 1990; Roseman & Smith 2001; Reisenzein, 2006; Moors, Ellsworth, Scherer & Frijda, 2013). In his seminal body of work, Lazarus argued that we appraise our environment continuously and generate a variety of different appraisals, which reflect not only explicit but also subtle differences in our perception of the environments and situations changes (Lazarus 1966, 1990). The 'primary appraisal', or initial, often intuitive, reaction, is based on the perceived significant relevance to our well-being, and the 'secondary' appraisal is an evaluation of our coping potential in regard to the situation (Lazarus 1966; Folkman, Lazarus, Gruen & DeLongis, 1986; Ellsworth & Scherer 2003). Because emotion corresponds to a variety of appraisals of the continuous changing environment, emotion is malleable and is fundamentally a process for our survival and adaptation to the world (Ellsworth, & Scherer, 2003; Oatley & Johnson-Laird, 2014).

Appraisal theory asserts that emotion is a multidimensional process composed of five interrelated *components* (i.e. sub-processes):

1. Appraisals of events or evaluation of the situation
2. Psychophysiological changes or built-in somatic reflex
3. Motor expressions (face, voice, gestures)
4. Subjective experience or feelings
5. Action tendencies and action readiness, i.e., a particular emotion can motivate or incite a person to carry out certain expressive or instrumental behaviors, such as fight or flight (Scherer 1984; Ellsworth & Scherer, 2003; Fontaine, Scherer, Roesch & Ellsworth, 2007).

The following example is provided to clarify the progression and interrelatedness of these five components:

When a young boy who is attending a circus event sees a tiger, he appraises it as dangerous (1). His heart pounds extremely fast and he gets sweaty palms (2), his jaw drops (3), and he feels very frightened (4); he feels he needs to run away (5). He realized (1) that it is a trained tiger (1), his heart doesn't pound as hard (2), his facial expression relaxes (3), he becomes curious and interested (4), and he continues to watch the performance (5).

These components, initiated by the appraisal of events, progress individually, but are interrelated among themselves in such a way as to elicit an emotion episode. As the example shows, emotion contains built-in somatic reflex components, an instinctual physiological component, and a motor component with expressive and behavioral responses. However, emotion also draws on the person's intelligence and learning from his/her environment, and it contains a) cognitive evaluations of the environment and the person-environment interaction, i.e., appraisal, and b) a motivational component with action tendencies or readiness (Frijda 1986, 1987; Moors, Ellsworth, Schere & Frijda 2013; Roseman 2013). Briefly, as Roseman (2013) commented, "emotions can be understood as a coherent, integrated system of general-purpose coping strategies, guided by appraisal, for responding to situations of crisis and opportunity" (Roseman 2013). That is, emotion, guided by appraisals informed by cognitive processes, is our built-in mechanism to adapt to the unpredictable and changing world (Ellsworth 2007; Oatley & Johnson-Laird, 2014). Emotions

are, accordingly, instigated and guided by information processing with a set of criteria to examine and evaluate the significance of the environment or stimulating situation and its underlying characteristics along specific appraisal dimensions (Smith & Ellsworth 1985; Scherer 1984; Rosman 1984; Frijda 1986; Ellsworth & Scherer 2003). The dimensions enable us to characterize and classify emotions and function as a route to the identification and differentiation of emotions.

Within the research community, many different theories have emerged from this central concept, but the generally agreed-upon dimensions are novelty, valence, certainty, goal conduciveness, agency, and control, as shown in the chart in Ellsworth and Scherer (2003). For this research, the most important of these dimensions are control and certainty, because the emotionality that is characteristic of the IVF experience arises from patients' sense of being out of control in a highly uncertain situation.

Appraisal theory asserts that the emotions characterized by the dimensions drive actions and behavior in particular and predictable ways. Because emotion is built from a series of appraisal processes that generate alternatives for the person experiencing emotion to respond to the environment, emotion implies action tendencies (Frijda, 1986, 2011; Ellsworth & Scherer 2003). This is because states of action readiness have motivational properties, as Frijda stated; he argued that different states of action readiness mirror the differences in individual's appraisals of the environment and in expressive behavior, emotional feelings, and other components of emotion (Frijda, 1986, 2011). Emotions can give different importance to a goal or place a particular prioritization on the dimension(s) of the individual's relationship to the environment. That is, because each emotion is elicited by a specific set of appraisals that lead to different responses, we can link particular emotions to the appraisals that generate them and thus, if we know what makes up the set of appraisals, we can predict the resulting emotions, which would be useful for anticipating the needs of IVF patients.

Appraisal theory asserts the connectedness between appraisal dimensions, emotion and behaviors; it provides not only the content of the appraisal, it also illustrates the pathways of how an emotion episode is constructed. Applying this concept to emotion episodes in general, Scherer proposed a set of stimulus evaluation checks, beginning with a (1) "novelty check," followed by (2) an

“intrinsic pleasantness check, based on innate feature detectors and learned associations; (3) a “goal/need significance check,” evaluating whether an event is relevant to goals, conducive to goals, expected, and urgent; (4) a “coping potential check,” evaluating causation, coping potential, control over consequences, relative power, and options for internal adjustment; and finally (5) a “norm–self compatibility check,” evaluating the compatibility of actions or events with social norms, conventions, or expectations of others, as well as with internalized norms or standards of self. Scherer assumes that the outcomes of these checks changes various subsets of appraisal that elicit emotion (physiology, expression, motivation, feelings), creating a telltale trace that distinguishes the emotion (Scherer 2001; Ellsworth & Scherer 2003), In addition, Scherer’s analysis emphasizes that emotions are fluid, reflecting constant evaluative activity, and recursive.

As we can see in this brief review of literature on emotion theory and appraisal theory, appraisal theory underlines not only the criteria for evaluating stimuli but also the pathway of the appraisals, highlighting the connectedness among thoughts, emotions, actions and behaviors and the context in which the appraisals occur. Thus, it provides a comprehensive framework in which to understand IVF patients’ lived experience as a series of emotion episodes in response to uncertainty and lack of control.

Chapter 4 - Method

I have chosen Grounded Theory (GT), an inductive, qualitative methodology, for this study. Established by Barney and Strauss in 1965, GT assumes that theory construction is grounded in data from practitioners in acts where they experience changes (Strauss & Corbin 1997; Charmaz & Belgrave 2012). GT applies gentle directiveness in conducting interviews and field observation; this allows unique co-construction between the participants and the researchers by adopting an exploratory and open-ended approach.

GT simultaneously uses data collection, coding, and memo writing. This method is systematic, and iterative, meaning that comparison is continual. (Charmaz & Belgrave 2012; Elliott, Fischer & Rennie 1999). Through a combination of analytical memo-writing and line-by-line and focus coding methods, new categories continuously emerge, thereby allowing for systematic exploration and interpretation for new theory construction. Data collection and analysis end when they reach theoretical saturation. GT was deemed a particularly fitting approach because of its strengths in discovering and theorizing processes over a lived experience, which is the central inquiry for this study.

4.1 Data Collection

The study was conducted within a reproductive endocrinology and fertility clinic at a major research university hospital. With its own ultrasound and embryology labs and full-time staff, the clinic provides comprehensive assisted reproductive technologies and services such as intrauterine insemination (IUI), IVF, and gamete micromanipulation/intra-cytoplasmic sperm injection (ICSI).

The clinic's staff includes 8 physicians and 3 nurses who specialize in IVF. The clinic also has 2 social workers on site, providing free psychological consultations.

At the time of the study, the cost of an IVF treatment cycle was approximately \$11,500 without fees for any pre-tests, Intra-cytoplasmic sperm injection (ICSI), Pre-implantation genetic tests (PGD) and processing and storages of frozen embryos

I started observation and stayed in the field for over 18 months starting in 2014. Observations were performed 4 ways: shadowing physicians on IVF patients' consultations; attending weekly staff meetings where physicians, nurses, and medical assistants collaborate and set up the patients' treatment plans; shadowing the IVF nurses when they conduct the educational meetings and provide routine updates to the patients; and observing nurses' phone conversations with patients. I volunteered as an aide and had regular interactions with staff, which triangulated my understanding about IVF and treatment management from a provider's perspective, which serves to assert validity for my findings.

Aside from the field observation and informal interviews with the clinic staff, data collection included formal semi-structured interviews and artifacts and document collection such as the treatment calendar and personal notes related to the treatment from the interview patients. Three patients also granted me limited access to look at their personal blogs and social media; although these observations gave me a better understanding of their social interactions online, they were not included in the record because of the patients' requests.

4.2 Interviews

With full support by the medical director of the clinic, I sent out invitations for participation to all IVF patients in the clinic who completed recent treatment within 3 months in one-on-one interviews with me. Because I come to this work with an interaction design background, my initial inquiry was focused on uncovering patients' strategies and practices that fortify their achievement of outstanding adherence. I soon, however, realized the more promising, critically important role that emotion played in the patient's experience, and promptly adjusted to

incorporate it. This realization resulted from observing the first three patients, who unanimously recalled their experience through a series of emotion episodes via which they talked effusively and at considerable length about their emotional states and emphasized intensively the challenges of tempering them. As a result, all interviews, including the first three, exceeded the originally planned interview time of one hour. I conducted 29 semi-structured, in-depth interviews, each lasting between two to six hours, totaling to an amount of 83 hours. These interviews were transcribed verbatim, and totaled 1180 pages single spaced (ranging from 32 pages to 69 pages per patient).

4.3 Recruitment and Screening

I placed recruitment flyers in the information packets for both new and returning IVF patients to recruit subjects for the study. The flyer included instructions and the following selection criteria: 1) patients had to be diagnosed with infertility problems; 2) patients had to have completed the egg (oocyte) retrieval at the clinic within 3 months before the interview. Any subjects expressing interest in the study were then screened with these criterions and subsequently contacted if they were suitable and an interview was set.

It is important to recognize that the recruitment was not completed before interviewing began; the framework of the study calls for rolling enrollment as the investigator sees the need for additional participants (up to data saturation). In this case, the clinic director contacted all eligible patients (over 120) and ascertained their willingness to participate. Of the 72 patients who expressed willingness in the initial contact, 30 did not respond or responded negatively when contacted by the investigator. Forty-two agreed to be interviewed; however, 13 of these subsequently retracted their agreement because the outcome of their treatment was negative. Ultimately, 29 patients were enrolled over a six-month period, resulting in the 29 extensive interviews that serve as the data for the study.

4.4 Interview Settings and Process

On the interview day, each subject was initially given a questionnaire: 1) asked for the patients' demographics; 2) confirmed if they are qualified for the interview; 3) any previous reproductive interventions; 4) any information tools such as day planner, smart phones they use to manage their regimens. Consequently, all subjects contacted were approved for the interview sessions and all completed the interviews.

The interviews were conducted in a private setting; depending on their preferences, I met many of the subjects at either their homes or the clinic office. I had also met a couple of them at my office on campus and a meeting room in the public library. All subjects' identities were kept strictly confidential. The interviews were all audio-recorded; some subjects had sensitive matters during the interviews which they requested not be recorded and I complied with these requests.

4.5 Interview Process

I asked each subject to bring their treatment calendars provided by the clinic to our interview meeting and use their own terms to answer the following sets of questions (Appendices A, B, C):

1) Regimen practice

How did they integrate the treatment regimen into their lives? Who and what other resources did they draw upon to comply with the treatment? What were the mechanisms, tools, strategies, and considerations they applied to achieve the regimen? I also asked all subjects to walk us through their individual treatment calendars step by step to understand how the adherence experiences evolved.

2) Retrospective thoughts and feelings

What were the thoughts and feelings during the treatment? What and how would they do differently (if they were to repeat the treatment) and what will they advise new patients to have

better experiences? If they were repeating the treatment, how would they compare this treatment to the previous one? What were their suggestions on how the clinic can improve their experiences?

4.6 Interview Subjects

We interviewed a total of 29 subjects whose ages ranged from 28 to 43 years old. All had completed an IVF treatment cycle within 3 months of the interview. All 29 participants were diagnosed with the medical condition of infertility, which is defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse (Centers for Disease Control and Prevention [CDC], 2020). Four of them had secondary infertility (i.e., they were able to conceive naturally earlier), including one patient who underwent the IVF treatment to circumvent a previous tubal ligation. Two patients underwent the treatment because their husbands had cancers which compel them to use sperm stored prior to their cancer treatments.

Prior to the treatment, six of the women had biological children, including two who had had them through a previous IVF treatment. Seventeen interviews are from first-time IVF patients and 12 are from repeating patients. Of these twelve repeating patients, nine are on their second cycle, and the remaining three are on their third, fifth, and ninth cycle.

Table 1 below shows some critical details of the participants.

Patient Number	Age	Education	# of Completed Cycles	Outcome of Most Recently Completed Cycle
1	38	college	2	N
2	39	postgraduate	1	Y (w/ twins)
3	25	postgraduate	1	Y
4	35	college	2	Miscarried
5	32	postgraduate	1	N (undergoing treatment at the time of the interview)
6	35	postgraduate	1	N
7	37	college	2	N (undergoing treatment at the time of the interview)
8	29	college	1	Y
9	42	college	2	N
10	28	postgraduate	1	N
11	32	postgraduate	2	N
12	38	college	1	N (but ended up naturally pregnant)
13	38	postgraduate	3	N
14		postgraduate	2	Y
15	28	college	1	Y
16	28	community college	1	Y
17	36	postgraduate	1	Y
18	36	college	1	Miscarried
19	38	community college	2	N
20	31	postgraduate	1	N
21	35	postgraduate	1	N (undergoing treatment at the time of the interview)
22	35	postgraduate	1	N
23	32	college	1	Y
24	36	college	2	N
25	28	college	9	Y
26	33	college	1	N
27	33	college	5	N
28	33	college	1	Y
29	38	college	2	N

Table 1. Participant Details

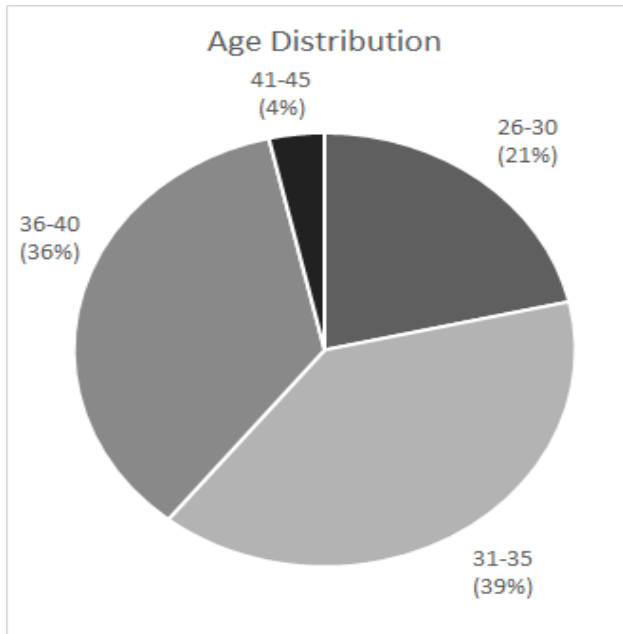


Figure 2. Age Distribution of Participants

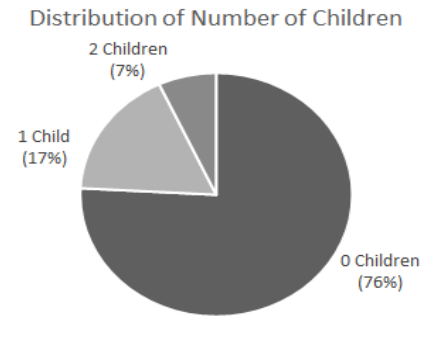


Figure 4. Distribution of Number of Children for Each Participant

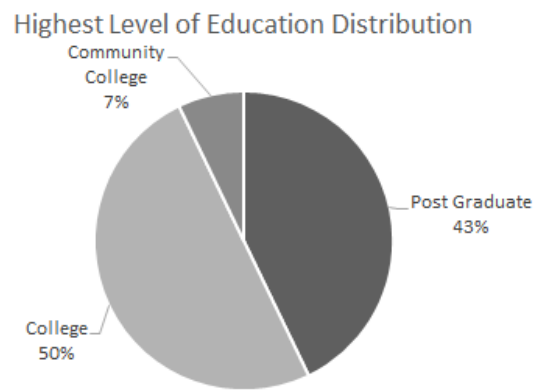


Figure 5. Highest Level of Education Distribution of Participants

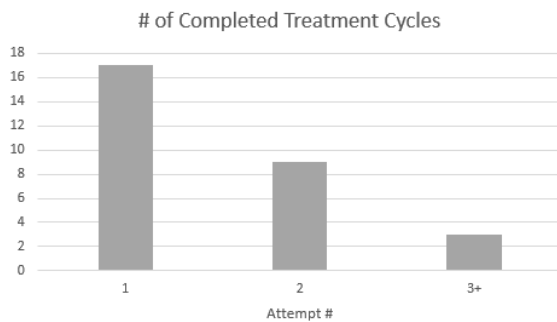


Figure 3. Distribution of # of Completed Treatment Cycles

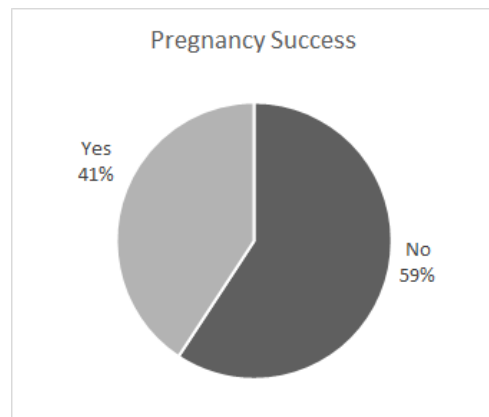


Figure 6. Pregnancy Outcome of Recent Treatment Cycle

The participants' ages ranged from 24 to 42 years old, with a mean value of 34. All 29 women had partners: 27 were married, one had a domestic partner and one was part of a lesbian couple. All but two (one was attending a community college at the time of interview) have a college education. All participants except one had either a full-time or part-time job. Eight women had various amounts of formal medical training and were working in healthcare.

Though the majority were Caucasian American, the participants included people from diverse ethnic and cultural backgrounds, including three Asians (one north-eastern Asian, one south-eastern Asian and one Indian), one European, one African American, and one Arab.

The participants had a wide range of total annual household income, from \$48,000 to over \$250,000. All participants described a lifestyle of reasonable comfort and means as well as access to pay for IVF, including funding at themselves, insurance, or personal loans.

All interviews were conducted with patients who had completed at least one treatment cycle. Of the 29 subjects, 6 had diagnoses of infertility of unknown etiology, 3 naturally conceived and had a child or children previously (secondary infertility). All but two subjects previously went through fertility treatments besides IVF.

All interviews were conducted after participants had completed the target treatment cycle; three women were in the middle of their subsequent treatment. Ten women had a positive outcome of pregnancy including one who used a donor's embryo, and 19 women had negative outcomes from the target treatment cycle at the time of interview. Six of the subjects stated that this was the last IVF/fertility treatment they were willing to undergo.

4.7 Data Analyses

All recordings were transcribed verbatim. To avoid the problem of personal bias and cherry-picking, I first coded the transcripts line-by-line to objectively assign the interview materials to categories informed by the appraisal framework. The data structure of the initial coding theme is shown in Table 2.

	Pre-stimulation	Stimulation	Egg Retrieval	Embryo Transfer	Pre-Pregnancy Support
Timeline					
Patient Activities	Consent to IVF treatment Attend patient education	Attend blood test appointments Attend ultrasound appointments Perform self-injections Manage drug supplies	Attend pre-ER preparation meeting Attend egg retrieval	Make decision about # of embryos to transfer	Administer progesterone medication (injection, suppository)
Information Provided by Clinic	Diagnosis and treatment recommendation IVF logistic information Injection instructions Treatment calendar	Lab Reports Feedback regarding medication changes Physician's feedback regarding treatment trajectory	# of eggs retrieved # and quality of embryos, if developed	Anticipated pregnancy/test day and post pregnancy/test follow-up appointment	Activity restriction information
Concerns	Can IVF help me to achieve pregnancy? What does it mean to conceive via IVF? What does IVF involve (e.g. cost, adherence requirements)? How do I acquire/plan resources (e.g. time, money) to undertake the treatment?	Am I performing the treatment tasks correctly? How do I do it better? How do I interpret information provided by the clinic? How do I minimize work/personal disruptions to accommodate the treatment? Am I on track? How do I monitor/interpret my progress? What can I do outside of the treatment that influences treatment success?	How do I manage the discomfort from the procedure? Will the eggs develop into good embryos so I can proceed with the treatment? What are the next steps based on possible results (e.g. # and grades of embryos)?	Am I pregnant? Will I have a healthy child? Will I repeat another cycle?	Am I pregnant? Will I repeat another cycle? What do the potential results mean to me? How do I deal with the results socially?
Predominant Emotions	Overwhelmed Unduly Optimistic Fear Shame/Guilt	Emotional Distress Aggravated Psychologically Drained Psychologically Aroused	Joy Happiness or Disappointment Fear Nervous Anxious	Relieved Happiness Thankfulness Worry Fear	Fear Sadness Worry Excitement
Background Emotions	Anxiety / Hope / Obsessive Worry / Despondence				
Behavior	Plan work/personal schedule	Form new task routine to be compliant	Manage schedule Coordinate support	Manage schedule Coordinate support	Emotion regulation Anticipate results
Information Seeking / Meaning Making (on- and off-line, social cues, etc.)					

Table 2. Data structure of the initial coding scheme

These top three rows including the headings (i.e., timeline, Patient mandated treatment activities, and information provided by clinic) are objective treatment contexts that are common to all patients. The bottom three rows (i.e., concerns, emotions, coping behaviors) are derived from patients' self-reported, or expressed contexts that are organized to correspond to events/activities, and concerns, emotions, and behaviors.

After this initial coding, I further assigned the patients' recorded accounts and observations to one or more areas of focus, which I call themes, to objectively capture the cognitive structure within which the patients I interviewed looked at their treatment events. Despite a great variety of experiences, four principal themes - outcome or treatment efficacy, physical sensations and symptoms, emotionality and changing uncertainties - repeatedly and consistently emerged from the data. Accordingly, I devised a methodological framework to conduct further analysis.

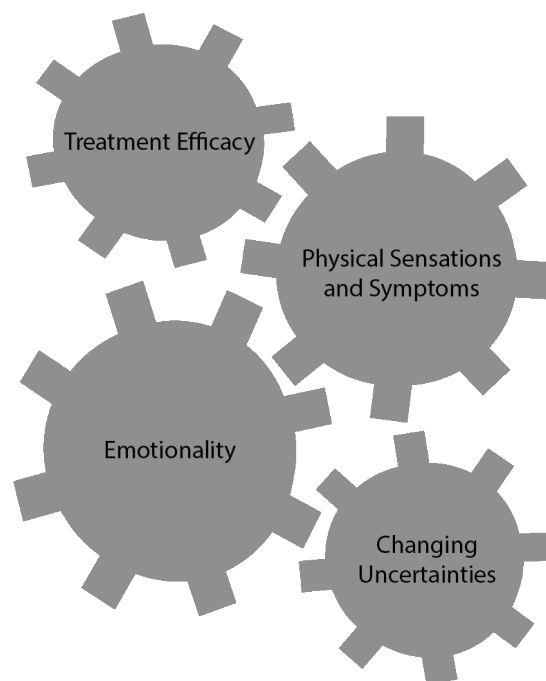


Figure 7. Four Principal Themes

Positing these four themes enables us to form a coherent and complete picture of patient experience. For the purposes of this study, patient experience is made up of 1) cognitive processing (e.g., appraisal); 2) emotionality; and 3) behaviors. The outcome theme is focused on

the treatment results, including both at intermediate stages and/or milestones, and the outcome of pregnancy. The physical sensations and symptoms theme are focused on how patients perceive, monitor, and interpret their body's sensations and discomfort and how they interpret and cope with them. The emotionality theme is centered on patients' feelings and moods. The changing uncertainties theme is focused on patients' perceptions of the uncertainties relationships and interactions domain pertains to patients' views of their roles and positions in relation to the healthcare providers.

Although for the purposes of analysis these four themes clearly delineate the separate components of patient experience, they are profoundly interconnected; they rarely stand alone or are presented in a stand-alone manner. Furthermore, the states of each theme's specific experience are dynamic and thus are constantly evolving within and interacting among themselves. For example, most patients' primary focus upon starting the treatment is on ensuring they have the competence to perform adherence tasks required by the clinic. That is, the performance of procedures, which belongs to the changing uncertainty theme, is foregrounded, and other concerns are backgrounded. As the treatment progresses toward egg retrieval, the outcome domain, such as the quantity and size of eggs, becomes the foreground concern as the dominant focus. Therefore, my coding reflects this evolution with overlapping coding assignments; often the statements in the transcripts were coded with multiple themes. They were then organized and prioritized according to which focus seemed to predominate at a given point.

The findings and analysis seek to

1. Iteratively analyze emerging emotion episodes to develop an understanding of experienced emotionality and emotion regulation practice.
2. describe the spectra of reported appraisals and behaviors for each focal domain, as identified above; and
3. develop an understanding of how patients experience (i.e., consume) IVF treatment (i.e., product, service) and identify implications for better service delivery and patient satisfaction.

As can be seen, the methodology described here partakes of more than one approach; while it is not mixed-method in the usual sense, it incorporates elements of grounded theory and cognitive appraisal therapy. Given the nature of the data and the questions, a single framework was less suitable than this combined one.

Chapter 5 - Findings

5.0 Introduction for Findings and Analysis

“There were a lot, so much. Oh my gosh, so much of this [IVF treatment] whole process was unexpected. They [the clinic staff] told me about it [IVF] but you really don’t know till you’re doing it, you don’t really understand.”

~Patient 7

“I say it’s a journey because you make the decision to do IVF and then oh, my God. We’ve had every possible [pause]. I mean not every possible, but things come up.”

~Patient 5

As the above excerpts suggest, the patient’s experience is complicated. While I started interviewing the subjects after 9 months of observation in the clinic, I still found that I had much to learn from each interview before I could create a coherent picture of the IVF patient experience. Therefore, I begin this ‘Findings’ chapter with an opening section that lays out for the reader the broad framework of the experience on the basis of transcripts; I detail the themes and supporting quotations in Sections 5.1, 5.2, and 5.3.

Three key ideas figure prominently in all 29 interview transcripts -- a perception of the experience as a “*constant emotional rollercoaster*,” a strong desire to “*know what to expect*,” and the need to “*(re)gain control*”.

