

EXPERIENCING A PGD CYCLE:
PREIMPLANTATION GENETIC DIAGNOSIS FROM THE PATIENT'S PERSPECTIVE
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ABSTRACT

EXPERIENCING A PGD CYCLE: PREIMPLANTATION GENETIC DIAGNOSIS FROM THE PATIENT'S PERSPECTIVE

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The application of Preimplantation Genetic Diagnosis (PGD) has seen a rapid expansion since its inception. Initially created to allow known carriers of genetic disorders to have children free of the known genetic diseases, PGD is now used to improve in vitro fertilization (IVF) outcomes for infertile couples. Also, PGD is used by fertile couples for the purposes of sex selection and family balancing. PGD is the procedure that determines the genetic makeup of embryos created through IVF. The information gleaned from PGD assists couples in determining which embryo/s to use as part of their IVF cycle.

This dissertation explores the experience of using PGD from the perspective of women/couples that used PGD to either combat infertility or have a child of a preferred gender. The women told their stories in their own words. In some cases, the woman's husband joined the conversation and talked about using PGD from his perspective. The reasons these two groups of women used PGD are very different, however their experiences are very similar. The treatment regimen for using PGD is the same for infertile and fertile women.

Drawing from the stories told by PGD users, I present a picture of what the participants consider to be most salient about their experience as well as the decisions they needed to make throughout their PGD cycle. PGD is considered a cycle because it is a process of treatments. Each stage of treatment cycle brings with it different trials and concerns. Decisions made in later stages of the treatment process are informed by the knowledge gained from and the experience of former

stages. The users of PGD do not always feel convinced about their decisions. They are often ambivalent and sometimes remorseful afterwards.

Their stories demonstrate their strong commitment to having their biological child. These women were willing to endure the physical and emotional pain associated with the treatment regimen of PGD because it is the only treatment that can give them the best chance of having a biological child. PGD is the latest, most advanced treatment in the hierarchical arsenal of medical treatment for infertility. Even the most advanced treatment does not come with a 100% guarantee.

I chose to use an ethnographic research method so I could get as close as possible to PGD. This included observing and working closely with a reproductive endocrinologist at a fertility clinic, observing surgical procedures, observing embryos being created and cryopreserved in a laboratory, and interviewing women/couples who used PGD. I allowed the participants to direct the analysis of their discourse. By doing so, the most salient aspects as well as the definitions assigned to those aspects by the participants became visible. I found that women/couples used PGD to get the child they desired, whether that was their biological child or a child of a specific gender. I also found that the destruction of the embryos was the most troubling aspect of PGD for the users. And thirdly I found that going through a PGD cycle is arduous both physically and emotionally regardless of the reason for using PGD.

This dissertation will contribute to the conversations regarding the use of the NRTs. The novel information PGD provides about an embryo along with the timing of this information makes using PGD different from using any other NRT. Women are now asked to make decisions about the fate of their embryo, which could ultimately become their child, while the embryo is outside of their body. Prior to this, women made decisions based on genetic information while pregnant. Now women's pregnancy experience is more closely related to men's experience.

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To Steven, Cole, and Alec for all their love and support.

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My two sons, Cole and Alec, have grown up watching me work at this degree. They have seen me work long into the night studying, but have also seen me bask in the joy of discovery. We have had many discussions about my research and findings. They know more about reproduction, PGD, and feminist causes than boys their age should probably know. But they have handled discussions on these topics with maturity beyond their age. I only hope my example of returning to school and pursuing my passion has fueled their interest in education rather than discouraged them.

This dissertation is about many things but most of all it is about women ardently pursuing the child they desire. They showed courage throughout a most challenging time in their lives. Their strength and perseverance inspired me to present their stories in a reverent and compassionate manner. I hope I have done their stories justice.

PREFACE

Natasha and Derrick had been married for only a year when they found out Natasha was pregnant. They were a young couple, happily married and eager to start their family. Their excitement about the pregnancy quickly changed to worry when a heart defect was detected during a routine ultrasound. An amniocentesis confirmed the birth defect. Natasha and Derrick were given the options to terminate the pregnancy or continue with the pregnancy and give birth to a child with a heart defect. They both felt it was “out of our hands” and proceeded with the pregnancy. After a full term pregnancy, their son was indeed born with a heart defect. He endured a strenuous surgery on his heart and subsequently died eleven days after his birth. Natasha and Derrick were devastated.

After a period of mourning, and considering this past experience “just a fluke,” they decided to “try again”. Natasha became pregnant but miscarried early on. They now knew that getting a family was not going to be easy. Natasha became pregnant again. This time she experienced spotting during the first trimester. Fearing that another miscarriage was imminent, and also being “just a bit numb” from their prior experiences, Natasha and Derrick decided to go on with their lives because they felt they were probably going to “lose another one.” They went to Cedar Point, an amusement park, and rode all the rollercoasters. Ironically, Natasha carried this pregnancy to term and delivered a healthy baby girl.

The birth of their daughter was followed by two more miscarriages. It was not until after the third miscarriage that her doctor finally ran tests to determine the cause. Natasha’s blood work came back with the diagnosis of a balanced translocation of chromosomes one and nine. Natasha’s balance translocation meant that a piece of Natasha’s chromosome 1 has traded places with a piece of chromosome 9. Natasha does not display any physical evidence of this because the switched

chromosome pieces are fully intact, leaving Natasha with a full set of chromosomes. The problem occurs in her gametes because these cells carry only half of Natasha's chromosomes. In the process of dividing, the gametes may end up with extra or missing chromosomes.

Natasha and Derrick were advised to see a fertility specialist if they wanted to have another biological child. They decided to disregard this advice since they already had one healthy child conceived the "natural" way. Their decision to proceed on their own resulted in another miscarriage. This miscarriage occurred at 11 weeks gestation, which was further along than any of Natasha's previous miscarriages. Their doctor told them that the miscarriages were a way of expelling genetically compromised children. Eventually, according to their doctor, Natasha's body would adapt and carrying a baby, which may be severely impaired, to term. At this point Natasha and Derrick decided to consult a fertility specialist.

After the death of their first child and four subsequent miscarriages, Natasha and Derrick found themselves at IVF Michigan to discuss options that would allow them to have a healthy biological child. According to Derrick the doctor said, "your case is a lot easier because we know what's wrong, versus someone who just doesn't know why they're having all these miscarriages. This we know how to fix." The "fix" the doctor was referring to is Preimplantation Genetic Diagnosis (PGD). This would be the first time Natasha and Derrick heard about PGD. As promised the "fix" worked. Natasha gave birth to a healthy girl as a result of a PGD cycle.

Emma became aware of PGD in quite a different manner from Natasha and Derrick. She and her husband had four daughters; the youngest two are twins. Before the twins were born, Emma's husband saw an advertisement for PGD while he was in Las Vegas. He came home and told Emma about this procedure with "100% guarantee sex selection." He wanted them to use this procedure to balance the genders in their family. Emma was a bit skeptical. After reading an

article about PGD and realizing that it is done in conjunction with in vitro fertilization (IVF), Emma was concerned about having multiples. There is a high incidence of having multiples with IVF. She knew that carrying multiples can medically complicate a pregnancy and she did not want to bring on anything that might result in problems. She had already had one miscarriage and wanted to avoid that experience again.

She convinced her husband to try for a boy the “natural” way. They conceived right away through coitus, which resulted in twin girls. Emma saw having twins as a sign from God that she did not have control over whether or not she would have a multiple pregnancy. Once her two girls were about a year and a half old, Emma and her husband went to the fertility specialist with the intent of using PGD. Their first attempt of getting pregnant with PGD resulted in a healthy baby boy. Currently, Emma is going through another PGD cycle to have another baby boy, however this time she would like the doctor to transfer two male embryos so that she could have twin boys. Emma and her husband would like at least eight children.

These two stories represent the diverse ways in which women come to PGD and reasons women use PGD. Their fertility histories inform their decision to use PGD. This dissertation explores the experience of women/couples who have met their fertility goals as a result of going through a PGD cycle.

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CHAPTER ONE

INTRODUCTION

Since its inception in 1990, the application of Preimplantation Genetic Diagnosis (PGD), the “designer baby” technique, has seen a rapid expansion. Initially created to allow known carriers of genetic disorders have children free of the known genetic diseases, PGD is now used to improve in vitro fertilization (IVF) outcomes for infertile couples. IVF practitioners saw the potential of PGD to improve the success rate of IVF for their patients who had multiple miscarriages and patients who were unable to get pregnant. PGD is the latest procedure in a physician’s arsenal to combat infertility. For the infertile woman/couple¹, PGD is the last rung on

¹ I use the terms women/couples to define the participants in this study for two reasons: 1) It is always the woman’s body that is the site of medically invasive procedures when using reproductive technologies, and 2) All the women I interviewed for this project were part of a heterosexual married couple. Some of the husbands were present for the interview. Christian Munthe made note of the distinction between referring to the patient as being the woman as opposed to the couple when using PGD. According to Munthe, “Many medical specialists in reproductive medicine would prefer to speak of their patient as being a “couple”, since the explanation of the heightened probability of having children with some disorder or disease may be found in either the man or the woman (or in some other factor). However, in PGD, it is not the couple that is being subjected to the various invasive procedures, but one specific person in the couple, namely the woman. For this reason, it seems to me more adequate to view the woman as the “primary” patient in PGD.” 30

the infertility hierarchical ladder of treatment. A PGD cycle² is the last hope for an infertile woman/couple of getting pregnant and having her/their biological child.

An unanticipated application that physicians discovered is the use of PGD by fertile women/couples that want to choose the sex of their child for either sex preferences or family balancing purposes. Fertile women/couples use PGD to transfer only embryos of their desired gender in hopes that a pregnancy will ensue and result in a healthy baby. Fertile women/couples may also choose to use PGD to create a donor sibling for an ill older child. Only embryos with an exact HLA-match³ to the older child will be transferred during the PGD cycle.

Using PGD for any purpose requires a woman to follow the same treatment regimen whether she is considered fertile or infertile. It is arduous, and both physically and emotionally painful, as well as expensive. A PGD cycle requires the woman to make a huge time commitment of a minimum of twice weekly doctor's visits, undergo two surgical procedures, and inject drugs daily, with side effects still unknown. It also requires its users to make decisions, some of which can be morally challenging. Even with a total commitment and following the treatment regimen precisely, PGD does not come with a 100% guarantee of a successful outcome. The degree of success varies according to the woman's age and fertility diagnosis. A woman could subject herself to the treatment regimen and end with no child in hand. Given the multiple hurdles associated with a PGD cycle, why would a woman choose to use PGD and subject herself to this treatment regimen? This dissertation is an attempt to answer that question.

2 A PGD cycle refers to an IVF cycle with PGD. PGD always occurs in conjunction with IVF however, an IVF cycle can occur without PGD.

3 Refer to Appendix A for complete listing of terminology and definitions.

The thrust of this study is to uncover the reasons a woman/couple would use PGD as well as to understand the experience of going through the treatment regimen. In order to do this, I became familiar with fertility treatment regimens by becoming a participant observer at a fertility clinic. While there, I sat in on physician led examinations, consultations, and surgeries. I paid particular attention to the terminology used to discuss treatment and diagnoses as well as the manner in which the women/couples discussed their concerns, fertility histories, and fertility goals. After spending time at the fertility clinic, I interviewed women/couples who successfully had their biological child as a result of using PGD. All the participants, except one, had a child or children born as a result of using PGD. The one participant used PGD but was unsuccessful. She had later given birth and at the time I interviewed her was pregnant with twins through the use of donor eggs. She asked if she could still participate in the research project. I felt her input regarding the process of using PGD was quite informative.

Background Information

In 1990, Alan Handyside, in collaboration with Robert Winston, successfully applied PGD to a human embryo. Handyside and Winston were following in the footsteps of Robert Edwards and Patrick Steptoe, who had been successfully performing PGD on laboratory mice. Handyside and Winston were working at the Hammersmith Hospital in London and applied PGD to an IVF cycle to allow their patients that were known carriers of genetic disorders have children free of the known genetic disease.⁴ Over the past 20 years, physicians have recognized the benefit of PGD in treating infertility. PGD is now used to treat infertility in women of advanced maternal age and women who have a history of miscarriages. PGD genetically tests an

4 Sarah Franklin, and Celia Roberts. *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis* (Princeton: Princeton University Press, 2006), 52.

embryo created during IVF to determine the genetic health, which in turn determines which embryo/s will be transferred to the woman's uterus. Transferring only healthy embryo increases the potential for IVF to result in a live birth. Physicians also use PGD to create a "donor" sibling for parents who have an ill child in need of a tissue donation. Only embryos that are an exact HLA-type match will be transferred to the mother to produce an optimal donor for her older child. According to Yuri Verlinsky and Anver Kuliev, pioneers in the development of PGD, there are many uses and benefits of PGD,

PGD offers special attractions not possible with traditional prenatal diagnosis. One is to avoid clinical pregnancy termination. This is especially attractive for couples carrying translocations, couples at risk for producing offspring with common disease of autosomal dominant or recessive etiology, and, finally, for couples wishing to have not only an unaffected child, but an HLA-compatible cord blood donor for treatment of an older sibling with a congenital disorder.⁵

The expanded use of PGD has created an increase in births. According to Verlinsky and Kuliev, from 1990 through 2005 PGD had been performed over 7000 times in 50 centers around the world. As a result more than 2000 children were born from PGD that would not otherwise have been born.⁶

PGD is the term used to define a very complex process involving the removal of one or two cells from a six to ten cell embryo. Predetermined genetic tests are performed on the removed cells to determine the genetic status of the embryo. Once the results are obtained, only those embryos that match the desired criteria are transferred to the woman's uterus in hopes of implantation. Depending on the woman's age and health, either 1 to 3 embryos will be

5 Yury Verlinsky, and Anver Kuliev. *Practical Preimplantation Genetic Diagnosis*. (London: Springer-Verlag, 2005), 8.

6 Ibid., 7.

transferred.⁷ The unused healthy embryos will either be frozen, discarded, donated to another woman for use, or donated to research. The fate of the frozen embryos will have to be determined at a later date. Unhealthy embryos are discarded immediately.

PGD provides information about the embryo that had not been known previously. The genetic makeup of the embryo, which includes gender, had not been known prior to PGD. Prior to PGD, the criterion for choosing an embryo to transfer to the woman's uterus during an IVF cycle was based on a visual analysis of the morphology. Some embryos could "look" healthy but turn out to be unhealthy and not viable. Knowing the genetic makeup complicates the decision of choosing the transferred embryo for some women/couples because they may be required to choose based on conflicting information. For instance they may have to choose one gender over another if there are equally viable embryos with the only difference being gender.

The determination of the fate of the embryo/s is often made in a short amount of time. Three very important decisions are made while the woman is lying on the surgical table, prepared for the embryo transfer. The woman/couple must decide which embryos to transfer, how many to transfer (1, 2 or 3), and what to do with the remaining embryos. They can consult with their physician, however it is the responsibility of the woman/couple to make the final decision. The magnitude of these decisions is not always recognized when embarking on PGD. It is only afterwards and reflecting upon the process that the significance of these last three decisions is realized.

⁷ Refer to guideline at American Society for Reproductive Medicine, "Assisted Reproductive Technologies: A Guide for Patients." *A.R.T. Guide for Patients*, 2008, 13.
<http://www.reproductivegenetics.com/ivf.html> accessed 2/2/2011. See further discussion of guidelines in chapters four and seven.

The concept of choosing embryos is the practice that generated the idiom “designer baby” used to refer to PGD. The “designer baby” idiom represents larger claims on the application of PGD than is currently realized. “Designer baby” implies that perspective parents can pick and choose human characteristics for their offspring. This implication is far from the motivations of the women/couples that used PGD. As we will see later in this dissertation, the women/couples of this study dissociated themselves from what is signified by “designer baby”. Through their justification for using PGD, they use the “designer baby” idiom as a marker to distance themselves from a trivialized use of PGD to one they claim as altruistic.

Conceptual Underpinnings

My research comes from a cultural studies and feminist bioethics perspective. The questions I asked the women/couples of my study were guided by my interests in cultural influences and interpretations of fertility treatment along with discerning the ethical issues inherent in the process of PGD. The works of Valerie Hartouni, Rayna Rapp, Donna Haraway, and Rosemarie Tong are the primary sources that inform my analysis. I used Hartouni’s work to guide me in paying particular attention to the “rescripting” the women/couples did to make their experience more palatable to themselves. Her work also guided me in noting the contributions the women’s/couples’ discourse provide to the overall “rescripting” of PGD to make the procedure more acceptable within our culture. Hartouni used the concept of “rescripting” to demonstrate how social forces work to reshape the discourse about a particular issue. As values start to change and shift, the discourse of a particular idea shifts and changes to meet the needs of society. To explain her use of “rescripting”, Hartouni uses the example of the manner in which discourse about IVF went from discussions of creating abhorrent babies to narratives that proclaim the benefits of IVF as being able to help nature along and create families where

previously there where none.⁸ The “rescripting” process that took IVF from a repulsive technology to an acceptable medical treatment lasted about 25 years.

The initial discussions about IVF were full of warnings to halt its use. According to Hartouni,

In the late 1960s and early 1970s, for example, when the first tentative steps were taken in the direction of in vitro fertilization, researchers feared and skeptics warned that unrecognizably human creatures would result from scientific interventions in life-producing processes. Theologian Paul Ramsey bitterly welcomed the birth of such monsters, suggesting that only with their birth would such interventions be halted and “authentic humanity” delivered from the threat of immanent erosion and loss.⁹

The “monsters” were never realized as a result of IVF. Only children, whose appearances were no different from babies conceived through coitus, were the result of IVF.

After years of assimilating IVF into the structure of “natural” pregnancies, this technique has become acceptable. Hartouni makes this point by saying, “As in the telling of most genealogical tales, then, where the monstrous was once spied roaming, mothers, fathers, and families now comfortably reside. Notwithstanding the often destabilizing effects of new reproductive practices, these new practices have been domesticated over the course of the past twenty-five years”.¹⁰ The discourse that dealt with the concerns that the babies born from IVF would resemble something abhorrent no longer exists. In its place are stories of families with happy, healthy babies created through the use of IVF.

