

**Autonomy and the Infertility Patient: Exploring the limits of the  
criteria that identify autonomous decision making with regards to  
the female infertility patient**

by

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## **ABSTRACT**

Autonomous decision making is the cornerstone of bioethics, as it respects every person's right to make decisions for themselves based on their own values and beliefs. Maintaining autonomy in medicine is especially important due to the long standing history of paternalism in medicine. Today best practice in medicine demands that competent patients be allowed to make autonomous decisions about their treatment. The criteria that we use to classify an individual as autonomous are crucial in medicine, where the validity of a patient's informed consent to receive treatment rests on whether they are recognized as autonomous. One area in which the classification of autonomy is most perplexing is that of infertility. The known causes of infertility are few, the number of effective diagnostic tests are limited and less than 50% of couples end up with a child. The uncertainty and limited prognosis mean that choices should be driven by personal preferences rather than paternalism. Due to the nature of infertility, the intricacies of its diagnosis and treatment as well as the heavy influence of social norms about femininity, infertile women may lose their identity as autonomous individuals, despite seeming to be autonomous in all other respects. While the traditional criteria for autonomy successfully identify those female infertility patients who are not autonomous, they give us no direction as to how to tackle the larger issue of societal influence on infertility patients. I will argue that a change in the theory used by medical professionals is necessary in order to address the concern of social influence on patient decision making. Instead we must replace the use of traditional autonomy by the medical institution as the paradigm with the theory of relational autonomy, since relational autonomy is the only theory that can properly account for societal influence on patients.

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## **GLOSSARY**

**Assistive Reproductive Technology (ART):** Any technology that replaces one or all the steps of human reproduction.

**Artificial Insemination (AI):** A form of ART in which sperm from a donor or the male partner is placed in the reproductive tract of a female for the purposes of impregnation through means other than sexual intercourse.

**Health Care Professional (HCP):** A term that refers to clinicians, nurses and doctors immediately involved in the health care of a patient.

**Intracytoplasmic Sperm Injection (ICSI):** A form of ART most commonly used when trying to treat male infertility. A single sperm is isolated from a sample and then injected directly into the oocyte (egg) for maximum fertilization potential.

**In Vitro Fertilization (IVF):** A form of ART in which the egg is fertilized by sperm outside of the womb. The process involves harvesting both eggs and sperm from couples or donors, inseminating the egg using one of a variety of procedures and then implanting the fertilized embryo into the woman or surrogate. IVF is the most common form of ART used in fertility clinics.

**Pre-implantation Genetic Diagnosis (PGD):** A form of ART also known as embryo screening. Individuals who undergo PGD go through the same procedures as IVF to obtain sperm and eggs and then inseminate the eggs. After the embryos have been created they are then screened for specific genetic diseases. Those embryos found to be free of the disease in question are then implanted into the uterus of the woman. PGD is considered an alternative to pre-natal screening since it avoids selective pregnancy termination.

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*To my Grandfather.*

*Your work inspired my questions and your patience and love have helped  
me figure them out.*

# INTRODUCTION

The question of whether we are able to exercise autonomy in actions is by no means trivial. Autonomous decision making is the cornerstone of bioethics, as it respects every person's right to make decisions for themselves based on their own values and beliefs. Maintaining autonomy in the medical system is especially important due to the long standing history of paternalism in medicine. Today best practice in medicine demands that competent patients be allowed to make autonomous decisions about their medical treatment. Only on rare occasions do doctors intervene in a paternalistic manner when the patient is competent. The criteria that we use to classify an individual and their actions as autonomous or non-autonomous are particularly crucial in the medical realm, where the validity of a patient's informed consent to receive treatment rests on whether they are recognized as autonomous. One area in which the classification of autonomy is most perplexing is that of reproductive medicine, and more specifically infertility. Due to the nature of reproductive medicine, its intricacies of diagnoses and treatment, female infertility patients are at the highest risk of “losing” the classification of autonomous individuals during the treatment process, despite seeming to be ordinary persons in all other respects. The “cultural epistemic authority” of physicians, as well as the gendered power dynamics that exist in our society can interfere with a woman’s ability to trust herself to choose in accordance with her values and goals<sup>1</sup>. The “loss” of their autonomous classification is a concern as it suggests that contrary to seeming common sense, female infertility patients simply do not have the capacity to make autonomous decisions, and so doctors should be acting paternalistically towards them in order to protect these patients.

By examining the definition of autonomy, as used by medical professionals today, I will outline the criteria for autonomy that is currently used in medicine to determine the autonomy of

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<sup>1</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 1.



individual patients. I will then show how these criteria find most infertility patients non-autonomous regarding their infertility treatment choices. I will also show that female infertility patients fail these traditional criteria due to heavy societal influences such as pronatalism, which informs both the social and medical realms surrounding the infertility patient and their decisions. Finally I will argue that using criteria developed from traditional autonomy fail to address societal influences on patients. Instead, by taking a relational approach to autonomy it may be possible to alleviate some of the strain that pronatalism puts on patients, while at the same time working towards the goal of eliminating pronatalism entirely.

# CHAPTER ONE: Autonomy and Infertility

## 1.1 Autonomy in Bioethics

### 1.1.1 The Origin and Value of Autonomy

The concept of autonomy is crucial to understanding the experience of the infertility patient and how they can be classified as non-autonomous. I will start by pointing out that the bioethical understanding of autonomy differs from the various philosophical conceptions. Instead of cleaving to one particular theory, bioethical autonomy seems to be constructed from various sources<sup>2</sup>. The traditional bioethical view of autonomy finds its roots in two major bioethical figures: Immanuel Kant and J.S. Mill<sup>3</sup>. Kant argued that we must be respected as self-determining subjects, capable of self-governance<sup>4</sup>. Bioethicists have interpreted this respect to be equivalent to respect for personal autonomy and an individual's autonomous decisions. This Kantian legacy has informed the traditional view of autonomy by stressing the importance of autonomy relying on the patient being an individual, rational person. By describing the ways to achieving autonomy with "self" actions such as, "self-control", "self-direction", "self-governance", and "self-rule" Kant is framing autonomy as an individual condition that is required to be individual in order to maintain the respect that it is given<sup>5</sup>. Interpretations of Kant's understanding of autonomy have culminated in the bioethical construction of autonomy being one that is both an individual and internal process.

Support for the individual construct of autonomy is not limited to Kant. J.S. Mill also described persons with individuality as being autonomous "in a very strong sense, reflectively

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<sup>2</sup>Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 5.

<sup>3</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 45-6

<sup>4</sup>Immanuel Kant. *Groundwork of the Metaphysic of Morals*. Trans. H.J. Paton. (New York: Harper and Row, 1964), 108.

<sup>5</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 46.

choosing their own plans of life, making their own decisions without coercion or manipulation by others, and exercising firmness and self-control in acting on their decisions.”<sup>6</sup> It is clear that for Mill there is a powerful connection between a person’s ability to introspectively make a choice and their autonomous status. For Mill those individuals who allow outsiders to choose or influence their life plans, leaving aside obvious cases such as allowing others to warn us of danger, have “no need of any other faculty than the ape-like one of imitation.”<sup>7</sup> Owing to their divergent moral theories, Mill and Kant value autonomy for different reasons and believe that what it means to act autonomously is different as well; however they share the belief that respect for autonomy is of the utmost importance for persons.

Due to the moral importance placed on autonomy, any infringement on autonomy by another agent must be rigorously morally justified. By extension all those who lack the ability to exercise autonomy should be protected, as they are unable to use autonomy to protect themselves from choices incongruous to their values. Bioethicists and health care professionals (HCPs) alike need a way to quickly and effectively assess and maintain a patient’s autonomous status. Identifying patients as autonomous is crucial to being able to identify those patients who are able to protect themselves by making decisions that are in line with their values and beliefs. This is why traditional autonomy theorists believe that the criteria for autonomy have to be inclusive, operationalized and procedural so as to make it possible to consistently identify autonomous individuals in any medical context. In the next section we will look at how the current conception of autonomy is employed in medicine.

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<sup>6</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 46

<sup>7</sup>John Stuart Mill. *Utilitarianism, On Liberty, Essay on Bentham*. Ed. Mary Warnock. (New York: New American Library, 1962), 187.

## 1.1.2 What is Bioethical Autonomy?

Following the traditions set out by Mill and Kant, the current construct of autonomy remains highly individualistic. Textbook accounts remain true to this understanding, focusing on the “importance of individual autonomy, [and] stressing the rights of autonomous decision makers to determine for themselves what will be done to their bodies.”<sup>8</sup> While there are different ways to conceptualize autonomy, the traditional, also known as the individualistic, paradigm, which focuses on the importance of autonomous patients being those who are able to act free of any outside influence, is considered to be the predominant concept of autonomy in the west, since it “squares with our ethical ideas about respect for autonomy.”<sup>9</sup> By describing the ideal autonomous individual as “the individual capable of acting on the basis of effective deliberation, guided by reason, and neither driven by emotion or compulsion nor manipulated or coerced by others” textbook accounts of autonomy hold fast to the philosophical conceptualization of autonomy as described by Mill and Kant<sup>10</sup>. Ethicists hold that definitions of autonomy should focus on the importance of the individual being free from constraint, exercising self-governance and the importance of the patient sufficiently understanding the information given to them. Over time these different ideas have become systematized by bioethicists so that they form a checklist for autonomy. Bioethicists, in particular Beauchamp, Childress, Mappes and Degrazia, have proposed four main criteria which they argue must be met in order for an action or an individual to qualify as autonomous<sup>11</sup>. While each individual criterion is necessary none of the individual criteria are sufficient on their own to classify an individual as autonomous. Each of these criteria are important from a moral perspective because

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<sup>8</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 40.

<sup>9</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 41.

<sup>10</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 46.

<sup>11</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 41.

they serve as concrete applications of the respect for persons that both Mill and Kant demand of us.

The four criteria are:

- 1) The individual must act intentionally
- 2) The individual must act based on sufficient understanding
- 3) The individual must be sufficiently free of external constraints
- 4) The individual must be sufficiently free of internal constraints

As functional as this check list is, it is meaningless without further investigation into the terms “intentionally”, “sufficient understanding” and “constraints”.

### **1.1.2.1 Intentionality**

I will start by briefly describing intentionality. Intentionality is important to the conception of autonomy as it implies the importance of self-driven action. An individual acts intentionally when the individual's end or purpose is reflected in the description of the action that the individual recognizes herself as engaging in. To illustrate the importance of intentionality consider this example from the medical field of infertility: An infertility patient is admitted to the hospital with severe pain. As she sits in her hospital bed a staff member of the obstetrics-gynaecology team talks to her, however the patient is very distracted by her pain and the anxiety of the hospital visit. When they are done talking the staff member has the patient sign a form. The patient is under the impression that the form is her admittance papers to the hospital, however had she not been distracted she would have realized that the papers are actually consent forms to be part of a study on infertility. In this case the patient is not acting with intention because the action and the intent are divorced. The patient's intent is to stay at the hospital while she is being treated, but the action she performed does not reflect the action the individual recognized herself engaging in. It cannot be said that her action was autonomous, and thus her consent to the study is invalid.