IVF is a notoriously demanding, expensive and complex procedure, particularly in terms of its arduous adherence requirements, as explained in Chapter 2, “Background”. Most clinics devote significant resources and efforts to educating patients to ensure that they can master the technical skills required for performing the compliance tasks, such as self-injection and drug administration, correctly. To my surprise, however, no patient stressed the difficulty of observing the treatment protocols or talked at length about the financial burdens. In fact, many reported that they had quickly come to a sense of competence regarding the technical treatment activities. Instead, they talked about the psychological and emotional demands posed by these activities. Prompted by their daily treatment calendar, patients reported how their lives were disrupted and affected by the complex daily treatment activities, physical sensations, and often ambiguous or uninterpretable information received from the clinic. Consequently, patients reported experiencing “the emotional rollercoaster” as a result of the sheer quantity of information they had to process, the experiential and somewhat astonishing sense of their physical discomfort and states of abnormality, and the unexpectedly inexorable psychological burden of the regimen⁵ (e.g., by the third day of the treatment, many patients said that they felt something along the lines of “I am so sick of this”). All of these --experienced daily throughout the IVF treatment cycle-- acted as constantly changing stimuli that heightened their sense of uncertainty and reinforced their feelings of being out of

⁵ Patients must maintain daily treatment calendars of required activities, such as performing daily self-administration of medicines, managing side effects, and understanding daily hormonal readings and regimen updates. Patients often report experiencing these treatment contexts as hyper-emotional and physically burdensome. For example, all patients reported having to check their treatment calendar “at least twice a day” as being annoying and toilsome. Below is one representative quotation describing the burden of the regimen:

“Then getting the calendar was what really brought it home, where it was like, ‘Oh, my gosh.’ All these shots and for how long you take the shots. Even afterward, I didn't really realize how much you have to do after the implant too. Then once I started it and was going through it, I definitely had times where I thought, ‘Oh, I wish I hadn't done this. Oh, this is too much. I can't give myself another shot. I'm so sick of this. I can't do it.’” (pause)

The emotions from the hormones were really hard and hard on my husband and hard on my daughter because I was just so emotional. It was at that point, towards the beginning to middle, of going through all of that, that I thought, ‘No, I'm not doing this again.’”

control. Such feelings and sensations produced emotion episodes, recursively prompting a need for control over their emotionality. This is the lived experience of IVF patients that is captured by the key terms and phrases identified in the opening paragraph: uncertainty -- wanting to know what to expect, dealing with emotionality, and struggling for acquiring or regaining control.

Uncertainty --about the outcome, the effects of the drugs, the side effects, for example--was omnipresent in patients' daily lives, (for some, explicitly called "*a fact of life*") during the entire treatment. All interview patients expressed the notion - some explicitly, others indirectly - that rather than being merely an abstract concept, uncertainty was grounded in what they referred to as their "*reality*". This is true regardless of whether patients felt that they had the ability to reduce or control it. It might seem that because of its omnipresent and pervasive nature, uncertainty might become mere 'background noise' that patients could teach and train themselves to ignore. The actuality for IVF patients, however, is that their day-to-day experience constantly and unremittingly redirects their attention to the uncertainty. This repeated confrontation with treatment events that stimulate the patient's awareness of uncertain risks and/or unpredictable outcomes is, in fact, one of the things that patients most identified as the hardest or most demanding part of the treatment. In brief, the IVF patient experience is, in its essence, a process of confronting and coping with uncertainty.

5.0.1 Governing Uncertainties

Patients expressed uncertainty in a wide variety of ways, for example, through the questions and concerns that they voiced during their clinic encounters (e.g., 'Is this [my symptom] normal?'), through the articulation of their contemplations, doubts, and self-inquiries during the interviews (e.g., 'Am I doing everything I can?'), through their self-reported mentation regarding the assertion of control (e.g., 'I can get through this'), and through their descriptions of devising information-seeking strategies and constructing their understanding of the experience.

Drawing from my field observations and interviews, I was able to categorize patients' reported uncertainty into three governing uncertainties, phrased as the following questions:

1. Will this treatment be successful? And am I doing everything possible to maximize the likelihood of treatment success?
2. What is the drug regimen's effects on my body, currently and in the future?
3. What is happening with my emotional and mental states? How can I manage my emotionality and preserve my view of myself?

Although these uncertainties address different aspects of the experiences, all derive from the central question of whether the patient will achieve the treatment goal of pregnancy. As per all 29 patients, treatment efficacy (e.g., “*I think I was so focused on just, 'Okay, what are my chances for this even working, number 1'*”) is the core uncertainty that loomed overwhelmingly over all patients' thoughts throughout the entire treatment. It manifested itself in various themes⁶ -- for some

⁶ Below I give some sample comments from the patients about their experience as examples of varying themes. For elaboration of the themes, see the discussion in Chapter 3, Section X ‘Data Analysis,’ where I give details about how the themes emerged and evolved.

About acquiring control and monitoring treatment process:

“Try to focus on the little picture, not the big picture because if you tried to focus on the big picture, I think it will crush you. It can be overwhelming. Every day is a step, so one step at a time. It’s how you get there.”

“The [treatment] calendar rules our life [pause], has prevented us from traveling, has prevented us from enjoying time together, that it’s always about, where are we at in the cycle?”

About becoming familiar with the injection process:

“Once you start the Gonal F and then when you add the Menopur, or even little things like Menopur. That burns when you inject it, right? That might be a good thing if somebody told you that the first time around to inject it slow. It hurts.”

About physical symptoms and patients’ expectations:

“It might be nice to have like expected side effects. [pause] Here’s a certain point where when you stop the pills and you’re still on Lupron, you expect to start a period, right? If you don’t know that you’re supposed to be bleeding, and you’re taking all these medications, and all of a sudden one day you’re bleeding, it could be scary, right?”

About treatment decision and clinic encounters:

“You really can’t make that decision until you know what quality the embryos are on the vial. [pause] It was like the embryologist doctor came in and said, “How many do you want?” It’s like[pause] ‘They’re good.’ ‘Okay. One [embryo].’ [pause]t would be better if there was more of a collaborative discussion the day of

patients, for example, in discerning the likelihood of success that best fit their particular diagnosis and health condition, and for other patients, in tracking their milestones, interpreting the lab reports, and figuring out evolving changes of treatment success potential. Almost every patient speculated on correlations between mid-stage results and outcome and attempted to use the results for prediction. All but two patients⁷ explicitly expressed projections about the treatment progress and outcome⁸.

Just as these are all rooted in the core uncertainty of treatment efficacy, as per all 29 patients' statements, these governing uncertainties are themselves interconnected. The interconnectedness of the themes is demonstrated in the commonly reported concern about unusual fatigue. A patient on the alert for physical symptoms may observe excessive fatigue and vacillate between attributing

the embryo transfer to say with the embryologist, with your doctor, with me and my husband. Maybe it's an hour before the procedure to sit down and say, 'Okay. Here's your embryos. Here's what they look like. We know you were thinking about one. Based on your age, based on this, based on how the embryos look, here's what we'd recommend. What do you guys want to do? and let us talk about it.'"

About gaining knowledge and tracking treatment progress:

"Almost like what you can expect [pause]I wanted to know what kind of levels we were looking for [from the lab reports and the physician's feedback]. Yeah, almost that built-in reassurance that, yes, you're on track or no, you're not on track.

One thing that I like knowing when we come in for testing, particularly during the IVF cycle like, 'How many follicles did we see? What kind of size were they getting at? What are we looking to as our goal?"

So our very first cycle, we didn't know what to expect, period, in terms of results. So I didn't really so much think about the size of the follicles as we were going along. I knew what our[pause] we were looking for 20, 21 so I wasn't focused on size at that point. And I wasn't super focused on Estradiol but the second cycle, I definitely then, 'cause our first cycle kinda dragged on a little bit. At that point I started to know more about particularly the Estradiol, I was more in tune with that. Third and fourth cycle, I would [pause]. I was starting to keep track of how many follicles we had. Again, we didn't have very many to keep track of so at that point I wanted to throw in too in terms of size of how quickly were our follicles growing; again, they weren't average. They took a little bit longer and just that helped manage my expectations I think. [pause] I kinda knew what questions to ask (the doctors) and it (treatment) did evolve as things went on. I wanted to know more information the more we did this"

⁷ These two patients were a physician-patient who also had a backup plan (surrogacy) and another who had had three successful natural pregnancies and was undergoing IVF to reverse the effects of a tubal ligation.

⁸ The question of specific numbers is treated in 'Methods,' where I explain that because patients express themselves so differently, I can rarely say '24 patients said that they were anxious about X' and the remaining 5 said that they were not.' The interviews were semi-structured, so not every patient talked about every topic in the same ways. This is a feature of the grounded theory methodology, which emphasizes free-ranging exploration instead of seeking statistical significance. I have tried to give numbers where I can.

it to the drug regimen's effects or to the mental stress from life disruptions caused by the treatment. At the same time, she may worry that it indicates a negative effect on her body, and she may question whether she should take some action, for example, taking vitamins, to guard against the negative effect on her chances of treatment success. A few expressed concerns about whether their fatigue might be the product of stress or depression, which they felt might not be helpful. Finally, a patient may also question the validity or strength of her emotional response to what may be normal or unimportant or wonder whether she can trust her own feelings⁹. In response, she may seek information that will enable her to compare her experience and reactions to those of others. As can be seen, the single stimulus and related mentation and actions can be traced back to the patients' needs to appraise and monitor their treatment progress regarding efficacy (i.e., the first governing uncertainty). Thought patterns such as those described above are the basis on which patients constantly seek to control their emotionality and behaviors in ways that are best suited to bring about the desired outcome of pregnancy.

5.0.2 Uncertainty and Information Behaviors

“I think that the recurring theme is knowing or wanting to know more. If it was bad information, or sorry, if it was negative information, I guess the age-old question of why and what you can expect the next step to be. I think that's the recurring theme.”
~ Patient 25

These governing uncertainties reflect a variety of patient difficulties in understanding, evaluating, or predicting their treatment events or encounters and identifying target areas where they may be able to address problems and exert some control. The ways that patients talked about reducing

⁹ Patients often second-guessed how they subjectively felt about their physical sensations. Below I give two representative examples:

“I felt like I was probably magnifying whatever I was thinking about or worried about.” ~ Patient 12

“I think probably [pause] there's a connection there between your mental well-being and your physical well-being, so I think, I was probably telling myself that 'It's okay.'” ~ Patient 14

uncertainty and acquiring control consistently referenced their information behaviors. Because patients typically said that they felt as if their knowledge and relevant information were insufficient to counter the uncertainties they felt, they engaged in information behavior. By this term I mean several things. First, it refers to information-seeking as that term is customarily understood (online and offline searching to obtain written, audio or video materials relevant to their concerns and inquiries directed to medical professionals and others). In this work, it also refers to the mental activity patients engage in when they interpret things in their environment, for example, when patients count ultrasound clicks to ‘tell’ how many follicles they have or take doctors’ facial expressions and body language as indicators of the treatment progress. Finally, it includes self-observation, which we see especially clearly in patients’ treating their physical sensations as information and their bodies as sources. The patients reported that acquiring control through the acquisition of information was their primary strategy for reducing uncertainty. As the quotations in the following sections will show, all 29 patients emphasized the importance of acquiring adequate knowledge to enhance their ability and competence to control the treatment progress to reduce their anxiety and maintain perseverance.

The stories told by the patients themselves of how their uncertainty evolved with their information behavior (i.e., their search for additional knowledge) undergirds the themes of uncertainty. Reported information behaviors include seeking and receiving information from the providers and from online and offline resources, such as peer patients, libraries, and friends¹⁰. Furthermore, in their fervent quest to assert control and combat uncertainty, they did not limit information-seeking to these sources; rather, they also sought cues and indications from their bodily sensations, from the physical environment, and from their social interactions, particularly with the medical providers. Patients present these information behaviors as the means by which they can target areas for control, such as managing their symptoms and their interactions with the providers and educate themselves to moderate their expectations and regulate their emotions. One of the patients explains the central importance of information behavior very well

¹⁰ Because patients’ efforts to gain and exert control are discussed thoroughly in a subsequent section, I will go into it in greater depth about the information behavior there.

“I mean there's what you can control and what you can't. And this isn't anything that I can control. So, I mean once you understand that it's not anything that you can do anything about, other than get educated, make sure you're getting the best treatment that you can get.[pause]. So, I can't make myself carry a child to full term. There's absolutely nothing I can physically do to make that happen. But I can make sure that [pause] I'm getting the best treatment I feel I can get for the limit of my education, and what I can get my hands on. And that kind of stuff. So for me, my coping mechanism, when it comes to that kind of stuff is just focus on what I can control, and put my energy there, because there's just things you can't.”

It is significant to note, however, as indicated previously, that most patients reported often feeling even more uncertain, more “out of control,” and less able to regulate their emotions because of the information behaviors they undertook. While patients themselves acknowledged the futility of many of these efforts, the continuous stimulation detailed above--the daily regimen activities, extensive information exchange, and changing physical sensations--coupled with their awareness of the high stakes, seems to have prevented them from making effective accommodation to the uncertainty and to have impelled them to continue seeking certainty in some way. In the patients' own words, the experience was characterized by their recurrent references to the conflicting thoughts and feelings (i.e., cognitive dissonance) created by their need for control and certainty while being constantly reminded that they were in an uncontrollable situation and that certainty regarding the outcome was nearly impossible. Thus, patients often displayed ambivalence regarding the information that they sought to resolve their uncertainty¹¹. Many narratives

¹¹ The excerpts below from the same patient are illustrative. Without prompt, she described her information behaviors:

“I did a search just for whatever I could. I looked up what the embryo looks like at five weeks just to see ... and it is just a bunch of little circles and I'm like, “Okay, I'm good.” It was just reading some of the other women that have gone through this. I mean I checked on the internet, I go to work, I'd be reading on the Internet, it was constantly on my mind. It was kind of like up and down, up and down. It was nervous, anxious, like, ‘Let's just get to the second part.’ It is just you're stuck in the house and with this winter we just had, it was a lot of anxiety.”

When asked about her advice to future patients in the later part of the interview, the patient said:

“Do not read the internet because you will make yourself crazy. First time around I was on that thing every night wanting to know; what's the process? Are these numbers good? Are they bad? Don't read the internet. Just reading every night and I was reading it to him (her partner). You try to read medical sites but there are medical sites from the UK, there are sites just everywhere that I was reading. When I started bleeding and I was losing the first one, instantly I'm reading and they're like, ‘Yeah, I bled through my whole

suggested that patients felt something of an unconscious dilemma in regard to their information behavior: whether or not they should seek information as a way of gaining certainty or exercising some control despite knowing that the information itself could sometimes reinforce their sense of uncertainty and being out of control. While these complex reactions will be discussed in depth below, an illustrative quotation here may help clarify some of the ambivalence I observed:

“Gosh, this [searching information online to validate her physical sensation] is embarrassing. I think I typed ‘pain, swelling, and bloating post egg retrieval.’ And I just waited to see what came up. The first five websites were blogs that had been generated by women, kind of just in community forums, and I found it really fascinating. I had, to this point, avoided the forums, because I just didn’t think I needed to look at them, but I think when I was surprised by how I felt after the egg retrieval, then I decided, ‘Let me see if other women were surprised, too.’ I was looking to see, are there other women that are going through this that are having the same symptoms I’m having, because I was a little surprised.”

~ Patient 21

As the above excerpt might suggest, while the patient does not actually say that the information disturbed or upset her, she does express surprise; clearly she became less certain than she was before she looked at the blogs even as she recognized that the sources she had looked at were not authoritative. Another patient also observed that non- authoritative information could have negative effects (*“For me, I think using the internet to read about other people’s things may be a little damaging and maybe not a great idea.”*). The same sensations of embarrassment or self-consciousness about their online information behavior occurred in several other patients’ transcripts as well, and many patients remarked on feeling ‘overwhelmed’ or even ‘confused’ or ‘lost’ while still feeling compelled to acquire more and more information. For example, one patient said:

pregnancy and I have a healthy baby and I’m like, “Okay so could something still be there?” and get the ultrasound.”

“Different opinions, there’s endless opinions and thoughts and endless information. I would [pause]especially when we didn’t know yet what are, we’re going to do, trying to decide that I felt like I needed so much information as possible. Let me stay up till 3 in the morning on the internet trying to figure all of this out. No, I need to sleep. Eventually you don’t need endless information, you need useful information and then you need to sleep.”
~ Patient 7

Another patient said:

“Because you have zero control over the outcome, that at least lets you think you have control by knowing information and managing your expectations so that you might continue to think, it’s not ideal but you can still go on in a positive direction, that was key. [pause] there’s a lot of information that you could get lost in and get completely overwhelmed with.”

~ Patient 25

The interaction between patients’ sense of uncertainty and their information behavior recursively shaped their mentations regarding their treatment progress. These mentations typically focused on the treatment success outlook or probability (treatment efficacy), which in turn triggered their emotionality and prompted reactive or control-seeking responses to foster their sense of positive progress. All 29 patients emphasized the importance that they had assigned to acquiring knowledge to maximize their extremely limited control over the treatment progress and thus to reduce their anxiety and maintain perseverance. As noted in the previous section, IVF patients’ experience is fundamentally a process of identifying the sources of uncertainty and seeking information as a (perceived) means to respond to, cope with or reduce the uncertainty and resulting emotionality. In short, as explained above, the themes of information behaviors, the need for control, and the need for emotion regulation emerge consistently, inseparably, and overwhelmingly from the stories told by all 29 patients, capturing the essence of the IVF patient experience.

5.0.3 Out of Control Feelings and Emotionality

The effects of this overall disquiet in the face of omnipresent and irresolvable uncertainty and the sense of being out of control are clear in patients' statements about the sources of their emotions. Patients reported that the inevitable ineffectuality of their information-seeking to reduce uncertainty and acquire control often produced emotionality itself. Nevertheless, they said repeatedly that they still felt it necessary to exert their best efforts to exercise control, and, when asked about their advice for future patients, all emphasized the importance of acquiring control. This was true even when the attempt to acquire it seemed counterproductive--for example, when lack of expertise prevented them from interpreting information that they found appropriate or judging its credibility, they felt loss of control -- and, often, this iteratively produced emotion episodes.

However, patients mostly described their emotion episodes through the lenses of their concerns about their treatment progress and speculations about the treatment outcome. All recounted, some more vividly than others, emotionality, especially "*out of control*" feelings, triggered by their perceived lack of control over the unpredictable treatment trajectory and the uncertainty of their probability of treatment success. All patients, even those who did not report extreme emotionality, made it clear that negative feelings such as anxiety, fear, worry, and uncertainty preoccupied their minds throughout the treatment. Other feelings besides these negative ones, interestingly, emerged when they described their experience in detail. In recounting their responses to specific treatment events, they again made it clear that they felt many other emotions, including hope, happiness, and pride. The fact that they rarely expressed these feelings straightforwardly or dwelt on them is probably the result of several things: one, that some level of optimism is a necessary precondition to undergoing the treatment; two, that the patients could not always put emotions into specific terms even when their interpretation of the precipitating event clearly revealed emotionality; and finally (and more important), that they felt a strong need to avoid excessive positivity, as will be discussed in detail later. In brief, as indicated above, uncertainty pervades the IVF context, and emotionality of expression reflects this pervasive effect.

Observations of the patients in their interviews are of the assertions made above. Although all patients attempted to maintain an appropriate demeanor, i.e., calm, rational, and not excessively

emotional, and nearly half (14 out of 29) had achieved the treatment goal of pregnancy at the time of the interview, twenty-one of them displayed visible signs of emotional distress, such as wavering tones, watering eyes, and tears. Two of them (both pregnant) even requested that I stop recording so that they could regain their composure. All 29 patients recounted frequently experiencing intense emotions--sometimes conflicting ones--throughout the treatment cycle. Nearly all (27 out of 29) patients¹² overwhelmingly emphasized the dominant effect of emotionality in their overall experience, deeming it the most underestimated yet most pronounced and most difficult aspect of IVF experience, "much harder than the injections and keeping count of vials and stuff," as one patient explicitly emphasized. It is clearly evident in the patients' descriptions of their lives during the treatment cycle that coping with and managing their emotions posed them the greatest challenge in every aspect of the process and led to many of the behaviors that others perceive as irrational.

Situated in uncertainty, driven by the patient's need for control, and manifested through emotionality and information behaviors, the IVF experience is essentially a psychological "*journey*"- the patients' own term - in which they explore and adapt to this context so as to be able to maintain psychological equilibrium and persevere in the treatment. Seen from the outside, this journey appears to be marked by irrational behavior and excess emotionality, and it is common for providers and others who are involved to attribute these to the drug regimen. Further investigation, however, will show that from the patients' perspective, this conventional attribution of the emotionality is not entirely valid, nor is the notion that their behavior is not rational or at least not functional. Just as they cannot desensitize themselves to uncertainty, as noted above, they cannot cease the behaviors intended to resolve it. In the extraordinarily intensively stimulated and uncertain treatment environment, behaviors and cognitive responses that appear illogical and emotions that seem excessive may in fact not be irrational but instead may be functional responses.

¹² These two patients were both physicians and were both also married to physicians. Both patients, despite reporting that they in fact experienced intense emotions of fear and disappointment, stated that they were able to regulate them to minimize negative effects to their daily life and adherence. The first patient explained that she did not identify herself as a fertility patient because her husband, who had cancer previously, was the one having fertility issues, and not her.

The second patient stated that her emotionality was ameliorated by her familiarity with the treatment protocol, her plan to have a surrogate mother (if the treatment failed again), and her busy work schedule.

These behaviors and the cognitive and emotional states that give rise to them, especially the state that we will call *calibrated uncertainty*,¹³ (to be developed further in Section 5.2). Briefly, it is the state of mind in which a patient simultaneously seeks certainty while entertaining doubt and even rejecting certainty because certainty in some aspects of the experience is psychologically unacceptable. The latter is surprising and has not, to the best of my knowledge, been discussed elsewhere. However, exploring this dissonance is critically important for our understanding of IVF patients' emotions, their behavior, their relationships, and the extraordinary perseverance these patients display in the face of great difficulty and low chances of success. This work treats deliberate cognitive dissonance and related concepts in depth.

It is essential to note from the outset that, although the organization of the findings in the following sections isolates the themes of uncertainty, control, emotionality, and information behaviors, these themes overlap in meaning and are discussed discretely only for clarity of the analysis. In the sections below, I will discuss each of the governing uncertainties in terms of how patients express them and how their descriptions of their experience reveal the underlying psychological mechanisms or processes, which can be explained in terms of the notion of calibrated uncertainty.

5.1 Governing Uncertainty 1: Treatment Efficacy - Will This Treatment Be Successful?

"I just felt like I was a mother and I didn't have a child. But, I was a mother. It was just scary to [pause], it just felt like my biggest dream - my biggest hope and dream - and, then I wasn't sure if that was gonna happen. So, that was the hardest part."

~ Patient 24

¹³ While cognitive dissonance is ordinarily understood as an uncomfortable state that demands resolution, this *calibrated uncertainty* is actually desirable in the IVF patient, where it functions as a coping mechanism.

Uncertainty about the treatment's efficacy is the most weighty and ubiquitous concern for all IVF patients. All emotion episodes and difficult situations that patients talked about at length, broadly speaking, revolve around this uncertainty. This is because for nearly all patients, treatment failure or the prospect of it is absolutely "*devastating*," as some described it, while treatment success means that their biggest "hope and dream" in life has come true, as shown in the above quotation. Patients were intensely aware that they were taking part in a risky, "*high stakes gamble*," as one patient also said. The treatment's perceived low success rate is a serious concern for every patient. One patient expressed this very directly:

"Yeah. I understood, okay there's risk to this, and there is a chance of multiples, but that's not the top thing on my mind. The top thing is, is this going to work?"

~ Patient 2

Another patient, who was discussing her decision not to have a subsequent treatment, also captured the experience confronting the perceived low success probability.

"It's a roller coaster, it's mentally stressful. It's not the nuts and bolts of the shot and it's not the side effects. All that stuff is part of it but it's more just the mental drain of dealing with the potential disappointment. The feelings of is it going to work? Is it not going to work?"

~ Patient 4

While both interview excerpts clearly express the enormous concern, patients had regarding the low success probability - it is the heart of the treatment efficacy concern - these excerpts understate the complicated nature of patients' actual experience in confronting it. As explained above, patients' actual daily experience is in fact tied to the objectively demanding and complex nature of the treatment process itself. That is, not only is absolute and regimented compliance required,

which by itself can overwhelm patients and foster in them a sense of ineptitude and impotence¹⁴, but they also have no way of judging how well or badly their performance may affect the outcome¹⁵, since evaluations or ratings of the effect of events during the treatment process in respect to the final outcome of pregnancy are also unavailable to them

One patient reflected on her changing perceptions of the treatment, stating,

“My concept of what IVF was before actually doing it was very simple. I didn't realize how [pause] yeah, there's maybe some surgery stuff. I don't know, but I didn't realize that I'd be taking injections all the time [pause], pills, [pause] and it would be very complicated, regimented and then what I didn't also realize is, from hearing about other people's experiences on the [patients'] forum, is that I feel like this is partly art, partly science, and people are doing all kinds of different things, and their bodies are all different.

I don't know [what questions I should ask the doctor about]. Part of me was curious about just data, just more data. What are our odds at each little stage? Can you find the estimate of the probabilities of things based off of our specific conditions? Given that we've made it this far into the process, what are our odds going forward?”

Although this patient was a nurse, her medical background and familiarity with the demands and practices of medication administration did not prevent her from reacting to the burdensome and complex nature of the regimen and from being inquisitive about her treatment progress and treatment efficacy. She articulated her desire to measure and appraise treatment efficacy while

¹⁴ On top of the lack of expert knowledge, the sight of large quantities and varieties of drugs (typically enough to completely fill a regular file cabinet), and the self-administered medication requirements often astonish patients, making them feel “overwhelmed” and inept, as one patient commented:

“If you're not a medical professional, it just seems like the first time you have to give yourself a shot it just seems like this is so wrong, somehow. You know? That you're under-qualified, you can't believe they turned you loose with this. [pause] You've got these needles. It just seems like, you're doing it in your bathroom and it seems like you should be at a hospital [chuckle] in a controlled setting. Yeah, that part kind of messes with you a little where you just gotta get over it. “

¹⁵ A representative statement expresses this commonly shared experience:

“You worry about all that stuff in the beginning because you don't know. Then I would tell you a lot of other things like when I first started IVF and they called me and said, “Well, you're not responding very well.” I don't know, it's like you want to know and they tell you these numbers and you're like, that doesn't mean anything to me.”

she was still in treatment progress; paradoxically, she simultaneously displayed her doubts and her recognition of the infeasibility of doing so because of the innate complex nature of the treatment. (e.g., she terms the process “*partly art, partly science...different*”; and says *I don't know [what questions I should ask the doctor about]*). Also of note, she stressed that what she desired was not merely the general objective ratings (i.e., quantitative or percentage expressions based on general conditions of a cohort of patients) of the ongoing treatment process in terms of its efficacy, but essentially a series of ratings individualized according to her personal condition and a corresponding outcome projection at different stages. (*What are our odds...our going forward?*).

The dissonance illustrated by the above excerpt between this patient’s desire to acquire more information to learn about and to track her progress and her co-existent acknowledgment of her lack of ability to do so effectively was, as mentioned above, not unique to this patient. In fact, this mentation is ubiquitous among IVF patients. All patients recognized and understood, to various extents, the objective truth of the unpredictability and immeasurability of the IVF treatment process. The experiential actualization of this understanding, however - while patients were being bombarded with demanding treatment activities day in and day out and subject to momentarily changing physical sensations, and while their mentation was constantly being inundated with unfamiliar, complicated and technical treatment information input-- was difficult for them in practical terms.