8 Valerie Hartouni, *Cultural Conceptions: On Reproduction Technologies and the Remaking of Life*. (Minneapolis: University of Minnesota Press, 1997), 115.

9 Ibid., 113.

10 Ibid., 116.

The women/couples of my study invoked the practice of “rescripting” throughout their PGD cycle. They were quick to rescript their discourse throughout the telling of their experience. They blended the knowledge they gained with each successive PGD cycle along with their understanding of their current situation to refine and edit their discourse defining their experience. Initially, all the women/couples wanted to conceive on their own, they abhorred the thought of using NRTs for conceiving their child. But when they were unable to conceive on their own they “suboptimized”¹¹ and turned to the NRTs for assistance. They slowly came to rescript their discourse about the NRTs as something that assisted them in reaching their goal and they were grateful for the assistance.

Hartouni’s work also sheds light on understanding the manner in which users of PGD “see” their experience. Hartouni leans on the Donna Haraway’s work when she discusses the mediation of making sense of a situation. According to Hartouni,

[W]ays of seeing —of decoding, deciphering, classifying, translating, and interpreting— are not something with which we are simply born, but constitute and are constituted by particular ways of life. They contain and are themselves contained by particular ways of organizing a world (and humans within it) that otherwise seems self-evidently what it is and objectively knowable as such.¹²

The meaning one assigns to one’s situation is based on her/his perspective that has developed over time from her/his past experiences. The women’s/couples’ discourses about their PGD

11 Suboptimized is a term often used in the organization of business. Griffin and Moorhead define suboptimizing as knowingly accepting less than the best possible outcome. Ricky W Griffin, and Gregory Moorhead. *Organizational Behavior: Managing People and Organizations*. (Mason, Ohio: South-Western, Cengage Learning, 2010), 201.

12 Hartouni, *Cultural Conceptions*, 14.

experience will shed light on what they “see” as most salient about their experiences as well as what was made visible to them throughout the process.

I have modeled much of my research after Rayna Rapp’s work. Her research, which looked at the experience of women that used amniocentesis as a means of testing fetuses for genetic diseases, informed my interviews with the women/couples who used PGD. Rapp argues that the discourse of the women who use amniocentesis to test their fetus for genetic diseases is somewhere between the discourse of the feminist scholars and scientists. According to Rapp, “the discourses of both feminism and bioscience are fraught with polarized reductions in which scientists are too frequently represented as either heroes or villains, and women are represented as their victims or resisters.”¹³ The women who used amniocentesis “were both grateful and critical of the technology” and knew their problems could not be simplified and defined by scholarly discourse. Their experience and interpretation of their situation, as well as their decisions were based on their past experiences. Their past experiences situated their knowledge about their current situation and guided them in their decisions making. Like Hartouni, Rapp used Haraway’s definition of situated knowledge to define the acquisition of knowledge obtained by her subjects. Like the women of Rapp’s study, the women/couples of my study found their own interpretations about their situation which came from a compilation of the information they received from their doctor and other sources such as the Internet, and their understanding of their fertility history.

Rapp’s work also prepared me for being particularly mindful of the personal nature of information I was gathering from my subjects. The topic she discussed with her subjects is a

13 Rayna Rapp, *Testing Women, Testing the Fetus: the Social Impact of Amniocentesis in America*. (New York: Routledge, 2000), 49.

precursor to the decisions the women/couples in my research needed to make. The women in Rapp's study needed to decide to use or reject amniocentesis then have or reject an abortion for an affected fetus. PGD was created to eliminate the decisions made by the women in Rapp's study. By eliminating one kind of decision others were created. The women/couples of my study also had to accept the use of an NRT as well as decide to accept or discard an embryo. Some equate discarding an embryo to aborting a fetus.

Rapp investigated the influences and means in which the women of her study made the decisions to have or reject an amniocentesis, then abort or keep a fetus that had been diagnosed with a genetic disease. She called the women in her study "moral pioneers" because, according to Rapp, they were "Situated on a research frontier of the expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own fetuses, making concrete and embodied decisions about the standards for entry into the human community."¹⁴ The users of PGD must make decisions about which embryo is suitable to enter "into the human community" also. The users of PGD could also be considered "moral pioneers".

The women/couples of my study experienced the medical system in a similar manner as the women of Rapp's study. Rapp explained that the women in her study became part of the system that used highly specific vocabulary that was not easily discerned. The medical professionals defined these women's situation in their terms based on what they considered to be important but that was not always what the women considered to be important. According to Rapp, "It was not always easy for them [the women of her study] to frame alternative descriptions with which to more accurately represent the impact of amniocentesis in their own

14 Ibid., 3.

lives.”¹⁵ I found the women/couples of my study vacillated between framing their experience from a medical perspective based on what they learned from their physician and the results of their tests, and framing their experience from a perspective of what it meant to their lives. The women/couples were getting information about their situation from many different places. Sometimes, the information from the various places did not mesh.

Both Hartouni and Rapp used Haraway’s concept of situated knowledge to define the manner in which the women of their studies understood their situation and acquired their knowledge. Haraway defines situated knowledge as knowledge acquired through embodied experiences.¹⁶ Situated knowledge is partial and comes from a particular position. The partiality, according to Haraway, is not isolating but offers connections to others who come at the information with similar goals.¹⁷ Like Hartouni and Rapp, I also used Haraway’s concept of situated knowledge to explain the understanding the women/couples have of their experience using PGD and the similarities in their experience. Their fertility history, and understanding of their role as a patient, plays key roles in their experience and the telling of their stories.

While designing my research project and interviewing the women/couples, I leaned on Rosemarie Tong’s work in feminist bioethics to discern the origin of ethical influences. Tong argues that traditional means of judging moral dilemmas and decisions do not always account for feminine values and women’s moral development. According to Tong, “people who adopt a feminine approach to ethics are generally interested in exploring the ethical implications of

15 Ibid., 5.

16 Donna J. Haraway, “Situated Knowledge: The Science Question in Feminism and the Privilege of Partial Perspective.” *Feminist Studies*, Vol. 14, No. 3 (Autumn, 1988), 589.

<http://www.jstor.org/stable/3178066> accessed 11/20/2010.

17 Ibid., 589.

allegedly feminine concepts such as care and connectedness contrasting them with the ethical implications of allegedly masculine concepts such as justice and autonomy.”¹⁸ By using the word “approach” in her definition, Tong conveys that there are multiple feminine perspectives and approaches to ethics and not just one feminine consciousness.

Tong’s use of feminist approaches to bioethics provided me with a means of understanding the way the women/couples came to their moral decisions. According to Tong, “feminist approaches to bioethics provide an epistemology of perspective, of positionality, as opposed to an epistemology of certitude, of Archimedean point. I know who I am. And what I see is a function of who I am...”¹⁹ The women/couples of my study were required to make ethical decisions regarding their embryos. Tong’s work provided a means for me to listen as the women/couples were telling their story about the decisions they made regarding their embryos, and connect their decisions to all the experiences they had had regarding their fertility treatment up to that point. Their decisions regarding their embryos were not made in isolation. The decisions reflected their understanding of their situation as well as their morals. This connected nicely to Hartouni, Rapp and Haraway’s work of knowledge coming from an embodied experience and a positioned perspective.

Listening to the stories the women/couples told, reminded me of Tong’s description of the purpose of conscious raising groups. Tong uses legal theorist Catherine A. MacKinnon to define conscious raising as “the major technique of analysis, structure of organization, method of

18 Rosemarie Tong, *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications*. (Boulder: Westview Press, 1997), 10.

19 Ibid., 244.

practice, and theory of social change of the women's movement."²⁰ Tong goes onto explain the benefits of conscious raising. According to Tong, "Consciousness raising enables individual women to realize not only how gender oppression affects them negatively but also how their experiences of personal hurt are related to other women's."²¹ She adds, "Hearing other women express their own concerns about an issue provides the crucial 'I'm-not-alone-in-feeling-this-way' realization for many women."²² Although the women of my study were not together when they told their stories, I felt that just by being allowed to tell their stories there was a "conscious raising" of sorts about their collective experience. One most profound statement consistently made by the women of this study was that they were willing to participate and tell their story if it could possibly help other women who would use PGD in the future. There was a palpable kinship with other women who experience fertility treatment, and my participants wanted to reach out to these women through my research. There are similarities in their stories that reminded me that they "were-not-alone-in-feeling-this-way".

There are other works by scholars that have researched the use of NRTs that have influenced my work. I gained insight from Sarah Franklin and Cecil Roberts' research. Currently, their work is the only published ethnographic research on the use of PGD. They focused on the use of PGD by couples that live in the United Kingdom that are known carriers of genetic disorders. At the time of their research, PGD was not used to assist infertile couples in the UK.

I designed my research using an ethnographic method of data gathering so I could learn what was most salient about using PGD from the patients' perspective. I became a participant

20 Ibid., 91.

21 Ibid., 92.

22 Ibid., 92.

observer at a fertility clinic then interviewed users of PGD. Using an ethnographic research method, as opposed to a historical or quantitative research approach, brought me as close to PGD as I could get without actually being a user. Rapp explains the benefit of becoming a participant observer when she says, “That professional umbrella is a catchall label for hands-on research that is open-ended, and locates the researcher as far into the experience of the people whose lives are touched by the topic as she can figure out how to go.”²³ An ethnographic approach allowed me to hear the stories of users of PGD directly and adjust my questions according to what I learned. Like Rapp, who “set out with one set of research questions, and was forced to enlarge and transform them as people educated me on the complexity of the issues as they perceived them,”²⁴ I continued to learn about PGD as I worked in the clinic and with each interview.

The sample size of this research project is small. I believe the sample size is a reflection of the relative newness of the technology and people’s discomfort with talking about something so personal. Therefore, like Elizabeth Bott’s study on family and social networking, the contributions of this study are in the interpretations and the new questions that have arisen from this study.²⁵ Bott’s made it clear that because her sample size was so small, she and her team were not claiming to “make a contribution in the form of a systematic survey of the facts of English family life, for it is clear that the twenty research families cannot be treated as a representative sample of a wide population of families.”²⁶ This small sample of PGD users cannot speak for all PGD users, but the interpretation of their discourses can reveal common

23 Rapp, *Testing Women*, 2.

24 Ibid., 2.

25 Elizabeth Bott, *Family and Social Network: Roles, Norms, and external Relationships in Ordinary Urban Families* (London: Tavistock Publications Limited, 1957), 2.

26 Ibid. 2.

practices and develop further inquiry into a larger sample. The knowledge gained from this research project about the experience of these particular women/couples is an end in itself. I am not attempting to overstate these findings and project these experiences onto other users of PGD. But from these findings, I hope more questions will come about and interest in understanding the experience of using PGD will be expanded.

Statement of Purpose

This research project is an exploration of the experience of using PGD from the patient's perspective. The purpose is to uncover what the users of PGD consider to be the most salient aspects of their experience. The participants of this project have all gone through at least one PGD cycle. Participants were successful in using PGD to either rectify their infertility or have a child of a chosen gender for the purpose of sex selection/family balancing. While there is another ethnographic study on the experience of using PGD for its initial purpose, to avoid passing on a known genetic disease, I chose my participants because their experience has not been studied. The applications of PGD used by my subjects are relatively new compared to its initial use. Also, I chose people who were successful with their use of PGD, meaning had a health baby, because the subject matter is very personal and potentially painful, and I thought it might be difficult for people that were not successful to relive their experience.

My dissertation is an exploratory research project. I allowed the exploration of this topic to be led by the women/couples interpretation of their experience. I did not want to impose theory on their view however; the lack of analysis of their discourse would render this data worthless. Therefore, my interpretive analysis of their discourse was done by piecemealing theoretical work.

Limitations and Assumptions

One of the first limitations I ran up against in doing this project was the number of subjects available to interview. I was given a total of 36 women who were interested in talking to me about my research project. Of the 36, thirteen women agreed to meet with me. All the women are part of a heterosexual married couple. Eight husbands participated in the interviews. All husbands were invited, however because of scheduling, some of the husbands could not be present. Three women did not want to participate in this research because they said they did not want to talk about their fertility issues. The other women did not participate because they did not want to commit the time to an interview. All the women were busy with either newborn babies or toddlers. I believe the relative small sample size is reflective of the number of people who are taking advantage of this technology.

Another limitation I experienced was gaining access to women that used PGD. The laws involving privacy issues dictate what information I had access to regarding patients. I did not want to be in violation of the Health Insurance Portability and Accountability Act or my Internal Review Board approval, therefore I did not read any of the medical charts of my subjects. By not reading their charts, I came to understand their medical diagnosis from their point of view. The benefit of this was that I had no preconceived ideas about their situation prior to our meeting. The downfall was that I did not know why they used PGD until I met them.

When reading the findings in the following chapters, you can assume that the participant was fully engaged in participating and volunteered to participate. Each participant was given a consent form²⁷ to sign that explained the purpose of this research project and their rights as a participant. An important right was that they could discontinue the interview at anytime without penalty. In addition, their participation in this research project had no bearing on their treatment

27 Refer to Appendix B for a copy of the consent form.

at the fertility clinic. Every participant eagerly told their story and went well pass the hour originally scheduled for the interview.

Summary of Chapters

In this chapter, I have described the DNA of this research project. I have explained a little of the background of PGD with the understanding that more details will be provided in chapter four. I have also described the scholarly works that influenced my research and the purpose of this project. I will conclude with a description of each of the following chapters.

In Chapter two, I provide an overview of the current literature available on the topic of the NRTs. Many scholars have researched the topic of the NRTs from a cultural and feminist framework. I present the main subject areas discussed in the literature such as the social mediation of reproductive choices, the development of the personification of the fetus and its impact on pregnancies, definitions of motherhood, the significance of genes, the acquisition of knowledge, the impact of class and race on reproduction, and reproduction choices. After summarizing the current research on these topics, I position my research into these discussions.

I explain my methodology and describe my experience as a participant observer in Chapter 3. My goal for chapter 3 is to demonstrate the depth and uniqueness of my experience as it contributes to the method of data collection and analysis. I worked at a fertility clinic where the staff was very generous with their time and willing to teach me about the procedures involved with PGD. The physician I shadowed allowed me access to surgeries and procedures that are not typically accessed by outsiders. The experience at the fertility clinic fully prepared me for the interviews I did with the women/couples who participated in my study. By observing patients in the office, I not only became acquainted with the terminology they used, but I also came to understand the depth of emotion that permeates the patients' discourse. This experience

reminded me to be mindful and respectful of the personal nature of information I was asking the women/couples to share with me.

In chapter four I define PGD by explaining the genesis of the technique and its original purpose. I follow that by the progression that lead PGD to other uses. It is the “new” uses of PGD that ignite most of the controversy, however there is controversy regarding the inherent procedures of PGD. These controversies will be revealed along with the discussions that inform and result from these controversies.

In chapters five through seven, I will follow the trajectory of PGD as women/couples encounter the process. In chapter five I examine the initiation into PGD and the position PGD holds in the hierarchy of fertility treatment. Most of the women/ couples that use PGD to combat infertility arrive at their first consultation appointment unaware of the existence of PGD. They learn about PGD through the process of their examination and at the suggestion of their physician based on the results of their tests. Once exposed to PGD, women/couples begin to define the process based on its application to their situation. Not only are they hoping PGD will be the panacea that will eliminate their infertility, but also they hope it will determine the reason for their infertility.

Fertile women/couples come into their initial doctor’s appointment knowing they want to use PGD. Their initial engagement with the PGD treatment regimen is similar to infertile women/couples. It is during the initial phase of fertility treatment using PGD that the women/couples begin to understand the commitment required of them as well as the decisions they will have to make throughout the cycle. Initially, PGD is only recognized as the “quick fix”, it is not until later in the process women/couples realize there is no such thing as a quick fix.

Chapter six covers the time period after the egg retrieval until the embryo transfer. During this time, the PGD cycle is carried out away from the woman's body. This is an important time in the process because the embryo is biopsied and the information from this biopsy will determine whether there is an embryo healthy enough to transfer. A pregnancy is contingent upon the results of this information and the process will not continue if the embryos do not pass the genetic tests. Women/couples pay close attention to numbers and statistics during this time. The number of embryos created as well as the number of healthy embryos is important to them. It is an emotionally challenging time in the PGD cycle. Women look to their husbands for support, as well as God, to get them through. Women/couples also rely on their doctor to guide them through the treatment process.

In chapter seven, I focus on the time after the embryo transfer, which for these women resulted in a pregnancy, through the birth of their child. I focus on how using PGD informs and shapes the experience of pregnancy for these women. After these women reach their 12th week of gestation, their fertility specialist no longer follows their pregnancy. At that time, they are referred back to their obstetrician (OB) and it is up to the woman/couple to decide whether they will tell their OB about the conception. Once in the hands of their OB, they are launched onto the routine medicalized maternity trajectory. They are asked to make decisions regarding which medical tests they are willing to have. Their decisions are based on their understanding of the values of using PGD as well as their conception history.

I also present the reflections of the women/couples have regarding their experience and thoughts about PGD. They felt compelled to justify their use of PGD however their justifications were informed by their reason for using PGD and their moral values. The status they placed on their embryos was also a topic they felt needed explanation. Many women/couples brought God

into their discussion about their use of PGD but none relied on their religious affiliation to rationalize their use. Many women/couples dissociated themselves from Nadya Suleman²⁸, Octomom, through their justification. Suleman's case was prevalent on their minds because she had gone through treatment about the same time as these couples. Although Suleman did not use PGD, she did use IVF as these couples had. What becomes evident in the discourse of the women/couples in this chapter is that their proximity to PGD creates a deep respect for the technology as well as an obligation to protect the integrity of the representation of the technology.

In chapter eight, I present a summary of the findings of my research and answer the questions I presented in the introduction. I also present the findings about the use of PGD that became evident through this research. The evidence demonstrated that there are three prominent findings. These findings along with other findings will contribute to the literature regarding the cultural and social aspects of the NRTs as well as the impact of biomedical literacy on engaging in biomedicine. I finish this chapter by discussing future research projects involving PGD. PGD is still in its infancy and aspects of the procedure are yet to be understood. There are ample directions in which to approach a research project using PGD as the platform.

28 Nadya Suleman had eight children from one pregnancy as a result of six embryos being transferred during her IVF cycle. Two of her embryos split to result in twins. More details about Suleman and the relationship between her case and the women of this study are discussed in chapter seven.