### 1.1.2.2 Sufficient Understanding

In many ways the above example can also be seen as one of insufficient understanding, which brings us to the second criteria for autonomy. Sufficient understanding is a crucial idea in bioethics. Being properly and sufficiently informed of the benefits, risks and alternative treatments is considered essential in order to make an informed choice. “Understanding” is interpreted as an understanding of not only what is at stake when one makes a choice and follows through with an action, but also an understanding of the implications and possible consequences of the action, as well as an understanding of the available alternatives<sup>12</sup>. Beauchamp and Childress illustrate the importance of sufficient understanding with an example pulled from the medical field: “If a misperception prevents a person from adequately understanding the risk of a death and this risk is material to the person's decisions, then the person's choice of a procedure does not reflect a substantial understanding and does not qualify as an autonomous authorization [...] A single false belief can invalidate a patient's or subject's consent.”<sup>13</sup> In the medical realm the “informed” part of informed consent often stands in as a proxy for sufficient understanding, as informed consent is the exercising of a patient’s autonomy to agree or disagree with the treatment offered to them, based on the information that is provided. Unfortunately there are many difficulties in determining what this criterion specifically requires, as there is no agreed upon standard against which to measure the sufficiency of a certain type or amount of information<sup>14</sup>. How much information an individual patient needs varies on a case by case basis and an individual has the right, as an extension of exercising their autonomy, to demand as much or as little information as they deem necessary to sufficiently understand the situation. Insufficient

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<sup>12</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 42.

<sup>13</sup>Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 130.

<sup>14</sup>Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 122.

understanding can be the result of a number of variable situations and is a frequent barrier to autonomy that patients face. A common cause for a patient's insufficient understanding is being misled by their HCP, specifically through the manipulation of data or by the omission (intentionally or not) of information that the HCP may not consider to be important, but is in fact relevant to the patient. In more extreme cases sufficient understanding may not be possible due to a patient's mental capabilities and data processing skills, however this is often related to internal and external factors that we will discuss momentarily.

Despite these concerns it is understood that no one can perfectly understand a situation. Instead there is an accepted threshold such that sufficient understanding is considered the gateway between autonomous and non-autonomous action<sup>15</sup>. To that effect sufficient understanding is often defined as an “understanding of what is at stake—of implications and likely consequences of one's action, and those of available alternatives—as a condition of autonomous action.”<sup>16</sup> This is how we will define sufficient understanding.

### **1.1.2.3 Constraints**

A constraint can be conceptualized in two ways: internally and externally. There are a wide variety of states that can inhibit autonomy because they are considered internal constraints. Examples include: strong emotions like rage or grief, mental illness, addiction, and intense fears. These examples illustrate how internal constraints are those that interfere with the mental faculties of the individual. Internal constraints can refer to impediments to the mental capabilities of a normally functioning adult, or to those people who simply never developed functioning mental facilities to begin with. External constraints are more tangible as they encompass those things that physically constrain our ability to make a choice, such as too little time to reflect, the lack of alternative

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<sup>15</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 42.

<sup>16</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 42.

choices, physical restraint, coercion, persuasion, deception, withholding of information and manipulation.

External constraint is an idea that is picked up in many philosophical discussions of autonomy. Beauchamp and Childress place constraint centre stage by focusing on the importance of voluntariness in the medical context<sup>17</sup>. Voluntariness is described through action, such that “a person acts voluntarily if he or she wills the action without being under control of [another person's] influences”<sup>18</sup> While circumstances involving illness or drug addiction are considered to diminish or void an individual’s autonomy (i.e. internal constraints), Beauchamp and Childress argue that they do not exert control over it and so are not external constraints to that individual’s autonomy<sup>19</sup>. Instead, control is exercised through coercion, persuasion and manipulation<sup>20</sup>, key concepts to autonomy that I will now discuss.

#### **1.1.2.3.1 Coercion**

There are different ways of defining coercion. One of the more popular definitions comes from Beauchamp and Childress, who define coercion as occurring when an individual uses a “credible and severe threat of harm or force to control another”, as well as harm itself<sup>21</sup>. Occurrent coercion is coercion that uses physical force, while dispositional coercion uses the threat of harm. An individual has been coerced only if the harm or threat displaces a person’s self-directed course of action and it makes those decisions associated with the coercion non-autonomous. However, occurrent and dispositional coercion seem like a rather narrow scope with which to view coercion,

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<sup>17</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 132.

<sup>18</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 132.

<sup>19</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 132-3.

<sup>20</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 133.

<sup>21</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 133



which can be implemented and felt by individuals in a wide variety of ways. Coercion can also be understood as an act or threat which compels or restrains the actions of an autonomous individual such that “external pressure shades into coercion.”<sup>22</sup> While this move in the definition of coercion from harm, to threat of harm, to perceived external pressure seems quick and dirty, it is clear that in medicine coercion can have many different faces that must be considered. In order to properly address the issue of coercion with regards to patient autonomy I will take coercion in the broader sense of the word, focusing on the importance of the threat, however it may be delivered, and its ability to displace the infertility patient’s capacity to self-direct action with regards to their medical care.

### **1.1.2.3.2 Persuasion**

Persuasion in medicine typically occurs when the patient comes to believe something through the merit of reasons another person advances<sup>23</sup>. While this definition of persuasion seems to suggest that persuasion occurs every time an individual agrees with the arguments of another, it is important to distinguish between persuasion that appeals to reason and persuasion that appeals to emotion. The problem arises when the HCP has to “distinguish emotional responses from cognitive responses and to determine which are likely to be evoked.”<sup>24</sup> In medicine it is of particular importance that HCPs are careful about the way information is disclosed to a patient, as disclosures that might rationally persuade a patient, which is perfectly acceptable and promotes autonomy, may emotionally overwhelm another patient such that their fears or panic would “short-circuit” reason<sup>25</sup>. I will look at the specific effects of emotionally-overwhelming persuasion on infertility patients in

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<sup>22</sup>Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 43.

<sup>23</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 133

<sup>24</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 133.

<sup>25</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 133.

later sections.

### 1.1.2.3.3 Manipulation

Manipulation is considered a generic term that covers several types of influences that are not persuasive or coercive<sup>26</sup>. Manipulation can be understood as “swaying people to do what the manipulator wants by means other than coercion or persuasion.”<sup>27</sup> Since this definition may seem vague and overly generalized, it helps to consider that in health care the most common forms of manipulation come in the form of “informational manipulation” which can occur intentionally or unintentionally<sup>28</sup>. Examples of informational manipulation include lying, withholding information, misleading exaggeration, as well as the manner in which HCPs present the information<sup>29</sup>. Tone of voice and framing information positively and negatively, for example, can manipulate a patient’s choice as much as outright lying<sup>30</sup>. All of these manipulations can invalidate the voluntariness of the patient that is so crucial to preserving their autonomy<sup>31</sup>.

All four of these criteria (intentionality, sufficient understanding, internal and external constraints) are essential for the deliberation process that individuals undergo when making an autonomous choice. Having a subset of the four is not sufficient for determining autonomy, since these criteria serve as tests in the medical setting for determining whether a patient is in a position to give valid consent to medical treatment. As autonomous individuals, when we intend to make a decision we need to be free of constraints and be sufficiently informed and understand that

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<sup>26</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 133.

<sup>27</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 134.

<sup>28</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 134.

<sup>29</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 134.

<sup>30</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 134.

<sup>31</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 134.

information in order to weigh the risks, benefits and alternatives against our individual values.

According to the traditional concept of autonomy, without this individual, internal, deliberative process we are unable, or at least less reliably able to identify the choice that is best in line with our needs, beliefs and values.

## 1.2. Infertility: Disease or Social Condition?

Fifty years ago a woman who wished to conceive and could not was considered to be profoundly unlucky. If she could not, or would not adopt, it was expected that faced with a relatively lonely life she would throw herself into bake sales and church bazaar organisation, watching other couple's miracles of life run around while she considered what might have been. Fifty years ago medicine was unable to cope with the complexities of blocked fallopian tubes, low sperm count and late-in-life conception.

Today the medicine has changed, but the social importance of reproduction remains the same. In the past 50 years we have made remarkable leaps forward in the understanding, diagnosing, and “treating” of infertility in both men and women. Due to the modern medicalization of reproduction, infertility has been categorized as a disease, dealt with through hospitals, obligating infertile individuals who seek treatment to become medical patients, as it is the only way to access assistive reproductive technologies (ART). While this may seem like an innocuous shift, by virtue of becoming a patient women that seek ART become subject to the multitude of new and different barriers to autonomy brought on by entering the medical system that can affect the infertility patient's ability to maintain her autonomy throughout the process. The use of assistive reproductive technologies is a further step in the medicalization of pregnancy and birth, which is very different from the traditional relationships between pregnant women and midwives that promoted an environment of mutual trust that cannot be replicated in hospital settings<sup>32</sup>. This old environment of trust was more likely to preserve an individual's autonomy than the hospital setting; however reproduction has been moved out of the private realm and thrust into the public sphere of clinical medicine, a move that is not without its lasting effects on both patients and health care workers. Moving infertility into the public sphere has

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<sup>32</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian Journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

also opened up the doors for greater social concern and criticism regarding infertility, infertility patients and infertility treatment. As such, one aspect of infertility that cannot be ignored when discussing autonomy is the way that infertility is considered both a medical and social problem. I will start by examining infertility as a disease and then turn to how infertility is viewed in our society.

### **1.2.1 Infertility as a Disease**

Before we move any further in our discussion of infertility, we must first define the medical terms of reproduction, reproductive technology and infertility. Human reproduction is defined by four major steps: sexual intercourse, tubal fertilization, implantation in the uterus and in utero gestation<sup>33</sup>. Assistive reproductive technology (ART) is any technology that replaces one or all the steps in the natural process of reproduction<sup>34</sup>. I will also include some technologies used for genetic screening in the definition of ART, as some genetic diseases will cause spontaneous abortion of the fetus, thus contributing to the infertility of the individual or couple involved. Examples of commonly used assistive reproductive technologies include: in vitro fertilization (IVF), pre-implantation genetic diagnosis (PGD), artificial insemination (AI), egg and sperm donation and surrogacy. Infertility is diagnosed when one or both partners are unable to achieve conception naturally after trying for a year, or if the woman is over 35, after trying to conceive for six months. Women who experience multiple miscarriages without any pregnancies to term are also diagnosed as being infertile.

Many advocacy groups for infertility characterize it as a disease, since a disease occurs

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<sup>33</sup>Thomas A.Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 514.

<sup>34</sup>Thomas A.Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: MicGraw-Hill Higher Education, 2006), 514.

when one deviates from normal function<sup>35</sup>. It is important to pause here and consider the consequences of this characterization. In our society medical treatment for diseases is almost always viewed as THE answer<sup>36</sup>. Medicalizing infertility through the use of ARTs sets up norms (bodily, behavioural and ethical norms) that are expected to be met by those individuals using ARTs<sup>37</sup>. Regardless of a woman's decision to have children or not, biological infertility, meaning that there is something medically and biologically different about the woman that impedes them from being fertile, for example early menopause or blocked fallopian tubes, is a deviation from normal function. Since suffering from infertility can be distressing for the person, coupled with the fact that reproduction is a basic, but essential function in the sense that reproduction is necessary for our species survival, many advocacy groups argue that it should be considered not only a disease, but one of high priority for treatment and research<sup>38</sup>.