Excessively and continuously burdened in every aspect - physically, mentally, and medically, patients constantly re-experienced and elaborated on their concerns. In other words, the numerous daily demands of the treatment (including performing self-injection; tracking drug inventory and

managing drug supplies¹⁶; adhering to the treatment calendar¹⁷ for appointments for blood tests, ultrasound examinations, physician's consultations, and egg retrieval and embryo transfer procedures; understanding perplexing lab reports; coordinating with nurse or clinic staff for potential daily drug dosage changes; making both anticipated and consequential decisions, such as the number of embryos to transfer, and impromptu judgments about relevant matters; and dealing with physical discomfort and side effects serve as an incessant stimulus for self-questioning and doubts. In response, patients dwell on their uncertainty, asking themselves, for example, *Am I performing as perfect a compliance as I possibly can?*, *What's going on with me today and right now when I am observing such a strict and complicated compliance?*, and *Are there additional things I should or can do to increase my chances?* This fact of life for the IVF patient, confounded with the personal significance of the treatment outcome, leads these patients, understandably, to feel trapped in an inevitable state of cognitive dissonance, in which both their desire for control and their sense of uncertainty about their ability to achieve it are magnified.

More importantly, the excerpt quoted above reveals the patient's key underlying concepts that drive her mentation and prompt her actions: the meaning of expectation, the evolution of the success outlook, and the search for control. The interview excerpt below, provided by another

¹⁶ Patients are required to track their drug inventory daily to ensure they have sufficient drugs for continuing their regimen. This process can be complicated and stressful, not only because of the unpredictability of the treatment trajectory and patients' unfamiliarity with different drugs' labels but also the operational constraints of the clinic, specialty pharmacy, and delivery service. That is, IVF drugs are mostly carried only by a few specialty pharmacies, which, in addition, typically do not stock the drugs for over 48 hours. Therefore, patients must diligently track their drug inventory and plan ahead. When additional drugs are needed, patients must 1) promptly initiate a request to refill the needed prescriptions from the clinic; 2) ensure that the prescriptions reach the specialty pharmacy in time and the pharmacy processes the drug order correctly and in a timely manner; and 3) confirm the delivery of the drugs and verify the accuracy of the drugs received.

This whole process may involve many back-and-forth communications with insurance, the nurse, the pharmacy, and if applicable, the delivery company, and all must be done in an accurate and timely manner. Clearly, even a calm and well-organized patient would find this stressful, especially when the stress is coupled with the fear that any mistake could sabotage the entire regimen.

¹⁷ The clinic schedule is tentative, subject to change depending on the patients' condition and their response to the drug regimen. For example, the stimulation stage may last from 8 to 16 days. Patients' embryo transfer day may also move from the original planned 5th day to the 3rd day, or vice-versa, because of the actual development of the embryos. The disruption that these irregularities bring to patients' daily lives produce significant stress.

patient ¹⁸who was a typical member of the cohort of patients, further exemplifies this mental state of preoccupation with uncertainty about treatment efficacy:

"So I think it's oftentimes, around issues of odds, and likelihood, and trying to understand my specifics. ² So if I start with 28 eggs retrieved, and then on day three I had this many, and then on day five I had this many, what is the likelihood of success?

³ Should I be really excited? ⁴ Should I not be really excited? ⁵ What's the likelihood, like how excited should I be? ⁶ How much should I be thinking this is gonna work? ⁷ I think that seems to be my big question; all the time it gives me some sense of, should I keep going down this path or do I need to look into alternatives? ⁸ And I know there's no answer, but you always wonder like, 'Were we close'?

⁹And how much should I be preparing myself for, there's a really high chance? ¹⁰ 'Cause I think sometimes what I'm trying to understand is how much I should manage my expectations. ¹¹ And so if I know how to manage my expectations, then I'm setting myself up better to survive this process." (S13 A133)

5.1.1 "How Should I Feel?"

As in the above extract, uncertainty is clearly evident and explicitly expressed in both the patient's language and her cognitive patterns. With respect to language, the extract consists of eleven separate utterances (as determined by the transcriber on the basis of pauses and sentence contours), of which only five (1, 7, 8, 10, and 11) take the form of declarative statements and three (or, arguably, four) contain an embedded question. The others are all explicitly interrogative. The sheer number of questions to the self-shows a high level of uncertainty. Further, the frequent use of "I", which occurs 18 times in these eleven utterances, indicates a consistent elaboration of personal meaning-making mentation through self-interrogation. The verbs she most often associated with the subject "I" (e.g., "I think" or "should be thinking") emphasize doubtfulness or a lack of certitude rather than the sense of certitude shown in her statement "I know there's no answer"; in her choice of verbs we see both her strong desire to understand the changing efficacy of the treatment and her recognition of the difficulty --or even impossibility-- of achieving that understanding, given the complexities involved. The one sentence in which the subject is not "I"

¹⁸ This subject is in her late thirties, middle class, and a working professional.

occurs at the end of utterance 8, which contains single instances of the generic “you” and the personal “we” as subjects(...*but you always wonder like “Were we close?”*). Although there is perhaps some room for doubt, the generic ‘you’ reflects some distancing of herself from the assertion, and the “we” here can be plausibly interpreted as referring to the patient and her partner and to the medical staff at the clinic. The patient’s shift from “I” to “we”, in addition, reflects her need to bring the provider and his/her expertise into her evaluations to give validation to her estimation or thinking. Last, but not least, the repeated uses of the modal verb of obligation *should* accentuate, furthermore, her value judgement and her strong need to regulate or control her emotionality and mentation as well as her treatment progress. Overall, this long sequence of self-questionings gives the extract the air of an internal monologue revealing her troubling indeterminate state between antithetical pairs like “*Should I be really excited?*” and “*Should I not be really excited?*”.

She starts out by attempting to deal with all the uncertainties through focusing on specific tangible facts—by assessing “*the likelihood of success*” in terms of the numbers of retrieved eggs at certain stages in the IVF treatment. But in the second section, she expresses consternation and anxiety about how to “read” such tangible facts in terms of how they are directing her outcomes and decisions (...*my big question all the time is...should I keep going down this path or do I need to look at alternatives?*) Finally, in the third section, she admonishes herself for not doing a better job at managing her expectations, of learning to be realistic and avoiding the wild swings of optimistic hope and pessimistic fear, thus setting herself up “*better to survive the process*”. Looked at as a whole, the series of utterances reflects both her need and her inability to appraise the status quo of her progress during the IVF treatment, i.e., to determine how “close” she is to reaching the goal, and shows how this tension gives rise to feelings of uncertainty, disquiet and concern. More importantly, it reveals the patient’s key underlying preoccupations that drive her mentation and prompt her actions: the meaning of expectation, evolving success outlook, and control-seeking.

5.1.2 “Expectation”, the Evolving Success Outlook and “Control-Seeking”

The meaning of “*expectation*” is important to examine closely because it is crucial for consideration of how patients manage their expectations, which was an important and commonly expressed concern in all transcripts. There is an interesting discrepancy--which again manifests itself as a kind of cognitive dissonance in the patients--between the ordinary usage of ‘expectation’ and the patients’ use of the term. This can be explained partly by the clinic’s efforts to provide thorough and well-delivered patient education and procedure management. Patients were well-informed about the sequence of events and milestones and were given detailed descriptions of all of them. No patient expressed the inability to know what to expect with regard to the procedures and treatment events; the regimen requirements, actual treatment tasks, and treatment activities, day in and day out, are known to the patients, as the ordinary usage of the term would convey. For them, ‘what to expect’ translates rather to “what the likelihood of success is for me.” This meaning of *expectation* is the prevalent one among my interview participants. Frequently used expressions like “*I want to know what to expect*”, “*I don't know what to expect*”, or “*I just don't know what's going to end up happening*”, which reflect emotional episodes in most cases, all pertain to this particular notion of their term “expectation. That is, *expectation* is associated with the absence of predictability and knowability or the inability to obtain reassurance regarding the success outlook and probability, or, as we termed it above, treatment efficacy uncertainty.

For many of the patients, adapting their mentation and strategies to changing stages as the treatment evolved was the primary concern throughout. Patients emphasized the importance of *expectation* management to combat this core uncertainty, as is shown in this patient’s speech above, where it is clear that *expectation* can be understood as a mechanism derived from control-seeking, i.e., the patient’s desire to track progress and monitor treatment efficacy. This sense of expectation is reinforced by patients’ frequent talk of expectations or expectation management in the context of their difficulty (re)interpreting of lab reports (as with this patient), or their inability to predict their treatment trajectory.

The patient whose voice is heard in the excerpt quoted above fixates on a succession of intermediate staged results (28 eggs...*I had this many*) to formulate her expectations, i.e., the success outlook or probability. This is because, as the statement strongly implies, for her the

success outlook is fluid, evolving, cumulative, and subject to change. In other words, her treatment outlook needs to be constantly updated, though it at times appears to be idiosyncratic in the methods they used, as she progresses through new encounters and receives additional information.

Moreover, the success outlook she particularly concerns herself with is the “*specific*” one that fits her individual condition, not the general success rate provided by the physician or by the data she acquired from other patients (“*trying to understand my specifics...what are our odds*” [emphasis mine].) She realizes that this individualized outlook is difficult to obtain or to calculate, (“*I know there’s no answer, but you always wonder like, ‘were we close?’*”), and thus she does not aim for precision or a definitive answer. Rather, she emphasizes establishing an appropriate state of mind that accurately reflects her treatment success/failure potential so that she can manage her expectations as preparation for her anticipated emotionality. Although idiosyncratic ways of adapting to and coping with changing conditions appear in the interviews, it is clear that *expectation management* can, as noted above, be understood as a mechanism derived from the patients’ awareness of their inability to control the treatment progress as it continually evolves or the emotionality that this produces.

5.1.3 Establishing a Realm for Control

Although there is room for other interpretations, we can reasonably posit that the patients emphasize expectation management in their description of their experience because it reflects their/an overarching desire to regulate their emotionality and acquire control. For them, it is important because it is profoundly tied to their emotional well-being--even to their ability to function well enough to persevere through the treatment. Like the patient quoted above, the majority stated, explicitly or implicitly --that the challenge of managing their expectations was the main source of their emotionality.

Patients also expressed, directly or indirectly, that their emotions were the primary instigation of their search for control; most patients admitted that emotionality did cause some disturbance in

their psychology and decision-making¹⁹, whereas most also aspired to be rational decision-makers and believed that they have reasonable competency to complete the treatment. The control-seeking, thus, becomes a natural response to such a sense of self-belief. The triangular relationships among expectation management, emotionality, and the need for control determine the mentation of the patients and their quality of the experience.

All that notwithstanding, despite the importance that most patients accord to formulating and managing their expectations, they are aware that doing so is not entirely within their control. The patient quoted above directly pointed out this difficulty, or near impossibility (“*I know there’s no answer*”) of arriving at a correct or even an adequate success probability. Nevertheless, this patient continued to speculate on how she might work toward arriving at it, apparently presuming that it would help her to preserve herself from her emotionality in anticipating the future outcome. In other words, the entire deliberation on expectation management was directed by control-seeking mentation to establish the most suitable expectation for her adaptation to control emotionality and to complete the treatment. In psychological terms, the tension between this strong desire and the practical inability to monitor and predict treatment efficacy conditioned patients' psychological context, which recursively prompted emotionality. That is, sensing or realizing that the emotionality may not be conducive to maintaining psychological equilibrium, patients aimed to establish a sensible range based on which they could better function and maintain perseverance.

As the account of the patient quoted above shows, despite the dissonance between their desires and the feasibility of satisfying them, patients were in most cases determined to establish a realm of control, that is, a sphere in which they could to some degree resolve their uncertainty and regulate their emotions. It is important to stress here that while there are indeed individual differences in the relative strength of their concerns and their styles of expression, the focus on acquiring control appears, sometimes frequently, in all 29 interviews. The patients' words reveal that they long to be able to measure or estimate their treatment progress in terms of its efficacy so they can adjust adaptively and respond with better practices to influence the path, i.e., the treatment

¹⁹ For example, one patient, a physician, deferred treatment because of an exaggerated fear of the potential detrimental physical effects). Another five patients decided to not to undergo the subsequent treatment because of unbearable emotional distress s had experience.

progress, to a desirable outcome. This mentation is seen in the stories told by many of the patients, about confronting discomfiting ambiguity, e.g., in lab reports, [*What does it mean? Is 15 eggs good [given my condition]? Or about over-reacting to or over-analyzing physician feedback, (e.g., “What did Dr. Jones²⁰ mean by ‘looking good/not responding’?”)*], We see this cognitive behavior particularly clearly in some patients’ determined pursuit, whether via their own information-seeking or inquiring of their physicians, of answers to questions that even specialists cannot provide (e.g., “What makes my FSH (hormone) level high?”, " Why did my last treatment fail?" or "Does 20 retrieved eggs this time indicate a better chance to become pregnant than 18 eggs that I had last time?" Patients’ frequent expressions particularly related to expectation management (e.g., *“I want to know what to expect”*) and their information behaviors (i.e., information seeking and interpretation) for success outlook all evince this control-seeking mentation.

5.1.4 Treatment Efficacy - Interpretation of Success Rate

“So the fact that in an IVF cycle, you can spend upwards of \$15,000 out-of-pocket, put your body through enormous distress, and strain your relationships, and have to take time off from work, and still at the end of the day not have a result guaranteed, that's difficult. But the part about not controlling has to do more with you can do everything the doctor says, and it may not work. And that's true of very few other diagnoses. It's true of things like cancer, things like heart failure. It's true of major chronic illnesses, but not true, usually, of things like infections, things like a fracture.”

~ Patient 21

The principal measure for treatment efficacy, conceded by both patients and physicians, is the treatment success rate. Physicians customarily supply a percentage to help patients in decision-making and managing their expectations. An individual estimated success rate, based on the physician’s diagnosis and prognosis, is given to all patients, mostly at the time when IVF treatment is recommended. This physician-provided success rate is typically between 4% and 40% and is dependent on a patient’s age and individual health. Regardless of where within this range an

²⁰ The name was replaced as part of the de-identification process.

individual patient's percentage fell, all interviewees perceived their rate as low, and nearly all (28 out of 29) perceived IVF as a matter of beating the odds.

While all patients were conscious of their success rate and most were well-educated professionals, surprisingly, only one patient talked specifically about her individual success rate. She mentioned it in the context of how she had factored the success rate into her decision-making of the number of embryos to transfer. She said that because of the low success rate (in her case, 15%), she decided to transfer two embryos, instead of the single one that was recommended by the physician.

More typically, patients focused on the movement/trend of the success rate, instead of on a static and precise number. Every treatment encounter stimulates patients' updating of their success outlook despite feeling emotional exhaustion in doing so. Patients rarely talked about success rate just by itself during interviews, even though they were all fully aware of its significance in their expectation management. Rather than discussing and analyzing it at length, they often mentioned it briefly.

Furthermore, when they spoke about it, rather than using the exact statistics, interestingly, they described it with the broad understanding they had from the overall treatment outlook perspective. Patients' expressions of their success rate include an exaggeratedly high or low discrete number, such as "99%", "0%", "75%" or "50%", or a qualitative or emotional adjective with or without a number, such as a "high", "low", "good" "bad" or "better" success rate or a "depressing" or "awful" success rate. This seeming vagueness and broadness was common even among patients from whom precision might normally be typical.

Moreover, as noted above, patients fixed on the perceived movement and ongoing progression of the success rate more than on the static number they were initially given²¹. Information from their treatment encounters, whether a lab report or physician's verbal feedback, always served as a

²¹ The following two statements exemplify this theme. The first patient described how she focused on charting the trend while the second patient emphasized making comparisons with reports she found online:

- a) *"you're always looking ahead at what the next possibility could be [pause], that kind of thing";*
- b) *"I've looked at medical studies in terms of age and number of follicles [pause] all these different factors trying to figure out [how to interpret my daily incoming lab reports]."*

stimulus to adjust or update their notions of the success rate²². Extraordinarily, these adjustments occurred even though many said explicitly that constantly updating and (re)interpreting their success outlook was mentally draining and caused mood swings or vacillation in their emotional states.

Interpreting and revising the success rate typically starts with patients' consideration of the baseline obtained from the "credible" sources, which include the physicians in the clinic, SART, other fertility clinics, other medical professionals, published articles, magazines or books, popular patient forums, their trusted friends/family, someone that they identified as having a physiological resemblance to them, or, in most cases, a combination of these²³. No matter where the information comes from, patients tend to interpret the success rate in their own way. This is because the ways in which patients formulate their success rate or success outlook are almost always affected not only by their presuppositions of its dynamic evolution, as discussed in the previous subsection (i.e., success probability is cumulative and subject to change), but more significantly, by their individual control-seeking drive, which arises in response to their emotionality as a means of combating treatment efficacy uncertainty.

Below I will describe three typical methods by which patients arrive at their interpretation of their success rate: (1) fixating on a 50-50 probability, (2) assuming a binary (successful/unsuccessful) dichotomous grouping, and (3) calculating a cumulative probability. The first two of these focuses primarily on emotion regulation and the third on reducing uncertainty. It is important to note that I describe these methods separately primarily for clarity. Most of the patients actually used all

²² Except in a few cases (5 out of 29), statements describing patients' mentation about tracking and updating their success rate (notions) were explicit in the transcripts.

²³ Common patterns of formulating a baseline success rate typically starting with the physician-provided success rate, followed by subsequent adjustments accordance to one or a combination of the following:

- a) Patients use their understanding about their health condition and diagnosis and information sought from other resources such as SART, other providers, or other medical professionals.
- b) Patients arbitrarily factor in or compare their condition or situations with those of other patients. The factors patients used included age, diagnosis, lab results, physiological attributes, physical symptoms, severity/extents of the physical sensation, number of treatment cycles experienced, progress and duration of the ongoing treatment, lifestyle, or even profession, social status, and social relationships.

three methods interchangeably and/or in combination, though individual patients typically use one of the three methods predominantly. All patients talked about cumulative probability at some point, and most patients spoke of themselves as pregnant or not pregnant. Patients' coping styles, while in many ways similar, vary; the separate descriptions show how coping styles are related to patients' preferred methods. Moreover, patients' preferences also change as new information comes in through treatment encounters. The patients' thought patterns displayed many similarities, as the separate descriptions will show. This is because patients' application of the method, whether it was a deliberate choice or intuitive response to the circumstances they were in, primarily depended on their sense of their emotional and control-seeking needs at the time.

5.1.5 Success Probability I: Fixating on "50-50"

One patient spoke clearly about her notion of success rate, naming it "50-50." For this patient, "50-50" captures her thinking about her success rate: *"It is essentially 50-50; either you are pregnant or you are not pregnant"*.

This interpretation, according to the patient, enabled her to manage her emotions of despair and hopelessness after a poor prognosis. She justified this reasoning as sensible because after all, the treatment would, no matter how low or high the chances of success during the treatment stages, stochastically conclude with only one outcome, pregnancy or no pregnancy. This "50-50" interpretation essentially allows patients to obfuscate and disconnect intermediate results from the final outcome, enabling them to dismiss or devalue the significance of any progress reports, either positive or negative ones.

This statistically illogical 50-50 conceptualization was extended and used in relation to matters other than the success rate; for example, it was employed in a difficult decision-making process faced by two patients, both of whom were highly trained medical professionals. Because of their low egg counts (fewer than 3), these two patients received strong advice to discontinue treatment. In the face of this statistical argument against it, however, both made the decision to continue the treatment, claiming that they needed only one egg to become pregnant.

5.1.6 Success Probability II: Assuming a Binary Dichotomous Grouping of Patients

In a similar way, other patients described conceptualizing given their chance of success (x%) by logically dividing patients into two groups, the successful group (the x% - invariably a very low percentage) and the failed group (non-x%). The figure a patient was given as her likelihood of success (typically <40%) did not matter to her, because she could determine by her own volition which group she assigned herself to. To explain how the patients are thinking about this dichotomous grouping: although the patient does not articulate it to herself in these terms, by placing herself in the 'successful' group, she is aligning herself with those whose chance is predetermined to be 100% by definition. Conversely, aligning herself with the 'unsuccessful' group would, in her mind, be tantamount to saying that her chance is 0%.

To give a specific example, one patient said that when she made the decision to undergo treatment, it was in the certainty that she belonged to the group that would be successful, despite the fact that this group was a small minority. After the first treatment failed, she reported that she was in emotional limbo because the failure forced her to readjust her way of thinking about her chance to become pregnant. Confronted by reality, she had to accept intellectually the possibility of being in the unsuccessful group in her second treatment, but emotionally she rejected that possibility and constantly changed her mind about which group she belonged to, the X% or the non-X%, group. While this approach defies any real logic with respect to the results of intermediate events or milestones to the final outcome, (e.g., "low/high egg counts don't necessarily predict final treatment success") it does enable patients to deal with the psychological impact of their percentage of success in their own way-- a way that preserves their emotional equilibrium.

5.1.7 Success Probability III: Calculating Cumulative Probability

5.1.7.1 Patients' Bodies as Controllable Sources of Information

Much as some patients downplayed the importance of intermediate stage results, i.e., they adopted the 50-50 and probability irrelevancy mentation, as discussed above, other patients took the opposite position. They fixed their attention on trying to identify and extract information predictive of the outcome from complex medical reports or to establish a precise correlation between each of their intermediate stage results and the final pregnancy outcome. Because no such information or correlations are available, these patients, in order to compensate for the infeasibility, resourcefully used everything in the environment as a source of interpretable information. For example, they kept a watchful eye on their treatment encounters, surveilling exhaustively the setting and social cues, such as the tone or body language of the physicians, for any hints or additional information. One patient described how she paid attention to the clicks emanating from the ultrasound machine during her routine ultrasound exams. She said she could get information, such as the total number of eggs produced, their developmental condition, and how “clustered” they were, by counting the number and duration of the clicks. She said some of these details are often missed by the physician when providing feedback, but it was important to her because such information helped her to know her treatment progress and “how to feel” about it.

Perhaps the most noteworthy form of resourceful information-seeking is patients' treatment of their own bodies as sources of information and their bodily sensations as data. This is critically important because it is tied to their sense of self-agency; the body is the only source of information that is entirely theirs, not subject to anyone else's interpretation or control. Patients often go beyond physicians' recommendations in eagerly extending their observation to other biophysical states. They explained this behavior to collect more data about their condition and treatment progress. One patient, for example, reported that she had formed a routine to get up at 4:30 am daily to record her basal temperature, mucus clarity, and other physical symptoms/states. She not only recorded them but also charted and analyzed them. She presented me with multiple pages of trend charts displaying hundreds of numbers quantifying the data. She characterized this behavior as “insane”, and it was in fact quite extreme, but her active approach - using her body to generate

data and information useful for assessing her treatment progress - is not uncommon among IVF patients, who, as noted above, exhibit cognitive dissonance regarding the importance they assign to actions they know or suspect to be ineffectual.

5.1.7.2 Compulsive Information Behaviors

Admittedly, these overenthusiastic information behaviors, particularly those involving seeking or generating specialized medical information for confirmation or calculation of treatment efficacy, may temporarily afford patients some illusory sense of control, enabling them to place their attention on and exert effort toward "doing something" to reduce uncertainty. The information they acquired or generated - for them, mostly uninterpretable, however clear it might be to the medical professional - in fact, increased their sense of powerlessness, rather than decreasing it and thus magnified their uncertainty--and thus their need for control--rather than reducing them. Nearly all patients were intellectually cognizant of the futility of these attempts, like the two patients described in the previous subsection; nonetheless, almost all of them (28 out of 29) recounted, in one way or another, an effort or efforts she made to initiate such information behavior so as to be able to interpret her ongoing treatment results and thus to cope with treatment efficacy uncertainty.

The chart on page 80 displays the extent to which patients acquired, generated, and/or used specialized medical information and the importance of the information behavior as a means of managing and resolving objective treatment efficacy uncertainty. I generated this chart by analyzing, classifying, and comparing expressions in the recorded transcripts. The right end of the spectrum represents one extreme; patients placed at this end expressed the least fixation on such information to predict the outcome of pregnancy. These are exemplified by the patients who used the 50-50 and fixated at binary (successful or unsuccessful) probability methods. The left end represents the opposite extreme; patients placed at this end made exhaustive (cognitive) efforts to acquire and use specialized information, not only tracking the number and size of their follicles and their follicle development daily but also dwelling on uninterpretable technical details-- some of questionable relevance to her individual situation, such as the "right" or "normal" quantity and

quality of her follicles; the proper estradiol (E2) and Anti-Mullerian Hormone (AMH) hormonal levels; the pros and cons of different insemination technologies; the efficacy of various cultures for embryo development; and the properties or ingredients of the drugs and their efficacy correlated with various physical symptoms.

As might be expected, the majority of patients fall in the middle range of the spectrum, which means that they did not dwell obsessively on scientific explanations or technical calculation of the mid-stage-to-final outcome correlation but did respond to obviously good or bad news, such as ‘egg production less than 3’ or ‘embryo quality is graded as AA.’ It is important to note that because I did not use or devise any quantitative measurements to count the frequency of the expressions or uniformly obtain patients’ specific assessment of the significance of the behavior, through iterative analysis and comparison, I determined the placement of the individual patients relative to one another and to the group as a whole. That is, patients on the left side in general are those who displayed these information behaviors more prominently than the patients next to them on the right side (e.g., patients 13 and 18 showed more prominent information behavior than patient 21).

While this chart places each patient in approximately her most characteristic position relative to the rest of the group, the positioning is not rigidly prescribed. Rather, the positioning should be understood as bounded within one of the five large groups, indicating that differences among patients within each group are not so stark that strict placements would be meaningful. The circles are also intended to convey the important fact that patients typically do not remain stationary at a single point in the spectrum; rather they move in response to treatment events and other occurrences, but mostly within a limited range. I use a dotted line and gradient shade to indicate the nature of the movement. Although it is not to be expected, nor is it common, patients may drastically change their methods of interpretation; for example, consider the two patients, patients 8 and 22, in the dotted circles as examples. These two patients shifted their positions from a more scientific investigative mode of interpretation (i.e., toward the left end) after being told that they had produced fewer than three eggs. They decided to dismiss the scientific facts and the physician’s advice to discontinue the treatment because “*you only need one egg to get pregnant.*” as one of them said.

As noted above, this visualization scale, rather than relying on quantitative measurements, reports the expressed prominence of relevant expressions in patients' voluntary accounts of their coping or characterizing the information-seeking behavior for reducing treatment efficacy uncertainty. Given that all patients are cognizant of the objective unpredictability and uncertainty of the treatment, the scale also reflects the relative strengths of patients' control-seeking desires for combating treatment efficacy uncertainty. That is, the patients at the left extreme manifested the strongest control-seeking desire through their information behavior and those at the right end showed the least. This chart has both theoretical implications, which we will discuss in the next chapter, and implications for practice, because patients' information behaviors are mostly recursively directed by provider - patients' interactions and treatment encounters.