CHAPTER TWO

THE LITERATURE REVIEW

As the New Reproductive Technologies (NRTs) came into use, scholars focused on researching the impact these technologies had on women's lives. Some of the scholars researching the NRTs include: Valerie Hartouni, Rayna Rapp, Faye Ginsburg, Sarah Franklin, Celia Roberts, Charis Thompson, Laura Mamo, Barbara Rothman, Rosalind Petchesky, Rosemarie Tong, Susan Sherwin, Donna Haraway, Ruth Schwartz Cowan, Gena Corea, and Kaja Finkler. They found that NRTs were changing the way women became pregnant, experienced pregnancy, and had babies. These experiences also changed the words and manner in which women discussed their reproduction experiences. No longer were women viewed as the expert overseer of their pregnancy. Technology monitored and determined the status of pregnancies, as well as changed the status of the fetus from a speculative entity to the other patient in a pregnancy. As more and more technological intervention became routinely used to achieve and monitor pregnancies, it became imperative for women to gather information about the medical procedures available to them. Many advances in biomedicine, such as reliance of genetic information, offered women choices regarding their reproduction intervention. At times these choices were only perceived choices. Women often feel coerced into making a decision. And although some women have the ability to use NRTs, others do not have access. The NRTs are highly stratified biomedical procedures. Preimplantation Genetic Diagnosis (PGD) is one of the latest NRTs to be developed.

Social Mediation

The discourse regarding the NRTs often shifts based on the latest developments and cultural interpretations (Hartouni, Cowan, Rapp, and Franklin and Roberts). Valerie Hartouni presents many incidents where the discourse regarding new technology changes and leads to the technology becoming more acceptable. Even when, as Hartouni says, the technology may have been seen to initially create “monsters”, those very “monsters” can later be seen to stabilize the use of a technology. The stabilization occurs because of the way society “sees” the technology. Society does not just visually see something according to Hartouni; their visual definition is worked out materially and socially. In her research, Hartouni presents several examples of conflicts regarding reproductive technologies being reworked through “rhetorical strategies”.²⁹ Boundaries are moved and crossed through the use of discourse about the NRTs. Rapp concurs with Hartouni when she says, “Indeed, recent developments in science studies remind us that biomedical technology is itself a highly contested cultural object, porous in its diverse social constructions, uses, and exclusions”.³⁰ The works by these scholars demonstrate the manner in which society assimilates a new technology. Where once a technology may seem abhorrent, society can rework the discourse about the technology to make it acceptable.

The biotechnology and medical systems, of which the NRTs are part, conspire to have people buy into their ideology and consider important what they deem important. The manner in which these two systems word information as well as the information presented directly impacts people’s perception and understanding of their world. How someone “sees” a situation is based on his or her material conditions and life experiences. According to Hartouni, “ways of seeing – of decoding, deciphering, classifying, translating, and interpreting—are not something with which we are simply born, but constitute and are constituted by particular ways of life. They contain

29 Hartouni, *Cultural Conceptions*, 118.

30 Rapp, *Testing Women*, 5.

and are themselves contained by particular ways of organizing a world (and humans within it) that otherwise seems self-evidently what it is and objectively knowable as such.”³¹ Decision-making is influenced by the way one “sees” her or his world.

The choices women make regarding their reproduction options are socially mediated. According to Rothman, “The question is not whether choices are constructed, but how they are constructed.” To be sure, their decisions are made on an individual basis, however their decisions are influenced by cultural ideologies. According to Petchesky, “the very nature of reproduction – is social and individual at the same time; it operates ‘at the core of social life’ as well as within and upon women’s individual bodies.”³² Cowan concurs with Petchesky when she says; “Every reproductive decision, every reproductive event, is as much social as it is personal”.³³ As women become part of the biomedical system, their procreative stories are ascribed by this system. The social embeddedness of procreation has been well researched (Petchesky, Hartouni, Mamo, and Rapp) and shown to influence women’s decisions regarding procreation and motherhood. Women’s reproductive decisions reflect the cultural values of the time. According to Mamo, “As cultural contexts change over time, individual decision-making may therefore reflect generational experiences”.³⁴ Currently, it is the biomedical model that offers infertile women the best chance of having a biological child. And according to Finkler, “Like all other knowledge systems, biomedicine is a socially and culturally constructed curing enterprise, reflecting the

31 Hartouni, *Cultural Conceptions*, 14.

32 Rosalind Pollack Petchesky, *Abortion and Woman’s Choice: The State, Sexuality, and Reproductive Freedom*. (Boston: Northeastern University Press, 1990), 2.

33 Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening*. (Cambridge, Mass.: Harvard University Press, 2008), 5.

34 Laura Mamo, *Queering Reproduction: Achieving Pregnancy in the Age of Technoscience*. (Durham, Duke University Press, 2007), 62.

themes of the society and culture of which it forms a part while concurrently imposing these themes on cultural conceptualizations”.³⁵ NRTs are not only creating new forms of conceiving but are reflecting cultural values.

Personifying the Fetus

Biomedicine encourages regulation and monitoring of pregnancies. The tools of biomedicine such as sonograms, prenatal testing, as well as genetic testing have, according to Hartouni, “recast the uterus as public space, embryos as public entities, and pregnancy as a state of endangered captivity, refigured the state’s interest in prenatal life, and rehabilitated notions of ‘natural motherhood’”.³⁶ Hartouni argues that the tools of biomedicine, such as the ultrasound, changed the way a pregnancy was “seen”. No longer was the pregnancy about the woman, nor was the woman the most important informant about the pregnancy. Suddenly, the pregnant woman was rendered silent and the fetus became an important entity. The status of the pregnancy is no longer determined based on the woman’s input, but is determined by the results of tests performed by medical personnel using the latest technology. The ultrasound is one such technology that directly gazes onto the fetus. The ultrasound not only made the fetus visible but it also personified the fetus.

Discussions regarding the transformation of the fetus from an unseen, secondary entity of a pregnancy to becoming personified through the use of technology is well documented in several scholars’ work (Hartouni, Rothman, Petchesky, Rapp, Thompson). Rothman discusses the transformation by describing the way a pregnancy was monitored in the 1970’s “was to

35 Kaja Finkler, *Experiencing the New Genetics: Family and Kinship on the Medical Frontier*. (Philadelphia: University of Pennsylvania Press, 2000), 11.

36 Hartouni, *Cultural Conceptions*, 18.

watch the laboring woman”.³⁷ Then as technology became available to monitor the fetus, the woman and the fetus began to be seen as two separate patients.³⁸ Using the technology to monitor fetal development and the status of the pregnancy undermined the input from the woman. It took away the authority of the woman as the one who knows her pregnancy.

Ultrasounds also changed the way pregnancies were viewed. The once “opaque” womb now became transparent for the world to see.³⁹ According to Hartouni, this technology rendered the fetus visible and made the womb public domain. She says, “The fetus is clearly personified, perceived, presented, and produced as a person who has simply been awaiting discovery or awaiting the development of the right optical instruments for its true nature to be fully revealed and apprehended”.⁴⁰ Ultrasounds personified fetuses and allowed the pregnant woman to see the form that represented her child. This in turn contributed to the maternal bond that later developed into a parent-child bond. Hartouni found that bioethicist Joseph Fletcher and physician Mark Evans claimed that ultrasounds were “more likely to lead women ‘to resolve ‘ambivalent’ pregnancies in favor of the fetus’.”⁴¹ This implies that ultrasounds reduced the number of terminated pregnancies.

The process of personifying the fetus was not only due to “seeing” the fetus but also through the use of language used to describe the image produced by ultrasounds. The same terms used to describe children were used to describe the fetus. According to Hartouni, “Dr. Frederic

37 Barbara Katz Rothman, *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. (New York: Viking Penguin, Inc., 1986), 27.

38 Ibid, 28.

39 Hartouni, *Cultural Conceptions*, 24.

40 Ibid, 24.

41 Ibid, 36.

Frigoletto, a pioneer on the frontier of fetal therapy, describes it, observing the fetus in utero is ‘almost like going to a nursery school to watch the behavior of 3-year-olds’.⁴² Rapp concurs with Hartouni as she describes the personification of the fetus, as ultrasound and amniocentesis became part of the routine of being pregnant. “Among medical peers, they describe sonograms in the neutral language of science, but when speaking to pregnant woman, sonographers attribute motives to fetal activity and presence. A fetus that is hard to visualize is ‘hiding’ or ‘shy’; an active fetus is described as ‘swimming,’ ‘playing,’ or even ‘partying’”.⁴³ Using a language, which attributes human activities to the fetus, contributes to the practice of privileging the fetus. The ability to “see” the fetus along with the terminology used by professionals to describe the in utero behavior of the fetus contributed to the personification of the fetus.

Defining Motherhood

The cultural meanings of pregnancy and motherhood shape the discourse of the women who use NRTs. Defining motherhood is an important aspect when discussing NRTs. Fertility treatment is carried out on the woman’s body in an attempt to make her pregnant. Some would point out that pregnancy is the beginning point that marks motherhood. But is motherhood something that women are or is it something that women do? And if it is something that is done, does it have to be gender based? These are the types of questions that have been researched regarding the definition of motherhood. Hartouni looks at the way motherhood is perceived and how different accounts of motherhood give meaning and value to discussions. To make her point, she uses a headline that tells a story about a comatosed mother giving birth. The headline

42 Ibid, 37.

43 Rapp, *Testing Women*, 121.

reads “Brain-Dead Mother Has Her Baby”.⁴⁴ Hartouni argues that the headline only becomes intelligible if the reader relies on the definition of motherhood that says it is what women are. Hartouni points out that the definition of motherhood that says it is a “historically specific set of social practices, an activity that is socially and politically constructed and conditioned by relations of power, and that differs according to class, race, history, and culture” is “not culturally pervasive”⁴⁵ and therefore renders the headline meaningless. She goes on to say, “so deeply entrenched is the assumption that motherhood is a (natural) condition, a state of bodily being rather than deliberate activity”.⁴⁶ It is this assumption of motherhood that contributes to the “desperate” desire of women who are experiencing infertility to get pregnant. For them, motherhood begins with pregnancy.

Contributing to this “deeply entrenched assumption about motherhood”⁴⁷ is the strong pronatalism ideology prevalent in our society (Corea, Farquhar, Berg, Mamo, Petchesky, and Throsby). Mamo points out, “Pronatalist ideology perpetuates the belief that biological motherhood is the most valued path toward parenthood for women and that, therefore, a women’s social worth is inextricably linked to her ability to achieve biological motherhood”.⁴⁸ According to Corea, “Century after century, the message seeped deeply into woman: If she cannot produce children, she is not a real woman, for producing children is the function that

44 Hartouni, *Cultural Conceptions*, 29.

45 Hartouni, *Cultural Conceptions*, 30.

46 Ibid, 30.

47 Ibid, 30.

48 Mamo, *Queering Reproduction*, 258.

defines woman”.⁴⁹ In the past, the only way for a woman to achieve “biological motherhood” was for her to get pregnant through coitus and carry that pregnancy to term. Medical intervention now provides alternative means for women to become “biological mothers”.

Genes

PGD is the latest medical intervention to assist women who are experiencing difficulty conceiving and maintaining a pregnancy to term. It is the ability of the process of PGD to genetically test and determine the health of the embryo that offers these women the most hope in having a biological child. Along with the hope offered, comes the increase in monitoring and controlling women’s pregnancies. NRTs constrain and control pregnancies as much as they offer women the possibility of having their own healthy biological child. The biotechnology and medical systems conspire to have people buy into their ideology. Currently, the most prevalent ideology has to do with the importance of genes.

The most advanced biomedicine finding currently is the identification of genes. Since the completion of the Human Genome in 2000, scientists have been promising great cures from the knowledge that comes from understanding genes. The mapping of the Human Genome gave only the location of the genes. Understanding the role genes play in humans’ health is an ongoing project. According to Hartouni, “In and of themselves, genes have no transparently meaningful or socially significant stories to tell that researchers simply discern or transcribe; they contain no intrinsic or self-evident social truths, and suggest, explain, guarantee, prescribe, predict, codify,

49 Gena Corea, *The Mother Machine: Reproductive Technologies from Artificial Insemination to the Artificial Womb*. (New York: Harper and Row, Publishers, 1985), 169.

confirm, and document nothing”.⁵⁰ She goes on to say that the power of genes is “clearly derivative and contextual.”

Genes are used as a powerful explanatory tool when justifying the use of PGD. Knowing the genetic makeup of the embryo assures the ability to choose only the healthiest embryo to transfer. Here genes are used to foster control and choice, and presented as the best determiner to obtain an optimal outcome. Franklin and Roberts describe the power of genes in the following manner: “Genes are powerful, and consequently they are political – indeed they are a classic example of what historian Michel Foucault terms “biopower,” in that they are inextricably linked to the idea of management of the population (in terms of health, for example), while also being regarded as inherent qualities of the individual”.⁵¹ Genes are used to describe “facts” about an embryo that has undergone testing. These “facts” are evidence based and according to Franklin and Roberts, the term gene is “highly varied and imprecise, despite being “scientific” in origin”.⁵² At the time the genetic makeup of an embryo is presented to users of PGD, genes hold all the power. The decision on which embryo/s to transfer is determined by choosing the embryo with the perceived healthiest genes. This information is regarded as facts and given total authority.

A concern with the rhetoric surrounding genes is the argument that genes control human individualism. But by giving genes so much power, the argument supports genetic determinism. Hartouni explains:

What most interests me about this skirmish, aside from the way it reiterates many of the same apprehensions that accompanied the introduction of new conceptive

50 Hartouni, *Cultural Conceptions*, 128.

51 Franklin and Roberts. *Born and Made*, 15.

52 Ibid., 17. Franklin and Roberts rely on Evelyn Fox Keller’s description of genes.

technologies in the late 1960s, are the rhetorical strategies that were deployed to rescue humanism's "unique individual," in particular, the appeal to genetics as a self-evident guarantor of individual originality and authenticity as well as cultural diversity. What is curious about the argument from genetics, as we will see, is that it appears to secure "individual identity" at the expense of "autonomy" and "agency" and, thus, to displace what it aims primarily to rescue. While rendering us genetically distinct individuals, in other words, it also, is the end and rather ironically, renders us genetically determined.⁵³

Finkler concurs with Hartouni when she says, "the ideology of genetic inheritance encompasses two important if contradictory themes: predetermination and its counterpoint, mastery of one's fate".⁵⁴ Genetic determinism eliminates agency and yet in the use of NRTs encourages agency and control over what nature was going to deliver. In the case of using PGD, women are trying to eliminate the randomness of nature and choose what they are willing to accept in terms of genetic makeup of their embryo. Franklin and Roberts point out that because of PGD the desired pregnancy can be "achieved" and that pregnancies are more "contingent". According to Franklin and Roberts "The paradox made more explicit through this change is visible in how it pits the view that biological identities are "given" to us by our genetic origins against the opposite view – that we can, and sometimes have an obligation to, remake who we are by intervening in the basic biology of beginning of life."⁵⁵ The discussion about genes and understanding the role it plays in our society is imperative when researching PGD.

Knowledge

The study of acquiring knowledge, what is available to know, and who creates the information to know has been extensively researched (Haraway, Harding, Hartouni, Mamo, Rapp, and Thompson). From a social constructionist view point, much of what is known about

53 Hartouni, *Cultural Conceptions*, 18.

54 Finkler, *Experiencing the New Genetics*, 77.

55 Franklin and Roberts, *Born and Made*, xvi.

the NRTs come from what the creators deem important to know. The creators present the information as if it is self-evident. Understanding and interpreting information creates knowledge and is based on one's personal experience. The one giving the information is in a position of power by controlling the dissemination of knowledge. According to Mamo, "power shapes what can be known and what remains invisible and presumably unknown".⁵⁶ Information that is deemed by the person in the position of power as not worth knowing or not important to share will not be disseminated.

The person with the power becomes the specialist and is separated from all others. The specialist has knowledge that is considered "objective" from a scientific point of view. Donna Haraway would contend that this type of knowledge is not objective. She says it cannot be objective because it comes of a position above the experience of a situation and purports to know all. According to Haraway, "only partial perspective promises objective vision".⁵⁷ Haraway is calling for a feminist position about science that locates claims within an embodied experience rather than being located outside the experience and claiming objectivity. Haraway calls for a transformation of the idea of 'scientific objectivity' in order to "foreground specific positioning, multiple mediation, partial perspective, and therefore a possible allegory for feminist scientific and political knowledge."⁵⁸ Rather than making large claims about science that create transcendence and splits the subject and object, Haraway would like claims based on experience and specific understanding based on experiences. Haraway calls the type of knowledge gleaned from an embodied experience "situated knowledge." Alison Wylie further explains the

56 Mamo, *Queering Reproduction*, 11.

57 Haraway, "Situated Knowledge, 583.

58 Donna J. Haraway. *Simians, Cyborgs, and Women: The Reinvention of Nature*. (London, Free Association Books, 1991), 3.

mechanics of situated knowledge. According to Wylie, “social location systematically shapes and limits what we know, including tacit, experiential knowledge as well as explicit understanding, what we take knowledge to be as well as specific epistemic content.”⁵⁹ Our interpretation, understanding, and definition of our experiences are manifestations of our social location. Wylie goes on to say, “What individuals experience and understand is shaped by their location in a hierarchically structured system of power relations: by the material conditions of their lives, by the relations of production and reproduction that structure their social interactions, and the conceptual resources they have to represent and interpret these relations.”⁶⁰ It is important when considering situated knowledge that the individual perspective is not privileged and adopted as a truth claim. In using situated knowledge it is the collective experience that demonstrates the potential to shed light on what is made visible and how that is made visible. In examining the experiences of women who use NRTs, researchers found that women often had similar experiences and defined their situations and made their decisions based on their understanding of their material conditions.

There are many decisions that need to be made during the process of using any NRT. Some of these decisions will be considered moral decisions, however according to Rothman the decision to use NRTs is never considered a moral decision because it is viewed as a means of gathering information. Value is placed on gathering information and then acting upon that information. Rothman explains, “There may be moral (and immoral) decisions to be made, but whether or not to enter into the decision-making process it self is not widely recognized as a

59 Alison Wylie. “Why Standpoint Matters.” *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. Ed. Sandra Harding. (New York: Routledge, 2004), 343.