Viewing infertility as a disease is not merely a question of vocabulary. Defining infertility as a disease opens up those patients to certain expectations. Once infertility is classified as a disease, by extension "the infertile woman is expected to obtain treatment to 'normalize her into pregnancy'"<sup>39</sup>. This expectation for treatment is both societal, as well as medical, stemming from infertility specialists who believe that infertility patients should "pursue all available treatments" and a society that highly values reproductive abilities<sup>40</sup>. Infertility is also complicated by the fact that it is not like the average disease: it affects not one individual, but in most cases two people,

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<sup>35</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>36</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>37</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>38</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>39</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>40</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

the couple. Since reproduction is by definition a process that requires a male and female, infertility treatment requires the same as well, or at least the egg and sperm components. There are a variety of possible scenarios where one half of a couple is required to undergo medical treatment in order to make up for the reproductive deficiencies of the other<sup>41</sup>. Women can be “treated” for infertility that is the result of their male partner’s low sperm count, requiring invasive medical procedures on the woman such as hormone shots, egg retrieval and IVF in order to implant a viable embryo. So, for example, women in couples where the man is infertile suffer from the stigma of infertility as well. As a result it can be argued that much of infertility medicine is more female centred in terms of treatment, since the female bears the brunt of the procedures regardless of their fertility status. The imposition of treatment on an individual who does not have the disease is one way in which infertility has more complex medical and social costs than other diseases.

Many approach infertility at a different angle by comparing infertility treatments to glasses or insulin: both help you live with the symptoms of the disease without actually treating the disease itself<sup>42</sup>. However if the fertility treatment works, then one isn’t really living with the symptoms anymore because they can no longer claim that they are incapable of conceiving a child, so the comparison between glasses and ARTs is strained at best.

For those who desire children, not being able to have them is a deviation from a normal ability to reproduce and the symptom of the disease “Infertility”. Some may argue that if a woman chooses not to have children, an imposed “infertility”, then the fact that she does not become pregnant is not a deviation from the norm. The use of contraceptives, abstinence and surgery is an attempt to create a state of infertility that they would consider the norm. Many

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<sup>41</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>42</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

feminists object to the characterization of infertility as a disease, arguing that the social focus on infertility as a disease that must be solved is “distorted”<sup>43</sup>. Instead, they argue, infertility should be viewed as a physical difference between people which some people may want to change and others may not<sup>44</sup>. Conceiving of infertility in this way means that fertility loses some of its medical and social importance by being re-framed as an individual choice. However there is a danger that this characterization makes infertility sound trivial; as if being infertile and wanting to use ART is the same as being a blond and wanting to become a brunette, though this may be oversimplifying the feminist case.

It is important to rigorously define infertility, as we need a working definition of infertility in order to determine how to deal with it on a medical, social and cultural scale. How we define infertility dictates individual and societal response to the entire realm of infertility<sup>45</sup>. For this reason I will classify infertility **as a disease that has both a physical and psychological component and manifests itself when an individual who is trying to conceive naturally has been unable to for a year or in the case of a woman over 35, 6 months**. I will also push the definition further to encompass not only the infertile individual, but their partner as well. I will be focusing specifically on the role of the woman, whether they are the infertile individual or not. For simplicity I will leave aside the questions of heterosexual vs. homosexual couples, singles vs. couples etc, since regardless of the ART these patients choose it will still involve a sperm and an egg and it will still involve a female patient. Characterizing infertility as a disease allows us to look at the narrative that has grown up around infertility and how that has influenced both society and the infertile, and by extension the autonomy of the infertility patient.

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<sup>43</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>44</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

<sup>45</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104



Defining infertility as a disease reinforces the “specialness” that society and medicine place on reproduction and that by extension this specialness places a certain amount of pressure on infertile women to correct the infertility and achieve conception. In addition, characterizing infertility as a disease makes it harder for women to define themselves in other ways outside of being reproducers<sup>46</sup>. While classifying infertility as a disease clearly sets limits on infertility patients, I will hold to this classification since, as we will see, that is how society and medicine views infertility, thus it is relevant when discussing how infertility patients are viewed and the effect this has on their autonomous status.

### **1.2.2 Infertility as a Social Condition**

We have discussed how medicine currently views infertility, however how society views infertility is of even greater importance as the social opinion informs the health care workers involved with infertility treatment, as well as the people that the infertile individual encounters every day. The social opinion of fertility colours how individuals approach the problem of infertility, as well as help the infertility patient identify what information is pertinent in determining the “right” course of action for dealing with infertility.

The language that we use to describe infertility is socially constructed, pointing out how society understands infertility as a condition where something is “lacking” in both men and women. Susan Sherwin uses the terms “incomplete”, “lacking in fulfilment” and “face a barren existence” to give voice to what she sees as the typical characterization of infertility<sup>47</sup>. As ARTs become more mainstream in our society, philosophers—in particular feminist philosophers—have become more and more concerned with the effect that infertility treatments have on the female infertility patient's ability to make decisions that are truly aligned with their values and

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<sup>46</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>47</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

beliefs<sup>48</sup>. Many of these concerns have to do with the attitudes surrounding the importance of reproduction and fertility in general in society and in medicine.

In our society “women are persuaded that their most important purpose in life is to bear and raise children.”<sup>49</sup> The focus on bearing and raising your own genetic child is reinforced by the socialization of women to be fearful of close friendships with others, in particular males who are not their husbands<sup>50</sup>. In addition women are further socialized to distrust other women<sup>51</sup>. As a result biological children are presented as the last hope for real intimacy<sup>52</sup>. In addition, not only do a woman’s intimate relationships depend on having children, but her very womanhood does as well. Reproduction and femininity are so intimately linked that those women who fail to achieve conception, whether purposefully or because of infertility, may see themselves as a failing to be true women<sup>53</sup>.

The importance of reproduction in society can also be attributed to the importance of reproduction to the human species. When you strip away all the effects of society and culture on a human, you will find that the need to reproduce is one that has deep evolutionary roots. Reproduction is an intrinsic “good” for the survival of humanity—without reproduction humans would cease to exist in less than 100 years, thus our animal instinct to stay alive pushes us to reproduce and protect those offspring already born.

Regardless of where the importance of reproduction in our society stems from, bioethicists are concerned that techniques and treatments for artificial reproduction removes control over

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<sup>48</sup> Though it should be pointed out that some think that ARTs help to promote individual autonomy in some cases.

<sup>49</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>50</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>51</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>52</sup> Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>53</sup> R.J. Arneson, “Commodification and Commercial Surrogacy,” *Philosophy and Public Affairs* 21, no.2 (1992): 132-164.

reproduction from women by making it a solely medical event, dictated by doctors and current medical practice. Feminists are further concerned that the use of ARTs is simply another manifestation of male domination and oppression<sup>54</sup>. In addition, there is concern that infertility and its treatments, like every emerging field in medicine, has not had sufficient ethical consideration to be considered truly respectful of the patient, especially in an era that still has vestiges of a male dominated society where a premium is placed on women's reproductive value, regardless of how women view their own reproductive value<sup>55</sup>.

The social opinion that women without children are not fully women, as well as the socialization to distrust other women and to stay away from children who are not their own, suggests that the only way to fulfil their womanhood is through the birth of a biological child. These social pressures may constrain the female infertility patient too greatly to be considered autonomous<sup>56</sup>. We must ask what it means to autonomy to conceive of infertility as both a social and medical problem. I will attempt to address this question in chapter two as we examine how the current conception of autonomy in medicine interacts with infertility medicine.

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<sup>54</sup> Susan Sherwin, "Feminist Ethics and In Vitro Fertilization," *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>55</sup> Aline H. Kalbian, "Narrative Artifice and Women's Agency," *Bioethics* 19 no.2 (2005):93-111.

<sup>56</sup> Carolyn McLeod, "For Dignity or Money: Feminists on the Commodification of Women's Reproductive Labour," in *The Oxford handbook of Bioethics*, ed. Bonnie Steinbock (Oxford: Oxford University Press, 2006), 258-281.

## **CHAPTER TWO: Applying the Criteria**

### **2.1 Is it Possible to be Infertile and Autonomous?**

Given the background information we have learned about the medical and social opinion of infertility patients, as well as what we know about the bioethical principle of autonomy, it seems important to now apply our criteria for determining autonomy to the female infertility patient interested in using ARTs. I will start by presenting the dominant views in medicine and feminist philosophy concerning the autonomy of female infertility patients in order to make explicit the assumptions contained in both opinions. Then bearing in mind these assumptions, I will then look at three major barriers impeding infertility patients from making decisions autonomously, drawing on the criteria for autonomous decision making that these barriers violate. Finally I will show how according to the current criteria for autonomy most decisions by female infertility patients to use ART fail to count as autonomously made.

#### **2.1.1 Dominant Views in Medicine and Feminist Philosophy Concerning the Autonomy of Infertility Patients:**

Feminists and medical practitioners seem to be diametrically opposed when it comes to considering the effect of ART on determining the autonomous status of the female infertility patient. Both camps are answering the question “Is it possible for a woman who uses or wants to use ARTs, to autonomously make the choice to receive or deny said ART”<sup>57</sup>? Many feminist scholars answer that true autonomy in the realm of infertility is impossible to achieve due to the heavy pressure of societal norms concerning femininity and maternity<sup>58</sup>. The medical community counters with idea that as long as there is informed consent then this *is* respecting the

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<sup>57</sup> Aline H. Kalbian , “Narrative Artifice and Women's Agency,” *Bioethics* 19 no.2 (2005):93-111.

<sup>58</sup> Aline H. Kalbian , “Narrative Artifice and Women's Agency,” *Bioethics* 19 no.2 (2005):93-111.

infertility patient's autonomy<sup>59</sup> The two concerns seem unrelated, with the feminists concerned more with the autonomy of women of child-bearing age in general and the HCPs concerned mostly with avoiding those things that may undercut the patient's autonomy, however these two concerns are more closely linked ideologically than they appear. The social influence on patients that feminists worry about actually undermines the ability of infertility patients to give valid, informed consent to treatment, thus affecting the concerns of the HCP that their patients give valid informed consent, but we will focus on that relationship more closely in coming sections.

What remains true is that neither the feminists nor the medical community fully address the reasons why an infertility patient's autonomous decision making should be called into question. To understand that I will turn to examining the impediments to autonomy that infertility patients come up against throughout their medical encounter. These are not just obstacles to overcome, but rather defects of these sorts should give HCPs reason to withhold treatment regardless of the medical speciality. There are three grounds on which to doubt the autonomous decision-making of the infertility patient that have been identified in the literature that I will discuss in relation to infertility treatment. They are: the lack of sufficient understanding concerning ARTs, the internal constraints and the external constraints brought on by the process of using ARTs. Each barrier to autonomy is in some way connected to the others, especially since it is possible for one to cause another, or add to the detrimental effects of another. For example the lack of sufficient understanding of ART information is also related to some of the external constraints felt by infertility patients. It is important to keep this association in mind when considering the different ways an infertility patient's autonomy can be impeded.

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<sup>59</sup>Thomas May, *Bioethics in a Liberal Society: The Political Framework of Bioethics Decision Making* (Baltimore: The John Hopkins University Press, 2002), 16.

## 2.1.2 Internal Constraints on the Autonomy of the Infertility Patient

Recall that internal constraints are a broad category that encompasses a wide variety of phenomena, including intense fears, pain, strong emotions like rage and grief, as well as addiction and mental illness. Experiencing these phenomena can “sometimes cause us to act out of character with the result that we later feel that we were ‘not ourselves’ in doing what we did.”<sup>60</sup> The chief internal constraint acting on the majority of female infertility patients that has been identified in the literature is the effect of the trauma caused by using ARTs on autonomous decision making.

### 2.1.2.1 The Trauma of Infertility Treatment

Infertility treatment, like many medical treatments, cannot be considered a foolproof solution to the problem. Some individuals simply cannot become pregnant, despite the wide range of ART options available. This inability to conceive can be more damaging to a patient than one may think; especially if the patient attempts multiple ART procedures. Each failed procedure becomes more and more traumatic for that patient as she experiences the first child’s death over and over with every failed embryo implantation<sup>61</sup>. This trauma is of particular concern for its effect on the patient’s autonomy. Personal traumas<sup>62</sup> can “hamper the ability to make autonomous decisions”<sup>63</sup> because they can negatively influence the will of the woman concerned. The personal trauma manifests itself through feelings of rage and grief, as well as helplessness about the infertile individual’s diseased status.