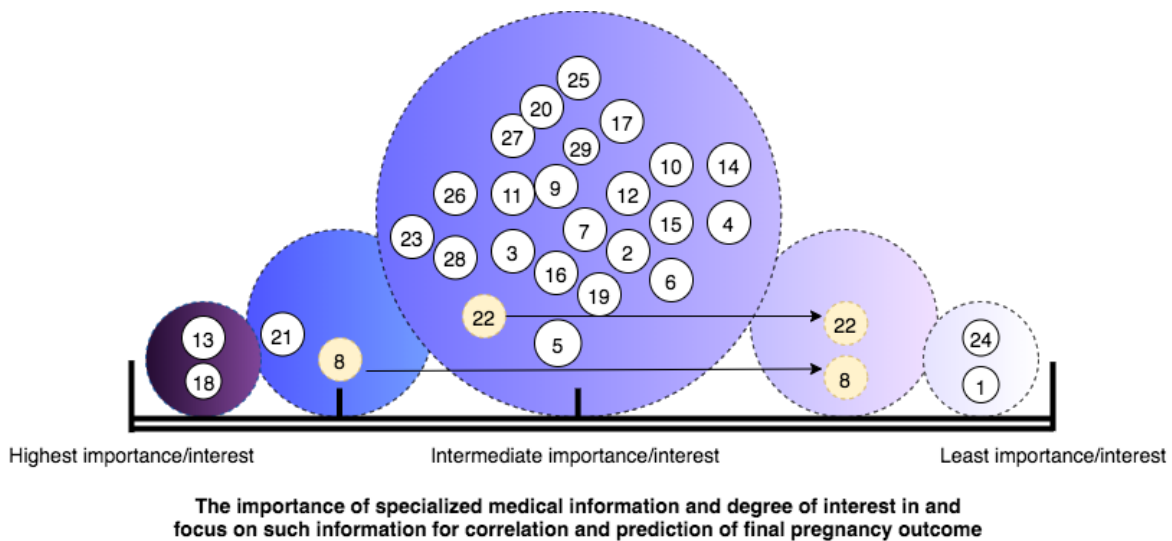


Figure 8. Order of Importance of Specialized Medical Information

5.2 Governing Uncertainty 2: Uncertainty About the Drugs' Effects on the Body

My stomach was expanding, I was just really, really uncomfortable, I spent a lot of days in bed, I'd have to come home from work and so I was just thinking, 'Is this really how I am supposed to feel, maybe this isn't right?' Started questioning things."

~ Patient 14

As the excerpt above might suggest, concerns, and worries about their physical sensations, symptoms, and potentially negative effects of the IVF drugs are pervasive; all 29 patients repeatedly raised the topic in their interviews and said that it was a concern. In one sense, this is hardly surprising. Not only does the IVF procedure involve the ingestion and/or injection of a tremendous quantity of unfamiliar medications, the administration and management of these drugs impose daily burdens that continually direct patients' attention to this aspect of the treatment. The side effects and physical sensations also serve as constant and unavoidable stimuli. Finally, the high stakes and uncertain outcome of the procedure magnify the patients' awareness of their physical state, particularly at procedure milestones.

In another sense, however, these concerns and worries about the drugs' effects on the body, including possible deleterious effects on patients' health, might seem inexplicable. As noted previously (see Chapter 2 "Background") in this work, IVF is a well-established procedure that has been shown to be safe. The physical effects of the drugs are, with rare exceptions, tolerable and insignificant²⁴. IVF patients are fully informed about what to expect in the way of physical sensations, and they are in constant contact with providers who can in most cases reassure them that their symptoms and sensations are normal. Abundant reliable science-based sources reaffirming the safety of the procedure are widely available to anyone who seeks them out.

Yet all of my patients --most of them well-educated professionals who characterized themselves as rational and generally in control of their emotions --spoke of being 'concerned', 'worried,' 'scared', 'frightened', and even "surprised' about what might be happening in their bodies as a result of the drug regimen, and, for many, the uncertainty surrounding the question of the drugs' effects was a source of intense emotion episodes, conflicts (overt or unarticulated) with providers, seemingly irrational behaviors, and information behavior that appears odd but is similar in a very profound way to that which was common in response to uncertainty about treatment efficacy. The excerpt quoted as epigraph is typical: in the space of three lines it expresses the patient's anxiety about treatment-related risks and her acknowledgement that, in light of the science-based, authoritative information she has been given, her fears are (or she thinks that they should be)

²⁴ See attached appendix "In vitro fertilization (IVF): what are the risks?" by Society for Assisted Reproductive Technology (SART).

groundless. It is reasonable to ask why this sort of seemingly self-contradictory thinking occurs so commonly in IVF patients.

The answer must do in the first place with how patients interpreted the scientific reports about IVF patients' side effects and treatment risks that were given to them during the patient education. The interview excerpt below is illustrative:

"I remember going home and reading [the consent form] and saying, 'There's no way I'm doing this. Because it talks about all the risks, and some of the risks, while very rare, are very serious. I remember reading it and just thinking, 'I don't picture being able to do this to my body, because there was just so much that it talked about, I guess. And it seemed very scary and it seemed like all of these things will happen to you even though it's not what it was saying.

I thought that was scary, and I know exactly why they're [the physicians] doing it, and I think all of those things are definitely important to know. But to take it in all at once, I thought that was kind of overwhelming. I think I changed my mind [one year later] just knowing that I had to do it to try to have our own kids. And I think, [pause] I don't know [long pause], it's hard."

~Patient 17

In contrast to a typical doctors' objective and scientific approach to assessing treatment risks, as shown, this patient - a physician herself, intriguingly--demonstrated that the intellectual understanding of the scientific information provided by the clinic, presumably written for generic patients, offered little help, either in her decision-making or in her emotion regulation. In fact, it seemed to be counterproductive. While she understood intellectually the extremely low likelihood that she would experience any of the serious listed drugs' effects, she was psychologically unable to accept even this vanishingly small risk because of the treatment's importance to her and the potential for serious physical harm. She deferred treatment for one year because of this exaggerated fear. As she stated: *"it seemed like all of these things will happen to you even though it's not what it was saying."* Eventually, she decided to undertake the treatment; however, as she admitted herself, *"it's hard"* to overcome these concerns and worries.

Although this case may be a bit extreme, and no patient, including this one, specifically used the term 'exceptional', or 'abnormal' in regard to themselves, the idea that statistical probabilities did

not capture a given patient's particular situation--i.e., that she would be the non-generic patient--seems to underlie many of the statements patients made about their concerns pertaining to the 'typical' side effects. This is partly because of the personal significance the treatment had for them, partly because of the sheer complexity of the treatment--as many repeatedly remarked, that the treatment was "a big deal", and "the most important thing" in their lives--and partly because patients genuinely did believe that the treatment was fundamentally "unnatural" and "invasive". In the excerpt below, another patient, also a medical science professional, described her difficulty accepting the lack of control and the risks involved in what she implied was an unnatural process:

"... we always felt that things [getting pregnant] would happen naturally. As I think anyone who might have concerns about science and technology, I have qualms about taking the reproductive process out of my body and then putting it back in, because I think there's a lot we can't control.

~ Patient 21

When patients read scientific reports in this frame of mind, as one might expect, they focused on the difference between what might be true of a generic patient and what might be true of their individual selves, highlighting the uniqueness of their conditions and physiology. Although they in general accept the validity of the statistical risk for a generic patient, the impossibility of absolute certainty about the drug's effects, both positive and negative, troubled and frightened the patients. As one patient summarized:

"And what's my risk?"

'Cause they (the providers) weren't offering that up. They weren't talking about it willingly, so I had to ask. [pause] It's my body. [chuckle] It's my reproductive future."

~ Patient 5

As will come as no surprise, the patients reported that their sensations were heightened by this constant comparison of their experience to what they had been told to expect. Their accounts

suggest that they focused on two questions centering on the idea of normality: 1) ‘what is normal?’ (specifically, whether their sensations were “normal”, and 2) whether the sensations signified that the treatment was proceeding ‘normally.’

The root of the uncertainty about the drugs’ effect on the body is, ultimately, ‘What is the meaning of my symptoms? Am I on track (i.e. for a successful outcome)? How can I know? The patients’ attempts to deal with the uncertainty by ascribing meaning to symptoms and treatment events, which they perceive quite differently from the way their providers perceive them, produce what we will call ‘the uncertainty gap, as we will discuss later in this section.

In my patients, we can see the manifestation of the uncertainty particularly in

- how patients’ interpreted *normality* in regard to their physical symptoms and displayed mixed emotional responses toward their physical discomfort, and
- how their information-seeking tended to focus specifically on anecdotes and personal accounts for validation of their subjective feelings

While in this instance, some key aspects of the experience are relatively certain (i.e., that the drugs are generally safe), the main uncertainty--whether any symptoms or events are predictive-- is objectively irresolvable. Thus, as in the case of treatment efficacy uncertainty, the patients’ narratives reflect their constant struggle to manage uncertainty. The sections below will discuss the patients’ responses to and attempts to cope in the face of this challenge in detail.

5.2.1 Patients’ Self-Questioning: “Is This Normal?”

“I remember, always kind of thinking, like ‘Do I feel a twinge of pain? Is this pain or is this normal? Have I ever felt this kind of thing before? Is this from the IVF or is this something else?’ and like I would always kinda wonder that.”

~ Patient 7

"I'm having trouble sleeping, is this normal? What side effects might I experience from medications?"

~ Patient 24

"I wanted to look up and see if my symptoms were normal."

~ Patient 21

As all the above excerpts illustrate, the patients reported that their most prevalent and ubiquitous concern was whether they were normal. In the interviews, patients reported experiencing a spectrum of physical sensations, from heightened sensitivity to their physical state to extreme pain from severe hyperstimulation. Their questions about normality are particularly intriguing because all the symptoms the patients reported experiencing, such as bloating, cramping, discomfort, disrupted sleep, headache, backaches, bruises and soreness at the injection sites, feelings of fatigue, distress and mood swings, had been previously identified as “normal” or ‘expected side effects’ during the patients’ education. The daily lab reports provided to them, in theory, should have served as further confirmation of the ‘expectedness’ of their symptoms. The questions of normality, nevertheless, persisted throughout the entire treatment cycle among all patients, even the most knowledgeable, medically trained professional patients. The statement below, again from a physician-patient, provides a clear example:

I was having some symptoms and I didn't really know what to make of it. And, I finally just gave up and called and I think I talked to Christina [the IVF nurse] and she said that was totally normal and expected and all this. So, that was good."

~ Patient 16

This interview excerpt indicated the core notion of “normality”: in most medical contexts the term *normality* is used interchangeably with *expectedness*. When a physician tells a patient that her condition is ‘normal’, he/she means that the patient's physiological responses to the drugs are within expectation, nothing is alarming, and additional interventions are not needed. More

critically, this interview excerpt highlighted a rather complex and emotionally charged quandary about *normality* in patients' minds. The patient "*didn't really know what to make of it*" because she, like all other patients, was experiencing a physical state that was nothing like "normal," especially when she was comparing her states prior to and during the fertility treatment. That is, their physical experiences during treatment were, objectively, abnormal physiological states. As patients might put it, how are they supposed to judge the "normality" of their sensations and symptoms when they actually felt and saw indications of non-normality: for example, that their "*tummy was expanding*" in an unusual way and the injection sites were swollen and bruised?

5.2.2 Meanings of Normality

Clearly, 'normality' is an elusive concept in an abnormal situation. Constantly inundated with lab reports and incessant uninterpretable sensations, which remind them their state is constantly changing, patients find this contradiction difficult to resolve. What is important to recognize is that in the patients' minds, the term 'normality' refers to the set of benchmarks by which they think that the treatment progress and the appropriateness of their feelings of physical experience can be judged, both at a particular moment and into the future. When a patient talks about whether she is in a "normal" state, she refers not only to the state she is in and whether it meets the expected criteria at a specific time but also to her projection of her future state and whether the treatment is on track. In other words, patients who asked about the normality of their sensations and symptoms did not focus only on comparing their current state with the previous state, they also used the comparisons as a basis for conjectures and predictions of their future state. In brief, the question 'is this normal', is really asking how the patient can use the physical sensations as signifiers, not only as warnings of danger but also as indicators that the treatment progress is on track and that her experience will unfold as expected--which in this case is conditioned by their strong desire for a successful outcome.

Thus the real questions underlying the questions 'is this normal' and 'what should I expect?' are more psychologically complex: They can be formulated as follows:

- I know what the consent form says, but I feel different; is what I feel what is meant in the patients' education literature?
- What is the extent of the discomfort that should I expect to feel, given my diagnosis and conditions, at this stage of the treatment? Shall I expect to feel better or worse tomorrow?
- Am I responding as predicted? How do other patients like me respond? Is my treatment progressing on track to be successful?
- Are these symptoms in agreement with what the physician predicted considering my unique condition? Are these side effects indicating anything we should do to prevent the potential risks and/or increase my chances?

This more complicated self-questioning relating to normality can be seen in patients' statements in varying degrees throughout all the transcripts. The descriptions of their physical symptoms were never merely just objective descriptions alone. Rather, they were always coupled with patients' concerns, understandings of or conjectures about their diagnosis, health condition, prognosis and the treatment events, and they were couched in terms of a fluid timeframe that takes in the past, the present, and the future. Below I give a couple of excerpts as illustration of how the patients use this framework to address their uncertainty. When asked about their physical experience, one patient stated:

“You can start to feel every bump in the road kind of thing. It doesn't exactly hurt but you're just a little too aware of what's going on there. After the retrieval, it sort of hurt in the same way, kind of. Like the day after that, I was [pause] when I was there, I was asking myself 'How am I going to feel tomorrow, it was going to feel terrible, am I going to feel okay?’”

~Patient 7

As shown, this patient started with evaluative descriptions of a series of feelings or sensations perceived as in a continuum (“start to feel... After the retrieval...”). She then continued by stating her conjectures and concerns for her future state (“am I going to feel okay?”). This patient seemed to stay in a constant exploratory self-questioning mode, which is commonly seen in most transcripts; we can see in another patient’s words the use of current symptoms as a basis for prediction of a future state:

I got really bloated. In fact, it was painful for me to walk in here [the clinic] for the egg retrieval; I was already so bloated and uncomfortable.

And so I knew it [the treatment] was all over at that point [she conjectured her treatment outcome]. [chuckle]. So yeah [pause], the hyperstimulation ²⁵, definitely! That was horrible.

~ Patient 18

In the above excerpt, the conjecture of her condition (*hyperstimulation*) and the significance she ascribed to the sensations -- her anticipation of a failed treatment (“*knew it was all over at that point*”) were emphasized. As it turned out, the patient was in fact misinterpreting her own symptoms (she did not have hyperstimulation), but it is clear that she believed in the accuracy of her assessment of her condition and based her prediction on that. This kind of thinking, seen repeatedly in the transcripts, has implications for the uncertainty gap and the patient-provider interaction, which will be discussed below.

As is obvious in both excerpts, the underlying framework of meaning-making of the physical sensations was exhibited. When the patients spoke of their physical experience, as all of them did quite commonly, they rarely just objectively described the sensations they felt at a single time point in isolation. Instead, the patients talked about their subjective feelings and interpretations in succession to make comparisons to understand the evolution of their treatment experience, which

²⁵ This was the patient’s own speculation, her medical record did not show that she had hyperstimulation. Had she had hyperstimulation, the doctor would have stopped the treatment.

they always attempted to relate to their individual case. Briefly, meaning-making of physical sensations and symptoms is an all-consuming cognitive task that all patients felt compelled to undertake because they could not avoid feeling them and being aware of the incessant and constantly changing nature of the sensations. The patients were confronted with uncertainty about their ‘normality’ almost literally on a moment-by-moment basis during the treatment. One patient’s statement captured this theme:

“I drive myself crazy, especially since I had been pregnant. I know how I felt and every time I was nauseous, I would be like, ‘oh, maybe I’m pregnant.’ Then it would be, ‘oh, maybe I’m just nauseous,’ because you feel a little nauseous sometimes randomly, which is a really terrible mind game.”

~ Patient 10

The patients’ engagement in this complicated meaning-making thinking, furthermore, gave rise to particular lenses through which they viewed their interactions with the physician and had profound implications for the patient-provider relationship, as I will discuss in the following.

5.2.3 The Uncertainty Gap: Conflicting Patient and Physician Perceptions

“I don’t know, it’s like you want to know [about the drug’s effect on her body], and they [the clinic] tell you these numbers [the scientific measurements], and you’re like, ‘That doesn’t mean anything to me.’”

~Patient 5

There is a significant disjunction, as shown in the above excerpt, between the way the patients perceived the uncertainty arising from the physical sensations they experienced and their interpretations of them as individual patients, and the way the medical professional perceived the patients’ reported sensations. The doctors’ responses emphasized objective measurements of the physiological conditions based on generic patients. This disjunction -- I term it the ‘uncertainty

gap' --produces a number of important effects on the patients' own experience and on the relationship between the two parties. As used in this study, this term refers to the cognitive and emotional gulf between IVF patients and their doctors resulting from their differing senses of what can be treated as certain and uncertain in the IVF experience. That is, it is the mismatch between the provider and the patients in their approach and focus of the treatment concerns. The uncertainty gap derives mainly from 1) the discrepancy of expertise and knowledge, 2) the different focus dictated by the roles they play (the doctor as a care provider and the patient as a receiver), and 3) the discrepancy between objectively observing and subjectively experiencing the physical effects of the treatment. It is particularly pronounced in the case of uncertainty about bodily sensations both because the doctors obviously cannot feel what the patients feel and because they do not share the patients' desires to treat ordinary side effects and symptoms as predictive of the treatment outcome. On the basis of their expert knowledge, physicians can assert with certainty that the procedure is safe and that the patients' bodily sensations are inconsequential. The conflicting approaches in addressing the uncertainty of physical sensations between the patients and the physicians are a major -- and commonly overlooked or dismissed--source of miscommunication, as shown in the above excerpt. This miscommunication leads patients to emotional episodes and distinctive information behaviors during the IVF treatment.

The uncertainty gap is difficult to avoid for the simple reason that bodily sensations are inherently subjective. Not only did the patients know how they felt but they also first-handedly owned deep-seated and particular knowledge about their bodies, i.e., the patients (and the patients alone) had access to their bodies and the information their bodies provided. This differs from the attitudes of both parties in respect to the governing uncertainty about treatment efficacy. In posing and addressing questions of treatment trajectory and the outcome, patients accept that the expertise and scientific knowledge of the doctors give them authority and so supersede the patients' own judgments. This is, however, quite different from the case of uncertainty about physical sensations and symptoms, where the inherent power to assess these, whether recognized or not by either party, is shifted and redistributed. My patients felt that they had complete discretion and autonomy over whether to accord importance to symptoms and physical sensations, whether to report them to the doctor, and to make decisions on how to deal with and how to make meaning of them. Thus, they had a kind of certainty that the doctor did not share. On the other hand, they felt the need to believe

that the doctors could in fact provide certainty about the safety of the treatment and the possibility of a successful outcome. The search for certainty, accordingly, takes contrasting forms for the two: doctors rely on --and expect patients to rely on--the scientific measurements and scientific knowledge. The patients rely on, to a greater or lesser extent--and expect the doctors to give some credence to--their own interpretations of their bodily sensations.

Patients typically accept the doctors' view of 'certainty' intellectually but not emotionally. Furthermore, physicians, however sympathetic they may be to the patients' concerns and however much they may share the patients' desire for a positive outcome, cannot genuinely feel the patients' anxieties and fears about the drugs' effects, for which they see no basis. Of course, there are differences in the levels of uncertainty the patients and doctors feel, e.g., in regard to the treatment efficacy, but these do not generally produce the same sorts of emotional effects in the patients.

In concrete terms, we can see this gap when the doctor downplays or even dismisses a patient's reported concerns about a symptom that, objectively, is not significant for the typical patient. His/her intention may genuinely be to reassure the patient with his/her expert knowledge; however, the effect of the doctor's exercise of his/her authority (as the patient might perceive it), may be that the patient feels that her authority over her own body is being undermined²⁶. She may also feel that she was not understood and even more, that her knowledge about her own body and its

²⁶ Two representative statements listed below illustrate such theme:

- a) *"There's a 'script' there. And also there's a bit of condescension too. So I had called [the clinic] to find out 'Is this something that you would advise against? Is there an issue? 'Cause if you think there's an issue, what's the risk?'" So, she [the provider] had said flippantly, 'Oh, yeah, no, you'll be fine,' kind of thing.*

So, I think there was a little bit of [pause]. And there's been a number of communications with that individual where I've gotten like a momentary bit of contempt almost, like, 'You're questioning me?' You know, 'Why would you think you're special?'"

- b) A patient reported to her response upon receiving advice from her physician for addressing her uncertainty about her side effects.

"I was like, 'Okay, now you're [her doctor] just sort of throwing spaghetti at the wall and hoping something will stick.' and I don't wanna feel like my doctor is just doing that. I wanna feel like, 'Okay, this is the solid recommendation and this is what we'll get [pause, sigh], I don't know'."

unique physiology was not appreciated. This has profound implications for her experience as her treatment evolves.

These troublesome feelings set up a dissonance in her mind--on the one hand, she feels uncertain about, for example, the safety of the treatment, but she intellectually accepts the doctor's authoritative assertion that it is safe. On the other hand, she feels that her subjectively experienced sensations have validity and that her concerns about them were reasonable and important, which accorded her authority that she considered unquestionable. Completely accepting the doctor's authority therefore means that she must, to a certain degree, distrust her own authority and her judgments. This prompted more self-questioning and, in many instances, emotion episodes.

The uncertainty gap manifested specifically in the IVF context is grounded in the ambivalent notion of normality; it was expressed in the frequent dichotomy between the patients' and the physicians' perceptions about what may be genuinely uncertain. Based on their 'certainty' that the patients' sensations are mostly normal, the doctors may think that patients' uncertainty and fears in general are unnecessary, irrational and emotion-based. Patients, however, base their 'certainty' on their subjective experience of the sensations (e.g., "*I can feel...*", "*I know how I feel*" and "*I know my body.*"), which they feel are constantly changing in unusual ways, and, understandably, about which they cannot refrain from raising questions.

Without exception, the patients said that they were affected emotionally to various extents by their struggle to achieve certainty regarding the 'normality' of their physical sensations. Many also reported, unexpectedly, that the reassurances of the providers and the scientific literature did not sufficiently help them deal with this uncertainty about their physical experience (e.g., "*Because I didn't know what [physical experience] to expect. I didn't know how painful it would be; and no, I didn't prepare for it.*"), which produces many emotional effects. They, in fact, in some cases incite the patients to further assert their "certainty" (regarding the importance of the physical sensations they experience) with the physicians, in turn often widening the uncertainty gap even further and recursively triggering the cascading emotional effects. Patients' management of these emotions and the information behavior they undertook for this purpose thus became very important for them in dealing with this governing uncertainty.

5.2.4 Complex Emotionality

“I know that I knew what happened and I know I made it through last time so I can make it through again. It might be horrible again but I can do it as far as side effects go, after that [the last treatment].”

~ Patient 7

This statement came from a patient undergoing her second treatment; as we can see, she expressed a sense of accomplishment or even pride in her endurance of discomfort in her first treatment (“*I can do it*”). This is not uncommon among my patients; apparently, the ability to endure the physical discomfort afforded them pride and emotional comfort. These positive feelings co-existed with feelings of being worried, anxious, scared, and out of control; the patients also reported experiencing excitement, curiosity, hopefulness, and happiness because of their physical experience of sensations and symptoms. The emotion episodes relating to the uncertainty about physical sensation and symptoms were complex, cycling from one emotion to another, often nearly simultaneously (the so-called ‘emotional roller coaster’), and was for nearly all patients extremely challenging. Regulating these mixed and sometimes mutually reinforcing emotions while also tending to their physical discomfort was very taxing.

All of these emotions are tied to not only the immediate and backward-reflective responses to the physical events but also the patients’ anticipation of continued progress in the treatment; that is, how the symptoms make them feel physically and how, looking forward, they make meaning of them. The patients may feel positive emotions when they perceive that the drugs are having effects and anticipate that the treatment progress will continue to be on track; at the same time, however, they feel negative emotions at the physical discomfort and possible risks throughout the treatment²⁷. To give a concrete example, a patient whose physical sensations make her ‘feel

²⁷ vivid negative adjectives, such as “*scary*”, “*terrible*”, “*horrible*”, “*painful*”, “*hurtful*”, “*very graphic*”, “*very difficult*”, and “*very uncomfortable*”, and expressions such as “*I couldn't move*”, “*I could barely walk*”; “*That was horrible. I missed a couple days of work*”; and “*cry(ing) a lot*”, etc. frequently appear in conjunction with patients’ descriptions of physical sensations.

horrible' may nonetheless welcome the discomfort as a sign of her endurance and of the progress of the treatment, feeling simultaneously proud and excited.

The physical sensations the patient commonly reported often recurred in various degrees and with slight variations throughout the treatment, reflecting their constantly changing states throughout the various stages of the treatment. Thus, seemingly identical symptoms can, in the patients' minds, have different meanings, which resulted in different emotions. The different contexts, furthermore, condition the patients' varying interpretations and hence their emotional responses, as some patients remarked "*it's [the physical experience] so different person to person, cycle to cycle.*"

We can take one of the most reported sensations, cramping, as an example. Even though cramping is invariably described in the patient literature as 'normal' and 'to be expected,' many patients still dwell on their instances of cramping, examining, and speculating about them. Below I provide several excerpts from different patients that demonstrate how they scrupulously related cramping to their treatment progress, adherence, and efficacy of the drugs. These excerpts also reflect the different emotions the patients had in response to the cramping; though all were physically disturbed by the sensations, their emotions about them differed, both from patient to patient and in single patients at different stages of the treatment.

First, at the beginning of the stimulation stage, one patient reported:

"'Oh my gosh. I have a weird cramp.' [pause] I took my medicine late. I'm really scared. Why aren't my meds working?'"

~Patient 22

As we can see, she is physically aware of pain but does not emphasize the discomfort; the emotional response 'really scared' is dominant because of the meaning she assigns to it.

Another patient who had advanced to the next stage, in which she received the ultrasound reports on the increasing counts of her follicles, responded very differently:

I also have a full feeling in my tummy and cramping, which makes me feel excited that I may be responding to the meds.”

~Patient 29

Her excitement clearly reflects her association of the physical sensations with the treatment progress. The significations that the patients assigned to the cramping in these two cases determined the differing primary emotions that they reported. This is despite the fact that these significations are entirely subjective: in both cases, there is limited scientific basis for their interpretations of their sensations.

A patient’s description in the excerpt below depicts some of her thinking about her physical sensations. The context of the description is that it referred to the day before the egg retrieval. She said:

“I could feel my ovaries, I could feel the cysts actually changing, like after the trigger shot. So, I could feel like these internal sensations, that I knew things were happening in my body, and so I didn't sleep very well. And then the following day, I didn't sleep that well either, but, I was excited.”