60 Ibid. 343.

moral dilemma”.⁶¹ She goes on to say, “ We are entering into what has been called the “information era,” and it is reflected in the very way we think. Something beyond knowledge for its own sake is involved: it is the idea that action is based on information, and the fullest possible information is needed to determine action responsibly”.⁶² Gathering all the information or using the latest biomedical technology is the responsible thing to do. “Such is the contemporary, secular definition of mature, responsible behavior”.⁶³ Gathering information also is empowering and gives a sense of control.

It has been demonstrated through research that women feel a strong obligation to use the latest biomedical technology to monitor their pregnancies or create their pregnancies (Rothman, Sherwin, Petchesky, Franklin and Roberts). The ideology of seeking out the most advanced medical treatment available is pervasive in our society. Sherwin recognizes this behavior when she says; “The pursuit of technological intervention in reproduction is part of a larger general pattern in our society in which a search for technological solutions is often the first response to the recognition of human problems”.⁶⁴ Women feel they must use the latest biomedical technology in order to feel as if they did everything possible to give their child the best chance at life. Petchesky found this to be especially true with middle class women when making the choice to have an amniocentesis. According to Petchesky, “In addition, the technologies reinforce a sense on the part of middle-class pregnant women (those with access to high-tech obstetrical services in private hospitals) that a failure to submit to thorough medical surveillance will indeed

61 Rothman, *The Tentative Pregnancy*, 83.

62 Ibid., 83.

63 Ibid., 83.

64 Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care*. (Philadelphia: Temple University Press, 1992), 118-119.

leave them personally to blame should anything go wrong with the pregnancy”.⁶⁵ Women felt personally responsible for the wellbeing of their fetus and felt their behavior directly affected the outcome of their pregnancy more so than any other influence. Rapp agrees with these researchers and says; “Yet women and their supporters from many backgrounds believe that the behavior they define as healthy or unhealthy is responsible for a pregnancy’s outcome, and they do not distinguish genetic health from any other cause or manifestation”.⁶⁶ Some of the women in Rapp’s study considered their lifestyle as much of an influence on their fetus’ health as genes. These women were concerned that the food they ate, or any strenuous activities they participated in might adversely affect the health of their fetus. From their understanding and experiences with previous pregnancies or pregnancies of friends and family members, they came to consider the mother’s behavior as being the most influential in the development of their fetus. These women did not understand the influence or role genes had on the development of their fetus. Their understanding of fetal development played an important role in their decision to accept or reject having an amniocentesis.

Class and Race

The NRTs may offer hope to many women but not to all women. It has been well documented that the NRTs are a highly stratified medical service (Rothman, Petchesky, Mamo, Rapp, Franklin and Roberts). Not all women have access to the NRTs. According to Mamo, “It is ironic and unjust that in an age of expensive, high-tech healthcare, many women (mostly poor, immigrant, black, or Latino) cannot and therefore do not receive even basic medical services such as routine check-ups and prenatal care. Reproduction is historically a key site of social

65 Petchesky, *Abortion and Woman’s Choice*, 392.

66 Rapp, *Testing Women*, 87.

control over women and women's agency, as well as a site in which stratifications have been profoundly exercised".⁶⁷ The assistive reproductive technologies, such as IVF and PGD, are offered as a fee for service. Most insurance plans do not cover the costs. Therefore, those who cannot afford the services do not gain access regardless of their diagnosis.

Not only is there unequal access to NRTs, but also the services provided are not the same based on class and race. According to Petchesky,

This conjuncture of medical, corporate, and state interests in the "management" of reproduction has defined the choices of all women, but in a way that is crucially different depending on one's class and race. Still the major providers of birth control and abortion information and services to women, physicians are widely known to vary the information and the quality of services they provide based on the class and race of their patients.⁶⁸

Physicians assume they know the level of comprehension of their patients and adapt their explanations accordingly. Patients may or may not understand the explanation of the recommended treatment and physicians may or may not give a comprehensive explanation. According to Rapp, "Matters of class, for example, figure large in problems of scientific literacy, confidence, and agency in medical settings".⁶⁹ Class not only affects the patient's ability to pay for services but also affects the manner in which a patient goes through the system.

There is a hierarchal order of NRTs used for treating infertility. The more technologically involved and successful treatments of infertility are also the most expensive and may not be offered to someone who cannot afford to pay the fee. Mamo found that "Financial stability is increasingly significant in the U.S. for-profit healthcare system, particularly in the infertility system with its technological imperative, which swiftly moves patients up the ladder of high-tech

67 Mamo, *Queering Reproduction*, 14.

68 Petchesky, *Abortion and Woman's Choice*, 11-12.

69 Rapp, *Testing Women*, 10.

(and expensive) services. Today even the most noninvasive methods of assisted reproduction are costly”.⁷⁰ She goes on to add, “since infertility services are not covered by most health-insurance plans, most specialists provide services only to those with the financial resources to pay in advance”.⁷¹ Providing services in this manner limits the accessibility to only those who can afford treatment.

Choice

The NRTs offer women choices regarding their reproduction. The idea of choice within the context of the NRTs has been amply researched. Women’s choices are embedded in the material conditions of their lives and are socially mediated (Rapp, Rothman, Petchesky, Mamo, Franklin, Ginsburg). This became evident to Rapp while she was conducting her research about the use of amniocentesis as a means of determining the health of a fetus during the second trimester of the pregnancy. According to Rapp, “Thus, the “choice” any pregnant woman makes to take or reject the test, and to keep or end any specific pregnancy, flows from the way that both pregnancy and disability are embedded in personal and collective values and judgments within which her own life has developed”.⁷² A woman’s decision regarding her pregnancy is based on how she has come to define her values, which have been influenced by her lived experiences and cultural ideologies. Ginsburg found this to be true when women consider having an abortion. According to Ginsburg, the reasons women chose to have an abortion, “had to do with women’s desire to choose if, when, and with whom they would have children, taking into account existing family size, financial considerations, marital status, and work conditions, motives not unlike

70 Mamo, *Queering Reproduction*, 69.

71 Ibid., 71.

72 Rapp, *Testing Women*, 91.

those of American women born a century earlier”.⁷³ Women take many aspects of their lives into consideration when making decisions.

Rothman argues that women have very few “choices” when it comes to using the NRTs. According to Rothman, the NRTs give “an illusion of choice”.⁷⁴ She goes on to say,

Perhaps what we should realize is that human beings living in society have precious little choice ever. There may really be no such thing as individual choice in a social structure, not in any absolute way. The social structure creates needs – the needs for women to be mothers, the needs for small families, the needs for “perfect children” – and creates the technology that enables people to make the needed choices”.⁷⁵

In the case of choosing to use amniocentesis and aborting an affected fetus Rothman found that the women expressed a sense that they “had to” do what they chose to do. Her subjects used the words “my only choice”⁷⁶ to describe their feelings about their decision. Rothman defines an ‘only choice’ as, “when the other choices are yet more horrible, too horrible to choose. Not everybody agrees on what the “only” choice is: but they are agreeing on the experience of no-choice in a choice situation”.⁷⁷ Women who are either pregnant or trying to get pregnant find themselves in a system with implied choices when really they feel there are no choices. Franklin and Roberts also found that the users of PGD in their research felt similar to what Rothman found with her subjects. According to Franklin and Roberts, “A prominent finding of this study, as in Franklin’s earlier study of IVF, is the extent to which PGD patients described their decision

73 Faye D. Ginsburg, *Contested Lives: The Abortion Debate in an American Community*. (Berkley: University of California Press, 1989), 40.

74 Rothman, *Tentative Pregnancy*, 14.

75 Ibid., 14.

76 Ibid., 180.

77 Ibid., 180.

to undergo PGD in terms of “having no choice” or there being “no decision to be made” by the time they had reached their initial consultation as prospective patients”.⁷⁸

New choices brought on by advances in biotechnology are shrouded in multiple interpretations regarding their advantages and disadvantages. According to Franklin and Roberts, “On the one hand, assisted conception and genetic diagnosis are celebrated as means of overcoming obstacles to pregnancy, avoiding genetic disease, and offering greater reproductive choice and control. On the other hand, these very same new forms of choice and control are often criticized, and feared, as unnatural, immoral, or unsafe”.⁷⁹ Franklin and Roberts found users of PGD were ambivalent about using the new technology.

Feminist Bioethical Approaches to Using NRTs

Using a feminist approach to the bioethical decisions inherent in using NRTs would differ from using a traditional bioethical approach. According to Tong, “feminists insist that many of the Western tradition’s principles, concepts, and virtues need to be reinterpreted, reassessed, and transformed in order to reflect women’s as well as men’s perspectives.”⁸⁰ Feminist bioethics pursue combining “culturally associated ‘female’ values” with “culturally associated ‘male’ values”⁸¹ to create a bioethics that can account for women’s moral development. By doing so, women’s moral decisions would not be judged as immoral if they do not adhere to traditional moral standards.

Feminists are concerned that women may feel coerced into using the NRTs if they are unable to achieve and maintain pregnancy on their own. The coercive power of NRTs has been

78 Franklin and Roberts, *Born and Made*, 108.

79 Ibid., 18.

80 Tong, *Feminist Approaches to Bioethics*, 1.

81 Ibid., 2.

researched by many scholars (Tong, Strong, Sherwin, Rothman, Farquhar). Feminist scholars are concerned that the availability of the NRTs may compel women to use them thereby reducing their agency to choose. According to Tong, “Feminist critics of IVF also worry that simply owing to IVF’s availability, society will pressure infertile women who are currently happy without children to “do something” about their childlessness”.⁸² Sherwin adds to this by saying, “By accepting the presupposition that (particular) women ought to bear children, even if they must risk their lives to do so, IVF implicitly reinforces many of the sexist, classist, and often racist assumption of our culture”.⁸³ Not all women will feel compelled to use the NRTs, nor will all women who want to use them have access, however those who can gain access may feel pressured to use the NRTs.

Feminist advocates for the NRTs argue that woman should be allowed to weigh the benefits against the risks of NRTs for themselves before they use a technology (refer to Sherwin, Berg, Murphy, Tong, and Greil). Advocates go on to say using an NRT should be a personal decision and government policies should not restrict their use. According to Sherwin, “Any public policy that restricts access to this technology will be experienced by those in search of relief for their childless condition as a serious interference with their personal reproductive freedom.”⁸⁴ Using an NRT may be the only way for some women to realize their desire to get pregnant and have a child. According to Berg, “using these technologies to achieve biological

82 Ibid., 183.

83 Sherwin, *No Longer Patient*, 134.

84 Ibid., 126.

motherhood does not necessarily reflect that a woman is acting out of mindless socialization.”⁸⁵

It may simply indicate a woman is exercising her choice to use an NRT.

My Research Project

The scholars who researched the NRTs discuss the importance of understanding the lived experience of women who use NRTs. My research will explore my participants’ lived experience of using PGD. The participants of my research were either unable to get pregnant ,maintain a pregnancy to full term, or have the child they wanted without using PGD. The current literature primarily examines the experience of women who are already pregnant and use NRTs to monitor their pregnancies. There is very little literature specifically researching the use of PGD. My research will contribute to discussions about women’s use of NRTs with emphasis on using the latest technology in its infancy stage. This research will also contribute to understanding the ways in which people engage with biomedicine as well as how women make bioethical decisions.

My theory is that these women/couples do not think about the difficulties associated with the PGD treatment regimen or the decisions required of them prior to embarking on the treatment process. Their focus is solely on having the child they desire. The women/couples who experienced infertility, either by their inability to get pregnant through coitus or their inability to carry a pregnancy to a live birth, desired their biological child. The women/couples that used PGD for sex selection purposes desired a child of the gender that would balance the genders in their family. By examining the experience of using PGD from the perspective of the users, it will

85 Barbara F Berg. “Listening to the Voice of the Infertile.” *Reproduction, Ethics, and the Law: Feminist Perspectives*. Ed. Joan C. Callahan. (Bloomington: Indiana University Press: 1994) 85.

become clear that this single-minded focus maintains its importance throughout the process and eclipses any other consideration. It is important to understand the power of this focus and its ability to overshadow any information or other considerations the women/couples may encounter during a PGD cycle.

I have used Valerie Hartouni's concept of "rescripting" to demonstrate the manner in which these women/couples make their experience acceptable to themselves. Each step in the process of PGD provides the women/couples with an opportunity to make decisions that could reflect their ideology. Some decisions may require adopting conflicting ideologies. For instance initially in the process the women/couples considered every embryo as having potential for human life and there was great concern for the embryo/s wellbeing. Then as the PGD cycle progressed and the embryos were either no longer needed or deemed unacceptable, they were discarded by some women/couples. At that time, these women/couples rescripted their story to justify and make the discarding of the embryos acceptable.

I have also used Donna Haraway's definition of "situated knowledge" to demonstrated the significance of the role a positioned perspective plays in the decisions made by these women/couples. They came to their perspective by way of a very complicated fertility history coupled with their desire to have their biological child. Their experiences became the lenses and filters through which they processed their understanding of their inability to independently meet their reproductive goals and created their "situated knowledge." I look at the patterns of behavior demonstrated and described by these women/couples to uncover the most salient aspects of using PGD.

By using Hartouni's and Haraway's frameworks, I will reveal as much about the experience of using PGD as the manner in which these women/couples engage in medical

technology. The medical technology these women/couples engage in is the latest in the development of NRTs. The genetic testing of an embryo marks the beginning of our understanding of the role of genes in pregnancy, and embryo and fetal development. The genetic information gleaned from the biopsy of the embryo is new information. Considering the embryo in this manner is also new. The way in which these women/couples use this information will reveal how novel information is put into the service of personal gains. In addition, the timing of this decision is new. Most women are pregnant when they have to make a decision about their future offspring. Using PGD allows women to have a similar experience as men when making the decision about their future child. The decision is made when all the material is outside their body. These are the primary contributions of this dissertation to the literature on NRTs.

CHAPTER THREE

THE METHOD: DISCOVERING PGD

Preimplantation Genetic Diagnosis (PGD) is the latest arsenal in the combat against infertility. It is a highly technical and complex procedure layered with meanings. It is a relatively new technique, having only been used for the last 20 years, and embedded in controversy. Because of its newness, not all of the uses and implications of PGD have been realized. The concerns, controversies, and meanings associated with PGD are similar to those associated with other NRTs. When Rayna Rapp researched the use of amniocentesis in its infancy, she described the topic in the following manner:

The topic on which I am working is a highly charged one. It lies at the intersection of personal pain and national political struggles concerning health care, abortion rights, and disability rights; of “the right to informed consent” and the meanings of sexuality, pregnancy, and parenting; of the role that biomedical science plays in a society with no commitment to equal access to health care for all its members; of the uncertain links between new knowledge generated in genetics research and applications in clinical medicine.⁸⁶

This same statement could be said about PGD. There are those who have developed PGD, those who create policies that effect PGD, those who administer PGD, those who have opinions about PGD but are not directly involved with the procedure, and those who use PGD as part of their fertility treatment. Those who use PGD struggle with the decisions they are required to make throughout their treatment. And even after they have been successful with their treatment, their decisions haunt them. With hindsight, they question whether they made the right choice.

I came to understand the struggles associated with using PGD as I interviewed the participants of this research project. The interviews were part of the ethnographic methodology I

⁸⁶ Rapp, *Testing Women*, 17.

chose to use to get an accurate portrayal of the experience of using PGD. Emerson, Fretz, and Shaw say, “Ethnographic field research involves the study of groups and people as they go about their everyday lives.”⁸⁷ Although I did not observe every aspect of the participants everyday lives, I did observe most every aspect associated with using PGD as part of a fertility treatment plan.

Ethnography involves two “distinct activities.”⁸⁸ The first is participant observation, which involves first hand experience observing and getting involved in the setting. The second involves writing an account of and examining what was observed. Writing ethnography requires a constant interplay between actual footnotes taken in the field and an analysis to give meaning to the observation. According to John Van Maanen, “The trick to ethnography is to adequately display the culture (or, more commonly parts of the culture) in a way that is meaningful to readers without great distortion.”⁸⁹ My main interest is to understand PGD from the perspective of the women and men that have used PGD as part of their fertility treatment. In order to do this I needed to immerse myself in the environment where PGD takes place.

Preliminary Research

My official foray into researching women’s experience with new reproductive technologies (NRTs) occurred three years prior to my dissertation research when I attended a prospective patient seminar sponsored by IVF Michigan and Organon Drug Company. IVF

87 Robert M. Emerson, Rachel I. Fretz, and Linda L. Shaw. *Writing Ethnographic Fieldnotes* (Chicago: The University of Chicago Press, 1995), 1.

88 Ibid. 1.

89 John Van Maanen. *Tales of the Field: on Writing Ethnography* (Chicago: The University of Chicago Press, 1988), 13.

Michigan is one of the largest fertility treatment facilities in Michigan with seven clinics. Dr. T, vice-president of IVF Michigan, led the seminar. After Dr. T welcomed everyone, he explained the importance of respect for other's privacy and asked that people not reiterate the personal details mentioned during this discussion. After everyone nodded her or his head in acquiescence the meeting began.

Dr. T presented a PowerPoint presentation on all the services IVF Michigan could provide. He also proudly displayed his success rate compared to other clinics. At the time I did not realize the significance of these statistics. Later, I came to understand that prospective patients use these statistics to choose a clinic. Dr. T provided a brief summary of the cost of various techniques and assured the audience that his clinic would work out a payment structure that would be mutually beneficial. He briefly touched upon the emotional cost and quickly went back to reiterate his success rate. After working in the field for more than a year since this seminar, I now understand the decision to limit the time dedicated to the emotional cost. These couples do not need anyone telling them about the emotional toll; they are well aware of it. They need information about treatment options and information that will allow them to make an informed decision in choosing the best clinic for them. The emotional toll will be well spent if they can find success. At the time of the seminar I did not understand the basic needs of infertile women and men.