These emotions act as internal constraints to the autonomy of the infertile person, making

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<sup>60</sup> Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 44.

<sup>61</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>62</sup> In this case personal traumas refer to mental traumas.

<sup>63</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

it harder to achieve autonomous decision making<sup>64</sup>. In addition, experiencing the failed infertility cycles<sup>65</sup> most often results in two possible courses of action for the infertility patient: Either they push the patient to become hopeless when the situation may not be, so that they falsely give up on reproductive technology, or the opposite can occur and the infertility patient becomes obsessed with, and in some cases addicted to the treatment<sup>66</sup>. Since the case of misunderstanding the meaning of a failed ART cycle is directly linked to the sufficient understanding criteria we previously discussed I will save further discussion of the ramifications of this misunderstanding until the next section on barriers to sufficient understanding.

Addiction to the infertility treatment is a substantial barrier to the infertility patient's autonomy as well. The next round of hormones and the next cycle of ART act as the gate way to the "high" of success, which is pregnancy to term<sup>67</sup>. In addition to the personal hope that drives the addiction, the fertility clinic structure works to fuel the addiction as well by structuring infertility treatment such that it is open-ended, meaning that there is always the opportunity for "another combination of hormones, another cycle of artificial insemination, another go at IVF that can be embarked upon"<sup>68</sup>. One individual in a chat room expressed her addiction in terms of seeking hope: "I'm still struggling with the desire to keep running back for another infertility cycle. The hopefulness of a new cycle was acting like an anti-depressant for us when we came off a disappointing one."<sup>69</sup> The pharmaceutical metaphor and the language of the addicted infertility patient is similar to that of a drug addict. Just as the drug addict is considered internally constrained by their addiction, it is impossible for the infertility patient in this situation

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<sup>64</sup> Kristin Zeiler, "Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis," *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>65</sup> Cycle is the clinical term for a course of infertility treatment.

<sup>66</sup> Aline H. Kalbian, "Narrative Artifice and Women's Agency," *Bioethics* 19 no.2 (2005):93-111.

<sup>67</sup> Aline H. Kalbian, "Narrative Artifice and Women's Agency," *Bioethics* 19 no.2 (2005):93-111.

<sup>68</sup> C. Cussins. "Producing Reproduction: Techniques of Normalization and Naturalization in Infertility Clinics," in *Reproducing Reproduction: Kinship, Power and Technological Innovation*, eds. S. Franklin and H. Ragone (Philadelphia: University of Pennsylvania Press, 1998), 76.

<sup>69</sup> Aline H. Kalbian, "Narrative Artifice and Women's Agency," *Bioethics* 19 no.2 (2005):93-111.

to make an informed decision, since their true values are blurred by the overwhelming, uncontrollable need for a “hit”. While the similarities between the drug addict (who always needs another hit) and the infertility patient end once the infertility patient conceives and gives birth to a child, the addiction analogy remains true so long as the infertility patient is attempting ARTs. Until pregnancy is achieved the addicted infertility patient seeks out the ARTs the same way the drug addict seeks his next fix. Thus the presence of ART can restrain the autonomy of the individual because it seems to be a set of endless alternatives that they cannot say no to.

### **2.1.3 Sufficient Understanding and Sufficient Information**

Information and how it is conveyed and received is of the utmost importance in medicine because “the practical importance of value difference is directly related to the treatment options and alternatives available.”<sup>70</sup> Medical patients used to have only two choices: follow the doctor's orders and live or refuse treatment and possibly die<sup>71</sup>. However as medicine has evolved, the number of choices for patients to make has increased exponentially<sup>72</sup>. This shift from one choice to many choices has caused a demand for not only obtaining consent, but sufficiently informed and understood consent that outlines the risks, benefits and alternatives, especially since inadequate disclosure can lead to treatment decisions that fail to reflect a patient’s values. Ironically this same shift towards increased options, which should supposedly increase autonomy has actually had the opposite effect, instead causing confusion and insufficient understanding of the possible treatments available to patients.

Consider the previous example of the patient who has just endured a round of failed ART

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<sup>70</sup>Thomas May, *Bioethics in a Liberal Society: The Political Framework of Bioethics Decision Making* (Baltimore: The John Hopkins University Press, 2002), 15.

<sup>71</sup>Thomas May, *Bioethics in a Liberal Society: The Political Framework of Bioethics Decision Making* (Baltimore: The John Hopkins University Press, 2002), 15.

<sup>72</sup>Thomas May, *Bioethics in a Liberal Society: The Political Framework of Bioethics Decision Making* (Baltimore: The John Hopkins University Press, 2002), 16.



procedures and chooses to end all treatment because of this failure<sup>73</sup>. While this is the patient's prerogative, it is often done due to insufficient understanding of the meaning of a failed ART procedure. These patients are not making autonomous decisions because they do not have all the information they require in order for them to understand the situation. This is an especially pertinent point when it comes to the failure and success rate of individual infertility clinics, as well as specific ARTs. More often than not the patient is informed of the success rate but not the failure rate. One might argue that the failure rate is simply the reciprocal of the success rate and so is readily available should the patient desire it. However, as Kahnemann and Tversky's rationality studies showed, individuals identify strongly with the success rates<sup>74</sup> even when they are as low as those for IVF, a distinct case of insufficient understanding for the patient. In Canada, the average success rate is low, around 27%, however depending on the patient it can be slightly lower or slightly higher than that<sup>75</sup>. "Success" in this case refers to pregnancy to term. Perhaps if patients were informed of the failure rates as well as the success rates they would understand how many tries are necessary before they should expect results. Regardless of what the solution may be the patient's lack of sufficient understanding can act as a barrier to their ability to make an autonomous decision in certain situations.

### **2.1.3.1 The Effects of Information Load and Vagueness**

The informational load that the patient takes on is also crucial to their ability to sufficiently understand the information given to them by the HCPs. Unfortunately infertility patients have a difficult time processing and then trusting their understanding of the information

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<sup>73</sup> We'll leave aside the over possibility of the addicted patient for now since that is more closely linked with internal constraint which we have already discussed.

<sup>74</sup> Amos Tversky and Daniel Kahneman, "The Framing of Decisions and the Psychology of Choice," *Science New Series* 211 no.4481 (1981): 453-458.

<sup>75</sup> Helen Branswell, "Success rate climbs for in vitro fertilization," *The Globe and Mail*, December 16, 2008, National News Section, Toronto edition.

given to them due to how complex and vague infertility information can be<sup>76</sup>. While the problem of informational load is not unique to infertility treatment—it seems to be the problem for all complex conditions/procedures, the effect it has on autonomous decision making still needs to be addressed. To understand the complexities of even the simplified language used in a clinic consider the following example: An infertility patient would like to switch from ovulation-induction agents to try a different form of infertility treatment. There are number of different, increasingly complex and expensive options to choose from, however the patient would most likely be presented with the following popular options: ovarian hyper stimulation, IVF, IVF with ICSI, IVF with PGD etc.

The simplified version of the simplified version offers only some elucidation of what is going on. In this example the patient would like to stop using fertility drugs, which are increasing the number of eggs they release every menstrual cycle. The options presented to them are to manually increase the number of eggs released, or to try a variety of in vitro fertilization procedures. Simple IVF means that eggs are harvested from the women and inseminated with sperm and then implanted in the uterus of the woman hoping to conceive. IVF with ICSI, or intracytoplasmic sperm injection means that the conception between the egg and sperm is done by injecting the sperm directly into the egg with a microsyringe. IVF with PGD, or pre-implantation genetic diagnosis refers to a procedure where IVF is done and an embryo is conceived. After the embryo has grown to about 8 cells in size one of the cells is removed, a harmless procedure to the embryo, and tested for genetic diseases. When a couple chooses IVF with PGD only those embryos that do not have the genetic markers for the disease in question are then implanted in the uterus of the woman. As the reader can see a simple switch of protocol opens up a whole new set of vocabulary that must be presented, explained, understood and

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<sup>76</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 115.

eventually used by the patient in order to make an autonomous decision that they have adequately reflected on, while at the same time try and obtain some fluency in the technical terms so they can efficiently and adequately communicate with their doctors. While it is obvious that most doctors will understand the language in which they practice medicine, a patient saying “I want a baby” is much less clear than a patient communicating their likes and dislikes for different ART. Being able to understand the differences between the ART available is crucial, since each ART has its own specific risks and benefits that must be considered by the patient in order to make an autonomous choice.

Sufficient understanding of the terms would allow for true reflection on the part of the patient, however this type of understanding can be elusive. As a result vagueness is also a problem associated with infertility treatment information, in particular when it comes to treatment explanations, as well as the success rates of individual treatments and clinics<sup>77</sup>. With each degree of complexity comes more information about potential health risks, conception rates and financial costs<sup>78</sup>. The information load can be overwhelming at times, so much so that patients often fall back on the one thing they know, their general opinion about medical technology<sup>79</sup>. This “falling back” is problematic since most patients are not comfortable with all medical technology and they end up deferring to their HCP, picking up on any suggestion or bias that they detect<sup>80</sup>. When patients do this the choices they make are not really their own because they are not choices that consider the patient’s values, beliefs and life goals. This means that “if, for whatever reason, patients cannot rely on information they receive about ARTs, but they trust a decision to use those technologies nonetheless, their decision may not be fully autonomous.”<sup>81</sup>

Weighing all these different costs can cause infertility patients to have faulty judgement because

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<sup>77</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 116.

<sup>78</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 115.

<sup>79</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 116.

<sup>80</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 117.

<sup>81</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 117.

they cannot process the wealth of information given to them and therefore they cannot make autonomous decisions.

Unfortunately, not only is there rarely time to process the information given, in practice there is not sufficient information being given to individuals seeking infertility treatment in the first place<sup>82, 83</sup>. As we observed above, disclosure occurs, however the amount of disclosure is not sufficient enough to be practical<sup>84</sup>. Take McLeod's example of the reproductive endocrinologist who gives the same dry speech about infertility so that she takes “little time to consider how a woman or couple is coping with the information or how relevant that information is to them[...]She probably will not succeed in conveying all of the information that is relevant to her patients because of differences in their informational needs, arising from differences in their concerns about infertility and in their cognitive capacities.”<sup>85</sup> This situation is further exacerbated by the fact that the two competing standards of disclosure currently used in medicine, the professional practice standard and the reasonable person standard, fall short of truly informing the patient.

The professional practice standard is less reliable when it comes to fulfilling the criterion of sufficient understanding as it sets its threshold for information giving according to the “professional community’s customary practices”<sup>86</sup>. In short the amount of disclosure needed is the amount professionals in general believe they are required to give. This is problematic for many reasons, the first of which being that only contrary testimony from another professional could prove that the physician violated the patient’s right to information. However, it is unclear

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<sup>82</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>83</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 61

<sup>84</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>85</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 61

<sup>86</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 122.

“whether a customary standard exists for the communication of information in medicine”<sup>87</sup> and whether that customary standard is ever policed. It also seems objectionable for custom to be the sole deciding factor, since it would then be acceptable for the majority of physicians to provide inadequate information if that was the professional custom<sup>88</sup>. It also seems negligent to allow physicians to determine what amount of information best serves the patient, especially since “it is questionable whether many physicians have developed [this] skill”<sup>89</sup>. Using the professional practice standard may “subvert” the autonomous choices of patients as it disregards the need in medicine to free medical information from the “entrenched values and goals of medical professionals” so that patients can weigh that information in context against their beliefs and values<sup>90</sup>.