~Patient 16

In the excerpt, we can clearly see the patient dwelling on the sensations she felt, envisioning that they signified powerful drug effects and that they were particularly meaningful to her as indicators of a positive treatment progress (e.g., “*the cysts actually changing*”, and “*things were happening in my body*”); her sleep was disturbed, and she also said she felt excited. Her construction of the experience occurred despite the fact that the physician was unlikely to put much stock in her conjectures, deeming them mostly products of the patient’s positively biased and emotional responses. This excerpt implies a potential magnification of the uncertainty gap. More critically, it depicts many patients’ psychological state: they are constantly guessing about the meanings of their sensations based on feelings that are constantly changing. The assignment of meaning

produces emotionality, and the emotionality can cloud their thinking. However, the irresistible dwelling on their meaning-making, triggered by the unremitting and ongoing physical sensations throughout the treatment, produces a vicious circle. This sensation-meaning making-emotionality cycle recurred - literally moment by moment during the entire treatment cycle.

Many patients, not surprisingly, found this cycle of thinking, overthinking, and reacting both taxing and stressful, even with the patients who had previous success, as the patient quoted below makes clear:

“It’s just as stressful [as a previous treatment cycle]. Wondering if it worked, and analyzing everything you feel and every twinge, “Does this mean something? Did it work? Didn’t it work? I think it’s still stressful no matter what that part of it [pause] ‘Do I feel more bloated?’ ‘Am I hungrier today?’ ‘Did I feel a twinge in my ovary?’ ‘Oh, I don’t know, what was that?’ ‘Did I feel any cramps?’

‘Did I think I felt something?’ All these different things that your mind tries to compare with last time, and does it mean something? I think all that is still stressful for me this time around.”

~Patient 4

As in the case of the other governing uncertainties, the patients desired to acquire control to cope. Notably, the patients often felt that their distress was not understood--not only by the doctors, but also by the people in their social circles. After all, other people were, as the patients recognized, not the ones who were subjected to these inescapable and relentless sensations. Thus, patients often turned inward and felt somewhat isolated. This has a profound implication for how they strategized their information-seeking, which, for privacy, tended to take place online. The distinctive information behavior that is characteristic of this governing uncertainty is discussed in the next section.

5.2.5 Information Behavior²⁸ Related to the Uncertainty about Physical Sensations

“Just any different question I have, ‘Here’s this symptom. Is this normal?’

Whatever thing I worry about, I google and see if somebody else worries about the same thing. What do you know? They do. It just makes you feel better to know that everybody else is feeling the same way you are about it.”

~Patient 25

All but one patient reported engaging in information seeking to address uncertainty about their physical response to the IVF drug regimen. They said they were often unsure about whether the relevance and significance they assigned to the sensations they experienced were indeed objectively appropriate, and they were seeking validation. Emotionally overwhelmed and feeling isolated, they desired to seek support. Remarkably, instead of relying on the authoritative figures and scientific information, they sought it from non-authoritative sources. The excerpt shown above is representative of my patients.

Although some particularly mentioned that they themselves perceived their information behaviors as ‘absurd’, ‘embarrassing’, ‘silly’, ‘not rational’, ‘not logical’, ‘not useful’ or even like ‘a double edged sword’, the patients said they were typically seeking information from personal accounts provided online by other patients. They said that they found it easier to relate this type of information to themselves. This is particularly intriguing because almost all patients, when asked what advice they would give to future patients, emphasized the importance of information seeking, and quite a few of them, particularly recommended searching for official, “credible”, “reliable” and authorized information, even though this was contrary to their own approach. This contradiction gave rise to several questions: what motivated the patients to particularly seek out anecdotes or personal stories, often with vivid, borderline-emotive expressions, despite knowing intellectually that they were over-dramatic, “funny (in the sense of ‘crazy’)”, or “not reliable” and they could “waste a lot of time”? How did patients reconcile the conflicting information from

²⁸ Information behavior, which encompasses more than just the notion of information-seeking, is defined above in Section 5.1 “Uncertainty and Information Behavior.”

their multiple sources? And the most critical, what did they get out of this peculiar information behavior?

We can see one motivation clearly: the patients engaged in some of their information behaviors for the purpose of reinforcing the knowledge they deemed to be beneficial for best compliance and optimal decision-making. Another motivation, also expectedly, was to acquire emotional support. This motivation is consistent, in a broad sense, with the motivations we see in the other medical contexts and with conventional assumptions.

If we look below the surface, however, we can see a much more interesting information behavior that springs from a different motivation: in the case of the uncertainty about the drug's effects on the body, the patients' common core concern was uncertainty about the concept of normality -- the notion on which they were often in discord - consciously or not - with the doctors because of the uncertainty gap, and the sources they sought out were not typically 'scientific' or 'authoritative.' The excerpt below, which is representative, explicitly identifies this concern:

"I see people posting and there is some value to be gained from some of those sites and stuff, especially the softer stuff. You don't necessarily find a lot of hard data [authoritative and scientific information] and stuff like that, whether it has to do with the spotting [pause] because it seems like that's not covered well [pause] and especially in the layman's terms, in more graphic terms, so that it's not that easy to find that kind of information.

And even health professionals don't, they won't give it to you as graphically as it might be necessary to actually know - normal, real normal or not normal.

So, I think that's probably where I would use those kinds of sites more, like I said, for the softer side of stuff. So with regard to symptoms, or especially if it came to discharge of some sort or something."

~ Patient 18

Clearly, this patient highlighted her needs for the "softer stuff", a type of information that featured more descriptive expressions (more 'graphic' and 'in layman's terms') that allow her to relate her actual physical experience and to "actually know" the meaning of her condition ('normal, real normal or not normal'). She emphasized that she could not obtain this type of information from the physicians, health professionals or authoritative and scientific information, (i.e. "hard data"). She determined that she would specifically adapt her information seeking approach so that she could properly address the uncertainty of normality about her physical experience.

While this patient particularly highlighted her needs for identifying her symptoms to make meanings of them, another patient talked about her needs with a similar focus on meaning-making but more from the emotionality perspective:

“Gosh, this [searching information online to validate her physical sensation] is embarrassing. I think I typed “pain, swelling, and bloating post egg retrieval.” And I just waited to see what came up. The first five websites were blogs that had been generated by women, kind of just in community forums, and I found it really fascinating.

I had, to this point, avoided the forums, because I just didn't think I needed to look at them, but I think when I was surprised by how I felt after the egg retrieval, then I decided, ‘Let me see if other women were surprised, too.’ I was looking to see, are there other women that are going through this that are having the same symptoms I'm having, because I was a little surprised”

The patient in the above excerpt expressed her needs to compare, notably, not only her symptoms and sensations but more so the emotional reactions directed at how patients’ anticipated the development of them; she specifically mentioned her validation of her anticipatory emotions, instead of other directly responsive emotions toward the physical sensations itself. She was able to make herself feel better by reading other patients’ stories about their meaning-makings. This meaning-making emphasis was apparent in both excerpts shown above. The deeper motive of the information seeking, as shown in both excerpts above, was to be able to make meaning of the physical sensations and symptoms they experienced.

The patients were able to address their uncertainty about their physical experience, specifically by searching for certainty about normality. Both excerpts suggested that the patients were seeking certainty because there were important aspects of the physical experience that the scientific information and patient literature failed to provide. What the patients claimed, from the first glance, was that they were seeking information to be able to tell the normality of their physical experience. What they were really doing, however, was seeking certainty about their assignment of meanings from other patients. This particular information behavior, intriguingly, reveals inconsistent logic: if the patients’ intention was to search for certainty, why do they look for other patients who mostly had similar senses of uncertainty and who could in the best case only echo, and in most cases,

magnify their sense of uncertainty? Briefly, the patients, consciously or not, inadvertently sought information to become potentially even more uncertain.

As expected, this information approach allowed a wide-open searching space, including anecdote, dramatic expressions, and systematic self-observation reports. Patients who found the scientific information too dry and lacking in detail about the intensity of the physical experiences were particularly drawn to these sorts of sources, even while they recognized that they might be unreliable or exaggerated. Even though this information was, for many patients, valuable for meeting their emotional needs, it gave them conflicting messages. It is interesting to consider how patients dealt with this inconsistent information from multiple sources.

What seems to have drawn the patients to this information seeking approach was the freedom it gave them to choose the information source and interpret the information they acquired from their sources.

The words of one patient encapsulate this approach to information seeking: despite her persistent negative comments about online blogs during most of the interview section (e.g., “*blogs are really scary*”; “*It's nerve-wracking. Yeah.*”), and discouragement, as she mentioned, from both her husband and her doctor, she engaged in information seeking online from other patients, particularly when she had concerns about her physical experience (e.g., “*Yeah, just like bloating, hyper-simulation, discomfort, those sorts of things*”). She explained:

“You're like, ‘Oh maybe this is working.’ Then you mentally think, ‘Oh, I feel pregnant.’ You can tell yourself that you think and feel a certain way.

...you look at blogs or something, you search for anything. Then you hear all of these women saying different things, good or bad. They're just entertaining to me. If these women were going through some bad things, I'm like, ‘Oh my experience has been much better than that, so it's great, good for me.’ Or if they were positive things, I'm like, ‘Oh great. I can look forward to that.’”

~ Patient 14

While this patient was very conscious of her contradictory approach and was aware that she was choosing what to put credence into and what to reject, other patients who behaved similarly did so less consciously. All the patients, however, used the information they gathered from these various sources to bolster things that seemed indicative of treatment progress and to maintain an emotionally viable balance between certainty and uncertainty about their situation. This was, for most, the benefit of their information behavior.

5.2.6 Information Behaviors as a Means to Create *Calibrated Uncertainty*

For all the reasons discussed above, patients could not refrain from seeking information that would make them feel better. The patients felt overwhelmed and out of control. It stands to reason that the form of information seeking that others may see as irrational may actually help them. The patient from whom the excerpt below was taken (who was a science professor) explained:

“I know good [sources] from bad, but sometimes, even somebody like me who should know better can’t help but read those, the self-reported blog kind of message boards or whatever. [pause] I read those. Again, it’s not rational, it’s not logical, but in the moment, you’re just like trying to understand what that [her physical symptoms] means.”

~ Patient 13

As shown, this patient justified her engagement in information-seeking particularly from what she deemed as rather dubious sources (e.g., the self-reported message boards); she underlined her overpowering needs for relating to other ‘real’ patients for meaning-making “*in the moment*”. While she appeared to feel abashed about her approach, her particular information behavior was, in fact, nearly ubiquitous among my patients.

What fundamentally accounts for and motivated this seemingly oxymoronic information behavior is that it gave the patients the power of control in making choices about both the information they would acquire and its significance and relevance to them. The patients could therefore exercise freedom by way of their selection, to adjust the meanings of normality and the level of uncertainty according to their emotional needs at the moment. In other words, it ‘gave them permission’ to

maintain a calibrated uncertainty between certainty that made them uncomfortable and uncertainty that also made them uncomfortable. Seeking information this way goes beyond merely acquiring information to learn about the treatment, or to relate their experience to others for empathy. It might seem to be “irrational”, “not logical” and a “double edged sword” at least when the patients indulged too much in it. However, it functions, essentially, as a means for the patients to regulate their emotions, which is crucial to their perseverance and psychological well-being.

In this work, this term *calibrated uncertainty* refers to the state of mind that patients experience -and in a sense, actively seek out-- when they simultaneously seek or maintain both certainty and uncertainty. It is a way for patients to address irresolvable uncertainty: instead of simply trying to reduce it, they focus on meeting their emotional needs so that they can persevere through the treatment. While it is usually assumed that patients want to resolve uncertainty, this is only partially true of IVF patients, who in fact do not want to acknowledge and live day in and day out with the certainty that their odds of success are extremely low. Because they know that they have to prepare themselves for a potentially undesirable outcome, they direct their efforts to what will enable them to achieve cautious optimism and maintaining uncertainty about the treatment outcome enables them to persevere. However, *calibrated uncertainty* is not confined to this single looming uncertainty. Patients use it as a coping strategy when incoming information of any sort seems to suggest the certainty of a negative outcome. For example, patients who find anecdotal information implying that a physical symptom they are experiencing correlated with a failed treatment may choose to assign uncertainty to the correlation; the same patient may, if she finds accounts suggesting that the symptom indicates pregnancy, treat these as less uncertain. She will, however, almost certainly simultaneously entertain uncertainty and certainty about the meaning of her symptoms to protect herself from too much optimism or too much pessimism.

5.3 Governing Uncertainty 3: Uncertainty about Regulating Emotionality

“I could cry really easily at something that was either sad or even happy and just sort of feeling quite not, just not quite my normal equilibrium.”

~ Patient 15

“I could do [various things, e.g., yoga][pause] that would avoid using medication to overcome all these symptoms: feeling guilty, feeling bad, feeling sad, feeling depressed, feeling like I couldn't control when I would cry.”

~ Patient 10

“Some women describe this whole process as very similar to grief. It's not normal grief though; it's more like a constant gray cloud, that just kind of follows you everywhere.”

~ Patient 21

As the excerpts above might suggest, my patients repeatedly expressed concerns and worries about their emotionality. Emotional expressions permeate the transcripts. Unanimously, my patients recounted their experience through a series of emotion episodes at considerable length; they also emphasized intensively the challenges of managing intense and mixed emotions that they frequently experienced. All patients, including the single one who de-emphasized her emotional life, talked about their experience in emotive language and stressed the importance of regulating their emotions. All but one said that uncertainty about their emotionality was the most challenging aspect of the treatment experience; they said they constantly examined their own emotional and mental states, questioning themselves whether they could gain control so as to persevere through the treatment.

The uncertainty about patients' emotionality, as shown in the above excerpts, is extremely complex and of great importance for our understanding of the IVF patient experience. As noted above, my patients reported experiencing a wide variety and wide range of emotions on a spectrum of intensity and frequency, feeling often that their extreme emotionality was “outside [their] expectation” and ‘out of control’ at times. These emotions include both positive (e.g., hope, excitement, pride, relief, and happiness) and negative (e.g., anxiety, worry, fear, sadness, anger, frustration, stress, isolation, jealousy, envy, and depression). More than that, feelings of exhaustion and fatigue, both mental and physical, were commonplace; many patients said, for example, ‘I am so sick of this,’ referring to both their physical and their psychological depletion.

Patients stated, furthermore, that they experienced the so-called ‘emotional rollercoaster’, a constant cycling from one emotion to another, as the excerpts below suggest:

“I was up and down. Up and down. I'd be happy one minute and then the next just upset, depressed, angry.”

~ Patient 2

Hardly surprisingly, attribution of this emotionality mainly to the hormonal drugs’ effects, as the conventional wisdom holds, is prevalent. This supposition is shared not only by many medical experts but also by the majority of the patients’ themselves²⁹. My findings, however, show that the reality is more complex than that: despite what they stated they believed, the patients’ reports about their emotional life showed the dependence of their emotions on their perceptions and evaluation of the psychological context and physical environment they were in. While the drugs undoubtedly exacerbated their emotionality, they were not solely responsible for producing it; in fact, in many cases the physiological triggering of emotion appeared to be far less significant than the patients’ reactions to what was happening in and to their bodies.

5.3.1 Sources and Patterns of Emotionality

Based on the stimuli that provoke them, I classify emotions into two categories: *immediate*, or the direct reaction to current or past treatment events, and *anticipatory*, or responses prompted by consideration of future events or outcomes. This distinction is important, because these two types of emotions occur in two different patterns over the course of the treatment. For my patients,

²⁹Below are a couple of representative excerpts for this theme of patients attributed their emotionality to the hormonal drugs:

“I think that having those high levels of hormones adds to some of that stress, too. I felt like when I was in the middle of putting all of that medication in my body that I was not quite myself. So, I felt more emotional.”
~ Patient 9

“we have so many hormones that were being injected, that just from the beginning I felt kind of tired and sick and really just exhausted” ~ Patient 17

immediate emotions were strongest during the first part of the treatment; typically, they lessened over time, as patients began mastering compliance and became more comfortable with the protocols. Anticipatory emotions were strongest during the mid- and latter stages of the treatment and became increasingly difficult to control. Below I give two excerpts in each category to demonstrate the distinguishing characteristics.

The first two present emotionality that was induced by patients' direct responses to an experience that occurred at a particular time in a specific physical environment (in the first case, embryo transfer procedure).

"It was really emotional going in there [the embryo transfer procedure room] and again, it's just not how you envision becoming a mother, legs up, there's equipment and sterile environment everywhere. The procedure was probably one of the hardest ones for me because it wasn't how I imagined getting pregnant, I felt like a cow."

~ Patient 14

Clearly, this patient's emotional reaction to the technological aspects of the embryo transfer procedure was direct and unfiltered. The experience generated feelings of embarrassment, self-consciousness, and even anger at being deprived of the natural conception process. While the drug may have heightened her sensitivity to these feelings, the feelings were not in any way irrational or unmotivated.

The second excerpt shows an emotion episode triggered by receiving a negative pregnancy test result from the physician. This patient stated

"These [the physicians in the clinic] are supposed to be the experts. These are supposed to be the doctors, these are supposed to be the [pause]. And so don't just give me the sad face, do something about it, dammit! So, it was like I was angry, I was [pause]. And so I didn't want to come here and see these people that should have been able to do something and I know now that's totally not rational. But at that moment I couldn't see these people that should've been able to do something, or should've been able to predict this, or should've warned me more, or should've something."

~ Patient 13

This patient's strong emotions, although directed to the doctors, were her immediate reaction toward the confirmed pregnancy test³⁰ that showed a failed outcome, as she herself admitted. The emotions were complex: under her expressions of anger toward the doctors were mixed emotions of upset, disappointment, and remorse at assigning blame unjustifiably, and even some delusional thinking that she might have acquired control over her expectations so that she could have prepared for her disappointment. Again, while the drug effects might have had some influence, her emotions were primarily driven by her responses to the situation with which she was confronted.

Frequently reported stimuli that induced patients' immediate emotions include lab and test results and doctors' comments on them; the physical features of the clinic (e.g., lack of privacy in the lobby, the '*sterile*' and '*unnatural*' setting in the procedure room); physical discomfort, as described in the previous section; burdensome compliance activities (e.g., administering daily injections and drug intake, undergoing routine blood draws), and the associated life disturbance (e.g., coordinating work and social schedules to accommodate treatment activities). The emotions that resulted typically included feeling annoyed and sick of the protocols, feeling guilty, disrupted, or pressured by work and social obligations. Although these emotions could be strong and somewhat unexpected when patients first encountered them, they could be (eventually) tempered. They were mostly negative, though a few were sometimes positive, such as feeling proud of their ability to administer the complicated medication regimen or feeling happy about receiving clearly good lab reports. They were, nevertheless relatively easy to control, because they could typically be attributed to one specific event; ways of regulating them typically could be learned because as the treatment progressed the patients' understanding of the regimen increased and their skills for compliance also improved. These straightforward and relatively predictable emotions, though prominent in the transcripts, are less interesting than the more complicated ones associated with anticipatory emotions. While coping with immediate emotions is not, on the whole, difficult for my patients, who are intelligent and capable, management of anticipatory emotions becomes an important aspect of patients' coping strategies

³⁰ The beta test (i.e. pregnancy test) is scheduled at the end of each treatment cycle. Sometimes, the test result can show an inclusive result (e.g., chemical pregnancy) and the second test will be scheduled, typically in a few days to conclude the treatment.

Below, I give two excerpts to illustrate two emotional episodes that were induced by patients' anticipation of future states or outcome. The first example below, which is also taken from the Patient 13 who provided the excerpt above, illustrates the differences between the immediate and anticipatory emotions:

“I’ve let myself, like, indulge in buying things, and being like, ‘Okay, I’ll buy some stuff and order this thing that’s really cute.’ And you begin to think, okay, well, I’ve marked in my calendar, like, okay, especially when we had a pseudo-positive, in those weeks, like looking at, like, okay, so here’s the point at which I would be, past the first trimester. Here’s when the baby would be due. Okay, then, you start, I let myself start thinking about what would my life look like, how would that be, to be positive and excited, and think positive about it and do that sort of thing. It’s hard not to.”

~Patient 13

The obvious positive emotions seen here did not result from any specific event; instead, they arose from the patient's fixation on a potential positive pregnancy outcome. These emotions -- excitement and optimism--were drastically different from the emotions she subsequently experienced when confronted with the negative pregnancy outcome. It is reasonable that the emotions would be strong in both instances, because of the personal significance of the treatment outcome. The situations, however, from which they arose are quite different -- one is ‘real’ (i.e., actually experienced in the present) while the other is created in the patient’s mind and has to do with a potential future state. More important, the intensities of both anticipatory and anticipated emotions mirror each other; i.e., the more hopefulness she felt as she was anticipating the outcome, the deeper the disappointment she felt when she received negative results. Not entirely consciously, the less hopefulness the patients felt in anticipation, the less intense they anticipated that their disappointment would be. These two emotions are irretrievably associated with each other in the patients’ minds.

While the excerpt above expressed positive anticipatory emotions, below I give an example from a patient who dwelt on a potentially negative pregnancy outcome and therefore experienced negative emotions:

“I just couldn't comprehend it [the IVF treatment] not working. [pause] [sobbing] I would not have killed myself, but I was thinking of, I want to. [pause] And I thought I was gonna get my [medical] chart flagged about what I should say and not say [to her doctor], and I'm like, 'I'm not gonna do anything, but I don't see myself surviving if this doesn't work.' [pause] So that's where I was at for a little bit, which makes me sound crazy.”

~ Patient 23

Clearly, we can see the emotions expressed in the above excerpts are multilayered. Beneath the strong emotions directed toward the negative treatment outcome lie emotions induced by the patient's own judgmental reaction (“[I] *sound crazy*”) toward her own initial anticipation of the event (“*I don't see myself surviving if this doesn't work.*”).

These excerpts bring up an important characteristic of anticipatory emotions: they are intimately connected with the overall uncertainty inherent in the IVF process because they are projected onto unpredictable future states. Because individual patients' treatment outcome and individual patient's physical responses to the drug's effects are never entirely predictable or guaranteed, the patients were preoccupied with all the possible outcomes, positive or negative; these anticipatory emotions can be engendered literally moment by moment. The patients rarely experience anticipatory emotions of one single value; no patients reported consistent feelings of hopefulness or anxiety all the way through the treatment. The patients, in fact, because their uncertainty about their own emotional responses is compounded with the other governing uncertainties, experienced mostly emotions oscillating wildly between extreme positivity and extreme negativity within a short duration of time. (i.e., the ‘emotional rollercoaster’). In brief, unlike the immediate and direct emotions, the anticipatory emotions are much more elusive and intricately interrelated.

These two categories of emotions manifest different patterns of intensity during the treatment. As noted above, immediate emotions typically were most intense during the early part of the treatment before the patients developed familiarity with the treatment routines. While they persist throughout, they are less omnipresent, for the most part, after the first week or two, and they vary less. The anticipatory emotions, on the other hand, grow in intensity as patients begin focusing less on the routines and increasingly familiar physical sensations and more on the treatment

milestones and the outcome. In other words, as the immediate emotions become less intense as their comfort level evolves, the patients begin fixating more and more on the outcome; their anticipatory emotions take over their emotional life. The overall intensities reach their peaks intermittently at each milestone: they intensify at egg retrieval, drop immediately afterward as the patient feels relief, and then sharply go up at embryo transfer. They drop again but remain at a heightened level through the period leading to the pregnancy test; the highest peak typically occurs the day before the test. During this stage, management of emotions becomes an omnipresent difficulty that almost every patient spoke about repeatedly in the interviews.

The excerpt below provides evidence of some of the thought processes that are typical of patients during this portion of the treatment:

I think that because I didn't really know [at the time when she committed to undergo the treatment], I had a better balance between hope and disappointment. [pause] Whereas, I almost, I think I've had too much hope now. Well, I've had six embryos that, Dr. X said, 'This doesn't look like a 39-year-old woman. These are high quality eggs.' And that just raises your expectations and your balance between hope and disappointment shifts, like, 'Okay, this should work for us. This is gonna work.' And for some people, it does. But what if you're not that? And that's been really hard. Because on paper, we should've had a baby by now, I think, just by the statistics and by what we've produced."

~Patient 13

As shown, this patient was in internal conflict as she attempted to discern whether her feelings of optimism or pessimism were at the right level. On the one hand, she wanted to align her feelings to reflect the positive news she just received. While she desired to feel an optimal level of hopefulness so that she could feel good about her experience, on the other hand, she hesitated to feel good because she wanted to be best prepared emotionally to face the “reality” of a possible negative outcome. The patient, notably, contrary to expectation derived from the conventional wisdom of positive psychology, did not seek to stay relentlessly positive (“*I think I've had too much hope now.*”) Rather, she spoke of a psychological range of emotionality delimited by positive and negative anticipatory emotions, “*between hope and disappointment*” as she put it. This emotional range, as her words also suggested, was not fixed: its extent and position were evolving and were influenced by the unfolding treatment activity (in this case undergoing egg

retrieval procedure) and incoming new information (in this case her receiving of a positive lab report about her egg quality). This is noteworthy because all the patients expressed similar ways of thinking as they spoke of their attempts to cope and regulate their emotions during the middle and latter part of the treatment regimen.

The psychological mechanism that appears to be characteristic of patients who are attempting to gain control of their emotions is, I suggest, the construction, consciously or unconsciously, of an emotional range within which patients attempt to remain so as to protect themselves from the effects of the ‘emotional roller coaster’ and potential unbearable emotionality. This emotional range spans both positive and negative emotions and is dynamic; its extent and position varied for each patient over the course of the treatment depending primarily on the patients’ understanding and anticipation of their progress toward the pregnancy outcome. In their construction of their emotional range, the patients attempted to figure out an optimal level of optimism or pessimism (and the associated emotions of anxiety, eagerness, disappointment, hope, etc.) to enable themselves to face an unpredictable and uncontrollable outcome and to complete the regimen. The patients could, accordingly, use not only up-regulation -- shifting their emotions upward toward more positive states, but also down-regulation -- shifting their positive emotions downward to arrive at less positive states. Briefly, the patients address the uncertainty about managing their emotionality through their crafting of this emotional range and finding an emotional equilibrium. This approach to emotion regulation --intuitive for some and perhaps for others more deliberate-- enables patients to create a suitable psychological state in which they are able to persevere through the treatment in spite of the objectively irresolvable uncertainty of the outcome and the uncertainty related to the physical experience of the treatment.

We can also see evidence of creation of an emotional range from the patients’ common responses to the suggestion that they maintain “cautious optimism”³¹, the advice given by the clinic for their

³¹ “Cautious optimism” was given to the patients by the clinic to help them to manage their emotions. A representative quote to explain cautious optimism:

“I would tell them [other future patients] this word I learned that stuck to me recently, ‘Go into it with cautious optimism’. So you shouldn’t be so pessimistic but you shouldn’t be optimistic either. So guard your emotions while being optimistic. I feel like that it’s a good advice, because the truth is, success rates are

emotion regulation. The excerpts below demonstrate the patients' attempts to figure out what they should allow themselves to feel. Upon receiving an ambiguous lab report, at which the doctor advised her to remain 'cautiously optimistic,' the patient questioned:

"Okay, so how should I feel about that? Like, is that [her lab result] good or bad? I don't know that I knew what 'cautiously' meant, like what could be within 'cautiously'?"