The seminar participants were given time to ask Dr. T questions. There was a palpable sense of urgency present in their questions and quest for reassuring answers. The underlying theme constantly presented by Dr. T was that the one aspect of infertility that is not curable is a woman's advanced age. One woman who was over weight said she wanted to lose weight before she tried another procedure. Dr. T strongly discouraged her from doing this. He said he could

help her manage her weight while pregnant but the longer she waited, the older she would be, and the harder it would be for her to get pregnant. The concern of potential problems associated with delaying childbirth is evident throughout research. E.H. Stephen says, “There are several potential consequences of delayed childbearing, including a greater incidence of late fetal death rates, increased risk of lower birth weight, increased risk of multiple birth and greater incidence of infertility... The one variable that has shown consistent association with infertility is age of the woman.”⁹⁰ Dr. T emphatically stressed this point.

The camaraderie among the participants was immediately apparent. Everyone supported the others’ questions and gave antidotes of similar experiences. People also exhibited a knowing laugh when they recognized themselves in a story someone else told. Upon leaving the meeting, the couples all wished each other luck and the men shook each other hands. The woman who was in attendance without a partner was the only person who slipped out of the room without any formal good-byes.

I had an opportunity to meet with Dr. T at his office in Ann Arbor weeks after this seminar. Dr. T was very generous with his time and information. He explained to me the types of patients he primarily sees and how he gets his referrals. Most of his patients are heterosexual couples; however he does work with lesbian and gay couples as well as single women. Patients come to him after being referred by their gynecologists or by a friend. Some find him through his advertisements.

90 E.H. Stephen, “Postponement of Childbearing and its Effect on the Prevalence of Subfecundity” *Female Reproductive Aging*. Edited by E.R. Tevelde, P.L. Pearson and F.J. Broekmans (New York: The Parthenon Publishing Group, 2000), 59.

I discussed my research project with him during this meeting. He was very supportive of my ideas. According to Dr. T, genetics is the future of reproduction. The most interesting and promising research is in genetic testing of the embryos. My discussion with Dr. T led me to research the experience of using PGD, paying particular attention to the many decisions users need to make throughout the process.

Observing Office Procedures

My research project was carried out at the Ann Arbor office of IVF Michigan. IVF Michigan has six offices in Michigan and one office in Ohio. I worked closely with Dr. T, a reproductive endocrinologist, who sees patients at all seven offices. He allowed me to sit in on consultations and examinations of his patients. Dr. T was interested and supportive in my research project from the very beginning. He felt the information I proposed to glean from my project would assist him in understanding and addressing his patients' needs and concerns.⁹¹

I began by shadowing Dr. T at IVF Michigan in Ann Arbor. I was struck by the quiet that permeated the office. When I first walked into the office I noticed the serenity projected in the waiting room. There are comfortable chairs positioned in groupings of two and four around the perimeter of the room as well as a small grouping in the middle of the room. It is tastefully decorated with pictures on the wall and end tables filled with magazines. The waiting room was very tranquil with serene paintings on three walls. On the fourth wall, there was a black and

91 Upon completion of my research project, I reviewed the findings with Dr. T. He was very excited and encouraged by these findings. He found the information to be very useful in his practice. He asked if he could share the findings with his colleagues in his office as well as his patients. I got a sense that by sharing these findings with his patients he would be contributing to the “conscious raising” of the women and the assistance of future PGD users that was important to my participants.

white enlarged photo of Dr. T along with a colleague sitting in the middle of several babies. This is a picture of him with his success cases of the previous year. As I went from the waiting room to his office, I noticed several other black and white photos of the same ilk. Lining the hallway walls are bulletin boards full of individual pictures of babies and children conceived through treatment at IVF Michigan.

When I first began my fieldwork, I sat in on initial consultations with patients who came to discuss treatment options with Dr. T. The initial office visit is regarded as a consultation, a time to inquire about options to treat infertility. Once the patients are brought into the doctor's office, the consultation begins with a review of the case history form filled out by the patient. Then Dr. T asks more detailed questions about the woman and her partner's fertility history as well as pertinent information about lifestyle. Questions that touch on lifestyles and workplace environments are relevant to fertility history. After a discussion of health and fertility history, Dr. T explains treatment options appropriate for their particular situation based on his expertise. The options presented typically include procedures that are less medically managed to those that are more medically managed. The more medically managed procedures are more controlled and yield a higher percentage rate of success. There are always treatment options, but typically one has better odds of success over the others. For instance, a couple could use IVF without PGD and the odds of getting pregnant might be higher than trying to conceive using intrauterine insemination, but lower than using IVF with PGD. Each option has an inherent success rate as well as unique risks and costs. Prior to engaging with any of the options, further tests, such as blood tests and semen analysis, along with a thorough examination of the woman is completed.

I observed and shadowed Dr. T at IVF Michigan for six months. My presence there was a bit awkward at first although everyone was very welcoming. I eased in slowly by assisting with

tasks in the office. When I was not shadowing Dr. T, I assisted with filing and making copies. I was the first PhD. Candidate to observe in the office. The staff was not sure of my role in the office. Typically, Dr.T has obstetric and gynecologic residents following him. The staff is very comfortable integrating the residents into the office routine. Once while I was observing Dr. T in surgery at the Rochester Hills office, a nurse assumed I was a resident and put her hand on my back and guided me closer to the patient on the table saying, “Come on, you can get right in here.” She started to point out various parts of the female anatomy. As she pointed out the cervix, I realized I had never seen a cervix before other than in a picture. I was struck by the rosy red color and that this one was attached to a woman’s body. I remained standing in the spot the nurse led me to, conscious of the close proximity to the patient. I stood still so I would not be disruptive or in the way of what was occurring. I was observing an egg retrieval. Once the surgery was completed, and we were out of the surgery room, I clarified my position and background with the nurse.

There had not been a resident present that day in surgery however, there were residents doing their rotation at IVF Michigan throughout my time there. The residents’ presence enriched my experience. Only one resident was there at a time. Their rotation lasted about two months, and then another resident would begin a rotation. I was fortunate to be allowed to listen in on conversations between Dr. T and the residents. These conversations deepened my knowledge of the doctor’s role in fertility treatment. In addition, I also learned about procedures from Dr. T’s instructive narrations that he performed during examinations and procedures for the resident’s benefit. I was also allowed to sit in on their weekly instruction where Dr. T taught a topic to prepare the resident for their board examination. Although much of what was said was beyond my comprehension, I appreciated hearing the terminology used to discuss real cases.

Talking to the medical residents was also a valuable learning tool for me. I was able to hear about the research being done in obstetrics and also discuss my research project. For the most part, the residents were not familiar with PGD. They had heard of it but were not aware of all the implications. As an obstetrician and gynecologist they would not be directly involved with PGD, however they could recommend the procedure for their patients by referring to a reproductive endocrinologist.

In addition to sitting in on consultations, I observed office procedures. I observed many vaginal ultrasounds performed to monitor the development of the follicles. Women come into the office twice a week to monitor the size of their follicles once they are on the hormone regimen. The follicles are monitored to watch the growth, which indicates how well the woman is responding to the medication. Timing is very important. The follicles need to be a certain size before the ovum can be extracted. The vaginal ultrasound is performed with the woman reclined on an examination table and her feet in stirrups. The doctor performs the ultrasound with his nurse assisting. The nurse works the controls at the mainframe of the ultrasound, pushing the buttons that will take pictures of the follicles.

For the women who go through fertility treatment, measuring their follicles is a very important aspect of the IVF cycle. First, measuring the follicles gives an indication of how well her body is responding to the medication she is injecting into herself. The medication she has been injecting into her body has taken over her follicle development. Her body is no longer functioning “naturally” but is now under medical control. If her body does not respond appropriately, it could end the cycle and this attempt at getting pregnant. Second, measuring the follicles is a very time consuming procedure. The woman has to come into the office twice a week to monitor her follicular development. Her attendance at the doctor’s office marks her

commitment to the IVF cycle. Her partner no longer needs to be present. The appointment is very short but necessary. She must now coordinate these appointments into her weekly schedule. And third, once the eggs have reached the optimal size, they will be extracted from her body. Measuring the follicles determines when they can be extracted and prepared for fertilization.

Another procedure I often observed was a mock transfer. Prior to having the embryos transferred, Dr. T performs a mock transfer. Using a vaginal ultrasound and a syringe with a long tube attached instead of a needle, Dr. T injects saline into the uterus. He checks to see if there is anything that might block the transfer. This procedure is very uncomfortable for women. Typically, the woman winces with pain and often squeezes her partner's hand. I had the occasion to sit in on this procedure a couple of times when the woman had no one with her. I offered my hand for comfort. If the amount of squeezing was proportional to the pain, I can attest to the procedure being quite painful. Luckily, the procedure lasts only a couple of minutes at the most.

The mock transfer is a vital part in the success of the transfer. Dr. T performs this procedure to insure that there is nothing inside the woman's uterus that will block the passing of the embryo from the syringe. If something blocks the flow of the saline in the mock transfer, then it will be corrected prior to the transfer. Having a clear "picture" of what the transfer will look like adds to the success of the transfer.

The most joyful vaginal ultrasounds I observed were the ones confirming a pregnancy. At about six weeks in a pregnancy, a fetal heartbeat can be detected through a vaginal ultrasound and seen on the monitor. The pulsating glow on the monitor reassures the woman that she is indeed pregnant with a viable fetus. The beats per minute are counted and recorded to compare throughout the pregnancy. The fetus' length is measured as well as the heartbeats to determine if it is growing properly. Women continue to come into the fertility clinic weekly for fetal

measurements until their 12th week of pregnancy. At that time the woman leaves the care of the fertility clinic and is followed by her obstetrician for the remainder of her pregnancy. One more vaginal ultrasound is done during the woman's last office visit. At this time, confidence that this pregnancy will develop to become a healthy baby permeates the office. However, caution is always given. Success is not declared until the birth has occurred. Cautiously optimistic, the woman and her partner often ask Dr. T to predict the sex of their child during the 12th week ultrasound. Although he disclaims the accuracy of his prediction, he makes a guess based on what he sees on the ultrasound. He also gives an ultrasound picture of the fetus to the woman. This ritual brings joy to the pregnant women. She now has something tangible to hold onto. This representation of the life inside her confirms that she is getting closer to meeting her goal.

The first vaginal ultrasound that I observed was performed to confirm the pregnancy of a woman who had gone through IVF. Her husband was present for the examination. Her ultrasound revealed that the embryo transfer was successful and she was indeed pregnant. After hearing this information, both she and her husband asked how many embryos attached. Two embryos had been transferred, but only one had attached. They were happy with having only one although they would have preferred two. They did not show much emotion about either bit of information. They were not jubilant over the news that they were pregnant nor were they saddened by the news that they did not have two embryos attach. Their concerns turned to the rest of the process. They wanted to know what to expect and what they needed to do over the next few months. At the time of the observation, I was surprised by the lack of emotion. But as I became more familiar with the process of fertility treatment, I realized that it was too soon to celebrate the pregnancy at the time of the initial ultrasound. Unlike women who conceive through coitus or who have not experienced complicated pregnancies, the women who go

through fertility treatment understand the precarious nature of their pregnancies. The fact that an embryo successfully implanted into the uterus is a milestone but there are many more milestones that must be achieved. I also realized that the loss of the second embryo is superseded by the relief that at least one embryo attached and the concern to keep it viable.

Observing Surgery

While working with Dr. T, I was allowed in the surgery room to observe egg retrievals and embryo transfers. On a few occasions I was asked to “glove up” and assist, although only in a minor capacity. Once, Dr. T asked me to hold a speculum in place in a woman’s vagina, while he was preparing some instruments. Everyone else, the nurse and anesthetist, were doing what they needed to do to prepare the woman. This time of “gloving up” occurred during an egg retrieval so the woman was under general anesthesia. Once Dr. T began the procedure, I was relieved of my duties.

The second occasion of being asked to “glove up” required me to procure the test tubes filled with fluid and extracted eggs from the nurse in the surgery room, take them to the embryologist in the lab, and then come back into surgery and tell Dr. T the number of eggs in that tube. I continued to take the tubes to the lab then return to surgery with information only to get more tubes, until all the woman’s eggs were retrieved. This time of “gloving up” was a little more stressful than the first. This time I was holding very valuable material. I did not want to be the person who dropped, spilled, or contaminated the eggs. I felt like I was carrying a time bomb that could go off any moment. I walked very carefully and slowly. I completed the task without a problem. I was asked to do this same task another time in surgery. The second time I “gloved up” for this role I was much less nervous.

The women are anesthetized during an egg retrieval procedure however they still feel some pain. I observed women wincing and curling their toes as a reaction to the pain and discomfort during the egg retrievals. Fortunately, when the anesthetist sees the response to pain, she/he can adjust the anesthesia to reduce the pain.

Also, during retrievals, Dr. T pointed out the ovum present in the woman's follicles as displayed on the ultrasound monitor. I never could see them. They are so small and it was hard for me to discern the eggs from anything else on the monitor screen. However, I was able to see the embryos on the monitor during a transfer. It looks similar to shooting stars across the darkened sky. The little white dots that represent the embryos shoot into the uterus.

Observing in the Laboratory

I also had an opportunity to observe in the laboratory at the Rochester Hills office. This is where the eggs are fertilized with sperm. I watched as the embryologist performed intracytoplasmic sperm injection (ICSI). ICSI is the technique whereby the embryologist controls the fertilization process by taking only one sperm and injecting it into the egg. This allows for a better outcome and higher potential for the egg and sperm to develop into an embryo than putting several sperm in the dish with an egg and allowing the sperm to penetrate the egg on its own.

The embryologist projected the image he saw through his microscope on a monitor so I could observe what he was doing. His workstation looked like a high-tech video game. There are several joysticks that he maneuvers to get a better visual image as well as to manipulate the instruments that are manipulating the sperm and egg. I watched as he observed all the sperm and choose the best one to use for fertilization. He chose the sperm based on specific criteria that I later learned included the shape of the sperm as well as the motility. The embryologist watched while the sperm "swam" around in the petri dish. Once he determined the sperm he wanted to

use he rolled it to cut the tail so that the sperm slowed down and he could catch it. Then he sucked it up a pipette and injected it into an egg at a precise angle in relationship to the egg's polar body. The embryologist told me that the polar body had to be at either the 7 or 11 o'clock position before inserting the sperm. He preferred the 7 o'clock position. My description makes ICSI sound very simple, but in reality it is a very precise science, which takes incredible skill to perform.

What struck me most while observing the procedure was the reverence that permeated the atmosphere in the room. There were three embryologists all performing ICSI at their own work areas. There was extreme concentration and silence throughout the laboratory. I asked the embryologist about the silence and he said that while doing ICSI it was always quiet, "you need to concentrate." He told me in the morning during egg retrievals the laboratory is louder.

I was allowed to stand in one spot to observe in the laboratory. I did not move. I kept quiet and made sure I did not sneeze or do anything to interfere with the work being done. Before Dr. T left the laboratory to go to another office, he told me to be mindful of where I was because people were walking around with embryos. Once the embryologist was done with one set of petri dishes, he had to put them into storage units that looked like refrigerators, to allow the egg and sperm to grow to an embryo. Putting the petri dishes in these storage units required the embryologists to walk around me. They walked with such care and precision. I made sure to stay especially still while they were walking.

On another occasion in the laboratory, I observed an embryo being prepared for freezing. This was an extra embryo that the woman wanted to use at a later date. The embryologist carefully worked with the embryo, observing it under a microscope, as he put it through a dehydrating process. He allowed me to look at it through the microscope. Even magnified, the

embryo is very small. I watched the embryologist prepare the embryo for cryopreservation. I had a difficult time associating this group of cells with the person it had potential to become. I asked the embryologist what he thought about the embryos status and he said he did not consider an embryo in the same manner as a person. He said he would be upset if he dropped a petri dish and destroyed the embryo because of the disappointment the patients (meaning the woman/couple) would experience. He considers the embryos a cluster of cells. Although he took great care of the embryos, he said he did not think of them as people.

Having observed in the laboratory became very valuable during my interviews. Many women and their partners expressed their concern about not knowing what took place in the laboratory. None of the women and partners had actually been in the laboratory although they had the opportunity to look in the doorway while they were in the surgical room. I explained to them what I had observed and they were comforted by the reverence the embryologist gave the egg and sperm. They were glad to hear that the cells that resulted in their child/ren were well taken care of from the very beginning.

The experiences I had while observing and shadowing Dr. T prepared me for my interviews with couples that used PGD. I became familiar with the terminology doctors, nurses, embryologists, and patients use to describe the procedures. I also gained a better understanding of the details involved in the procedure. Listening in on conversations during the consultations as well as the examinations clued me in to the concerns of patients. I found out what they were most interested in regarding NRTs. I also had a better understanding of the medical regimen the women had to go through to get pregnant and then maintain that pregnancy.

The Interviews

After six months of observing in the office and shadowing Dr. T, I was able to make contact with women who were interested in participating in my research project. To qualify for this project patients had to have used PGD as part of the fertility treatment, have completed at least one cycle of PGD, and had a baby as a result of PGD. Dr. T insisted that I start with women who were successful with PGD. Success is being defined here as having a baby as a result of PGD. Dr. T and I felt it may be too painful for women who were unsuccessful to relive their experience by telling their story.⁹² I realize that by interviewing only success cases the data

92 Dr. T and I discussed the criteria for participation in my research project and we both felt that it would be best to start with success cases. We thought these women might be more willing to talk about their experience. Dr. T was not sure the women who did not meet with success would be willing to talk about their experience. I sat in a few conversations Dr. T had with women who had a failed IVF cycle. These conversations were tearful and painful. I did not want to cause any more stress or harm to women who used PGD. I was aware of the stipulations the IRB places on research using human subjects and their emphasis of causing no harm.

In addition, as I began my interviews with the women who were successful, I noticed that many had not been successful on their first cycle. It was then that they started to blame the doctor for their failure and started to look at themselves as being part of the business of reproduction. I felt that looking at the business of reproduction went beyond the scope of my project. I considered the possibility that women who only met with failure might want to discuss the business of reproduction as well as the culpability of the doctor. Therefore I felt that talking to unsuccessful cases would add more variables to this project than I wanted to analyze at this time. I knew that by eliminating the women who did not meet with success, I could be missing an aspect that might be revealed in their discussion. But since this is an exploratory research project and just the beginning of my research into this topic, I

might be biased and lean toward hearing only about the positive aspects of PGD. In addition, we both agreed that it would be best to interview women in hindsight about their experience because discussing decisions during the time they are making them may influence their decisions. I also considered the possibility that it may be difficult for people to remember their experience if I interviewed them much past their experience. Therefore, the women I interviewed had used PGD within the last two years.