The alternative standard for information disclosure does only a little to help the situation. The reasonable person standard determines its threshold of disclosure by referring to the amount of information a hypothetical reasonable person in a similar situation would deem pertinent or material to their decision making process<sup>91</sup>. This is a step in the right direction since the “authoritative determination of informational needs shifts from the physician to the patient”<sup>92</sup>. However there are still a host of difficulties associated with its use: Who is this “reasonable person” and how can we employ the reasonable person standard in a consistent manner? The reasonable person standard is also of little help to us as it is too abstract and hypothetical for it to

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<sup>87</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 122.

<sup>88</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 122.

<sup>89</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 122.

<sup>90</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 122.

<sup>91</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 123.

<sup>92</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 123.

be of any use in clinical practice<sup>93</sup>.

The confusion over how much and what type of information to give patients leads physicians to fall short of the ideal when it comes to informing patients. While it is unlikely that the physicians and health care workers intentionally mislead patients, the situation is exacerbated in the infertility setting due to the social norms surrounding reproduction. For example, one study found that health care workers in PGD clinics expressed having an unconscious “vested interest in performing and developing the technology” and they “get caught up in the enthusiasm of PGD actually working.”<sup>94</sup> This enthusiasm allows for less time and effort in discussing the downsides and alternatives to procedures like IVF and PGD<sup>95</sup>. The lack of knowledge is a serious barrier to the individual’s autonomy, as the patients are not given the tools necessary to make informed decisions about the options that are available to them. This lack of information is a stumbling block to exercising their autonomy. As Zeiler puts it, “For these couples, under these conditions, reproductive autonomy cannot be said to be present.”<sup>96</sup> Information is crucial to an individual’s ability to weigh risks and benefits against their personal values, however between the wealth of information requiring processing and discrepancies in the ways that the information is explained and defined, it seems hard for the infertility patient to sufficiently understand the information required for them to make a choice. This lack of information means that the deliberation process crucial to autonomous decision making is incomplete, and any actions or choices resulting from that deliberation cannot be considered autonomous.

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<sup>93</sup> Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. (New York: Oxford University Press, 2009), 123.

<sup>94</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>95</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>96</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

### 2.1.3.2 Alternatives: Blessings or Curse?

As I have already asserted the availability of realistic alternatives is crucial to an individual's autonomy. However, alternatives can be a double-edged sword. On the one hand, multiple alternatives can actually be illusory if they are not viable options, thus constraining the individual's freedom of choice<sup>97</sup>. This is especially true for women who experience infertility because they have delayed childbirth until a later stage in life under the mistaken assumption that ART works in a majority of the cases. This assumption is a major cause for concern among infertility HCPs, so much so that the American Society of Reproductive Medicine did an ad campaign in 2001 to warn women that using ARTs is not the same as pressing the pause button on their biological clocks<sup>98</sup>. The lack of information about possible alternatives to ART, such as adoption and foster care, can also constrain those individuals that have big decisions to make about reproducing when they know there is a risk of a genetic disease, but have little or no information to go on.

On the other hand, having multiple alternatives also constrains the patient's free will to choose not to treat infertility. Increased information about the number of options available means that some couples feel pressured to make a choice. The number of choices available suggests to those patients making the choice of "no treatment" that it is tantamount to giving up<sup>99</sup>. Especially in light of the societal opinion that a disease is something that should be treated, choosing to not pursue treatment seems to go against the socially accepted norm.

In particular, patients considering IVF and PGD felt that because the technology was offered and their doctors supported the use of that technology, refusing the technology was the

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<sup>97</sup> Kristin Zeiler, "Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis," *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>98</sup> Karey Harwood, *The Infertility Treadmill: feminist ethics, personal choice, and the use of reproductive technologies* (North Carolina: The University of North Carolina Press, 2007), 5.

<sup>99</sup> Kristin Zeiler, "Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis," *Medicine Health Care and Philosophy* 7 (2004): 175-183.

same as “denying their future children [something crucial] if they don’t take it.”<sup>100</sup> It appears that some women agree to infertility treatments presented to them simply because they feel they have little opportunity to refuse the options given to them, especially since the “dynamics of the relationship that some women have with physicians make it difficult for them ever to refuse what the physician recommends”<sup>101</sup>.

## **2.1.4 External Constraints on the Autonomy of the Infertility Patient**

As we saw in the first chapter external constraints are similar to internal constraints, except that the pressure exerted on the individual comes from an outside force. External constraints in medicine are most often caused by coercion, undue social pressure or manipulation which can prevent a patient from implementing their decisions<sup>102</sup>. A significant external constraint that exerts a manipulative and coercive force on infertility patients is linked to the clinical process of diagnosis and treatment for infertility patients.

### **2.1.4.1 Constraints Caused by the Process**

In order to understand the source of external constraints we must first examine the patient-physician relationship. Power imbalances in the patient-physician relationship, combined with the cultural norms and stereotypes surrounding medicine can interfere with patient autonomy<sup>103</sup>. This imbalance is most noticeable during the informed consent process. Informed consent is supposed to preserve patient autonomy, however “because of how it is often obtained in practice, it is not a way for many patients to become autonomous agents in choosing

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<sup>100</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>101</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 136

<sup>102</sup> Thomas A. Mappes and David Degrazia. *Biomedical Ethics*. 6 ed. (New York: McGraw-Hill Higher Education, 2006), 44.

<sup>103</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 134.



treatments.”<sup>104</sup>

Instead, in practice informed consent is a “discreet event” consisting of physicians fulfilling their legal obligations to disclose to patients the harms and benefits of the recommended procedure and then ask if the patient understands and agrees to the procedure<sup>105</sup>. There is little “significant communication” concerning the patient's options beyond those required to satisfy the informed consent requirements<sup>106</sup>. Patients are reluctant to ask for further information or options due to the authoritative knowledge of physicians<sup>107</sup>. Patients who trust their physicians to direct them to the best course of action consider accepting this authority as their autonomous decision, since their trust is in line with their beliefs and values about medicine and doctors. However, for those patients encountering new doctors, such as infertility patients, as well as those who do not trust old ones, this authority can act as a constraint on autonomous choice. These patients may feel they have no choice but to see a doctor and “refrain from questioning the physician's authority for fear of being abandoned.”<sup>108</sup> This is especially true of those patients seeking alternative treatments, who find their autonomy restricted by the epistemic hegemony of medicine, which usually ensures that alternative practices are not subsidized<sup>109</sup>. This hegemony makes patients hesitant to challenge their physician<sup>110</sup>. In infertility there is worry that couples that are interested in using ART may have concerns that they cannot voice for fear of losing their access to the infertility treatment<sup>111</sup>, especially since “patient-initiated questions are often dispreferred” in the clinical setting<sup>112</sup>. This fear of questioning leads to an

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<sup>104</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 134.

<sup>105</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

<sup>106</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

<sup>107</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

<sup>108</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

<sup>109</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

<sup>110</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

<sup>111</sup>Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>112</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 135.

unhealthy environment where the patients sound convinced, but never get the chance to voice the concerns and misunderstandings about certain treatments that are crucial for their decision making abilities.

This external constraint to autonomy is most evident in the language used by patients and doctors when discussing treatment options. As we saw earlier patients are wary of voicing opinions about their treatments that are contrary to the physician for fear of being labelled “non-compliant and uncooperative”, thus losing their care<sup>113</sup>. As a result patients who are even remotely interested in ART have to sound convinced even when they are not. One area of infertility where this problem appears to be particularly acute is PGD clinics. Zeiler found that couples needed to sound convinced in order to access the clinics, noting one particular health care professional as remarking that patients tailor their comments accordingly, often causing doctors to overlook the fact that the treatment may not have been right for the patient<sup>114</sup>:

(emphasis added)

“So they’re never going to say to the doctor, ‘I **think** I want to have this.’ You know, they might not turn up for treatment but they are going to have to say, ‘We **really** want this, we **must** have this **now**,’ and so then we end up saying ‘Yes, you **must** have it **now**.’ Before you know it, we’ve done the treatment. Well...we never stepped back to say, you know just because they wanted it, was it the right thing to do for that individual. (Interview 8)”

The importance of the words used to describe the situation of the infertility patient must be addressed. “Think” is a word that in this context connotes hesitation, lack of confidence and fear. It is a “stop light” word. The patient avoids using these words because they signal to the physician that they are not wholeheartedly invested in infertility treatment due to reservations or concerns. In contrast words that are heard the most often around infertility clinics are words such as: “must” and “now”. These words are “green light” words because they are confident,

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<sup>113</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 118.

<sup>114</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

emphatic and imperative. Patients are unable to articulate their concerns about using ART, which “results in a lessened opportunity to make autonomous choices”, consequently these infertility patients experience a constraint on “the power to make autonomous choices” about the treatments they are offered<sup>115</sup>. This constraint on autonomy is important to keep in mind, considering that one commentator found that infertility specialists did not acknowledge any differences among treatment types, nor did these specialists acknowledge that treatment may not always be the best solution for certain patients<sup>116</sup>. This means that not only are the patients unable to speak up and ask for what they really want, but that the treating HCPs are unconcerned with the nuances that may be critical factors about ART for a deciding patient. Patients do not see ARTs as interchangeable, nor do they take the decision to treat lightly, so HCPs shouldn’t either.

Both the referring doctors and the specialists are guilty of externally constraining the patient’s ability to self-govern, as they are manipulating the patient’s behaviour so that it conforms to some accepted norm, and is not motivated by the patient’s own values<sup>117</sup>. The referring doctor is reluctant to make the referral if they believe that the patient will back out and possibly damage the doctor’s relationship with the specialist, so they are conservative<sup>118</sup>. Due to the beliefs that we discussed earlier that infertility should be treated<sup>119</sup>, the infertility specialists have a vested interest in the patient being convinced of the ART treatment. Due to this vested interest, the infertility specialists fail to realize that not only are they are not taking the time to

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<sup>115</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>116</sup> P. Lauritzen, *Pursuing Parenthood: Ethical Issues in Assisted Reproduction* (Bloomington: Indiana University Press, 1993), xiv-xv.

<sup>117</sup> Kristin Zeiler, “Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis,” *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>118</sup> For example, couples wanting to use PGD in Britain and Canada must wait until their doctor deems it appropriate to contact a PGD clinic and refer them. They cannot go directly to the PGD clinic themselves. This type of conservative relationship between specialist and GP is the case for other types of referrals as well.

<sup>119</sup> *Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

address negatively worded questions, but they are actively dissuading the patient from expressing any concerns about treatment side effects, consequences and failure rates<sup>120</sup>.

Complicating matters further is the strongly held belief by the specialists that ART is THE way to treat infertility<sup>121</sup>.

Nevertheless, the female infertility patient is disadvantaged, as they either don't really autonomously agree to the infertility treatment, or they raise objections and lose the option of obtaining the treatment in the first place. This problem seems to be unique to infertility due to the elective nature of infertility. Infertility is unlike cancer treatment where, for example, if the primary care doctor doesn't refer the patient to an infertility specialist or clinic, the infertility patient will not get any sicker, nor will they die from the lack of treatment. Cancer patients, on the other hand, do not need to tailor their questions or comments so that they appear enthusiastic about treatment because they will be referred to an oncologist regardless of how they feel about the treatment. The non-life-threatening nature of infertility puts infertility patients at a disadvantage by obligating them to act certain ways in order to get to the next level of treatment, even if it is just to learn about that next level of treatment.<sup>122</sup>

It may appear from this first chapter that all female infertility patients are constrained in a variety of conflicting ways that make the constraints seem improbable. However, the reality of the situation is more reasonable than that. All these different barriers **affect not all patients all the time, but instead different groups of patients at different times**. When discussing female infertility patients we must be aware that not everyone is addicted to the treatment, not everyone

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<sup>120</sup> Kristin Zeiler, "Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis," *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>121</sup> Kristin Zeiler, "Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis," *Medicine Health Care and Philosophy* 7 (2004): 175-183.