~ Patient 12

Clearly, this patient was exploring the approximate boundaries of the emotional range in which she could maintain equilibrium in the face of the report. Although this might appear to be a direct emotional reaction, the primary emotions were triggered by the doctor's advice for her future state of mind.

Another patient emphasized the challenges she experienced establishing the emotional range:

"Going through these processes, these medical things are difficult because you wanna put your hope in this, that this is going to get you what you've been hoping for and longing for, but it may or may not and that's a very hard place to be because you wanna go through it and you wanna give it your best shot, but at the same time you wanna protect yourself and I mean, it's just, it's awful, it really is very hard.

I think the biggest challenge is just to remain positive and to remain grateful for the blessings you do have in your life and to be able to let go of some [unrealistic expectation], just whatever is gonna happen. It's just hard."

~ Patient 24

Clearly, this patient was very aware of the great difficulty, but also, the importance of deliberating and moderating her feelings. As she suggested, the purpose of emotion regulation was self-protection against the disappointment that she felt sure would overwhelm her in case of an

not [pause] People do get success, but a lot of them just end up in failures, and heart broken, and a lot of bills and then just [pause]. They need to know the reality." ~ Patient 11

unsuccessful outcome. Almost all patients asserted that emotion management of this sort is the most important factor in determining the quality of their experience; as one patient put it,

“It’s a roller coaster, it’s mentally stressful. It’s not the nuts and bolts of the shot and it’s not the side effects. All that stuff is part of it but it’s more just the mental drain of dealing with the potential disappointment. The feelings of is it going to work? Is it not going to work? You’re over analyzing every detail of every symptom you think you may or may not be feeling in that two-week time period. I think it’s really mentally stressful to go through that.”

~ Patient 4

Recognizing the psychological dangers associated with unregulated emotionality, the patients proactively sought to engage in activities that would help them bring their emotions within the bounds of the emotional range and avoid events that would trigger extreme emotions that could push them out of the bounds of their emotional range. Their primary strategy was, as in the case of the other governing uncertainties, information behavior.

5.3.2 Emotion-Directed Information Behavior

Throughout the IVF treatment regimen, patients constantly experienced events that triggered intense anticipatory emotions. Because patients were preoccupied by their experience, almost everything they encountered focused their attention on their concerns about the treatment. Thus every treatment event, such as undergoing egg retrieval and embryo transfer procedures and receiving lab results, and almost every social interaction with their friends and family during the course of the treatment could unexpectedly drive them to an emotional extreme -- intense feelings that were “*just too much*” for them to bear. Thus, the patients engaged in information behaviors to address the difficulties of managing emotionality and maintaining emotional equilibrium. They resourcefully treated everything within their environment, including their own bodies and their social network, as information sources and made them beneficial for regulating their anticipatory emotions. The common mechanisms that the patients devise include information-seeking intended

to create *calibrated uncertainty*, setting up communication protocol among friends and family to avoid emotional triggering encounters, and using home pregnancy tests to acquire a sense of control.

5.3.2.1 Targeted Positive or Negative Information Seeking

Patients set their information seeking goals according to their emotion regulation needs and specifically targeted either positive or negative information. “Cookies” and “real data” are nicknames given by a patient to describe these two different categories of information. The “cookie” refers to unreliable, episodic and often sensational, off-the-charts information that is used to boost the patients’ spirits and encourage them. The crucial feature is that the patient is free to take it as she wishes. “Real data”, on the other hand, refers to scientific, credible, factual, and objective information, which, while it can be positive, is not generally useful for this purpose because it is not really subject to variable interpretations. The “cookie” often comes from popular sources, peer patients, laypersons, or old wives’ tales. The “real data” is typically provided by recognized medical experts, reputable hospitals/clinics, and credible databases such as PubMed. Patients typically use “cookies” to get encouragement and comfort to uplift their emotions and use “real data” to tamp down their positive emotions, as needed, although it is certainly the case that anecdotal information can be negative and scientific data-based material can be positive, as when it can assuage needless fears about the possible meaning of a physical sensation.

The patient who coined these terms explained her use of the statement “It’s time for cookies” to encourage herself, for example, when she felt anxious and scared because she was experiencing bleeding. She perceived bleeding as a serious threat because she had experienced similar conditions in five previous treatments that had all failed. As an antidote to her anxiety about this serious threat she started desperately browsing online; she eventually found a miraculous story about a woman who had given birth to a healthy baby, despite experiencing severe bleeding throughout the entire gestational period. Even while knowing that the story was most likely untrue, or at least aberrant, this patient felt a glimpse of hope and comfort that enabled her to feel positive enough to continue the treatment. She explained:

“I mean if you were to phrase a question on there, ‘Give me some hope’ or ‘Tell me about this, that one that worked out for you,’ or something, you're gonna find people that were the anomalies that said, ‘Oh yeah, I bled all the way through my first trimester and I had a healthy baby’ or blah blah blah. So, I mean if you go looking for it, you can easily find something to either confirm or deny what it is you're trying to confirm or deny, but yeah. That's just, it's like eating Bon Bon's, or something. Sometimes you gotta give in and get a little comfort or whatever and then move on.”

~ Patient 18

Although not all patients are as deliberate in strategizing their information-seeking as this patient, this emotion-driven information seeking is typical. On the flip side of feeling the need to --search for “cookies” there is often the sense of a need for “real data” to anchor the patients’ emotions within the range that worked for them. This commonly took place, for example, immediately after a successful embryo transfer. For almost all patients, notably, this was the peak of anticipatory emotionality, both positive and negative, because of the patients’ heightened sense of their closeness to the goal of pregnancy, given that now an embryo(s) was implanted³². The actual awareness of having an embryo implanted of course produced positive emotions, but because it was coupled with their inability to do anything at that point to affect the outcome, their anxiety was also intense. Their information behavior during this so-called “wait period,” which most patients said was the most emotionally challenging time during the entire treatment cycle, reflected the difficulty they felt in maintaining equilibrium. Patients felt overjoyed at achieving this significant milestone, but they almost immediately sought out information that was credible and factual -- and hence not entirely encouraging -- to moderate what they perceived as extreme positive emotions. Patients said that doing so helped them remain conscientious and vigilant in

³² Many patients talked about experiencing an emotional rollercoaster particularly at the last stage of the treatment. Below is a sample quotation to illustrate this theme:

“I still didn't feel the hopefulness [after her embryo transfer], because at the back of my mind, there's this tremendous amount of fear that, ‘Yeah, this person had success’, but you can be in one of the people that will never have success. That's a possibility that lies and it's so scary. I don't understand why. If you're wanting to have kids and you can't have them, your whole life just seems too [long pause] sad and scary.”

compliance and protected themselves emotionally from potentially extreme disappointment in case of the failed treatment.

5.3.2.2 Using the Body to Generate Information for Emotion Regulation

The patients frequently treated their bodies as sources of information and used the information to anticipate the future, as discussed previously in the section on the governing uncertainty about the drug's effects on the body. Beyond merely noting changes and sensations, the patients often extended their observation to biophysical states, scrupulously monitoring, for example, the quality of their mucus or their daily basal temperature, even though these are, from the physician's point of view, superfluous and not meaningful, as we also discussed previously in the subsection "Patients' bodies as controllable sources of information" (see Section 4. 1.1). This targeted use of their bodies as information sources affords the patients a sense of control, since not only do they have unique access to bodily information, they can also interpret it as their needs of the moment demand; this is important in controlling their emotions and staying within the range that they have constructed.

Another common practice that the patients used to generate information from their bodies for modulating their emotions was to use off-the-shelf home pregnancy tests. Despite the clinic discouragement³³, all patients admitted to having considered conducting a home pregnancy test, and many in fact did so. Those who did not use the tests had various reasons for their choice. Some were simply adhering to physicians' advice; others recognized the inaccuracy of home pregnancy tests and did not want an inaccurate reading to disrupt their compliance, (mis)guide their anticipation, or affect their emotions, which they felt would be more difficult to control, whether the result was positive or negative. For these patients, waiting without taking action was less emotionally taxing than dealing with the heightened uncertainty about the accuracy or inaccuracy. For others, a sense of control was the dominant emotional need. Even though they

³³ The clinic discourages patients from performing home pregnancy tests because the drug's effects can potentially produce false results.

also recognized that the test results might be inaccurate, they felt the need to act; this helped them ‘rehearse’ their emotional response to the outcome, whether positive or negative, and thus to prepare psychologically for the beta test and future treatment plans. In both cases, patients consciously chose whether to use the information provided by these tests to regulate their emotions. The series of excerpts below, taken from a patient who was a medical professional herself, illustrates the way in which, for her, taking the test enabled her to “gain[ing] some control [of her emotions] back”:

“It was a long time but I didn't really anticipate how emotional I was going to get, especially towards the end. Then once I started doing the pregnancy test, that really helped me a lot because it was something to do instead of just waiting around and gave me some control back, which I think is important.”

~ Patient 8

She started the test, remarkably, on the day after embryo transfer, a point at which she could be certain that the test result would not be trustworthy. She described the process of taking tests over 14 consecutive days:

“Yup, then six days post and seven days post. Which is fine because HCG is usually not measurable at that time, but it didn't stress me out that those were negative. I think for me it actually gave me more control back that I actually had something to do.”

Seeing the color of the indicative line on the pregnancy tester darkening a little every day gave her confirmation that her treatment was progressing, even though the change of color does not in fact always indicate pregnancy. Nonetheless, it enabled her to feel that she had some control over her treatment rather than feeling in the dark, powerless, and helpless. For her, ‘just waiting’ generated powerful negative anticipatory emotions.

This intriguing behavior led to the question “were you considering the possibility that the color of the line might not change or might become lighter? She answered:

“I mean, I guess you could start accepting the reality sooner then. You'll probably be more emotionally prepared for it then when you get your beta test”

While few patients articulated their feelings about the use of the tests as clearly as this one, fully half of them did take at least one test during the waiting period. It seems clear that for some patients, the information they could generate or acquire from the home pregnancy test served as a powerful means of acquiring a sense of control for emotion regulation.

Some patients had more unusual ways of using their own bodies as information sources to gain a sense of control and regulate their emotions. Having dialogue with their body was prevalent. Many patients, for example, mentioned “feeling” their ovaries and having frequent conversations with them. They, to varying degrees, talked about their ovaries as if they were detached, stand-alone, reproductive machines, emphasizing merely their utility or performance aspects (e.g., “working” or “not working” ovaries). Some spoke as if their ovaries had a mind of their own, independent from them and out of their control (e.g., “my ovaries feel heavy” instead of “I feel bloated”; “I am 32 but have 42 year-old ovaries”). Some also talked to their embryos in the same manner. In all these instances, the patients ‘talked to’ and ‘listened’ to their bodies and the implanted embryo in a conscious, if not entirely serious, effort to influence their behavior. From the outside, this sort of interaction might not appear to be information behavior, but it is important as a means for patients to feel as if they ‘know’ their bodies and can influence the way their bodies (or their embryos) behave. For many patients, feeling as if they and their bodies were in some sort of communication also helped them with the regulation of their feelings.

Overall, generating information from bodily sensations is derived from the need to assert a sense of control. Patients reported feeling a sense of (re)gaining control over their bodies by being able to monitor, understand, or even influence what their bodies were doing. Not only the information

generated but also the actions itself – “doing” something - helped them to acquire a sense of control and emotion regulation, as I will discuss in the following section.

5.3.3 Acquiring Control

“Well, it makes you feel like you have some control, right? You're able to do something about it. It's like I'm doing something, it feels concrete and active and like, "Okay, I am in control 'cause I'm going to the doctor and I am taking these shots and I am doing all these things.”

~ Patient 6

“The two-week wait is the hardest. When you're getting the injections it's easier, because there you're just in control of it. When you have control over something, you're DOING the cycle, you're fine. But when the control is taken away, whether the two week wait [the pre-pregnancy support stage] or when you're not getting pregnant, it's just a lack of control, is what causes stress, anxiety, sadness.”

~ Patient 11

As the above excerpts suggest, having a sense of control means “doing something” that could influence the treatment process or outcome (“You’re *able to do something about it*”). The patients felt anxious and sad when they sensed a loss of control during the last stage of the treatment cycle because they had many fewer things to do. The patients ascribed having a sense of control to their ability to initiate or enact self-selected and self-executed actions related to the treatment.

Desire to gain a sense of control by taking action not only drives the patients’ information behaviors, it drives much of their behavior. Along this line, it is no surprise to see the patients burdening themselves with even more regimens and activities on top of the already demanding compliance requirements, for example, undertaking certain diets, special exercise or relaxation regimes, alternative therapies (e.g., acupuncture, pregnancy massage), folk remedies (e.g., eating pineapple core to improve blood flow and thicken uterus linings), and/or self-prescribed nutritional

supplements³⁴. The fact that these sorts of actions are, objectively, inconsequential is itself indicative of the strength of the patients' emotional-driven need to take control through their own actions.

5.3.3.1 Social Support

In the context of medical treatments, social support is generally understood to be crucial for the patients' well-being, and IVF is no exception; almost all patients acknowledged that they deemed the support of their families and friends essential to maintaining their psychological health throughout the grueling treatment. Much current literature about patient experience has focused on the nature and role of psychosocial support systems. The conventional wisdom is that positivity is an important component of this support. For my patients, interestingly, this was not entirely true. Many in fact found familial interest in and concern about their progress to be a double-edged sword, as some patients called it, and said that it sometimes unexpectedly obstructed their emotional equilibrium. This is because many well-meant remarks and observations felt intrusive and often had unintended effects that triggered strong emotions that threatened the patients' sense of control. Fear of possible loss of control prompted the patients to enlist and maintain their support system so as to avoid this: they carefully selected the persons in whom they confided and they set boundaries as to what they would talk about and how they would talk about it. While many expressed feelings of loneliness and isolation, they felt ambivalent about seeking the support of their families and in many cases preferred to go online to try to ameliorate their sense of isolation. Although privacy is sometimes assumed to be a major concern for IVF patients, nearly all my patients felt that they knew how to keep their treatment from being known except by those whom they chose to share it with. The problems that they most often reported came, surprisingly, from the close family and friends who were eagerly lending their support and enthusiastically

³⁴ One patient, for example, showed me over 15 bottles of supplements, costing her over \$3000; she said she believed taking these supplements helped her improve her egg quality. Although this may be an extreme case, many patients spoke of their engagement in alternative therapies and taking supplements; they said they felt the need to do so because all these were "natural", "healthy" "won't hurt" or 'can only help' them to improve their condition to achieve pregnancy.

anticipating treatment outcomes. The excerpt below demonstrates the context in which these sorts of difficulties arose:

“Oh, my gosh. People check the blog like crazy. It was funny because I know the day we got our blood draw, people were making comments on my random posts. I’m like, ‘They’re stalking the blog, they’re waiting for our pregnancy test results.’ I could tell. It was like, ‘Why are you on the blog, commenting on random posts’ They’re sitting there probably hitting the refresh button. After we posted, everyone texted us congratulations. You were right, we were stalking all day and H (Subject’s husband)’s mom was like, ‘Oh, my gosh, I was worried. It was 12:15 and you hadn’t posted on the blog yet.’ She was at home looking. Yeah. It’s funny. You can see the stats on the blog. You can see how many page views, so I know people are checking every day.”

~ Patient 8

This patient used a blog to inform her family and friends about her treatment, she described her experience on the day when she announced her beta test result (she had a positive result).

The excerpt showcases two things: one, the eagerness and enthusiasm of the patients’ support system (which is typical) and two, how patients sometimes felt obliged to keep their families informed, even when they might prefer not to. While in this case the news was positive, the patient clearly felt some distressing emotions, and this was true for other patients, especially those whose news was not unambiguously positive. The reason for emotional episodes of these sorts was that friends and families, who usually lacked understanding of the uncertainties involved, expressed emotions--both positive and negative-- that felt extreme to the patients. These emotions reinforced and heightened the patients’ emotions, which sometimes caused their emotionality to get outside the range in which the patients were comfortable.

Some patients also felt responsible for generating troubling emotions in their families and friends and felt burdened by the need to support and comfort them. We can see this clearly in the excerpt below:

I have close friends who we've talked a lot more and I've told my mom and she is a mixed bag, too, 'cause then I have to worry about her being disappointed on top of me being disappointed, so how many details I share, varies. But I also think that it's important for people to understand that there's challenges that can come with this [IVF treatment], and sometimes you only hear the positive stuff. And then sometimes when you start talking to people, they'll say, 'Oh, yeah, well, I had, or my sister had a lot of trouble.' And then, but you don't hear details about the challenges. All you ever hear is the, 'So and so's having a baby.' And you're like, 'Well, nobody really talks about any of the challenges that came with it.'"

~ Patient 12

This patient pointed out the difficulties of getting appropriate support and the potential emotional burdens that could contribute to the disappointment produced by bad news. Along the same line, another patient shared her experience:

"I only told my family about my first IVF. My mom gave me a diaper bag and said that will help me to have positive imaginary thoughts. That diaper bag never left my trunk and then went directly to the garbage. [she shook her head] I never tell them about my treatment anymore."

~ Patient 26

As this and the other patients' words show, their support systems did not always provide emotional support, despite the intentions of the friends and family members who interacted with the patients. The reason, as suggested above, is not a lack of empathy but rather an incomplete understanding of the treatment regimen, particularly in terms of the inherent nature of unpredictability and uncontrollability. Patients felt a strong emotional need to avoid the loss of equilibrium that resulted from the expression, even when well meant, of over-enthusiasm or undue pessimism. As a strategy for coping with this need, many patients devised ways to control their social interaction, going beyond merely choosing the people with whom they would share their treatment news. To head off insensitive or even harmful comments, the patients often stipulated communication protocols, such as not providing treatment details or treatment schedules, delaying the sharing of news, or

enforcing asymmetric ‘no questions asked rules’³⁵, that were designed to help them control their anticipatory emotions.

Confronted with constant emotionality arising from uncertainty, my patients focused on establishing control. They developed an emotional range -- within which they regulated their anticipatory emotions-- and within which they desired to stay to preserve their emotional equilibrium. This regulation process is recursive because the patients’ understanding of the treatment evolved as many clinic encounters and social interactions, expected and unexpected, took place. Patients’ desire to acquire control over their emotional state, especially during the later stages of the treatment regimen, gave rise to this striking and sometimes seemingly inexplicable information behavior and directed ways of managing their social interactions.

5.4 Summary of Findings

My patients perceived their experience as a psychological journey in which they were compelled to address the uncertainty with which they were constantly confronted. They reported a strong desire to “*know what to expect*”, feelings of being “*out of control*”, and the sense of experiencing a constant “*emotional rollercoaster*”. The patients emphasized uncertainty particularly in three areas (i.e., three governing uncertainties): 1) uncertainty about treatment efficacy; 2) uncertainty about the drugs’ effects on the body; and 3) uncertainty about regulating their emotionality.

The patients expressed the desire to make sense of their experiences and to fit them into a coherent internal narrative of persevering through the treatment and achieving pregnancy. They pervasively

³⁵The excerpt below gives an example of how a patient implemented the “no question asked” rule. This patient created a blog for her IVF treatment.

“I sent an email to everyone who knew. If you guys want to keep following up, this is my last email, so I don’t bombard you with emails. Let me know you’re interested and then I had to give them permission to the blog. We told people not to ask us questions like how things are going. If you want to know, just go to the blog. It will detail good or bad. Everything is on there.

I find that if people ask me, I get sad about it, but on the blog, it’s nice because it’s a good way for them to know what’s going on without having to ask me questions or send me emails.” ~Patient 8

engaged in information behaviors to interpret what they encountered and to cope with their uncertainty. Their descriptions of their actions and thoughts reveal that the underlying drivers for these information behaviors, essentially, were their strong wish to acquire control and their pressing need to regulate their emotions.

Three major findings were reported in this study. These are related to the psychological mechanisms of (1) *calibrated uncertainty*; 2) construction of an emotional range and a particular approach for emotion regulation, including both up- and down- regulation; and (3) emotional patterns during the course of the treatment.

5.4.1 Calibrated Uncertainty

The first major finding was that my patients devised a psychological mechanism that I have termed *calibrated uncertainty* or controlling the level of positive and negative affect, which predominantly manifested in their information behavior. Counter to the intuition that people search for information to gain certainty, my patients, intriguingly, often deliberately searched for information that might conflict with or create dissonances between what they desperately wanted to believe and what the objective, accurate scientific assessment of their condition and chances of a positive outcome was. They unconsciously sought to reduce or magnify their uncertainty because it gave them the psychological flexibility to deal with the unpredictability of the outcome.

The patients' application of the *calibrated uncertainty* mechanism was not as straightforward as it might seem on the surface. The patients seemed, and indeed genuinely felt, that they sought information to reduce uncertainty. Although they all acknowledged the irresolvability of the uncertainty inherent in the IVF procedure, nearly all of them repeatedly expressed the need for certainty, and all reported acquiring knowledge so as to manage their expectations about treatment progress and shape their anticipation of the outcome. Examining further, however, we found that their actual behaviors diverged, strikingly, from meeting this need for certainty. Conversely, they often looked for information that would enable them to maintain a manageable level of uncertainty- -sometimes greater and sometimes less.

Stories revealing this *calibrated uncertainty* appeared repeatedly in relation to all three governing uncertainties discussed in this chapter. It is shown in many patients' preferences for sources of information. While most patients asserted that reliable, science-based materials were their preferred information sources, many actually chose to seek information online from personal accounts of other patients rather than from the objective reliable sites, even when they also disparaged these kinds of sources. It is reflected in their frequent use of selective comparisons between themselves and patients they perceived as 'like them' in some ways for interpreting and revising their own treatment outlook, despite recognizing the arbitrariness of the comparisons. A particularly representative example is one patient's designation of anecdotal and admittedly unreliable information as 'cookies,' which she explained as information that could support what she wanted to believe, sometimes by increasing uncertainty. Other patients considered using home pregnancy tests - typically against their doctors' advice - but were in internal debate about whether these could provide certainty or permit uncertainty, as needed. In summary, *calibrated uncertainty* was developed as a coping strategy that enabled patients to achieve the levels of certainty and uncertainty that met their emotional needs at points in the treatment.

5.4.2 Emotion Regulation and Construction of the Emotional Range

Patients frequently stressed their need for emotion regulation. They reported that they were keenly aware of the uncertainty that is inherent in IVF treatment but also knew that one relatively certainty was the generic success rates (which are far below 50%). They were advised to be 'cautiously optimistic,' but the emotional balance implied by the phrase was not easy for them to achieve and maintain, since the perceived high likelihood of an unsuccessful outcome generated strong emotionality. Depending on their emotional needs at the moment, the patients scrupulously gauged the mixture of certainty and uncertainty that best enabled them to persevere in the face of the perceived low odds. Thus, when incoming information appeared to be obviously positive, the patients desired to feel positive feelings but also to reduce the certainty so that they would not become over-optimistic and thus expose themselves to the prospect of heightened disappointment. When the news seemed to be obviously bad, they wanted to dilute certainty they felt to avoid becoming too discouraged to continue the treatment. In short, they were constantly engaged in a

‘mind game,’ as one patient put it, to regulate their emotions and avoid extremes, either positive or negative.

To maintain what they deemed the most sensible emotional equilibrium, the patients essentially explored and tested out the psychological bounds within which they deemed it most sensible and functional for them to remain; that is, they sought a range in which they felt themselves able to cope as changing circumstances prompted positive and negative emotions. Dealing with their individual success rates, for example, was difficult for almost all the patients. To avoid discouragement, they devised several methods of interpreting the rates that relied on the uncertainty permitted by the odds and used these methods to keep discouragement at bay, switching from one mechanism to another as their emotional needs changed over the course of the treatment cycle. This up-regulation was obviously important for their emotional wellbeing; however, against the conventional wisdom of positive psychology, they recognized an equally important need to down-regulate their optimism so as to be prepared emotionally for a potential treatment failure, which was, objectively speaking, by far the likelier outcome. The ‘cookies’ mentioned above functioned in this way, but as up-regulation. They also devised ways of managing their social support to stay within the range rather than becoming affected by friends’ and family members’ excessive optimism or, much more rarely, pessimism.

5.4.3 Emotional Patterns

Finally, the third major finding is the distinct emotional patterns between the immediate and anticipatory emotions. The two types of emotionality thus produced different trajectories during the course of the treatment: in the beginning segments of the treatment, when the emphasis is on performance of prescribed actions, patients tend to feel direct emotions; in the latter part, when they are mostly inactive and the clinic encounters ceased, they experience drastically intensified anticipatory emotions. Typically, in a week or two, as they became familiar with the treatment regimen and gained the skills, they needed to achieve compliance, the patients felt comfortable and were able to tamp down most of the immediate emotions. The anticipatory emotions, on the contrary, fluctuated frequently and erratically and became stronger - in both the negative and

positive directions---- as the treatment progressed and new incoming information was received or acquired. Nearly all patients reported that the intensity of their anticipatory emotions was particularly heightened -- they felt “out of control”, as they put it -- during the last stage of the treatment. The anticipatory emotions are rooted in the patients’ evolving sense of uncertainty and are much more intricate and important for our understanding of the IVF patient experience.

5.5 Summary of Each Section

5.0 Introduction of Findings

1. The patients' day-to-day experience constantly and unremittingly redirected the patients' attention to the uncertainty. Moment-by-moment stimuli from physical sensations, daily treatment activities, and information from the clinic that was perceived as mostly uninterpretable heightened the patients' sense of uncertainty and reinforced their feelings of being out of control. Patients reported that managing expectation is particularly challenging; the IVF experience is essentially a process of confronting and coping with uncertainty.
2. Patients perceived the treatment efficacy as the core uncertainty. The patients said that they did not know how to judge their progress and what to track (e.g., follicle size or number development at a certain point of time) to determine whether their treatment was on track or not. Doctors’ feedback may at times address this concern somewhat but the uncertainty about treatment efficacy remained and unresolved and persistent concern throughout the treatment cycle.
3. Patients’ sense of uncertainty was concentrated in three major areas:
 - a. Uncertainty about the treatment efficacy and their desire to predict it.
 - b. Uncertainty about the drugs’ effects on the body and their desire to track their physical experience to know that the drugs were taking effect and that their treatment progress was on track to a potentially successful outcome.

- c. Uncertainty about how to regulate their emotionality and their desire to maintain optimal emotional equilibrium and persevere through the treatment.

These uncertainties were interrelated and evolved throughout the course of the treatment.