Once the qualifying participants were identified, contacted, and permission was obtained for me to contact them, I called to make arrangements to meet. Contact often required multiple attempts at connecting via the telephone. Most often I only got through to the voice mail of the participants. Because of the sensitive nature of the subject I was reluctant to leave much more than my name and phone number on the message. I did not want the wrong person to get the message. I also came to understand that many of the potential participants were busy with the responsibilities of being a new parent so returning a phone call about participating in a research project would be low priority. Therefore the responsibility to make contact rested on me. I continually called until I got an answer, always apologizing for the persistence.

Several times the initial phone contact resulted in setting up a more convenient time for me to call back because the woman had more questions to ask before agreeing to participate and did not have the time to talk right then. Many of the participants wanted to know about my background, and who would read the results, how would their identity be kept private, and why I was doing this. They were most willing to participate if doing so would help other women who would be going through this process in the future. "If it will help someone else," was a phrase I

felt that I could go back and add other criteria for participants at a later date.

often heard. I told them although I could not make any promises, my intention is to disseminate the findings.

The phone conversations ended with a meeting put in place. I allowed the women to chose the site of our meetings. I appreciated them taking time out of their busy schedules to meet with me and wanted to make our meeting as convenient as possible for them. All the interviews occurred at the woman's home except for three interviews. Two of those occurred at the women's office, although one woman's office was attached to her home, and one interview was done over the phone. Most interviews were audio recorded with permission. Some women asked not to be recorded because they did not want to be identified in any way. I assured them that their identity would be kept anonymous. I would use a pseudonym and disguise their identity. Each participant was given a copy of their interview transcript to approve or make changes.

A slight discomfort was always palpable at the beginning of each interview. So I started by introducing myself and talking a little about my background. I also reassured the woman that I had not read her chart at the office, so anything I learned about her case would be whatever she wanted to tell me. I also assured her that she could refuse to answer any question and stop the interview at any time. Then I suggested that she start by telling me her story. The woman's comfort level appeared to increase as she got further and further along in her story. She often had to go back and add something she left out previously but now thought important. The discussion continued and revolved around topics that were significant to the woman, however I did steer conversations in directions that I was interested in also.

I started off with a list of ten women who qualified for the project. All the participants are part of a heterosexual married couple. A total of six women agreed to meet with me. Four of the six women had their husband join the interview. All husbands were invited, however some were

busy at the scheduled time and/ or the women preferred to be alone at the interview. I told them the interviews would take no more than an hour. What I found was that once they started talking about their experience, they had a lot to say. Some interviews took closer to two hours. Along with the interviews, I asked the participants to fill out a survey. The first ten participants were given a paper copy with an addressed and stamped envelope so they could return it to me. I received 80% back.⁹³

After I completed the initial interviews, I reviewed my data and devised a more comprehensive survey and more detailed questions to ask during the interview. Then I was given a list of 27 women from all seven of the IVF Michigan offices that used PGD in 2008 and 2009. Seven women agreed to meet with me; four of them had their husbands join us. Again, all the husbands were asked to participate. Of the women who did not participate, most said they would have liked to participate but felt that they did not have time in their life right then. All of them had toddlers or infants and were busy with childcare and other responsibilities. All were given access to an online survey that I had developed as a result of the initial interviews.

I began what I considered the second round of interviews. Some of these interviews required me to drive over two hours from my home. While driving to the participants' homes, I realized that in some cases they also had to drive quite a distance for their fertility treatment. Regardless of which office a patient is seen for her doctor's appointments, all patients go to the Rochester Hills office for surgical procedures. For some of the women, the Rochester Hills office would be over a two-hour drive. That can seem quite far when you are on your way to have an embryo transfer. It can also seem quite far after the procedure when you are driving

93 Refer to Appendix C for initial copy of survey.

home and hoping that the procedure was successful. Both drives can be anxiety provoking because of their circumstances.

As with all the initial participants, the second round of participants were asked to fill out a survey. They were given the option of accessing the survey online or filling out a paper form. All agreed to complete the online survey. I also contacted the earlier participants to ask if they would fill out the online survey. I explained that I had developed a more comprehensive survey based on their interviews.⁹⁴ All agreed to do so but only a total of three people filled out the online survey, therefore I did not include the findings of the surveys in the results of this dissertation.

The primary source of information for my research is from the conversations I had with the women, and some of their husbands, who used PGD as part of their fertility treatment. I chose to use a semi-structured interview format, however I purposefully encouraged the women to tell their stories in the manner that they felt most comfortable. Some women and their husbands chose to give short answers to the questions I asked, others elaborated on the details of their experience.

The manner in which the women and men framed their responses indicated what was most salient to them. As I started to gather and sort through the stories, patterns of behavior started to emerge. Similar stories were told about fertility history, fertility treatment, and triumphs over infertility. There were stories of heartache and perseverance. Most importantly there was a consistent, unwavering commitment to reach their goal of having a biological child they so desired.

Participants

⁹⁴ Refer to appendix D for more comprehensive survey.

The criterion to participate in this study was that you had to have had a child as a result of a PGD cycle. Only one participant slipped into the research project that did not meet these criteria. I say slipped because initially, Paige led me to believe that her child was a product of PGD. I do not believe this was intentional. She discussed her experience of using fertility treatment and she gave birth to a baby, but it was not her biological child. Her child was conceived using IVF and an egg donor. I believe the confusion came as a result of her not fully understanding the technology she used. I found her discussion of the IVF process to be pertinent and valuable. So in some instances I added her discourse to the discussion.

I chose to interview women who had completed a cycle of PGD because I felt my presences might influence their decisions or change their experience if I had met with them during their treatment. The practice of asking questions during a cycle may alter their awareness about their experience. I was able to observe other patients who were just beginning their fertility treatment and chose to use PGD during the time I shadowed Dr. T at his Ann Arbor office. However, I did not interview these couples.

The first couple I interviewed, Marie and Donald, used PGD because of Marie's balanced translocation. Marie is a 33-year-old Caucasian female. She holds a master's degree in counseling. Her husband is a 39-year-old Caucasian male who has a master's degree and works as a business analyst. They both consider themselves Christian. Prior to having their son, as a result of using PGD, Marie had one miscarriage using IVF alone. This was prior to being diagnosed with a balance translocation. I interviewed Marie and Donald in their home in a suburb of Detroit. Their home is a modest size; two story somewhere around 1500 square feet. There was baby paraphernalia spread throughout the house. My interview with Marie was interrupted when she needed to attend to her son. That is when Donald joined in the discussion.

He was invited at the beginning of the interview but chose to stay in the other room, occasionally interjecting comments. Once Marie brought the baby in the room with us, Donald sat in and participated in the rest of the interview.

Isabel was 38 years old when she gave birth to her son after her first PGD cycle. She is currently 39 years old and her husband, George, is 38 years old. Both are Caucasian and identify as Christians Non-denominational. Isabel works in a laboratory as a color specialist and George is a quality engineer. Isabel had two miscarriages; one conceived the “natural” way and one conceived after using Clomid, prior to the birth of their son. I interviewed Isabel and George in their home. They live in a rural area about an hour south of Toledo. They live in a small home, less than 1000 square feet. Their home was well kept and decorated in a country motif. There was baby paraphernalia spread throughout the house. George chose to sit in the living room and watch the baby while Isabel and I sat in the kitchen. Like Donald, George interjected comments throughout the interview. Although he was watching television in the living room, it was apparent he was listening to our discussion. Towards the end of the interview George had more comments, so Isabel and I joined him in the living room. This also allowed Isabel to interact with their baby.

Monica and Chandler are of Indian descent and practice Hinduism. Monica is 34-years-old and Chandler is 39-years-old, both are engineers. Monica had had two miscarriages from pregnancies conceived the “natural” way prior to using IVF with PGD, which resulted in the birth of their son. I interviewed Monica and Chandler in their home. They live in a fairly new home of modest size in a suburb of Detroit. Their home was very well kept and also had baby items scattered throughout. Monica, Chandler, and their son were present throughout the

interview. Their son was just beginning to pull himself up to standing along side the furniture. He was very interested in my briefcase. He was a very social and happy baby.

Abbey and Sam are also of Indian descent. When asked about their religion neither offered to identify their religion but said they had no personal religious conflict with using PGD. Abbey is 29 years old and Sam is 32 years old. Both were present for the interview, which occurred in their home. They live in a modest sized condominium with their twins, a boy and a girl, which are the results of their use of PGD. Abbey's mother lives with them, also. Their home was sparsely furnished but had a lot of baby paraphernalia spread throughout. It was obvious that there were twins in the house because there was two of every piece of baby furniture. Abbey and Sam were reticent in their responses to the questions. They asked not to have the interview taped and to make sure I disguised their identity. They only agreed to participate if their input could help to make it easier for someone else who may need to use PGD. They used PGD after experiencing two miscarriages using IVF alone.

I interviewed Natasha and Derrick in their home in Northwestern Ohio. Their home is of modest size and well kept. There was not any baby paraphernalia around the house, but there were plenty of toys scattered around. Their daughters are 6 and 2 years old. Natasha is a 32-year-old Caucasian woman and Derrick is a 35-year-old Caucasian male. They had both just gotten home from work and were serving dinner to their two daughters when I arrived at their home. We sat in their kitchen and talked while their daughters ate their dinner. Natasha and Derrick are Christians and attend services regularly. Natasha and Derrick arrived at PGD with a complicated fertility history. Their first child, a boy, died eleven days after his birth. Natasha miscarried her second pregnancy. She got pregnant again and carried this one to full term resulting in a healthy baby girl. She had two more miscarriages prior to using PGD.

Emma is a 34-year-old Caucasian woman who used PGD for family balancing sex selection purposes. She is married to a 35-year-old Caucasian male. They are both practicing Lutherans. I interviewed Emma at her office that is attached to her home. Her husband was not present. Emma lives in a very large home approximately 3,000 square feet or more. She and her husband own a building and real estate business. Emma and her husband had four daughters and wanted a son. They were successful in having a boy with their first PGD cycle. Emma is currently in the process of a second PGD cycle to have another boy. She is hoping to have twin boys this time.

I interviewed Janet at her office. She and her husband own an ancillary health care business. Her husband was not present for the interview. Janet is a 35-year-old woman of Arabic descent. She used PGD to improve her fertility as well as to balance the gender of her family. She and her husband wanted another boy. Janet had one son and two daughters prior to conceiving her second son through PGD. Janet had several miscarriages in between the births of each of her children. Each child was conceived with assistance.

Addison is a 35-year-old Caucasian woman who is currently pregnant with twin girls as a result of PGD. I interviewed Addison at her office. She is a student advisor at a university. She had been having difficulty getting pregnant for four years prior to using PGD. She was unable to get pregnant for several years using intrauterine insemination and ovarian stimulation medication. Addison miscarried during her first IVF cycle.

I met with Hazel and Bill in their home, which was a large two story colonial, located in a prestigious suburb outside of Detroit. Hazel is a 42-year-old Caucasian female married to Bill, a 41-year-old Caucasian male. They consider themselves practicing Christians. Bill is an engineer and Hazel did work outside of the home but now stays home to take care of her children. She and

Bill have 17 month-old twins, a boy and a girl, as a result of using PGD. They have two frozen female embryos that they are planning to have transferred soon. Hazel has just recently started taking the hormone shots to prepare her body for the transfer. Hazel had two miscarriages prior to being successful with PGD. Her first miscarriage occurred after using IVF without PGD and the second miscarriage occurred after using PGD. Bill has three children from a previous marriage. He had a vasectomy that he tried having reversed. The reversal did not work so he had his sperm surgically extracted.

I interviewed Meredith over the phone. She did not want to meet face to face due to time constraints. I did not notice any difference in the manner that Meredith told her story compared to those I interviewed face-to-face. She was very forthcoming with information. Meredith did allow me to tape record her interview, so I had her on speakerphone with a recorder going. I was alone in my home at the time of her interview. Meredith was 29-years-old at the time she used PGD. She is a practicing Catholic. She used PGD for family balancing and sex selection. She and her husband had two girls and one boy. They wanted their son to have a brother. Also, Meredith grew up in a family of two girl and two boys, and wanted the same type of family for her children. The first time Meredith and her husband used PGD they did not produce any healthy male embryos. They discarded all the embryos created during that cycle. They had three healthy male embryos as a result of their second PGD cycle. They transferred one and discarded the rest.

Sienna is a 40-year-old Caucasian female married to Pierre, a 41-year-old Caucasian male. Sienna and Pierre are Christian. I met with Sienna and Pierre in their modest sized two-story home in the evening after the children were in bed. Their home was nicely decorated with antiques. We met in the living room where there were no toys present however there was a baby

gate blocking the entrance that had two steps leading down into the room. Sienna had 5 failed IVF cycles before giving birth to twins after using PGD. During that successful PGD cycle, she had four embryos transferred. Both she and Pierre were hoping that at least three would produce live births. They were happy that two did. They have an older daughter that was a product of a pregnancy conceived through assistance. Sienna was particularly interested in using PGD to discover an explanation for her infertility. They had frozen embryos left over from previous IVF cycles that they discarded.

I met Tina and Brad in their home in Northern Michigan. Tina is a 41-year-old Caucasian woman who was in customer service prior to having her son. Now she is a stay at home mom. Brad is a 47-year-old Caucasian man who works in sales. They were both raised Catholic. They live in a modest size home in a beautiful wooded setting. Tina had two miscarriages prior to having her son from her first PGD cycle. Her first miscarriage occurred after conceiving through coitus and the second occurred after being on Clomid for six months. They had only one healthy embryo as a result of using PGD. That embryo was transferred and continued to develop into a full term pregnancy, giving Tina and Brad their son. Brad has three children from a previous marriage.

Paige is a 42-year-old Caucasian woman. She is a hairdresser and currently has a one-year-old daughter and is pregnant with twin boys. I met with Paige at her home just outside of Lansing, Michigan. She lives in a new subdivision with large newly built homes. Paige's home was very contemporary with leather furniture throughout. There were quite a few toys and infant furniture around the whole downstairs. Her daughter was beginning to walk and was interested in my things. She crawled up into my lap and took my pen. I let her have it and showed her how to scribble with it. Paige commented that she should probably let her play with crayons. The little

girl sat contentedly on my lap for a good portion of the interview. Paige used PGD but was unable to produce any healthy embryos. She used an egg donor combined with her husband's sperm to produce the embryos for her daughter and twin sons. She used the same egg donor for all three children.

The participants of this study are all from the middle class or upper middle class.⁹⁵ Only those who can afford PGD can take advantage of its services. And although many infertile couples and couples who are known carriers of genetic diseases from all socioeconomic levels could benefit from the medical advances of PGD, it is not routinely covered by health insurance providers and is a fee-for-service business, therefore only those who can pay for the service will gain access.⁹⁶ According to Thompson, "a cycle of in vitro fertilization, if paid for out of pocket, costs patients several thousand U.S. dollars and is prohibitive for most people. Because wealthy people have much better access to the procedures than poor people the technologies only selectively increase reproductive choice."⁹⁷ PGD makes visible the stratification of reproductive choice created by the medical system as well as the insurance business. PGD is a manifestation of class.

In addition to interviewing women/couples that used PGD, I also attended two Resolve Meetings. Resolve is a support group for people experiencing infertility. This group promotes all options available to create a family. Kathy Rollinger, president of Resolve Michigan went to bat for me and pleaded my case to the coordinators of both the Resolve

95 For further discussions of the association of class and choice as they relate to NRTs refer to pages 32-34 as well as pages 126-127.

96 Refer to page 115 of this dissertation for costs of IVF and PGD.

97 Thompson, Charis. *Making Parents: The ontological Choreography of Reproductive Technologies*. (Cambridge, Massachusetts: The MIT Press, 2005), 68.

Ann Arbor and Resolve Royal Oak groups. This may not seem like a big task; however both groups were reluctant to have an outsider sit in on their meeting because they had just recently experienced a breach of confidentiality by a news reporter. Listening to the stories of the participants at the Resolve Meetings gave me a greater appreciation for the deep of pain infertility causes. I use some of my observations as a way to provide clarification and understanding about alternatives to having a biological child.

Conclusion

I have chosen to use an ethnographic methodology to gather data to learn more about the experience women and their partner have when they use PGD as part of their fertility treatment. The majority of the data comes from the interviews I did with the women. Some women were interviewed along with their husband. I conducted the interviews after spending six months shadowing a reproductive endocrinologist, observing office procedures and surgeries. I also had the privilege of observing embryologists performing ICSI and preparing embryos for cryopreservation in the laboratory. What is presented in this dissertation is an account of my experience in the fertility clinic and laboratory as well as excerpts from interviews, along with an analysis that positions the women's experiences within a cultural context.

CHAPTER FOUR

THE LIBERATOR: DEFINING PGD

Preimplantation Genetic Diagnosis (PGD) is a new reproductive technology (NRT) that was first used in 1990 as a means of giving couples that are known carriers of a genetic disorder the ability to have a healthy biological baby. Prior to PGD, the only option for such couples was to get pregnant then use prenatal tests to determine if the fetus had the genetic disorder. If the prenatal test confirmed a positive diagnosis, meaning the fetus has the genetic disorder, then the only recourse the woman/couple had was to terminate the pregnancy. Prenatal tests are done sometime near the end of the first trimester to the beginning of the second trimester.⁹⁸ PGD eliminates the need for terminating such pregnancies by testing the embryos created through in vitro fertilization (IVF) and only transferring disease free embryos to the woman's uterus. Although the benefits of PGD are remarkable, the procedure is very complex and associated with controversy.

The Impetus

98 Neil A. MacLachlan. "Amniocentesis," in *Prenatal Diagnosis and Screening*, ed. David J.H. Brock, Charles H. Rodeck, and Malcolm A Ferguson-Smith (London: Churchill Livingstone, 1992), 15.

MacLachlan describes the procedures and techniques used for amniocentesis and refers to the procedure being carried out at 16 weeks gestation. Refer to pages 15 and 16. In addition, Silverman and Wapner refer to the importance of finding a prenatal test that could be performed in the first trimester. CVS testing is performed during weeks 6-14 gestation, page 26.