<sup>122</sup> There is one final barrier to autonomy that some ART patients face that we will not discuss in this thesis: society's moralization of responsibility that leads to an emphasis on getting genetic testing done. The mere existence of the technology pressures couples into feeling that they should use them. However, an in depth discussion of PGD would lead us away from the issue at hand: namely the autonomy of infertility patients in general and so I merely mean to draw the reader's attention to the fact that I have explicitly left this issue out.

is insufficiently informed and not everyone is externally constrained by their physician's enthusiasm. Instead it is important to remember that even if one of the criteria for autonomy is not met, the individual in question cannot be classified as autonomous. There appears to be a barrier to autonomy, and thus a failure of the criteria for autonomy, for almost every possible situation that a female infertility patient may encounter. When one considers the entire picture as a whole, there is a disturbingly large number of infertility patients who appear to lack the necessary autonomy required to make decisions about their particular situation. What is important to consider is that there are very real barriers affecting the autonomous decision making of most female infertility patients and this is a problem that theoretical and applied bioethics must address. We have spent the last chapter discussing how infertility patients fail the criteria for autonomy, in chapter three I will tackle the reasons behind the barriers and what that means for infertility patient autonomy in the future.

# CHAPTER THREE: Society and Relational Autonomy

## 3.1 Societal Influences and Autonomy

### 3.1.1 Societal Influences on the Autonomy of the Infertility Patient

In chapter two we examined the many barriers that infertility patients face while trying to preserve their autonomy. Those barriers are held together by a common thread: the societal norms and influences concerning reproduction and womanhood. In our society reproductive identity is tied to feminine identity in such a way that it seems impossible to separate the two<sup>123</sup>. Due to this close connection, in this chapter I will consider the influences from society on the choices infertility patients make and explore the question: If women are in general being pushed to have children and adapt their preferences in a way that makes this social pressure seem more like their own idea, then to what extent can a tool, such as ART, that facilitates their “living up to” society's expectations provide an autonomous choice for them?

To get at the answer we must look more closely at the existing social norms in order to understand what society's “expectations” are. R.G. Edwards and David Sharpe argue that “The desire to have children must be among the most basic of human instincts, and denying it can lead to considerable psychological and social difficulties.”<sup>124</sup> From a purely biological point of view it is evolutionarily necessary for the survival of the human species to reproduce. From these scientific origins stems a social understanding of reproduction and women that has been slow to change with modern cultural considerations of women.

A discussion of societal norms of reproduction would be incomplete without first defining pronatalism. Pronatalism is best understood as an ideology that promotes child bearing and child rearing as a social norm. Feminism associates pronatalism closely with women in part

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<sup>123</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 275.

<sup>124</sup>Robert G. Edwards and David J. Sharpe. “Social Values and Research in Human Embryology,” *Nature* 231 (1971): 87.

due to the significant role women play in reproduction, but also due to the existing and past social norms that promote women as the ideal child-rearer of the stereotypical nuclear family construct. Pronatalism influences all aspects of our understanding of reproduction and fertility. For example, some feminists have argued that as a result of pronatalism, many of the social beliefs that we discussed in chapter one, for example the inappropriateness of being close to a child that is not your own<sup>125</sup> and the fact that women have been taught to be cautious of others have resulted in the belief that having a child is the only chance that women have for real intimacy and a sense of accomplishment<sup>126</sup>. In short there appears to be a social feedback loop that supports the presence of pronatalism in our society.

In addition, society is not as suspicious or scornful of childless men as they are of childless women<sup>127</sup>. For women, gender identity is bound to their ability and competency as mothers, and by extension their commitment to motherhood<sup>128</sup>. The pronatalist norms that are pervasive in our society are inextricably linked to what it means to be feminine, so much so that those women who go against the norm are subject to distrust from others, as well as themselves<sup>129</sup>. Since self-trust is an essential part of intentionality, any self-distrust acts as a barrier to autonomous decision making<sup>130</sup>.

A possible counter argument to this claim that can be raised is that if one “goes against the pro-natalist norm” then one is not likely to be seeking ART, and so the issue of self-trust doesn't seem to apply as a problem for autonomous health care decision making. However, as I mentioned earlier, we are leaving aside those women who choose not to pursue ART at all.

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<sup>125</sup>Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>126</sup>Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>127</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 5.

<sup>128</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 35.

<sup>129</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 114.

<sup>130</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 50.

Instead we are concerned with those female infertility patients who feel that they are obligated to in order to escape the distrust that comes with going against the norm of femininity. The concern with self-distrust is that it creates a reluctance to stop ARTs once the patient has started them, since pronatalism links femininity so strongly with motherhood by reinforcing negative stereotypes about childless females. For female infertility patients, social norms like pronatalism make it hard for women to resist using ARTs since they present a way to fulfil their social destiny. Since infertility patients who choose to stop using ARTs (or never start at all) are subject to the “voluntarily childless” stigma, in addition to distrust from those around them, it seems that there is significant pressure on all infertility patients to start or continue with treatment despite any reservations<sup>131</sup>. With such strong ties between femininity and fertility those women who stop treatment and opt for this “voluntarily childless” situation also seem to be “voluntarily” accepting that they are not “full” women. This seems especially true when we consider that “we live in a culture of 'obligatory fertility' for women, where women who are infertile are supposedly diseased and those who choose to be childless are **selfish** or **crazy**.”<sup>132</sup> When the above assertion is combined with the societal (and medical) belief that infertility is to be treated at all costs, it seems hard to imagine how infertility patients manage to maintain their autonomous decision making abilities throughout infertility treatment.

Furthermore, women often place the needs of others at the centre of their decision-making<sup>133</sup>, however this means that an infertile woman has difficulty and in some cases cannot separate out the demands of others on herself from her own demands of herself. However, this claim needs qualification. It seems reasonable for a married woman to consider the interests or needs of her partner, or a daughter to consider the needs of her parents when making choices that

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<sup>131</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 118.

<sup>132</sup>Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 118.

<sup>133</sup>Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women's health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 19–47.



drastically affect her life. This is especially true of reproductive decisions where more often than not the decision involves the cooperation of the female patient and her partner, in particular when the female patient is only a patient due to the infertility of her partner. If a female infertility patient is the kind of person who wants to consider her spouse's desires in her decision, do we want to automatically assume that her decisions are non-autonomous? No, that seems unrealistic since familial demands are often in sync with the patient's own desires as well. Instead we want to consider the effect that these desires may have on the patient's autonomy when combined with the heavy societal influences on women pervasive in the infertility sector. With competing demands, as well as the pronatalist push from society it seems hard for the female infertility patient to make an autonomous choice that is considered to be in line with the criteria we set out in chapter one. If the infertility patient has difficulty distinguishing societal demands from their own desires and if familial demands are not shared by the patient, it seems as if the patient may be unable to maintain autonomous decision-making that reflects their own beliefs and values. In addition, many of the barriers to autonomy that infertility patients face are rooted in the pronatalist norms of our society, meaning that it is not only the infertility patient who is dealing with pronatalist norms, but all members of society are biased by it. This makes it extremely difficult for infertility patients to escape outside interference on their decisions.

To fully understand the social context of infertility it is important to consider the more extreme feminist views as well. Fundamentalist feminists dislike ART because it showcases the socially constructed nature of women's desire for children, highlighting pronatalism's presence, as well as supporting the chauvinistic nature of the desire for biological children.

Fundamentalist feminists argue that this desire is considered to be unnatural and socially constructed and so by extension it is not "morally essential" that the desire be satisfied<sup>134</sup>.

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<sup>134</sup>Laura M. Purdy, "What Can Progress in Reproductive Technology Mean for Women?" *Journal of Medicine and Philosophy* 21 no.5 (1996): 499-514.

Further, if it is not morally essential there is no real need for the offending ARTs existence. However, conceiving of social influences in this way assumes that socially constructed/conditioned desires are “socially malleable” and can be easily denied by the individual they are acting on<sup>135</sup>. Purdy argues that even in the absence of pronatalism many women would still want to reproduce, in particular because some individuals’ ties to their children are the strongest and most enduring of all the human relationships they will have<sup>136</sup>. As a result the removal of ARTs would not solve the problem of determining the status of the female infertility patient’s autonomy, especially since the social influences on these patients would just be replaced by familial influences to bear children and achieve the strong bond to them.

Less extreme feminists are still concerned that ARTs exist as a response to a demand driven by “constraining social perspectives”, as opposed to genuine medical need<sup>137</sup>. Sherwin worries that adding ARTs to the mix only exacerbates the situation because the existence of ARTs highlights society’s recognition of infertility as a problem without also highlighting the alternatives to ART such as adoption and foster care. The strong connection between societal opinion and medical intervention makes it important to view issues such as IVF and infertility within the context of their social situation so we can grasp a bigger picture of what these technologies are truly designed for<sup>138</sup>.

Looking back at the question that we asked at the beginning of this chapter it becomes apparent that ARTs are an extension of the social pressures on women to reproduce. Additionally they are not providing an option that can be autonomously chosen because ARTs are not part of

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<sup>135</sup>Laura M. Purdy, “What Can Progress in Reproductive Technology Mean for Women?” *Journal of Medicine and Philosophy* 21 no.5 (1996): 499-514.

<sup>136</sup>Laura M. Purdy, “What Can Progress in Reproductive Technology Mean for Women?” *Journal of Medicine and Philosophy* 21 no.5 (1996): 499-514.

<sup>137</sup>Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>138</sup>Susan Sherwin, “Feminist Ethics and In Vitro Fertilization,” *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

an environment that promotes autonomous decision making. Even if ARTs have increased the choices available to infertile women, these new choices are still socially bound and so to some extent are “tainted” by pronatalist ideals.

### **3.1.2 Social Influences and the Barriers to Autonomy**

Examining the difficulties with determining autonomy first discussed in chapter two, quickly brings to light the weight of the social influence of pronatalism. However, one might wonder why the fact that female infertility patients are heavily influenced by social norms matters at all, especially given that societal norms are among the hardest to transcend? For infertility patients considering the social influences is of the utmost importance since they underlie the barriers to autonomy that we spelled out in the second chapter. Consider the trauma of experiencing failed infertility treatments. Earlier we classified this trauma as an internal constraint for infertility patients, however it is also important to note that this trauma is linked to both the societal belief that diseases should be treated<sup>139</sup>, as well as the importance of reproduction as a whole to society, and thus the patient. The trauma is founded in a desperation to be cured of a disease that is socially linked to the female infertility patient's achievement of womanhood<sup>140</sup>. The resulting emotions and/or addiction that act as internal constraints are felt individually, but are rooted in social norms and oppressive beliefs about fertility. Female infertility patients associate failed infertility treatment with failed womanhood, further fuelling the emotional despair that follows a failed procedure.