4. Patients engaged in information behavior to address uncertainty. Information behavior involves not only information seeking, but also the mental activities to interpret the information received and acquired. Information sources identified by my patients include their own body (i.e., self-observation and feelings of physical sensations and symptoms) clinic encounters and social interactions.
5. Nearly all patients emphasized the importance for acquiring knowledge for the treatment. While they all acknowledged their desires to address the uncertainty with information behavior, the patients reported feelings of ambivalence in engaging it at times, especially online information-seeking; they felt overwhelmed and out of control at times as a result of their compulsive information behavior.
6. The term *calibrated uncertainty* was introduced; it meant that patients simultaneously seek certainty and uncertainty and sometimes even reject certainty in favor of uncertainty because what is certain is unacceptable (e.g., low odds of success)
7. Patients' feelings of uncertainty engendered emotionality. Nearly all patients explicitly stressed that overall, they felt "*emotional*", "*anxious*", "*worried*", "*concerned*", "*scared*", "*sad*" and "*despairing*".

5.1 Governing Uncertainty about Treatment Efficacy

1. Patients reported experiencing an emotional rollercoaster, which often made them feel out of control; they attributed it to their inability to address the uncertainty about treatment efficacy.
2. The patients did not become fixated on the generic success rate given to them by the physicians prior to the start of the treatment. Perceptions of their individual success

outlook were dynamic; that is, they were constantly changing, evolving as the treatment progressed.

3. The frequently expressed term “*expectation*’ in patients’ mind was intimately associated with their desire to monitor the treatment trajectory. The patients’ expression “*unexpected*” referred to the absence of predictability of success outlook and probability, rather than lack of knowledge about the upcoming treatment events.
4. The patients emphasized the importance of expectation management, which resulted from their desire to have control over their emotions. Patients reported, however, that they knew that they were in an uncontrollable situation, which in turn prompted their emotionality iteratively. The patients’ strong need to seek control to address uncertainty and regulate their emotionality impelled them to engage in information behavior.

An in-depth analysis of a representative excerpt at length was presented to support the above claims. Important observations included:

- a. The patient recognized that the uncertainty about treatment efficacy was the primary source of her emotionality, which also directed her emotion regulation (she questioned “*how should I feel*”)
 - b. Her concerns about the treatment outlook was constantly changing and persistent throughout her treatment cycle. She expressed explicitly her strong desire to get a grasp of it; she fixated on the information (e.g., lab report) she received from the clinic and intended to predict her final outcome.
 - c. The patient regarded the treatment success as an accumulation of succession of intermediate stage results.
5. Patients developed three psychological methods to arrive at an acceptable interpretation of their individual success rate: 1) fixating on a 50-50 probability, 2) assuming a binary dichotomous grouping 3) calculating a cumulative probability. Patients used these methods alternatively, depending on their emotional needs at the moment, during the treatment cycle.

5.2 Uncertainty about the Drugs' Effects on the Body

1. Although the side effects and symptoms patients reported experiencing were all, objectively speaking, tolerable and within physicians' expectations, many reported concerns and worries about them.
2. When addressing the uncertainty about the treatment risks and side effects, nearly all patients said that the generic information was not entirely sufficient; because of the personal significance, many expressed a wish to have individualized information that is based on their unique physiology and condition.
3. The patients expressed heightened awareness of their physical sensations; they dwelt on their sensations and assigned meaning to them because they considered them to be signifiers of treatment progress, which would also provide indication of potential treatment outcome. They often spoke about monitoring their treatment progress via their symptoms.
4. Because they felt that others, particularly their doctors, did not recognize the importance of their concerns about symptoms and side effects, they often became introspective and felt somewhat isolated. In response, they turned to the internet to find corroboration of their feelings and a sense of emotional connection with other patients.
5. The emotionality engendered by the bodily sensations was particularly complex: the same symptoms and sensation (e.g., bloating) produced different feelings in different patients. The same sensation for a given patient, furthermore, in different stages of the treatment sometimes produced different feelings. The patients experienced mixed emotions about their sensations (e.g., one patient felt '*horrible*' about the sensations while also feeling '*excited*' and proud of her endurance).
6. The patients' thinking about their physical sensations centered on the concept of *normality*. The meaning of *normality*, in the patients' mind, went beyond *expectedness*, which was the way they perceived the physicians to be using the term. The patients reported making meaning out of their physical sensations so that they could predict their experience trajectory (e.g., '*How will I feel tomorrow?*') and monitor their treatment progress. The

patients reported difficulty in discerning whether their subjective experience of physical sensations was “*normal*.” This is partly because they were objectively in an unusual physical state resulting from the drugs’ interference with their familiar physical processes and sensations.

7. Patients reported a perceptual gulf between themselves and their physicians regarding the uncertainties associated with the patients’ bodily sensations. This ‘*uncertainty gap*’ refers to a discrepancy of perspectives derived from the disparity of expert knowledge, division between their roles, and dissimilarity between subjective experience and objective observation. The *uncertainty gap* often provoked patients’ emotionality and reinforced patients’ desires to assert control. They said that they had the authority over how they feel about their body and the meaning of their symptoms and reported doing a great deal of self-observation and information seeking in support of this sense of authority, which, again, they felt that they could not adequately convey to their physicians.
8. The patients’ actions suggested that in addressing the uncertainty about their physical experience. They preferred seeking information from personal accounts of other patients instead of authoritative and scientific information. They specifically sought personal anecdotes that could validate their emotional reactions or assignments of meaning to their physical sensations, which could -- as they may or may not have been consciously aware of --potentially increase their uncertainty (i.e., create *calibrated uncertainty*). This information seeking approach was driven by their desire for control; this approach allowed the patients not only to freely choose the information sources but also to freely interpret the information they acquired from these sources.

5.3 Uncertainty about Regulating Emotionality

1. Patients' emotionality is extremely complex, and nearly all patients reported that emotion regulation was the most challenging aspect of the patients’ experience.

2. Patients reported experiencing a wide variety and broad range of emotions on a spectrum of intensity and frequency; they also experienced a constant emotional rollercoaster. Based on the stimulus that gave rise to the emotion episodes, we classify these emotions into two categories: immediate and anticipatory emotions.
3. Immediate and anticipatory emotions exhibited distinct trajectories in their levels of intensity throughout the course of the treatment. The intensities of Immediate emotions reached their highs during the first part of the treatment, when most of the clinic encounters and treatment activities took place. As patients acquired skills to manage their compliance and became more comfortable with the treatment, the intensity of the immediate emotions lessened. They were also greatly heightened at three specific points: right before the beta test during the and at each of the two milestones intermittently (i.e., egg retrieval and embryo transfer). Anticipatory emotions reached their peak at the same three points; they dropped immediately as patients received results about their milestones and shot up again very shortly as they redirected their attention to prospecting the next milestone. The overall trend was downward for immediate emotions and upward for anticipatory emotions.
4. Patients engaged in emotion-directed information behaviors to explore the psychological bounds within which they felt comfortable staying, i.e., an emotional range between hope and despair. The patients sought specifically positive or negative targeted information (“cookies” or “real data”); when they received obviously good or bad news, the patients interpreted and assigned values to the information they acquired to accord with the level of optimism or pessimism they perceived, consciously or unconsciously, to enable them to persist and remain functional.
5. In exploring the emotional range they constructed for themselves, the patients gauged the level of hopefulness appropriate for achieving their optimal emotional equilibrium, that is, the balance between optimism and pessimism that they deemed suitable to preserve their well-being and enable them to persevere through the treatment.
6. The patients’ emotion-directed information behavior broadly included conducting self-observation of their bodily functions and sensations and establishing specific communication protocols to manage their social support. The underlying driver for these

behaviors was to maintain their emotional equilibrium and not to fall outside bounds of their emotional ranges.

Chapter 6 - Discussion

For this study, I interviewed 29 women who had undergone IVF, asking them to recall, using their treatment calendars, their thoughts, feelings, physical sensations, activities, and perspectives on every day over the course of the treatment. I also asked them to reflect broadly on the treatment as a whole and to talk about how they managed treatment activities, adherence, the disruptions to their ordinary lives, social interactions, and anything else that had concerned them. While most of the findings reported in this dissertation are based on my analysis of the interview transcripts, I also used field research to triangulate, i.e., to validate my interpretations of the data by my own experience in the IVF clinic, which involved shadowing doctors and volunteering as a nurse assistant. To the best of my knowledge, this is the only in-depth study of the lived experience for the entire course of the treatment of IVF patients, who are subjects of particular interest because they constitute a population in a challenging, high-stakes situation with significant emotional impact.

The most important findings of the analysis, briefly, are these:

- High uncertainty, an emotional roller coaster, the need to feel in control, and the need for information to address uncertainty were key features of my IVF patients' experience. The interaction among these features were complex and dynamic.
- The treatment can be usefully understood as falling into two distinct segments (the stimulation/ fertilization stages and, after the embryo transfer, the waiting stage), which

constituted quite different environments in which the patients' experiences, and thus their emotions, uncertainties, information behavior, and sense of control, differed significantly.

- The patients displayed two kinds of emotions, immediate (triggered primarily by present or past events) and anticipatory (triggered by patients' projection of their future states and the outcome). Their intensities and valences varied in accordance with the uncertainties, which varied between and within the two segments. Uncertainty was more strongly felt in the second stage, because no objective information typically comes from the clinic during this period, and anticipatory emotions, which are known to be more difficult to control, predominated.
- My patients were motivated to restrict the range of their emotions to maintain equilibrium and persevere in the treatment. They did this up-regulation and down-regulation by adjusting the positive/negative valence of information and the level of certainty. Surprisingly, they sometimes deliberately magnified their uncertainty or down-regulated positive emotions to protect themselves against anticipated disappointment.

The explanations for and implications of these findings are discussed in the sections that follow.

6.1 The Need for Control

The desire to exert control--despite the inherent uncontrollability of the IVF procedure, which all of my patients acknowledged--was for almost all of them a central preoccupation; it profoundly influenced their psychological state in their daily lives over the course of the treatment. The reason is, in one sense, quite simple: the patients, who in most other spheres of their lives felt themselves to be capable and self-reliant, could not make their bodies do the thing that they wanted most, to become pregnant. Furthermore, while they could choose to undertake IVF treatment and to endure the demanding protocol and could closely monitor their progress, they could not positively influence their bodies to respond to the drug regimen or in any significant way control the outcome.

These realizations had a great impact on their emotions and psychological well-being. Finding themselves in a highly uncertain situation, they experienced an emotional rollercoaster that further reinforced their sense of being out of control. The need to feel in control and to deal with the irresolvable uncertainties built into the IVF experience became a primary motivator of their behaviors. The patients' struggle to cope with uncertainty gave rise to heightened emotionality, which resulted in their feelings of being out of control, which in turn compelled them to seek control in a recursive process of information seeking and emotional regulation. The principal driver for my patients' emotions and their behavior, ultimately, was the desire to gain and exercise control.

The manifestation of this control motive was often intriguing because uncontrollability is inevitable in the IVF experience, and patients had to find ways of coming to terms with it. This is exemplified particularly by the patients' peculiar information behavior. As the excerpts provided in Chapter 4 demonstrated, the patients stressed the importance of engaging in information behavior to acquire additional information, and some explicitly said that they did so in order to increase their certainty, which they said would give them a greater sense of control -- in their words, 'know[ing] what to expect.' My analyses of the mechanisms that directed their information behavior, surprisingly, very strongly suggested that the actual driver of the behavior deviated strikingly from the desire merely to increase certainty. Rather than seeking information to maximize certainty in every aspect of the experience, the patients actually strove for the right levels of both certainty and *uncertainty* so that they could achieve emotional equilibrium, or a balance between extremes of emotion. This simultaneous seeking of --and embrace of-- certainty and uncertainty is the phenomenon I called *calibrated uncertainty*. It, too, reflected the patients' need to exercise control through their choices. The patients intuitively constructed for themselves an optimal emotional range, and they used *calibrated uncertainty* in their information seeking and meaning-making to remain within it. Patients targeted their information behavior to maximize their sense of control and thus to manage their emotions.

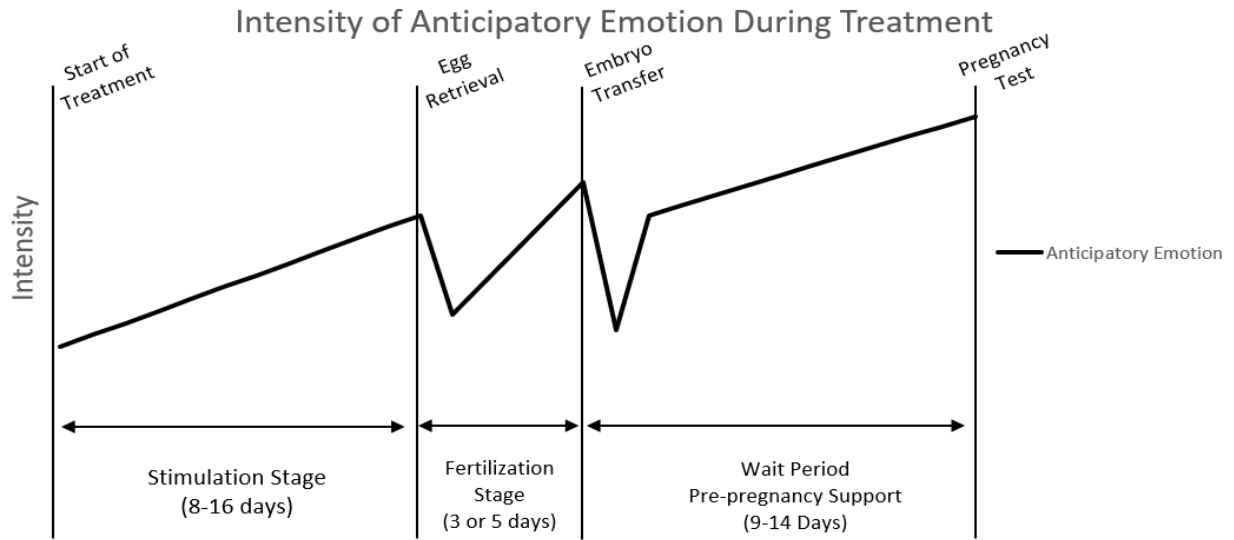
Although many patients did not explicitly express their need to acquire control - some in fact specifically stated that they knew they had little control -- most, contrarily, manifested it in other

statements and in their emotion episodes. The complexity of the patients' emotion episodes elicited by uncontrollability and the intensity of their perception of control evolved in conjunction with the uncertainties, which also metamorphosed with unfolding treatment events. The information behavior that was directed, accordingly, was also changing because of its reciprocal relationship with the changing perceptions of control, uncertainty, and their emotionality. Overall, a sense of control was the primary end of the information behavior, rather than increased certainty.

6.2 Two Information Environments and Emotionality

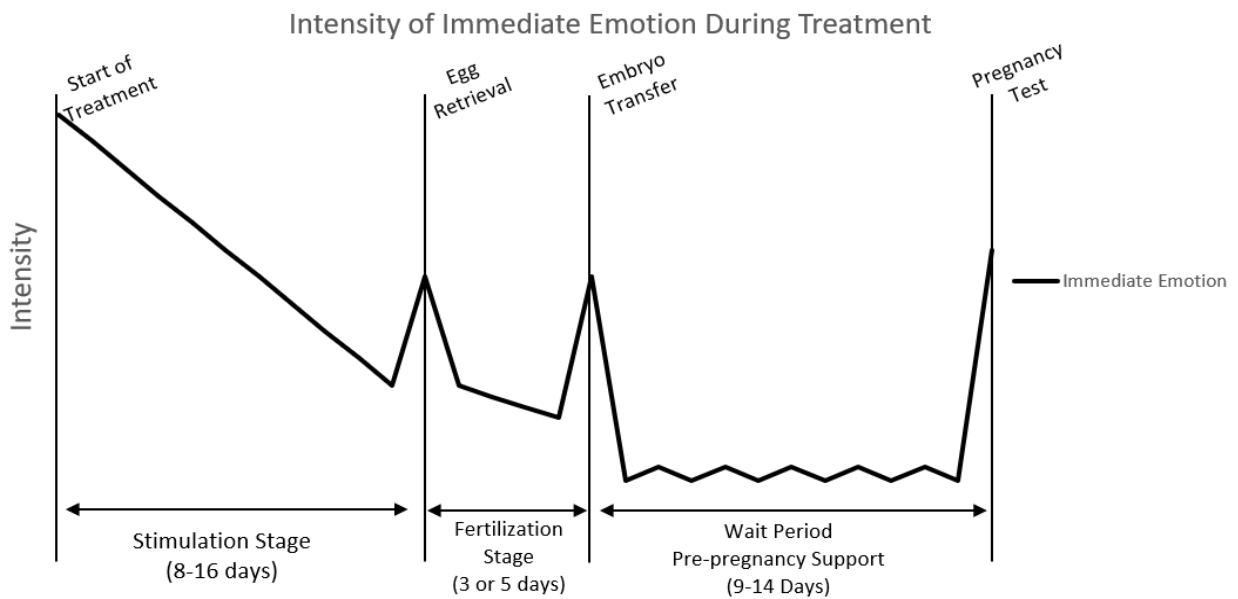
The underlying drivers of my patients' emotionality were two different psychological contexts corresponding to the two segments of the treatment period described above, that differed in important ways: in the patients' perception and exercising of control to achieve equilibrium, in the particular type of emotionality that predominated, and in the foci of the uncertainties that patients attempted to cope with. Just as we can see that the patients' states of mind were tied to particular aspects of the treatment progress, we can see that the treatment activities generated different information environments in which two disparate experiences were engendered and gave rise to different patterns of emotions. This accounts for the two dissimilar emotionality trajectories, the immediate and the anticipatory, as I will discuss below.

Depicted in the charts below are the trajectories of the two dissimilar types of emotions that together constituted my patients' overall emotional experience over the course of the treatment. As can be seen, these trajectories are quite different from each other, and in each there are differences between the trends shown in the first part of the treatment and those shown in the second.



Anticipatory emotions reached their peak at three points (egg retrieval, embryo transfer, and pregnancy test); they dropped immediately as patients received results about their milestones and shot up again very shortly as they redirected their attention to prospecting the next milestone. The overall trend was downward for immediate emotions and upward for anticipatory emotions.

Figure 9. Intensity of Anticipatory Emotion During Treatment



The intensities of immediate emotions reached their highs during the first part of the treatment, when the majority of the clinic encounters and treatment activities took place. As patients acquired skills to manage their compliance and became more comfortable with the treatment, the intensity of the immediate emotions lessened. However, they were greatly heightened at each of the two milestones (i.e., egg retrieval and embryo transfer) and on the day of the pregnancy test.

Figure 10. Intensity of Immediate Emotion During Treatment

These trend lines were situated in the two divergent information environments within the treatment, segmented at the embryo transfer procedure. As will be explained further below, different perceptions of (un)controllability emerged and different questions arose for the patients during each environment. Thus, they had different foci for their information behaviors, which, again, recursively affected their sense of control and perceptions of uncertainty, further provoking emotionality.

Before the embryo transfer, the patients' lives were filled with a busy treatment schedule with many routine clinic visits and daily compliance tasks, which was demanding and laborious. The patients' sense of controllability, consequently, was shored up because they were "doing something," in their words; that is, they felt they were somewhat "in control." As the treatment progressed, the patients, in addition, acquired and practiced needed skills with the regimen administration, which also fortified their sense of control. The reality of the uncontrollability built into the treatment seemed to them, therefore, lessened because of the busyness, the hard work and the increasing familiarity with the treatment regimen; these bolstered the patients' perception of control, which tamped down their immediate emotionality. A downward trend of immediate emotion, particularly in the first part of the treatment, thus resulted.

It should be noted that immediate emotions often sharply rose up at the milestones because they were new and important events; patients were stimulated physically by the procedures; in addition, many unusual environmental settings, such as the highly sterile, surgical room-like procedure room, also disquieted the patients. After the embryo transfer, the immediate emotions dropped to the lowest point and remained relatively low, in part because patients experienced short-lived relief and certainty, but mainly because all the clinic encounters ceased after the embryo transfer procedure except in a few atypical cases, no interactions with the clinic took place; i.e., external stimuli were completely paused until the pregnancy test. Under these circumstances, there was little to trigger or heighten immediate emotions.

During the time segment after the embryo transfer, the patients' lives became radically different from what they had been in the first segment. As noted above, neither procedures nor lab activities were taking place, and the patients had minimal interactions with the clinic; the compliance activities were also substantially reduced to merely taking the progesterone drug. The patients felt,

essentially, that they were no longer “doing” things, i.e., they were not acting so as to gain a sense of control and thus the sense of control that they had had in the first segment dwindled. As the treatment progressed, the patients' feelings of loss of control intensified, which in turn reinforced their desire to (re)gain control. This self-focused environment, furthermore, produced hyper-awareness of their feelings, which led patients to dwell on their feelings and to engage in speculation; thus, it elevated their anticipatory emotionality. The upward trend of anticipatory emotion that is seen particularly in the second part of the treatment thus resulted.

If we look at the chart showing the range of intensity and variability of emotions over the whole course of the treatment, we can clearly see a difference between the two treatment segments. The evolution of the roller coaster or oscillation emotionality between positivity and negativity reflects the patients’ different experiences during these time periods and displays the overall heightening of anticipatory emotion as the treatment nears the end. The differences shown here conditioned the patients’ peculiar information behavior.

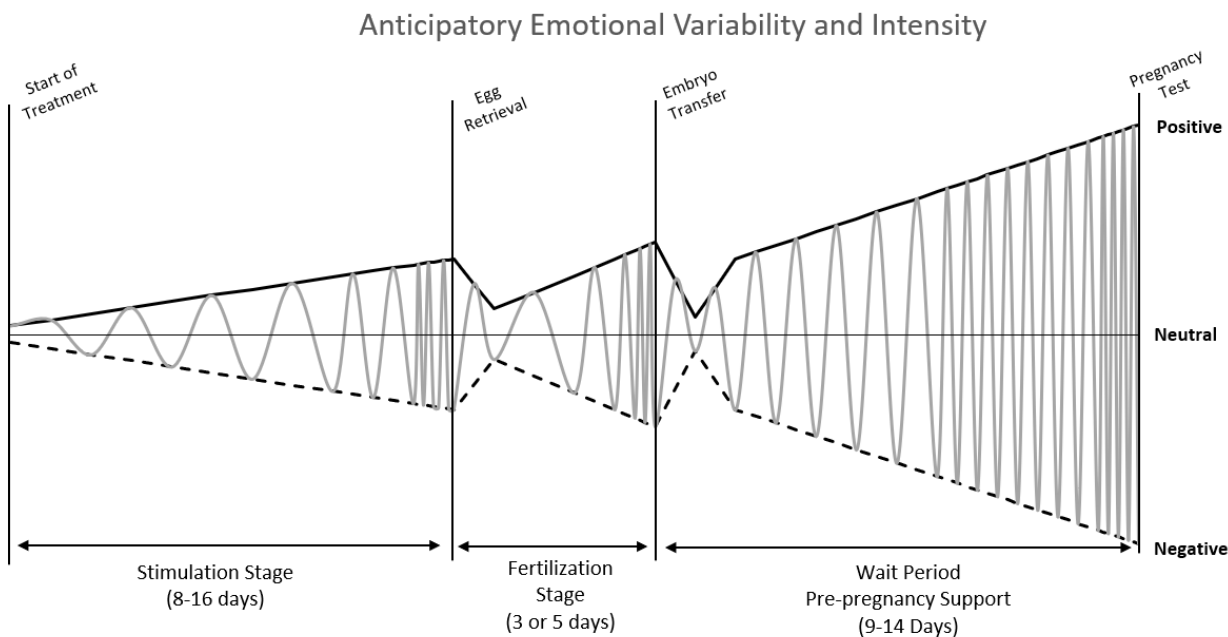


Figure 11. Anticipatory Emotional Variability and Intensity

During the segment before the embryo transfer, a stream of information, including the physicians’ feedback and lab reports, was regularly provided; authoritative information such as compliance and care instructions were also readily accessible. In this environment, for good reason, the

patients were directed to focus their concerns on interpretation and comprehension of this information, so that they could overcome the learning curve and effectively manage compliance. The patients' information behavior, consequently, mostly involved the understanding and tracking of objective measurements and medical reports. During their frequent clinic encounters, in addition, the patients also had opportunities to receive social cues that they could use to interpret this information. Regardless of whether the information they received was positive or negative, they received it with a degree of certainty; that is, they accepted it as evidence that the physician felt that they were on track and continuing to progress. The recurrent clinic encounters helped reinforce the sense that they were in the hands of experts. Because all these social interactions and their intake of information were relatively circumscribed, the patients' emotions, accordingly, were relatively less capricious because they were provoked largely by the prescribed treatment events, and the constant access to the physicians and the clinic staff also afforded them support and validation to a certain extent. The less volatile and narrower range of the emotional rollercoaster that patients reported experiencing reflect this relatively less free-ranging information environment, as shown in the chart above.

The psychological context during the time segment after the embryo transfer was vastly different from that of the first segment. My patients lived in the future during this time, not only because they were "doing" very few treatment-related tasks to directly impact the regimen, which diminished their sense of control, but also because they were receiving literally no information from the clinic about their present condition. Thus, their information behavior was very undirected by authority and unprompted by external events. The patients felt that they were completely on their own, and the uncertainties that they were dealing with became more broadly focused. Their interactions, which were mostly with other patients or with friends and family rather than with authorities, furthermore, were completely uncircumscribed. While they did have control of the information sources they sought, and while they were able to choose how to interpret the information, some of the information they acquired in these ways magnified their uncertainty. Because they knew that it might or might not be reliable, they could accept or reject it, but often they felt unable to control their emotional responses to it. This, coupled with the increasingly stronger recursive cycle of loss and acquisition of control (because of the absence of directed activities) to which they were also subject during this time, produced great variability; the patients'

emotionality, as one might expect, went unchecked and reached extremes of intensity. The increased fluctuation and broader range of the emotional rollercoaster that we see particularly in the second segment of the treatment thus resulted.

It should be noted that despite the overall trend of the range, which became broader from the beginning of the treatment and reached the widest at the end, the shape of the range narrowed sharply at the two milestones. This is because the patients felt a transient certainty after the milestone and thus, they perceived the valence of the uncertainty as narrower.

In summary, the divergent perceptions of control, which were driven by the treatment activities, interacted reciprocally with the changing uncertainties. This interaction gave rise to and directed information behaviors and meaning-making that differed noticeably in the two treatment segments. Differences between the psychological contexts of the two segments, further, resulted in distinct patterns of emotion, which recursively influenced the information behavior.

6.3 The Construction of the Emotional Range

I have argued that emotion regulation in my patients involved the construction of an emotional range and efforts, both conscious and unconscious, to remain within that range. This argument rests on three observations: 1) they appeared to focus on difficult anticipatory emotionality (rather than the more easily regulated immediate emotionality) as an important realm of exerting control; 2) they seemed to feel uncertain about how to achieve the recommended state of “cautious optimism”; 3) they used both up- and down- emotion regulation, sometimes explicitly, which was unexpected because it contradicts conventional wisdom. Emotion regulation, as discussed in the previous chapter, was identified by nearly every patient as the greatest challenge in their experience; thus, it is not surprising that it occupies a central place in the psychological journey that they are undertaking.