Silverman, Neil and Ronald J. Wapner. "Chorionic Villus Sampling," in *Prenatal Diagnosis and Screening*, ed. David J.H. Brock, Charles H. Rodeck, and Malcolm A Ferguson-Smith (London: Churchill Livingstone, 1992), 26.

PGD was developed to alleviate the anguish of couples that are carriers of genetic diseases and could not have a disease free child on their own. Prior to PGD, these couples had only one option of having a healthy biological child and that was getting pregnant and being subjected to prenatal testing then terminating any pregnancy determined to be disease ridden. The two prenatal tests most often used to diagnosis the health of a fetus are chorionic villus sampling (CVS) and amniocentesis. CVS is a procedure done towards the end of the first trimester or the very beginning of the second trimester of the pregnancy. Joyce Harper describes the process of CVS in the following manner: “A small piece of the placenta is removed by a transabdominal or transvaginal route and can be used for genetic testing and chromosome analysis.”⁹⁹ CVS gives a woman information about her pregnancy as early on in the pregnancy as possible. This allows women/couples the opportunity to make a decision about aborting the pregnancy well before the woman experiences quickening and, perhaps, bonds with the fetus.

The other most common prenatal test is an amniocentesis. During an amniocentesis, amniotic fluid is aspirated from the amniotic sac then analyzed for genetic disorders.¹⁰⁰ Amniocenteses are performed around the 16th week of gestation¹⁰¹, well past the first trimester, and are now part of the routine medical care for pregnant women over 35 years old. CVS and amniocentesis are performed to give women information they need to make a decision to either continue or terminate their pregnancy. If the results of these tests come

99 Joyce Harper. “Introduction.” in *Preimplantation Genetic Diagnosis*, ed. Joyce C. Harper, Joy D. A. Delhanty, and Alan H. Handyside (Chichester, England: John Wiley and Son, LTD., 2001), 5.

100 Ibid., 5.

101 For more information regarding the timing of amniocenteses refer to footnote 90.

back positive, meaning the fetus is affected by a disorder, then their only recourse to ensure having a healthy child is to terminate this pregnancy and try again. This option is difficult for some and unacceptable for other women. By the time an amniocentesis can be performed, the pregnancy has progressed quite a ways and the pregnant woman has begun to experience quickening. According to Gina Maranto,

As has often been noted, the psychological impact of deciding to abort a damaged conceptus or one carrying deadly disorders can be profound, especially if quickening has occurred, as it generally does around the time women undergo amniocentesis. In the weeks between the sampling of the amniotic fluid and the arrival of results from the test, the fetus will have begun to move, which for many women marks the beginning of recognition of the fetus as an individual.¹⁰²

By the time a woman has an amniocentesis, her pregnancy has become very real to her. Her body has gone through many changes and the pregnancy is evident. Generally, bonding with the fetus has begun. However, woman who anticipate having an amniocentesis hesitate to bond, and often are ambivalent toward their pregnancy. The time period between having the amniocentesis and getting the results can be quite agonizing, sometimes taking up to four weeks.¹⁰³ These women often hesitate to become fully engaged and invested in their pregnancy until they know the results of their amniocentesis and have made the decision about the fate of their fetus. Barbara Rothman refers to this experience as the “tentative pregnancy”. According to Rothman, “the problem, or one of the problems, with the

102 Gina Maranto. *Quest for Perfection: The Drive to Breed Better Human Beings* (New York: A Lisa Drew Book/Scribner, 1996), 269.

103 MacLachlan, “Amniocentesis” 15. MacLachlan describes the culturing technique and says, “The mean number of days to harvest the cultured cells when taken at 16 weeks is approximately 12 days, with a result being available in most units by 3-4 weeks.” 15.

technology of amniocentesis and selective abortion is what it does to us, to mothers and to fathers and to families. It sets up a contradiction in definitions. It asks women to accept their pregnancies and their babies, to take care of the babies within them, and yet be willing to abort them.”¹⁰⁴ She goes on to explain the dilemma, “If it is healthy, if it is genetically acceptable, then it is a person, her baby. If it is not, then it is just a fetus, a genetically damaged fetus.”¹⁰⁵ Labeling the fetus in this manner makes it easier to make a decision to terminate the pregnancy. A label of genetically damaged fetus justifies terminating the pregnancy and signifies an ideology that privileges humans that are genetically healthy.

The decision to continue or terminate a pregnancy is complicated and influenced by the circumstances of the woman’s life. Rapp found that the women in her study experienced the most conflict when they considered their own needs as an important aspect in their decision making process. In her work, Rapp described how these women talked about their decision to abort a disabled fetus as a continuous battle between selfishness and self-actualization:

Virtually all of the women I interviewed from this group.... Provided critical exegeses on the tension between “selfishness’ and self-actualization,’ melding their right to abort a disabled fetus and their right to plan an adult, working life. Their discourse revealed something of the limits of self-sacrifice that mothers are alleged to embody.¹⁰⁶

104 Rothman, *The Tentative Pregnancy*, 6.

105 Ibid., 6. Rothman argues that aborting an unwanted pregnancy signifies women valuing motherhood. She argues, “Women’s willingness to use abortion for unwanted pregnancies has been perceived as a devaluing of motherhood. That it is not. On the contrary, it is because women continue to take motherhood so very seriously that abortion is necessary. Women understand motherhood to change their lives, to involve a deep and permanent commitment.”,5.

106 Rapp, *Testing Women*, 138.

Rapp's work demonstrates the difficulty women have with making the decision to either continue their pregnancy or abort their fetus after a positive diagnosis is made. These women are exactly the women who could benefit from PGD. PGD eliminates the "tentative pregnancy" time and the need to terminate a pregnancy. PGD is used to ensure the production of a genetically disease free child.

According to Munthe, the benefit of PGD, "...is claimed to be that it makes possible the same kind of selection of offspring on genetic grounds as prenatal diagnosis, except that, with successfully performed PGD, abortion need not be considered"¹⁰⁷ PGD is offered as an alternative way for the women/couples, who are known carriers of a genetic disease to have a healthy child without experiencing the anguish of terminating a pregnancy.

In the Beginning

Alan Handyside first used PGD in 1990. Handyside, collaborating with Robert Watson, performed the first successful application of PGD on a human embryo at London's Hammersmith Hospital.¹⁰⁸ According to Gregory Stock, the two men performed PGD by "teasing a single cell from each of several eight-cell embryos and testing the gender of the cells, so they could implant a female embryo and avoid a sex-linked disorder that occurred only in males."¹⁰⁹ Single gene disorders are inherited and tend to run in families. According to the Reproductive Genetic Institute website, the clinic founded by Yury Verlinsky, "Single

107 Christian Munthe. *Pure Selection: The Ethics of Preimplantation Genetic Diagnosis and Choosing Children without Abortion* (Goteborg, Sweden: ACTA Universitatis Gothoburgensis, 1999), 81.

108 Franklin and Roberts, *Born and Made*, 52.

109 Gregory Stock. *Redesigning Humans: Our Inevitable Genetic Future* (Boston: Houghton Mifflin Company, 2002), 56.

gene disorders are genetic conditions caused by the alteration or mutation of a specific gene in the affected person's DNA."¹¹⁰ A few of the single gene disorders are, cystic fibrosis, sickle cell anemia, Tay- Sachs, and Fragile X syndrome.¹¹¹

PGD is the term used to define the process that genetically tests an embryo created through in vitro fertilization. There are two ways in which PGD occurs. One is by testing the polar bodies to determine the maternal contribution to the genetic makeup of the embryo. Polar bodies are by products of the maturation process of unfertilized eggs. They can be removed without ill effects.¹¹² The other method is by removing one or two blastomeres (cells) from an embryo once it has reached the six to ten cell stage. This method gives information regarding both the maternal and paternal contribution to the developing embryo.¹¹³ Both methods have advantages. Once the genetic health is determined, only the genetically sound embryos are prepared for transfer to the woman's uterus. One or two embryos are then transferred as part of her IVF cycle.

110 Reproductive Genetic Institute, "Single Gene Disorders"

http://reproductivegenetics.com/single_gene.html

(accessed October, 5, 2010).

111 For a complete list of the single gene disorders tested through PGD refer to Reproductive Genetic Institute at

http://reproductivegenetics.com/single_gene.html#singlegene

112 Carl Wood and Alan O. Trounson, "Historical perspectives of IVF." in *Handbook of In Vitro Fertilization*, second edition, ed. Alan O. Trounson and David K. Gardner. (Boca Raton, Florida: CRC Press LLC, 2000), 7.

113 Reproductive Genetic Institute, "What is PGD"

<http://www.reproductivegenetics.com> (accessed October, 5, 2010).

Reproductive Genetics Institute's website gives an understandable description of PGD. RGI was founded by Yury Verlinsky; a pioneer in assistive reproductive technologies.

PGD is an added service done in conjunction with IVF. IVF is the process that fertilizes ovum with sperm outside the body. IVF was first successfully performed in humans in 1978 with the birth of Louise Brown in London, England. Patrick Steptoe and Robert Edwards¹¹⁴ were the first to successfully perform IVF after years of research using laboratory animals.¹¹⁵ IVF has been successful in helping many women and men overcome infertility. A couple is considered infertile if they are unable to become pregnant after trying without assistance for one year, regardless of whether they have gotten pregnant in the past, either together or with other partners.

Often when a woman/couple go to see a fertility specialist, they have been to other physicians who have run diagnostic tests to determine a cause for their infertility. After the first appointment with the fertility specialist, some tests will need to be redone if the results are not current or well documented. Prior to starting fertility treatment, such as IVF, the fertility specialist thoroughly examines the woman to try to identify a cause of the infertility. The examination includes blood work to check for anemia, as well as rule out any infectious diseases. The man also goes through a series of tests including blood work and a semen analysis.¹¹⁶ In some cases there is no identifiable cause for the couple's infertility.

114 Robert Edwards was recently awarded the 2010 Nobel Prize for Medicine for pioneering IVF. Patrick Steptoe is deceased therefore he is ineligible for the prize.

115 Wood and Trownson. "Historical perspectives of IVF." 3. For a list of events that led to the development of IVF refer to Wood and Trownson pages 9-10.

116 Gillian Graves and Carl Wood. "IVF Patient Preparation." in *Handbook of In Vitro Fertilization*, second edition, ed. Alan O. Trownson and David K. Gardner (Boca Raton, Florida: CRC Press LLC,

Once it has been determined that the couple are good candidates for IVF, the woman will begin to take prescription vitamins three months prior to IVF to help prevent neural tube defects.¹¹⁷ Then the woman begins to inject follicle-stimulating hormones to stimulate her ovaries to produce many follicles. The fertility specialist monitors the size of the follicles through ultrasound to determine when the eggs will be ready for retrieval.

Once the follicles have grown and the eggs are ready to be removed, a retrieval date is set. The eggs are retrieved during a surgical procedure. The woman is under general anesthesia while a needle travels through her uterus then is inserted into her ovaries to extract the eggs. The doctor inserts the needle with the assistance of a transvaginal ultrasound.¹¹⁸ As the eggs are removed and placed in vials, the vials are taken to the lab where an embryologist counts the eggs retrieved. Once all the eggs are retrieved, the surgery is complete. The woman is sent to recovery where she stays until she is ready to go home.¹¹⁹ At this time, her job, for now is complete. Now the embryologist takes over and creates her embryos.

The embryologist works in the laboratory preparing the egg and sperm for fertilization. Once all is prepared, the embryologist uses a technique known as intracytoplasmic sperm injection (ICSI) to fertilize the egg. ICSI uses micromanipulation

2000), 16. Graves and Wood. For a complete listing of the recommended diagnostic tests refer to Graves and Wood page 16-17.

117 Ibid., 17.

118 Ariff Bongso and Alan O. Trounson, "In vitro fertilization" in *Handbook of In Vitro Fertilization*, second edition, ed. Alan O. Trounson and David K. Gardner (Boca Raton, Florida: CRC Press LLC, 2000), 128.

119 This is a description based on my observations of several retrievals.

techniques to fertilize one egg with one sperm as opposed to putting several sperm in a prepared petri dish with one egg and letting the sperm swim to the egg for fertilization. Reproductive Genetic Institute describes ICSI in this manner, “ICSI is performed by an embryologist, who mechanically inserts a single sperm into each egg. This is done by perforating the membrane of the egg with a glass pipette, which contains the sperm and it requires highly developed skills.”¹²⁰ The egg is held in place with a vacuuming pipette then a sperm is siphoned up a needle then injected into the egg. According to Verlinsky and Kuliev, “ICSI is required for PGD for single-gene disorders to avoid sperm cell contamination when performing polar body removal or embryo biopsy.”¹²¹ ICSI is also performed when there are only a few useable sperm available.

PGD is performed once the egg is successfully fertilized and has developed into an embryo. The description of PGD by the Reproductive Genetic Institute is as follows:

On the third day following fertilization, the embryo is at the cleavage stage, and a cell may be carefully removed for genetic analysis. With the embryo maintained in position by gentle suction from the holding pipette, an opening in the outer shell called the zona pellicula is made using a micro needle. Afterwards a new micropipette is used to remove a cell by means of aspiration. At this early stage of embryo development, all of the cells have the same potential for development, therefore, removal of a cell from the embryo is not detrimental and the embryo should continue to develop following the procedure. The cells that have been removed are then tested for a particular genetic disorder.¹²²

120 Reproductive Genetic Institute, “ICSI,” <http://www.reproductivegenetics.com/icsi.html> (accessed October 6, 2010).

121 Yury Verlinsky and Anver Kuliev. *Atlas of Preimplantation Genetic Diagnosis*, second edition (Abingdon, United Kingdom: Taylor and Francis Group, 2005), 19.

122 <http://www.reproductivegenetics.com/icsi.html> (accessed October 6, 2010).

It takes a team of highly trained specialists to complete PGD successfully.

The cells removed from the embryo during PGD are amplified and copied using a DNA copying technique called polymerase chain reaction (PCR). According to Verlinsky and Kuliev, “Genetic analysis in single cells, allowing performance of PGD for single-gene disorders, became possible after the introduction of the polymerase chain reaction (PCR) technique, which is an in vitro technique for the amplification of specific DNA sequences. PCR is a cycling process in which the number of DNA targets doubles in each cycle.”¹²³ PCR has improved the accuracy and proficiency of PGD.

Once biopsy has been done and PGD is completed, healthy embryos will be transferred back into the woman. The transfer occurs either three or five days after fertilization.¹²⁴ The woman/couple learn about their embryos’ status just moments prior to the transfer. The woman is prepared for the transfer and is lying on the gurney when she is given this information. She and her partner are given a written report of the genetic health of the embryos as well as the sex of each embryo. This is the first time the woman/couple are made aware of the number of healthy embryos they have as well as the genetic makeup of their embryos. Now they must make the decision as to which embryos to have transferred

123 Verlinsky and Kuliev, *Atlas of PGD*, 49-50.

124 Lynette Scott discusses the criteria to determine the difference between transferring a 3 day embryo versus a 5 day blastocyst on pages 361-366.

Lynette Scott, “The Biological Basis of Oocyte and Embryo Competence: Morphodynamic Criteria for Embryo Selection in In Vitro Fertilization.” *In Essential IVF Basic Research and Clinical Applications*, edited Jonathan Van Blerkom and Linda Gregory (Boston: Kluwer Academic Publishers, 2004), 361-366.

and what to do with the extra embryos, if indeed there are any. According to Graves and Wood, “A decision about the number of embryos transferred depends on local regulations as well as patient preference. Most centers no longer transfer more than three embryos and some restrict to two. The chance of pregnancy increases with the number of good quality embryos transferred, and the risk of multiple pregnancy must be balanced against this.”^{125 126} Often women/couples will look to their doctor for advice. The doctor will give his/her preference based on which embryo is believed to have the best potential to become a “take home” baby.

Prior to PGD embryos were selected based on visual analysis. According to Stuart Lavery, “In most IVF units embryos are selected for transfer on a combination of morphological characteristics (which include number of pronuclei, nucleolar orientation, number and appearance of blastomeres, degree of fragmentation) and rate of cell division. However, we have known for many years that normal-looking embryos can be chromosomally abnormal.”¹²⁷ Many IVF cycles were quite successful using visual analysis, however, some women had frequent implantation failure after IVF using what appeared to be good quality embryos. What scientist found was that an embryo could look healthy and seem to be a good candidate to transfer but for some reason would not implant or maintain to a full-term pregnancy. Later, it was discovered that some of these embryos had a genetic

125 Graves and Wood. “IVF Patient Preparation,” 29.

126 At the time I was conducting this research, the physicians at the clinic where I observed were involved in a study that looked at the correlation between success rate and transferring only one embryo for a distinct population.

127 Stuart Lavery, “Preimplantation genetic screening: do we need a degree of caution?” *Obstetrics, Gynecology and Reproductive Medicine* 17:10 (2007): 305.

disorder. In many cases the genetically compromised embryos were found to be aneuploidy. Aneuploidy is the condition where an embryo has too many or too few chromosomes.¹²⁸ According to Lavery, “It has been suggested that in women of advanced maternal age up to 50% of embryos may be aneuploidy, and similarly high rates have been found in younger women who experience continued implantation failure after many IVF attempts.”¹²⁹ What Lavery is suggesting is that aneuploidy is to blame for the lack of getting pregnant for many women who used IVF with what appeared to be healthy embryos.

During the embryo transfer, the woman is wide-awake and completely aware of the proceedings. The process of the embryo being transferred is displayed on an ultrasound monitor and both the woman and her partner can watch their embryos being placed in the uterus. After the procedure, the woman is monitored at the clinic for a period of time until she is ready to leave. She is told to go home and rest, and encouraged to take it easy for the rest of the day. She is also told not to take a home pregnancy test because the hormones in her body will give her a false reading. A pregnancy test will be performed at the doctor’s office sometime between one to two weeks after the transfer. If a pregnancy is confirmed, the fertility specialist will monitor the woman during her first trimester. After that time, her obstetrician will care for her for the remainder of her pregnancy.

Who uses PGD?