In the case of sufficient understanding, the effects of societal influence are not limited to the infertility patient. As we saw in chapter two, infertility patients often do not have the information necessary to make an informed, autonomous choice because the HCP involved in the

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<sup>139</sup> See Section 1.2.1, page 14

<sup>140</sup> A social concept that makes childbearing and fertility integral to the definitions of femininity and womanhood.

treatment unconsciously holds back information due in part to enthusiasm for the treatments<sup>141</sup>. The enthusiastic approach to ARTs in medicine comes from the belief that rectifying infertility is a **good** thing that **should** be done because women are supposed to have babies: again because it is a part of womanhood<sup>142</sup>. Again pronatalism informs the medicine, which in turn influences how the HCPs approach ARTs. Finally the external constraints related to the clinical process of diagnosis and treatment are influenced by pronatalist norms. As we saw in chapter two the power imbalances in the patient-physician relationship, combined with the cultural norms and stereotypes surrounding medicine can interfere by acting as an external constraint on a patient's ability to maintain autonomy<sup>143</sup>. In general, female infertility patients are failing the criteria for autonomy in large part due to the societal influences that act on them and so we must address the societal influences on those institutions who rely on autonomy (such as medicine) in order to find a way to reduce the societal effects on patient autonomy.

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<sup>141</sup> See section 2.1.3.1

<sup>142</sup> Susan Sherwin, "Feminist Ethics and In Vitro Fertilization," *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

<sup>143</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 134.

## 3.2. Relational Autonomy

While the traditional criteria that we have used throughout this thesis successfully separate the non-autonomous from the autonomous individuals, they give us no direction on how to deal with the alarmingly high numbers of female infertility patients who are assessed as non-autonomous. The traditional theory does not tell us how to preserve or even return autonomy to those patients who have lost it due to societal norms. Returning, preserving and bestowing autonomy on these patients is a critical step in fighting social influences like pronatalism. However, as previously stated, traditional autonomy doesn't give us the right tools to solve the problem, only to identify it. Instead we need to turn to a new theory of autonomy, relational autonomy in order to tackle the issue. However before we can apply relational autonomy, we must first define the theory.

### 3.2.1 What is relational autonomy?

Relational autonomy is an umbrella term for a range of related perspectives about autonomy<sup>144</sup>. These related perspectives are “premised on the shared conviction [...] that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity.”<sup>145</sup> Relational autonomy deals with the full range of influential human relations: personal and public<sup>146</sup> and often stands in opposition to the individualistic, proceduralist account of autonomy that we described in chapter one, as relational theorists

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<sup>144</sup>Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 4.

<sup>145</sup>Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 4.

<sup>146</sup>Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women's health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 19.

believe that the basis for autonomy is not just individualistic and rationalistic. Instead, the “self” that autonomy is supposed to be self-governing is actually derived from relations with others, and so our understanding of autonomy should take this into account.

Relational accounts of autonomy question whether individual autonomy is compatible with the social embeddedness of persons<sup>147</sup>. In particular Lorraine Code criticizes the autonomous ideal that is based on the notion that “human beings are capable of leading self-sufficient, isolated, independent lives”<sup>148</sup>. It is from this ideal that we get the “prescriptive conclusion” that humans should strive for self-sufficiency and individuality<sup>149</sup>. Over time autonomy and individualism have become fused together as necessary for each other, however the importance of society and relationships has been marginalized.

The difficulty seen by the relational theory that arises when using a procedural account is that eventually one “encounter[s] a series of difficulties in attempting to reconcile autonomous agency with socialization, especially oppressive socialization. In particular, since structural procedural theories analyze autonomy as a feature of an agent’s occurrent mental states, they cannot do justice to the historical processes of socialization leading up to those states.”<sup>150</sup> Relational autonomy theorists argue that because the procedural account is content-neutral, it cannot offer an explanation for the socialization of agents and is thus missing a crucial aspect of autonomy. This is exactly the difficulty that we encounter when examining infertility patients through the traditional lens. The traditional paradigm sees the individual as being separate from and existing independent of society and its criteria for determining autonomy reflect this

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<sup>147</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 4.

<sup>148</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 6.

<sup>149</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 6.

<sup>150</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 13.

individual focus. Given that infertility patients are obligated to fulfil their reproductive duties in order to achieve a state of femininity and meet their potential as persons, infertility patients cannot easily be separated from their social self, and that social self must be taken into account when considering how to maintain the patient's autonomous status. Traditional autonomy can identify criteria for autonomy that are not met by individual patients, however it cannot tell us how the patient got to that point. Since infertility patients seem autonomous in every other aspect of their lives it seems that we need a theory that does do justice to those "historical processes of socialization" that lead up to being classified as non-autonomous so that we can begin to understand the kind of remedial action required to restore autonomy to patients, if that is possible.

When examining the case of the female infertility patient it is necessary to look at a causal account of relational autonomy that focuses on the ways in which "socialization and social relationships impede or enhance autonomy."<sup>151</sup> In particular, the type of oppressive socialization that the female infertility patient has been subject to<sup>152</sup> undermines the patient's normative competence<sup>153</sup>. For example, the influence of societal norms extends to medicine as well. As we've already argued, traditionally patient autonomy is conceived of individually and this mirrors medicine's tendency to approach illness as an individual problem related to a particular patient. In general HCPs "respond to the symptoms troubling particular patients in isolation from the context that produces these conditions"<sup>154</sup>. For example, doctors often deal with infertility by telling patients to relax or by prescribing hormone/surgical treatments instead of demanding more research into the causes of infertility or to deal with the social pressures to

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<sup>151</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 22.

<sup>152</sup> i.e. Linking femininity to reproductive abilities.

<sup>153</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 20.

<sup>154</sup> Susan Sherwin, "A relational approach to autonomy in health care," in *The politics of women's health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 29.

reproduce<sup>155</sup>. Over time oppressive socialization like the kind described in the example “can lead to the acceptance of norms, which once internalized, block [an] agent’s capacities for detecting whether the norms are correct”<sup>156</sup>. When women lose the ability to critique the norms, they lose their ability to distinguish incorrect norms (i.e. oppressive ones) from correct norms and by extension they lose autonomy “with respect to the area of their lives that they take to be governed by the norm”<sup>157</sup>. In our case the area concerned is infertility medicine.

### 3.2.2 How Relational Autonomy Can Help

We can see from this exploration of relational autonomy that it offers even more support for our argument that female infertility patients cannot be classified as autonomous. I would like to argue that a switch by the medical institution to relational autonomy from traditional autonomy would better capture the barriers to autonomy that infertility patients face, while at the same time be better suited to identifying those points where change can occur in the system to help return autonomy to what is an otherwise autonomous patient base. There may be some concern that moving from a traditional theory to a relational one may too drastically alter how we conceive of autonomy such that we lose some of its traits that we value the most, however this is not the case. While traditional and relational autonomy are often characterized as being resolutely at odds with one another, there is nothing in relational autonomy that says being an individual thinker and acting on one’s own individual thoughts is wrong. The same is true for traditional autonomy, as Christman points out “there is nothing about a social conception of

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<sup>155</sup> Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women’s health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 29.

<sup>156</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 20

<sup>157</sup> Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000), 20.



‘self’ that is incompatible with an individual conception of autonomy.”<sup>158</sup> Adopting a relational approach to dealing with infertility patients doesn’t make the landscape unrecognizable from what it once was, in fact in many ways the requirements of traditional autonomy are mirrored in relational accounts as well. The difference lies in the fact that relational autonomy asks us to consider relational and social influences when determining autonomy. It is possible to adopt relational autonomy without giving up the useful philosophical goals of our original criteria from chapter one due to the similarity of the demands that the traditional and relational theories make on autonomy.

The close association between traditional and relational requirements of autonomy can be seen when one examines the demands of relational autonomy more closely. Take Carolyn McLeod's discussion of the three main aspects of relational autonomy, which synthesizes the core beliefs of relational autonomy. McLeod identifies level of choice, action and authenticity as integral to the relationally autonomous individual. When we unpack these terms we can see that the similarities between the two theories of autonomy are vast.

McLeod argues that choice requires decisional capacity in conjunction with adequate understanding in order to make a choice in bioethics<sup>159</sup>. Decisional capacity is crucial as it allows us to understand the nature of our options and to evaluate them in light of our beliefs and values<sup>160</sup>. When we look back to our definition of intentionality and sufficient understanding in chapter one the similarities between all three criteria become obvious: An individual acts intentionally when the individual’s end or purpose is reflected in the description of the action that the individual recognizes herself as engaging in. Sufficient understanding is defined as an understanding of not only what is at stake when one makes a choice and follows through with an

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<sup>158</sup> John Christman. “Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves,” *Philosophical Studies*, 117 (2004): 143-164.

<sup>159</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 107.

<sup>160</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 107

action, but also an understanding of the implications and possible consequences of the action, as well as an understanding of the available alternatives. The criterion of choice and the criteria of intentionality and sufficient understanding seem to espouse the same general message: that an autonomous individual understands both their situation and their options, including the risks and benefits, and is able to compare these options to their beliefs and values in order to make a decision.

The criterion of action rings a similar bell to those criteria of internal and external constraint. Action requires a voluntariness that is free from coercion and manipulation<sup>161</sup>. Just as we did in chapter one, McLeod argues for taking the term coercion in the broad sense since it can be subtler than the Beauchamp and Childress definition of coercion we defined earlier<sup>162</sup> and can have a much “broader target, such as a patient's appreciation for her own competence in making decisions.”<sup>163</sup> When we look back on the prohibition on constraints outlined by traditional autonomy we see that the focus is still on voluntariness of both body and mind when it comes to making autonomous decisions<sup>164</sup>.

As we can see, it appears that the four criteria for autonomy that we identified in chapter one are wholly encompassed by the requirements that must be met by individuals to be considered autonomous under the relational theory. The one point of deviation between the two theories comes with the relational demand that social and relational influences be considered when determining the autonomy of an individual. I would like to argue that the difference lies in the last criterion that McLeod presents to us, an authenticity clause that is far more sophisticated than the traditional criterion of intentionality, its closest relative in traditional autonomy<sup>165</sup>. In order to be autonomous, an individual has to define their goals and values for themselves. This

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<sup>161</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 107-8

<sup>162</sup> See Section 1.1.2.3.1 page 9.

<sup>163</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 108

<sup>164</sup> See Section 1.2.3 and Section 1.2.3.1 pages 8-9.

<sup>165</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 111-12

means that individuals have to figure out what they believe and define it accordingly.

Authenticity is a concern for relational theorists because oppression, which in this case is in the form of social norms about reproduction, can shape the desires and goals of people in such a way that their autonomy becomes limited and no longer authentic<sup>166</sup>. For example “a woman who is infertile may have learned to identify so strongly with pregnancy and motherhood that she is willing to do whatever it takes to conceive, even subjecting herself continually to treatments that she finds emotionally and physically harmful.”<sup>167</sup> Authenticity in decision making is important for all individuals, however it is particularly crucial for those individuals, such as infertility patients, who have been oppressed by societal norms.