First, the heightening of emotionality that consistently troubled the patients throughout the treatment cycles, as my analyses showed, involved primarily the anticipatory emotions because these were triggered by the unresolvable uncertainty about the treatment outcome, unlike the

immediate emotionality, which was triggered by patients' relatively greater certainty about how they felt toward a concrete event or a situation that was present or in the past.

The anticipatory emotions the patients reported experiencing were volatile and cumulative; that is, they could be generated by events or by patients' changing thoughts and imaginative creation of future states, which built on themselves, cumulatively producing a sense of increasing uncertainty that resulted in both positive and negative emotions. As the treatment progressed, the anticipatory emotions, both positive and negative, intensified; they sometimes became so overpowering that patients felt "out of control", as many remarked. Briefly, the anticipatory emotion often generated emotional rollercoasters. The extent and intensity of the rollercoaster, additionally, were amplified as patients approached every milestone, dropped sharply shortly afterward, and then began building again, as we can easily see in the chart shown above, because the results of the milestones gave transient certainty and the patients soon resumed to the mode of looking toward the next milestone.

Second, nearly all patients explicitly stressed the importance of maintaining emotional equilibrium because of the unpredictable and perceived low success rate. They acted, consciously or not, to maintain the 'right' -- rather than the maximum -- amount of hopefulness so that not only could they continuously act diligently to perform the required treatment tasks but also avoid being subject to the crushing effect of extreme disappointment from a potential treatment failure, which was, objectively speaking, by far the likelier outcome.

Third, when talking about coping with their uncertainty about regulating their emotionality, nearly all of the patients not only spoke about up-regulation of their non-positive emotions to lift their spirits, but also revealed, strikingly and often with more self-awareness, that they had tried to down-regulate their positive emotions to protect themselves against excessive optimism that might ultimately make them feel worse. That is, the patients perceived a need to regulate their emotions in both directions because it was vital for achieving emotional equilibrium.

As changing circumstances and new information incessantly prompted emotions, both positive and negative, the patients were compelled to continuously explore and test out the extent of this range, i.e., to gauge how well it corresponded with their changing perceptions of uncertainty and

certainty. Patients expressed this in repeated questions like “*how should I feel?*” or “*how optimistic or cautious should I be?*” While few were explicit on this point, some directly stated that they judged whether they had achieved emotional equilibrium by referring to whether their feelings were within the emotional range loosely bounded by the optimism and pessimism levels that they perceived as psychologically appropriate for them to manage their anticipation (e.g., “*I had a better balance between hope and disappointment*”).

To sum up, the patients’ anticipatory emotions, which were sensitive to changing uncertainties and perceptions of uncontrollability, were a dominant force in their experience. Relentlessly emotion-ridden, both positively and negatively, they sought emotional equilibrium, or ‘cautious optimism’, because the emotional roller coaster was difficult to manage and caused them psychological distress. However, rather than tamping down negative emotions and bolstering positive ones, my patients constructed an emotional range made up of both positive and negative emotions in which they felt comfortable staying. This has numerous implications for our theory-based understanding of emotion in uncertain situations where controllability is limited and for future work based on appraisal theory. It will also provide insights that can inform practical considerations about the design of the Information delivery systems and healthcare service.

Chapter 7 - Conclusions and Recommendations

This study describes in depth the patient experience of 29 women undergoing IVF treatment, who are well known to have heightened emotionality. IVF is a complex, intensively regimented and demanding treatment; the context is highly specialized and complicated. More importantly, patients--the users of the medical care service-- often consider the treatment as life-changing and high-stakes and intrusive by nature and need psycho-social support. Although many studies assert that IVF patients suffer from emotional distress and thus a (re)design for delivering better experience is desired, we had little understanding of the patient's experience. My goal for this project was to understand how the patients' experiences proceeded and how their lived lives unfolded during the treatment throughout the continuum of their care, i.e., the use of the medical care service. I designed this investigation to identify the building blocks of the experience and their interactions with both physical and psychological contexts to define the problem space for design of an improved patient experience.

I designed this investigation based on the appraisal theory framework. Appraisal theory asserts that appraisals define emotions, which then direct actions (see, e.g., Lazarus 1968; Scherer 1984; Smith & Ellsworth 1985,1987; Frijda, Kuipers & Ter Schure 1989; Roseman 2001; Ellsworth & Scherer 2003; Moors, Ellsworth, Scherer & Frijda 2013). That is, people always, consciously or not, interpret various aspects of the events they encounter and appraise how they will be affected. Emotions correspond to such appraisals rather than to the events themselves. These appraisal-generated emotions then give rise to particular behaviors. This process is recursive; emotions and emotion-driven behaviors further generate or act as stimuli that trigger new appraisals.

I was particularly interested in how patients' appraisals interact with their emotions and behaviors. Hence, the findings identify general patterns of how patients process information and appraise events such as clinical encounters and personal interactions that often have highly emotionally

charged consequences, and especially how they devise mechanisms that enable them to regulate their emotions and to persevere in the treatment. They also help to account for the extraordinary adherence to the treatment these patients displayed. The findings also show that the need for a sense of control is a dominant force in the patients' psychological state. Perceived absence or loss of control drives much of the patients' information behavior as well as their emotionality.

As with any interpretivist work, the findings from this study may be specific to the clinical context and site observed, and this is also true of the specific conclusions drawn from questions for the patients who participated in the interviews. Nonetheless, because the analyses focus on the fundamental elements of the IVF experience, I believe that some general conclusions may legitimately be drawn. Although the specific treatment context, including how the patient education is constructed and delivered and how the treatment regimen is administered and managed, and some of the findings may differ among different clinics, the primary motivations, emotionality and the psychological context that drive and direct the IVF patients behaviors that I have identified in this study are likely to emerge in other settings. I expect that the psychological mechanisms that my patients used and the emotional trajectories that were exhibited in this study will be seen in other IVF patients' psychology, both in this clinic and elsewhere. I also expect that the particular information behavior and emotion regulation practices in which my patients engaged will also show up in other IVF patients. As discussed in the introduction, medical service is a credence good, which has important implications for the design of its delivery, particularly the delivery of information to the patients. Despite many differences among medical regimens, almost all involve uncertainty, heightened emotionality and, in some cases, remarkably high stakes. As patient-centered medicine continues to become the preferred approach to service delivery, understanding how patients navigate emotionality is crucial in constructing effective service offerings.

7.1 Contributions

The specific contributions of this dissertation are these:

1. A conceptual framework was created to account for the underlying drivers (i.e., desire for control and changing sense of uncertainty) of the patients' behavior and development of these drivers during the treatment. That is, the factors that shape the IVF patients' experience and how the experience evolves have been spelled out in depth systematically, which enables us to better understand the evolution of IVF patients' experience thoroughly and holistically.
2. A research-supported basis for organizing the treatment context into distinct well-characterized realms is presented. The specific connections between important aspects of the environmental contexts and what the realms are highlighted and the interactions among the factors are explained. This treatment enables us to tease out the specific environmental factors, such as treatment activities and regimen requirements, and to show their role in the formation of meaningful psychological contexts that evoke particular emotion episodes. The insights provided by examining each realm individually enable the design of better responses to their emotional needs over the course of the treatment.
3. The two major types of emotions constituting the patients' emotional life during the treatment are identified and their divergent trends were described and explained. The overall trend for immediate emotional trajectory is downward while it is upward for anticipatory emotions. Looking at the two types of emotionality as distinct helps us better understand patient's emotional life, information behaviors, and practices intended to enable them to cope.
4. Specific emotion regulation practices that patients used to persevere in the treatment were illuminated and explained. Patients employ both up-regulation and down-regulation to

keep themselves within an emotional range that enables them to maintain emotional equilibrium. In a related mechanism, they adjust their sense of certainty in accordance with their needs: in an effort to head off disappointment they ascribe greater uncertainty to information that they perceive as negative and lesser uncertainty to information that they perceive as positive. This practice makes use of the psychological mechanism that we have called *calibrated uncertainty*, or the interpretation of information in ways that appear contradictory so as to maintain an appropriate degree of cautious optimism.

7.2 Limitations of the Study

Because this is a qualitative study, its strengths are the depth of analysis and the holistic view permitted by that approach. While I have used field observation and informal interviews with the clinic staff to triangulate my analysis, it would have been valuable to have included a quantitative analysis as well; since no objective measurements or ‘hard’ data were obtained. A pilot quantitative study was undertaken, and the hypotheses of this study were to a great extent based on the findings of this work; however, a larger sample size would have been useful as a basis for this study.

Additionally, it would have been beneficial to have obtained more data about the patients’ experience concurrently with the treatment itself. Many patients were undergoing a subsequent treatment at the time of the interview; thus, their descriptions were informed by reflections on and comparisons between their current and past treatment experiences. All patients had completed at least one treatment cycle within three months. Much of the data came from patients’ recollections of a highly emotional and very recent experience, and the memories often triggered vivid re-experience of some of those same emotions. However, the experiences were, unavoidably, re-interpreted by the patients to a certain extent in their responses to the interview questions. Of course, this is always true of interview-based research involving self-reporting, and the analysis rests not only on the self-reported data but also on my own extensive fieldwork and observations of ongoing treatments (noted above). Other factors such as the treatment outcome, regardless of whether it was positive or negative, and where patients were in a subsequent treatment at the time

of the interview, also influenced patients' reported memories of how they had felt during the most recently completed treatment. It should be noted that the final sample selection was also affected by a significant drop-out rate; a number of patients who had agreed to participate only on condition that they had a successful outcome withdrew from the interviews, which reduced the quantity of data and may have biased the sample.

Finally, as is true of any qualitative research, the investigator-patient relationship was potentially colored by outside factors, in this case the investigator's presumed endorsement by the treating physician. Particularly for those who were currently undergoing a repeat treatment, some reticence regarding their feelings about the clinic or the personnel may have affected their candor.

7.3 Future Work

Based on the conclusions of this study, I have planned out a research program for future study. I have also developed some guidelines and suggestions for medical care practitioners and interaction designers. I will describe both below.

7.3.1 Future Research Program

To expand on my previous work, I plan four future studies:

1. Real-time measurement of experience throughout the course of the treatment:

I will use the findings from this study to construct hypotheses to serve as the basis for a field experiment using the experience sampling method, as my earlier pilot study did, with a larger sample size to track daily changing concerns, thoughts, and emotionality concurrently with the treatment. The objective measurements we will obtain will enable us to fine-tune our findings, particularly in accounting for the generation of qualitatively different emotions and their trajectories, and further our understanding of interrelationships among patients' perceptions of uncertainty, controllability and emotionality.

2. Tracking of the evolution of online Information seeking

I plan to design a study to track patients' inquiries and online interactions during the treatment to better understand how patients' uncertainty changes with changing circumstances.

3. Interview-based investigation of the experiences of IVF patients' partners

This could provide further understanding of the patient's lives, particularly in their support needs and emotion regulation practices.

4. Comparative study of different populations in healthcare.

I plan to do a comparison study with different populations in healthcare, such as cancer patients or parents of autistic children in treatment for their condition, who are confronted with high stakes, heightened uncertainty, and emotionality for a set duration of time.

7.4 Suggested Guidelines for Medical Practitioners and Interaction Designers

The IVF patient's experience is usefully understood as an evolving process in which the needs for support constantly change and patients place great emphasis on acquiring perceived control to cope. When practitioners and designers think about the service that is to be delivered to these patients, they should approach and handle the design to align with the psychological contexts as well as with the treatment activity stages. Put differently, an IVF patient's experience should be treated as amalgamation of various experiences or design problems that are bounded by the patients' psychological states, cognitions, and emotionality. The practitioners and interaction designers should use these states as a basis for formulating their design goals and delivery protocols.

The overall support offered to patients should aim to address their changing needs for acquiring perceived control and managing anticipation. Making visible efforts to recognize these or communicating an understanding of them helps greatly. Some examples might be (1) acquainting patients with typical overall trajectories of emotionality and physical experience at the beginning of the treatment; (2) presenting lab results in the context of overall treatment progress so as to help patients focus on one day at a time or compartmentalize their expectations (e.g., saying ‘you have 6 eggs today; by the end of this week we hope to get 12 eggs’); and (3) providing validation for patient’s subjective experience of physical sensations (e.g., saying, ‘yes, most patients feel especially bloated and uncomfortable when approaching egg retrieval’), and similar statements that provide reassurance about specific details that may not be highlighted in the patient information materials. These are ways to avoid evoking anticipatory emotions and strengthen the patients’ feeling of being in control.

Equally important, in addition, most of my IVF patients emphasized that their goal in emotion regulation was to stay within a range, rather than maximizing their hopefulness or going to extremes of emotion in either direction. The information delivery or interaction protocols design and clinic setting must reflect this understanding and be sensitive about this need. That is, it is essential for designers and providers to understand the value of emotional equilibrium for patients and thus not to overemphasize optimism or inadvertently incite the patients to emotional extremes.

Different foci in different segments should be recognized, i.e., addressing immediate emotionality management in the first segment and anticipatory emotionality management in the second segment. For example, informing patients about the features of the procedure room settings may prevent the patients from overreacting to them. Altering the setting so that it has a friendlier and warmer ambience, such as by playing soothing music, may help the provider to avoid evoking strong immediate emotions. In the second segment, it would be beneficial to offer some concrete activities that are prescribed and that require some effort, for example, taking prenatal vitamins at a specific time or carrying out a pre-planned project, so as to help them in preserving their perception of control. This will help patients avoid dwelling entirely on themselves and their inner experiences.

Appendix

Appendix A. Preliminary Questionnaire

PRELIMINARY QUESTIONNAIRE

Age: _____

Marital Status:

Single Married Domestic Partnership

Other, please explain _____

Local Support:

Do you have anyone living close by (less than 1 hour away), other than your partner, that knows you are currently (or that you were) under treatment?

Yes No

If yes, who are they?

Family Friends Neighbors Colleagues

Social Acquaintances Other _____

Employment:

Are you currently employed? Yes No

If yes, please specify what type of job

Number of hours/week: _____

How many hours/week do you need to be at the office/on site? _____

How many hours/week do you need to be working from home? _____

Treatment:

When was your most recent egg retrieval date? _____

Have you undergone, or are currently undergoing genetic counseling?

Yes No

Have you arranged for someone to provide eggs/sperm? Yes No

If yes, who is providing them and how is the delivery coordinated?

Which treatments have you undergone?

Oral Fertility Medication ___ Clomid (Clomiphene/Clomitene)

 ___ Femora (Letrozole)

 ___ Other

Injection Fertility Medication ___ rFSH

 ___ Follistim (vials or pen)

Surgery for Fertility

Gonadotropin-releasing hormone (vials or pen)

Bravelle (vials)

HMG

Menopur (vials)

Repronex (vials)

Surgery for Endometriosis

Laparoscopy

Laparotomy

Hysteroscopy

Removal of one or more Fallopian tubes

Removal of Endometrial Polyp

Removal of Fibroids

What medications did you use during your most recent IVF cycle?

Microdose Lupron, Leuprolide

Lupron, Leuprolide

Antagon, Ganirelix, Cetrotide

rFSH

HMG

Which of the following do you regularly use (at least once a week)?

Communication:

Smartphone (e.g., iPhone, Android)

Feature phone (e.g., Motorola Razr, LG Black Label)

Online calendar/planner (e.g., Outlook, Google Calendar):

Health tracking devices:

Nike Fuelband

Fitbit

Jawbone UP

Other (please specify) _____

Social networking:

Facebook

Twitter

Tumblr

Instagram

Flickr

Other (please specify) _____

Health related sites:

Patients Like Me

Resolve

Medline Plus

WebMD

Other (please specify) _____

Appendix B. Interview Protocol

Fertility Patient Study

Interview Guide

Introduction & Background

First of all, I want to thank you for taking time to participate in this study. IVF treatment can be quite taxing and stressful. We intend to use the information you share with us to design electronic tools to better support you and other couples engaged in IVF. At the end of our conversation, I want to have a clear picture of your experiences and how you and your partner are going through them. I want to know about any roadblocks you encountered and how you got around them. I'm also interested in any additional resources including people and materials that assist you in getting through IVF.

Let me assure you that any information you share with me is strictly confidential; nothing you say will be identified as coming from you. Do you have any questions before we get started with the formal interview? Please feel free to ask for any clarification if what I ask doesn't make sense, or you want to know why I need the information.

INTRODUCTION

What specific part of the cycle are you currently in, for instance have you done your egg retrieval? Or when did you finish your last IVF cycle? (ice breaker)

Our discussion today will focus on the current cycle you are on (or have just completed). The purpose is for me to better understand what you are going through (or have gone through).

Now let's go back to when you committed to this particular treatment cycle.

Checklist / Pre-treatment Activities

I know you were given a checklist when you first enrolled in IVF.

(Note: bring a checklist to show to the interviewee)

(note: clinic, pharmacy, insurance, social worker, financial counseling, consent, OCP)

Were there any items on it that you did not complete before the start of the treatment? Why? Did you make up for them later?

Which items on the list, if any, did you not do with your partner?

Did you do anything additional, outside of the checklist to help you go through this treatment regimen (ie: join a support group, acquiring a home care/professional service)?

I know this is not your first IVF cycle. What things, if any, have you decided to change or improved from your previous one?

Who else, other than your partner, have you contacted, or plan to contact to help you since the start of the treatment? What are their specific roles? How have they been helpful/not helpful?

Start Date & Treatment Protocol

Let's talk about your treatment protocol -

What protocol are you on this time? Is it different from the last time? What differences, if any, are there in your treatment regimen from the last time? Did you anticipate them?

If yes, did you expect your experience to be better, worse or the same as your previous cycle? Why?

Did anything take you by surprise? If yes, what were they?

How did you coordinate your start date with your work and personal life? What were the challenges in scheduling them this time?

Clinic Calendar & Treatment Regimen Plan

I understand the clinic provided you with a regimen calendar where the medications, injections, egg retrieval and implantation dates are listed. (note: bring a calendar to show to the interviewee)

Was the calendar easier to handle than previously? Why?

How can the calendar be modified so that it is more helpful to you and/or your partner?

How did you adapt this calendar?

Have you added other personal activities to this calendar?

If yes, what are they? Can you show me how you did it? May I take a picture of it including any notes you may have?

What information, if any, did you transfer from this calendar to your personal calendar?
Can you show me how you did it? May I take a picture of your calendar, including any notes you may have?

Can you tell me what categories you have in the calendar that you use the most (it can be the IVF calendar or your personal calendar such as google calendar)?

What typical activities are on it and how are they scheduled?

Do you have to coordinate the information across different calendars? If so, what information are they and how do you do it? Can you show them to me and walk me through them? How do you like them? How can they be better?

Now let's talk about how you managed the treatment activities listed on this calendar including injections, medications, and so forth. Let's start with the injections -

Injections

How do you prepare the setup for your regular injection?

How does your partner participate, if any, during the injection?

What cues do you have if any to let yourself and/or your partner know it's time for your injection?

How did you keep track of the amount of medication you have left after each injection?

Have you missed any injection? What happened? Did you contact anyone regarding this? What did you do to prevent it from happening again?

Have you made any mistakes in the injection process? What happened? Did you contact anyone regarding this? What did you do to prevent it from happening again?

Did you do anything before and/or after the injection to make the process easier and less stressful?

What are the 3 most important pieces of advice you would give to any new IVF patient considering injection?

Medications

How do you prepare for your non-injected medication such as tablets and inserts?

How does your partner participate in this preparation, if any?

What cues do you have, if any, to remind yourself and/or your partner that it's time to take medicine?

Do you have any issues regarding actually taking the medicine? How have you addressed them?

Did you ever miss taking any medicine? If so, what happened? Did you contact anyone regarding this? What did you do to prevent it from happening again?

Did you ever take the wrong medicine or wrong dosage? If so, what happened? Did you contact anyone regarding this? What did you do to prevent it from happening again?

Do you feel any any physiological and/or psychological effects from any of the medicine? How did you address them? What did you do to minimize their impact?

Lab Visits, Clinic Visits & Egg Retrieval

Are there any special arrangements you have to make to get your and/or your partner's lab work completed?

Did anyone accompany you for your clinic visits? How did you coordinate your clinic visits?

What was the difficult part that you did not anticipate? How did you overcome it?

How do you explain your visits and activities to people that you associate with, but don't want to share your personal matters with?

How did you prepare for egg retrieval?

If and what special arrangements or activities did you do for egg retrieval and implantation visits?

Support & Other Routines

Have you and/or your partner developed new cues, nuances, or other unique ways to support each other as a consequence of fertility treatment?

What other activities, rituals, or routines did you develop to talk to your partner about your feelings, thoughts, and concerns about the fertility treatment?

Did you share the results of your visits with anyone? If yes, who were they? What exactly did you share? How have they been helpful or not helpful to you?

What new social activities and/or networks did you develop because of your fertility treatments? How have they been helpful?

What online activities have you been involved in to help you through the treatment?

Did you use any other tools or aids to manage your treatment and improve your health (e.g.: something to track symptoms, mood, etc.)? What are they?

Conclusions

What three major pieces of advice would you give to anyone considering IVF treatment?

Knowing what you know now, what things would you like to improve in your treatment?

Knowing what you know now, what would you do differently to manage your treatment?

Is there anything you'd like to share and we have not covered?

Appendix C. Risks of IVF

In Vitro Fertilization (IVF): What Are the Risks?

IVF is a method of assisted reproduction in which a man's sperm and a woman's eggs are combined outside of the body in a laboratory dish. One or more fertilized eggs (embryos) may be transferred into the woman's uterus, where they may implant in the uterine lining and develop. Serious complications from IVF medicines and procedures are rare. As with all medical treatments, however, there are some risks. This document discusses the most common risks.

What kind of side effects can occur with IVF medicines?

Usually, injectable fertility medications (gonadotropins) are used for an IVF cycle. These medicines help stimulate a number of follicles with eggs to grow in the ovaries. A more detailed discussion of fertility medications can be found in the ASRM booklet, Medications for inducing ovulation.

Possible side effects of injectable fertility medicines include:

- Mild bruising and soreness at the injection site (using different sites for the injections can help)
- Nausea and, occasionally, vomiting
- Temporary allergic reactions, such as skin reddening and/or itching at the injection site
- Breast tenderness and increased vaginal discharge
- Mood swings and fatigue
- Ovarian hyperstimulation syndrome (OHSS)

Most symptoms of OHSS (nausea, bloating, ovarian discomfort) are mild. They usually go away without treatment within a few days after the egg collection. In severe cases, OHSS can cause large amounts of fluid to build up in the abdomen (belly) and lungs. This can cause very enlarged ovaries, dehydration, trouble breathing, and severe abdominal pain. Very rarely (in less than 1% of women having egg retrieval for IVF), OHSS can lead to blood clots and kidney failure. For more information about OHSS, see the ASRM fact sheet Ovarian hyperstimulation syndrome (OHSS).

Earlier reports from several decades ago suggested a link between ovarian cancer and the use of fertility medicines. However, more recent and well done studies no longer show clear associations between ovarian cancer and the use of fertility medications.

What are the risks of the egg retrieval?

During the egg retrieval, your doctor uses vaginal ultrasound to guide the insertion of a long, thin needle through your vagina into the ovary and then into each follicle to retrieve eggs. Possible risks for this procedure include:

- Mild to moderate pelvic and abdominal pain (during or after). In most cases, the pain disappears within a day or two and can be managed with over-the-counter pain medications.
- Injury to organs near the ovaries, such as the bladder, bowel, or blood vessels. Very rarely, bowel or blood vessel injury can require emergency surgery and, occasionally, blood transfusions.
- Pelvic infection (mild to severe). Pelvic infections following egg retrieval or embryo transfer are now uncommon because antibiotic medicines are usually given at the time of egg collection. Severe infection may require hospitalization and/or treatment with intravenous antibiotics.
- Rarely, to manage a severe infection, surgery may be required to remove one or both of the ovaries and tubes and/or uterus. Women who have had pelvic infections or endometriosis involving the ovaries are more likely to get IVF-related infections.

What are the risks associated with the embryo transfer?

A catheter containing the embryos is used to gently place them into the uterus (womb). Women may feel mild cramping when the catheter is inserted through the cervix or they may have vaginal spotting (slight bleeding) afterward. Very rarely, an infection may develop, which can usually be treated with antibiotics.

If I conceive with IVF, will my pregnancy be more complicated (than if I conceived on my own)?

Having a multiple pregnancy (pregnancy with more than one baby) is more likely with IVF, particularly when more than one embryo is transferred. These pregnancies carry significant risks, including:

- Preterm labor and/or delivery: premature babies (regardless of whether or not they were conceived naturally or with IVF) are at higher risk for health complications such as lung development problems, intestinal infections, cerebral palsy, learning disabilities, language delay, and behavior problems
- Maternal hemorrhage
- Delivery by cesarean section (C-section)
- Pregnancy-related high blood pressure
- Gestational diabetes

The more embryos that are transferred into the uterus, the greater the risk. Your doctor should transfer the minimum number of embryos necessary to provide a high likelihood of pregnancy with the lowest risk of multiple pregnancy. For more information about multiple pregnancy, see the ASRM booklet titled *Multiple pregnancy and birth: twins, triplets and highorder multiples*. One way to avoid multiple pregnancy is to choose to transfer only one embryo at a time. For more information about this, see the ASRM fact sheet *Single embryo transfer*.

Will IVF increase the risk of my child having a birth defect?

The risk of birth defects in the general population is 2%-3%, and is slightly higher among infertile patients. Most of this risk is due to delayed conception and the underlying cause of infertility. Whether or not IVF alone is responsible for birth defects remains under debate and study. However, when intracytoplasmic sperm injection (ICSI) is done along with IVF, there may be an increased risk of birth defects.

In addition, there may be a slight increased risk of sex chromosome (X or Y chromosome) abnormalities with ICSI. However, it is uncertain if these risks are due to the ICSI procedure itself or to problems with the sperm themselves. Men with sperm defects are more likely to have chromosomal abnormalities, which can be transmitted to their children. However, these disorders are extremely rare. Rare genetic syndromes called imprinting disorders may be slightly increased with IVF.

Miscarriage and ectopic pregnancy

The rate of miscarriage after IVF is similar to the rate following natural conception, with the risk going up with the mother's age. The rate of miscarriage may be as low as 15% for women in their 20s to more than 50% for women in their 40s.

There is a small risk (1%) of an ectopic (tubal) pregnancy with IVF; however, this rate is similar to women with a history of infertility. If an ectopic pregnancy occurs, a woman may be given medicines to end the pregnancy or surgery to remove it. If you are pregnant and experience a sharp, stabbing pain; vaginal spotting or bleeding; dizziness or fainting; lower back pain; or low blood pressure (from blood loss), and have not had an ultrasound confirming that the pregnancy is in the uterus, call your doctor immediately. These are all signs of a possible ectopic pregnancy. There is a 1% risk for a heterotopic pregnancy after IVF. This is when an embryo implants and grows in the uterus while another embryo implants in the tube, leading to a simultaneous ectopic pregnancy.

Heterotopic pregnancies usually require surgery (to remove the ectopic pregnancy). In most cases, the pregnancy in the womb can continue to develop and grow safely after the tubal pregnancy is removed.

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