While we did show in chapter two the ways that social norms can cause barriers to autonomy, the importance of social and relational influence is something that we need to make explicit in the criteria for autonomy, since a common critique of traditional autonomy by relational theorists is that it often awards autonomy to those who are in fact constrained by oppressive societal norms. However in doing so we cannot lose sight of the fact that relational autonomy and traditional autonomy are different in kind, meaning that traditional autonomy focuses on the procedural approach while relational autonomy shies away from the types of accounts of autonomy that we have been using in the first part of this thesis. As Sherwin points out “by focusing only on the moment of medical decision making, traditional views fail to examine how specific decisions are embedded within a complex set of relations and policies that constrain (or, ideally, promote) an individual’s ability to exercise autonomy with respect to any particular choice.”<sup>168</sup> The point Sherwin’s critique of traditional autonomy is trying to make is that autonomy is not necessarily best protected by evaluating particular decisions, but rather by

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<sup>166</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 111-12

<sup>167</sup> Carolyn McLeod. *Self-Trust and Reproductive Autonomy*. (Cambridge: The MIT Press, 2002), 112

<sup>168</sup> Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women’s health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 32

shaping whole institutional practices such that they give rise to autonomous decisions and decision makers. This concern over proceduralist accounts does not negate our earlier argument about how relational and traditional autonomy are similar because the two theories remain similar in their core philosophical goals to protect the patient's decision making abilities. Part of the solution is turning an inquisitive relational eye on medical practice, specifically relationships between patients and HCPs, as well as changing the way that the institution of medicine views autonomy. It may also be the case, as we will see in the final section, that the baby steps required to move towards a relational approach to autonomy in health care requires that at some point we attempt to give physicians some semblance of the criteria for autonomy they had before, thus retaining a proceduralist-like account of relational autonomy may be beneficial. Having shown that we are not losing the important philosophical thrust of the traditional criteria laid out in chapter one, we can make the move to relational autonomy with confidence as we examine what solutions relational autonomy can offer in dealing with the effect of societal influence on female infertility patients.

### **3.2.3 What Relational Autonomy Means in Practice**

How can relational autonomy help deal with the effects of pronatalism? It is asking too much to say that relational autonomy can do away with social influences, instead we are going to use the philosophical thrust of the relational theory as a way to identify methods of dealing with the aftermath of the social influences on infertility patients to help get out of the socially oppressive rut medical autonomy has been in.

In practice, relational autonomy demands more from HCPs than traditional autonomy because it demands more than the bare minimum from medicine. One of the main weapons in the relational autonomy arsenal is that as a theory it demands increased awareness and

understanding of those social influences on oppressed individuals. As Sherwin argued in the previous section, relational autonomy seeks to shape whole institutional practice such that oppressed or previously oppressed individuals may become autonomous. When we parlay this idea into the infertility realm we see that incorporating the spirit of relational autonomy into the practices of medicine may not be as difficult as one might consider.

While it may seem like a heavy burden, those HCPs who practice fertility medicine should be educated in the history of gender oppression and the psychological effects of internalizing social norms. Because the definition of infertility is informed by both the medical and social realms, the practitioners of its treatments should be as well. Just as bioethics courses have become mainstream in medical schools, classes on gender and social norms should be mandatory for those who wish to specialize in fertility medicine. To the HCPs who bemoan that this is a waste of time or not part of their purview as doctors, I respond with a simple query. If you do not know what to look for, how can you possibly identify something's effects and resolve them? HCPs must be made aware of and be able to identify negative societal influences on patients and make the patients aware of these effects if patients are ever going to remain autonomous during treatment. The suggestion for further education of our doctors is not an easy solution, however, medicine is becoming more and more complex as we realize its potential and how that potential shapes the various other realms of the patient's life. Medicine can no longer take a telescopic view of the patient and see only those parts of the patient that are diseased, instead they must take a step back to view the patient in their entirety: social influences, family demands, cultural norms and all. This is because, to use an infertility example, while the patient may have a lazy ovary that makes reproduction difficult for them, how and why they are treated is based on their own values and beliefs, so the doctor must consider these values and beliefs when treating the patient.

Considering that societal influences on doctors are responsible for over half of the barriers to autonomy that we identified in the previous chapter (i.e. The insufficient information given to patients due to beliefs about needing treatment and enthusiasm for that treatment, as well as bulldozing patients through procedures by making it clear that questions about infertility were dispreferred) it is important that doctors are made aware through education of the background influences of society which are acting on themselves and their patients. Once they become attuned to the corresponding biases that they incorporate into their medical practice as a result of these negative social norms they will be able to curb their infractions on infertility patient's autonomy. In addition, making women more aware of the societal biases they experience and internalize, while at the same time providing them with a more supportive account of autonomy, may help with the internal constraints they face, in particular the trauma of failed infertility treatments that is brought on by pronatalism. Promoting increased awareness of what the societal norms are, as well as some of their common effects on infertile women is also a step towards achieving the authenticity in decision making that is necessary for individuals in the relational model.

Education and information help deal with the more practical concerns, however we still need to reduce the overall importance of many of the societal norms surrounding fertility and womanhood. Helping to support the female infertility patient's autonomy requires effort on all sides. As Sherwin laments "oppression-induced barriers to autonomy" cannot be removed simply by providing more information or removing explicit coercive forces; there needs to be more so as to avoid the internalization of messages of reduced worth that Sherwin warns is possible<sup>169</sup>. Women need more opportunities and support for exercising autonomous choice. Without these opportunities diminished expectations on what women should/can do leads to

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<sup>169</sup>Susan Sherwin, "A relational approach to autonomy in health care," in *The politics of women's health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 36.

beliefs in diminished capacity<sup>170</sup>. It must be the social norms, not only the agent that is subject to scrutiny under relational autonomy for the theory to reach its full potential<sup>171</sup>. It is the social understanding of reproduction as necessary for womanhood that must change and this is the more difficult thing to deal with. Medicine is informed by the social norms, and vice versa, such that a change in the social conception of infertility would be a change in the medical conception as well. For this reason it may be possible to effect a change in the medical approach to infertility by educating infertility HCPs about the affect of societal norms such that over time the social beliefs about infertility and womanhood may change. Sherwin suggests that “it may be necessary to spend more time than usual in supporting patients in the deliberative process of decision making and providing them with access to relevant political, as well as medical information when they contemplate controversial procedures [like ARTs]”<sup>172</sup>. Allowing for the supportive environment that relational autonomy demands may make it possible over time to remove the entrenched societal beliefs that have been supporting the barriers to traditional autonomy.

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<sup>170</sup>Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women’s health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 37.

<sup>171</sup>Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women’s health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 37.

<sup>172</sup>Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women’s health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 38.

# CONCLUSION

The bioethical principle of autonomy remains one of the most important lessons that bioethics has given medicine. Respect for patient autonomy is critical to the patient being treated fairly and with their own benefit in mind. The criteria established by bioethical theorists are designed to help identify those individuals who truly are not autonomous and require protection. By focusing on the importance of the patient acting with intention, once they have sufficient information about the procedure and are not internally and externally constrained, the criteria cover most of the ways that patient autonomy can be interfered with, however they do not offer a way to account for and deal with the societal norms that influence female infertility patients.

Female infertility patients are autonomous in every other respect—or at least they should be. However, there is something about infertility treatment that makes it hard for patients to maintain autonomy throughout their medical encounter. This “something” is the social norms of pronatalism that are inextricably linked to womanhood and femininity. Due to the pervasiveness of pronatalism in our culture female infertility patients find themselves struggling to retain their autonomy in the face of barriers such as too little information about ART procedures, HCP bias about why female infertility patients should be treated, as well as dealing with how their own beliefs and values are affected by pronatalism.

It is at this crossroads of pronatalism and autonomy that the infertility patient requires more than the criteria derived from traditional autonomy can offer. Relational autonomy may be able to offer female infertility patients what they need. By recognizing the extent to which women are influenced and shaped by the relationships and social norms that surround them, relational autonomy goes beyond the scope of the original criteria for autonomy, allowing us to pinpoint more specific areas in the infertility medical encounter where autonomy is lost. While



not an easy solution, working towards that supportive environment that relational autonomy demands may make it possible to lessen the detrimental effects of the entrenched societal beliefs that have been supporting those barriers to autonomy that infertility patients face.

However, the burden should not rest on the shoulders of the patients themselves. HCPs should also be educated about the effects of social norms on their patients, as well as themselves. In addition HCPs and the medical community should heed suggestions from feminists such as Sherwin, who argues that medicine must make it necessary for HCPs to “spend more time than usual in supporting patients in the deliberative process of decision making and providing [patients] with access to relevant political, as well as medical information when they contemplate controversial procedures [like ARTs]”<sup>173</sup>. By taking time to address the female infertility patient in her entirety, not just as the “host” for her disease, medicine may very well lead us down the right social path, obliterating pronatalism's predominance in our culture while, at the same time, preserving and in some cases returning the female infertility patient's autonomy.

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<sup>173</sup>Susan Sherwin, “A relational approach to autonomy in health care,” in *The politics of women's health: Exploring agency and autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), 38.

# BIBLIOGRAPHY

Arneson, R.J. "Commodification and Commercial Surrogacy." *Philosophy and Public Affairs* 21, no.2 (1992): 132-164.

Beauchamp, Tom L. and James F. Childress. *Principles of Biomedical Ethics*. 6 ed. New York: Oxford University Press, 2009.

Branswell, Helen. "Success rate climbs for in vitro fertilization." *The Globe and Mail*, December 16, 2008, National News Section, Toronto edition.

Cussins, C. "Producing Reproduction: Techniques of Normalization and Naturalization in Infertility Clinics" in *Reproducing Reproduction: Kinship, Power and Technological Innovation*. ed. S. Franklin and H. Ragone. Philadelphia: University of Pennsylvania Press, 1998.

Donchin, Anne. "Feminist Critiques of New Fertility Technologies: Implications for Social Policy" *Journal of Medicine and Philosophy* 21 no. 5 (1996): 475-498.

Harwood, Karey. *The Infertility Treadmill: feminist ethics, personal choice, and the use of reproductive technologies*. North Carolina: The University of North Carolina Press, 2007.

Kalbman, Aline H. "Narrative Artifice and Women's Agency." *Bioethics* 19 no.2 (2005):93-111.

Kant, Immanuel. *Groundwork of the Metaphysics of Morals*. Translated and analyzed by H.J. Paton. New York: Harper and Row, 1964.

Lauritzen, P. *Pursuing Parenthood: Ethical Issues in Assisted Reproduction*. Bloomington: Indiana University Press, 1993.

Mackenzie, Catriona and Natalie Stoljar. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press, 2000.

Mappes, Thomas A. and David Degrazia. *Biomedical Ethics*. 6 ed. New York: McGraw-Hill Higher Education, 2006.

McLeod, Carolyn. *Self-Trust and Reproductive Autonomy*. Cambridge: The MIT Press, 2002.

McLeod, Carolyn. Carolyn McLeod, "For Dignity or Money: Feminists on the Commodification of Women's Reproductive Labour" in *The Oxford handbook of Bioethics*, ed. Bonnie Steinbock. Oxford: Oxford University Press, 2006, 258-281.

Mill, John Stuart. *Utilitarianism, On Liberty, Essay on Bentham*. Edited by Mary Warnock. New York: New American Library, 1962.

Purdy, Laura M. "What Can Progress in Reproductive Technology Mean for Women?" *Journal of Medicine and Philosophy* 21 no.5 (1996): 499-514.

*Reproductive Technologies: Analysis and Recommendations for Public Policy*. (The New York State Task Force on Life and the Law, 1998), 95-104

Sherwin, Susan. "Feminist Ethics and In Vitro Fertilization." *Canadian journal of Philosophy*, Supplementary Vol 13 (1987): 276-284

Sherwin, Susan. "A relational approach to autonomy in health care," in the *politics of women's health: Exploring agency and autonomy*, ed. Susan Sherwin. Philadelphia: Temple University Press, 1998, 19–47.

Tversky, Amos and Daniel Kahneman. "The Framing of Decisions and the Psychology of Choice." *Science New Series* 211 no.4481 (1981): 453-458.

Young, Iris Marion, *Justice and the Politics of Difference*. Princeton: Princeton University Press, 1990.

Zeiler, Kristen. "Reproductive autonomous choice—A cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis." *Medicine Health Care and Philosophy* 7 (2004): 175-183.