A decision to use or reject PGD requires a firm understanding of its ethical issues, medical risks, and statistical outcomes. Navigating a path of comprehension about PGD is complicated by personal struggles of those using this technology. Women/couples, who use

128 Reproductive Genetic Institute, “Infertility Glossary,” <http://reproductivegenetics.com/glossary.html> (accessed July 21, 2010).

129 Lavery, “Preimplantation Genetic Screening,” 305.

PGD, come to the process after having either a personal experience with the genetic disease they knowingly carry or have had a long, complicated history with infertility. They may have had many miscarriages or years of trying to get pregnant without success. According to Basille et al.:

The couples asking for PGD procedure are firstly known to have a traumatic obstetrical history: birth of a child with genetic disease or previous termination of pregnancy after chorionic villus sampling (CVS) or amniocentesis. Secondly, they are couples with genetic disease, either known from family cases or from abnormality discovered during male infertility investigations (chromosomal imbalances, or CFTR mutation in patients with bilateral absence of vas deferens).¹³⁰

The couples Basille et al. describe are those who were the initial consumers of PGD. In 1990 when Alan Handyside first introduced PGD, it was still considered an experimental procedure to be used to assist couples that were known carriers of a single gene disorder, such as cystic fibrosis and Huntington's chorea, have a disease free healthy baby. In the early days, PGD was used to test the embryos created through IVF from the couple's own gametes for the specific disease they were known to carry. Only the embryos that PGD confirmed were disease free were transferred back to the woman's uterus. By using PGD in this manner, women/couples are guaranteed to have a baby without the specific genetic diseases the embryos were tested for, assuming the pregnancy is carried to full term. The other embryos marked as having the genetic disease are discarded.

The technology has continued to improve and the number of genetic diseases that can be detected in an embryo has increased. More women/couples who are known carriers of genetic diseases can now be assisted in having a healthy child. In Verlinsky and Kuliev's research they

130 Claire Basille and others, "Preimplantation genetic diagnosis: State of the art." *European Journal of Obstetrics and Gynecology and Reproductive Biology* 145 (2009): 11.

found that “the list of disorders for which PGD has been applied, according to our experience, now comprises close to 100 conditions, with the most frequent ones still being cystic fibrosis (CFTR), haemoglobin disorders, and some of the dynamic mutations.”¹³¹ Not only has the list of conditions tested for expanded but the number of cases has also expanded. Verlinsky and Kuliev noted in 2005,

The number of apparently healthy children born after PGD is already close to 2000, validating that there is no ostensible evidence of any incurred adverse effect. Approximately 7000 PGD cases have been performed in more than 50 centres around the world, allowing hundreds of at-risk couples not only to avoid producing offspring with genetic disorders, but more importantly, to have unaffected healthy babies of their own without facing the risk of pregnancy termination after traditional prenatal diagnosis.¹³²

Two years after Verlinsky and Kuliev made these calculations about PGD, both the application and the number of couples who used the technique rose dramatically. Philip Reilly noted that according to the Preimplantation Genetic Diagnosis International Society (PGDIS), “PGD has been provided to more than 30,000 patients at risk for bearing children with more than 170 different genetic disorders.”¹³³ These numbers indicate that more clinics are offering PGD services to their patients, and couples who are known carriers of genetic diseases now know of the availability of this technique. As word gets out about the success of PGD, more woman/couples will opt to use PGD as part of their fertility treatment.

131 Verlinsky and Kuliev. *Practical PGD*, 29. There are currently well over 100 genetic disorder which can be diagnosed using PGD. A complete list is on the website of Reproductive Genetic Institute. <http://www.reproductivegenetics.com/>

132 Ibid., 7.

133 Philip Reilly. *The Strongest Boy in the World: How Genetic Information is Reshaping our Lives* (New York: Cold Spring Harbor Laboratory Press, 2008), 246.

Initially, PGD was only used for women/couples that were known carriers of genetic diseases. The use of PGD has expanded to other women/couples that are experiencing fertility problems. According to Joyce C. Harper and Gary Harton, indications for PGD include, “patients with advanced maternal age, repeated miscarriage, repeated implantation failure, and severe male factor infertility.”¹³⁴

The application of PGD began to expand as providers of IVF saw its potential to benefit their patients who continually had miscarriages. Doctors were treating women who were able to get pregnant through coitus without difficulty but were unable to carry the pregnancy to term. Some of these same women also miscarried after conceiving through IVF. These women experience multiple miscarriages throughout their life and often are never able to carry a pregnancy to full-term. Doctors discovered that a condition known as aneuploidy seemed to be the cause of so many miscarriages. Aneuploidy is the “major contributor to spontaneous abortion and implantation failure,” according to Verlinsky and Kuliev.¹³⁵ Aneuploidy is a condition that occurs when an oocyte does not go through meiosis properly and ends up having either too few or too many chromosomes. When a fetus is conceived from an oocyte with aneuploidy a spontaneous abortion may occur or the fetus may result in a baby born with a genetic disorder. One of the most commonly occurring aneuploidy is Trisomy 21 known as Down Syndrome, where an extra chromosome 21 is present. Aneuploidy can occur in any pregnancy, however the chances of it occurring increase with the maternal age.¹³⁶

134 Joyce C. Harper and Gary Harton. “The Use of Arrays in Preimplantation Genetic Diagnosis and Screening.” *Fertility and Sterility* vol. 94, no. 4 (September 2010): 1173.

135 Verlinsky and Kuliev, *Atlas of PGD*, 1.

136 Harper, “Introduction,” 5.

IVF practitioners have found that using PGD with women who have experienced multiply miscarriages has improved the likelihood of carrying the pregnancy to term. PGD is used to test the embryos for aneuploidy. Then, only the embryos that are determined to be free of aneuploidy are transferred to the woman's uterus. According to Reilly, testing for aneuploidy is "the most rapidly growing application of PGD."¹³⁷ Reilly goes on to say that because of the incidence of disabilities associated with aneuploidy, such as Downs Syndrome, physicians are considering testing all embryos created by IVF.¹³⁸ According to Verlinsky and Kuliev, back in 2005 "more than two thirds of the procedure (PGD my insert) to date have been performed for age related aneuploidy."¹³⁹

IVF practitioners found that PGD could also be used to assist couples that were unsuccessful with IVF for unknown reasons. According to Verlinsky and Kuliev, "the greatest numerical impact of PGD is in standard assisted reproduction, where improved IVF efficiency through aneuploidy testing is evolving to become standard practice."¹⁴⁰ Live birth rates have increased since the addition of PGD for women of advanced maternal age who previously had little or no success with IVF. According to Verlinsky and Kuliev, "The overall pregnancy rate per transfer is much higher than in IVF patients of comparable age."¹⁴¹ Verlinsky and Kuliev attribute this statistic to the improved method of embryo selection. They go on to say, "Widespread confirmation of these results would indicate that the current IVF practice of transferring embryos based solely on morphological criteria is inefficient and in need of revision, given that half of these embryos are chromosomally abnormal and would compromise

137 Reilly, *The Strongest Boy*, 243.

138 Ibid., 243.

139 Verlinsky and Kuliev, *Atlas of PGD*, 1.

140 Verlinsky and Kuliev, *Atlas of PGD*, X.

141 Ibid., IX.

outcome.”¹⁴² Verlinsky and Kuliev are suggesting that PGD become standard practice when using IVF to treat infertility.

Another use of PGD is to create a “donor” or “savior” sibling. Parents who have an ill child in need of a tissue donation have the option of using PGD to produce an exact matching sibling. According to Katrien Devolder:

PGD has been used to enable families to have a child that is a tissue match for an existing sick sibling in need of an allogeneic haematopoietic stem cell (HSC) transplantation. HSCs are blood forming cells found in the bone marrow, the peripheral blood and the umbilical cord blood. For several lethal malignant disorders and also for some non-malignant disorders bone marrow or blood cell transplantations are currently the only therapeutic approach.¹⁴³

Only an embryo with the exact match to the older sibling will be transferred to the woman’s uterus. This application has the lowest success rate of producing a baby because there may not be an exact match from any of the embryos created, therefore no embryos would be transferred to the woman’s uterus during that cycle. Not only does PGD offer this couple a chance to save their older child, but it also allows them a chance to have a disease free child.

This use of PGD has unique ethical concerns for two reasons: 1. The donor child may not be valued as an individual, 2. Healthy unused embryos will be discarded. There is great concern that the donor sibling will be seen as merely a means to the parents’ desired end. A child growing up with the understanding that he/she was created merely to save their sibling could feel unwanted and become psychologically harmed. This child may feel an overwhelming sense of responsibility for his/her sibling’s health. This could be a burden too large for a child to bear.

142 Ibid., IX.

143 Katrien Devolder. “Preimplantation HLA typing: Having Children to Save our Loved ones.” *Journal of Medical Ethics*, Vol. 31, No. 10 (Oct., 2005), 582.

The other ethically concern directly related to this application of PGD is the understanding that there may be healthy embryos discarded. Couples wanting to have a child who will become a donor for their other child are not concerned about having just any healthy child. They want only the specific healthy child they need to save their other child. Carrying an embryo to term that does not match their older child, puts the cure for their child about a year behind. In some cases waiting a whole other year would make the cure too late to save their child's life.

In addition to the applications of PGD previously described, there is still another application, which is beginning to get more use. Couples who have had no history of miscarriages or fertility problems are now using PGD to choose the sex of their child. Couples create embryos from their own gametes and transfer only the embryos of their preferred sex back to the woman's uterus. Some couples use this method because one sex is preferred over another based on their values. For other couples, using PGD in this manner allows them to balance the gender of their family when the scale is tipped in favor of one gender over the other. Just as in the "donor sibling" scenario, this application only works if an embryo of the desired sex is created. The implication of such strict criteria for use of an embryo implies that if that criterion is not met, regardless of the health of the embryo, it will be discarded. Therefore, like the "donor sibling" use of PGD, healthy embryos may be discarded.

Another application of PGD that may become more prevalent in the future, and is raising concern, is testing for late onset genetic diseases. Couples who have a familial history of genetic disorders that have an adult onset, such as Alzheimer's disease, could have their embryos tested and transfer only those deemed disease free. These couples would be assured of not passing on this particular disease. According to Verlinsky and Kuliev, this application became available in

1999 and had not been previously considered. “ For patients with an inherited pathological predisposition this option provided realistic grounds for undertaking pregnancy, with a reasonable chance of unaffected offspring.”¹⁴⁴

The controversy surrounding this application of PGD stems from the fact that late onset diseases never present at birth and are not realized 100% of the time. Verlinsky et al. acknowledges the concern with this use of PGD, however he says, “because there is currently no treatment for AD [Alzheimer’s disease], which may arise despite presymptomatic diagnosis and follow-up, PGD seems to be the only relief for at-risk couples...”¹⁴⁵ Until effective treatment for adult on-set diseases such as Alzheimer’s is developed, PGD is the only solution for couples to avoid passing on the disease to their biological child.

Embryo Selection

Often, there are extra embryos created as part of an IVF cycle, with or without the use of PGD. Creating excess embryos increases the odds that at least one embryo will be transferrable. In the event that there are several transferrable embryos, the woman/couple must choose which embryo/s to have transferred and decide the fate of the unused embryos. The Society for Assisted Reproductive Medicine and the American Society for Reproductive Medicine have guidelines regarding the number of embryos that should be transferred based on the woman’s age and her medical status. These guidelines are made in an attempt to reduce multiple gestations thereby

144 Verlinsky and Kuliev, *Atlas of PGD*, X.

145 Verlinsky and others, “Preimplantation Diagnosis for Early-Onset Alzheimer Disease Caused by V717L Mutation.” *JAMA* 287, no 8 (2002), 1021.

minimizing the medical complications associated with multiple births for the mother and babies.¹⁴⁶

Deciding which embryo/s to transfer may seem like a daunting task if all embryos are indeed equal. When PGD is not used, embryos are selected based on morphology and development. With the advent of PGD, the genetic makeup of the embryo, including the sex of the embryo, along with the morphology and development are used to determine the viability of the embryo. With all the information available regarding the embryo, deciding which to transfer is sometimes quite evident. In some cases there may be only one embryo that is clearly more viable than all the others. Physicians and embryologist most often recommend which embryo/s to transfer based on their expertise and experience, but ultimately, the woman/couple must decide which embryo to transfer. A conflict can arise when there are more than two embryos of equal quality and only two will be transferred. Which two embryos to choose and which to leave behind can cause a conflict for the woman/couple. Their decision will reflect their values, some they may not have even considered prior to this moment. Science and medical expertise is available to assist these couples with their decision. The physicians, embryologists, and patients all have the same goal in mind when deciding which embryo to transfer: choose the embryo that appears to have the best chance of becoming a healthy baby.

Women/couples who have extra healthy embryos can opt to have them frozen for later use. According to Fenwick, frozen embryos give a woman/couple an “emotional cushion” while

146 Robert J. Stillman, “A 47-Year-Old Woman With Fertility Problems Who Desires a Multiple Pregnancy” *JAMA*, 297, no 8 (February 2007): 858-859. Also refer to embryo transfer guidelines on page 862.

going through the IVF process.¹⁴⁷ In the back of their mind, these women/couples know that if their current IVF cycle does not result in a baby, then they can use the embryos waiting in reserve for another chance. Having frozen embryos means the next cycle will be less costly and less medically involved than the previous one. The woman will not have to be injected with hormones to produce hyperovulation nor will she have to go through an egg retrieval. In addition, the fertilization process will not need to occur.

A decision to freeze the excess embryos comes with an understanding that a decision to determine the final fate of the embryos will come at a later time. Women/couples pay about \$500.00 a year to their clinic to maintain their frozen embryos.¹⁴⁸ Clinics are free to set their own policy on the handling of frozen embryos.¹⁴⁹ Their policy is typically discussed with the woman/couple prior to the inception of IVF and PGD. The policy stipulates cost, duration of storage, decision-making time frames, and ownership of embryos.

Eventually a final decision will need to be made regarding the frozen embryos. The clinic may contact the woman/couple informing her/them that a decision needs to be made about

147 Lynda Beck Fenwick, *Private Choices, Public Consequences: Reproductive Technology and the New Ethics of Conception, Pregnancy, and Family* (New York: Dutton, 1998), 187.

148 Nachtigall and others, "What do patients want? Expectations and Perceptions of IVF Clinic Information and Support Regarding Frozen Embryo Disposition." *Fertility and Sterility* (2010), 2. In their research, Nachtigall et al. found the average price of freezing and maintaining embryos is \$495.00 per year with the cost ranging from \$100.00-\$1,500.00.

149 John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton: Princeton University Press, 1994), 104.

her/their frozen embryos. Nachtigall et al. found the participants in their research relied on the direction of their physician when making a decision about the fate of their frozen embryos. According to Nachtigall, “Participants looked directly to their clinics and physicians for skilled, informed, personal guidance because they had established a trusting relationship during the IVF process and believed that physicians had greater access to relevant information.”¹⁵⁰ The decision regarding the fate of the embryos is embedded in layers of meaning. On one level the decision represents the woman’s/couple’s ideology of ensoulment and moral status given to an embryo, on another level it signifies one’s idea about parenthood and ownership. By relinquishing the role of making the decision to the physician, the outcome may be more representative of the physician’s values than the woman’s/couple’s.

There are only four options regarding the future of frozen embryo/s. It can be decided that the woman/couple will use them for a transfer at a later date, donate the embryos to another woman for use, donate to research, or discard. A moral dilemma only arises when the embryo is given full human status and given a fate of being discarded or donated to research where it will be destroyed. When making the decision about the fate of the embryo/s, the woman/couple must have an idea of the status they place on their embryo/s. The woman/couple is considered the owner/s of the embryo and therefore must determine what to do with the extra embryo/s. Clinics have acquiesced on the side of the law and the law states that the gamete providers own the embryos. According to Robertson, “The court assumes without question that embryos are the property of the gamete providers and finds that any transfer of their dispositional authority must be explicitly stated in the documents of participation provided by the program.”¹⁵¹ As property owners of the embryo/s, the woman/couple need to be prepared to make the decision about the

150 Nachtigall and others, “What do patients want?” 2.

151 Robertson, *Children of Choice*, 106.

future of extra embryos prior to knowing if there are any extra embryos. There is no time for deliberation when the decision needs to be made. The woman/couple will need to decide which embryo/s to transfer and what to do with the excess embryo/s just before the transfer. This is a very emotional time. At this moment in the IVF cycle, the woman is lying on a gurney and about to be impregnated with her embryo/s. Under these circumstances, it is very difficult to make such an important decision. For many woman/couples this is a novel experience with major consequences.

Embryo Status

The decision to either discard or donate the embryo/s to research comes with the understanding that the embryo/s will be destroyed. Destroying an embryo is charged with a moral dilemma if the embryo is given the same moral status as a sentient human. There are varying degrees of moral status imposed upon embryos. According to Robertson, the main ethical positions regarding the status of an embryo are: 1) At one extreme is the view of the embryo as a human subject after fertilization, which requires that it be accorded the rights of a person. 2) At the opposite extreme is the view that the embryo has a status no different from that of any other human tissue, and can be treated accordingly. 3) The most widely held view of embryo status takes an intermediate position between the other two. It holds that the embryo deserves respect greater than that accorded to other human tissue, because of its potential to become a person and the symbolic meaning it carries for many people.¹⁵² Kaplan and Tong further describe the rationale supporting the position that Robertson describes in claim one. They turn to natural law theorist to define the full protectionist position:

Preimplantation embryos have the same moral rights as adult persons. ...By virtue of the simple fact that an individual is a Homo sapiens, she or he is far more than

152 Ibid., 102

a mere human being; rather, she or he is a potential human person – that is a human being with a capacity for sentience, self-consciousness, the ability to communicate and rationality.¹⁵³

Full protectionists contend that from the moment of conception embryos are given full human rights because of their potential to become a human. On the opposite end of the spectrum are the non-protectionists that Kaplan and Tong describe in the following manner: “Non-protectionists have no objections either to experimenting on existent surplus embryos or to creating embryos deliberately for experimental uses. As they see it, only self-aware human beings can have interests, including the interest not to be used as an experimental subject.”¹⁵⁴ People typically adopt one of the three positions. The decision regarding the fate of an embryo signifies ones position regarding the moral status of an embryo at the time the decision is made.

Embryos donated to research may be used for embryonic stem cell research. Scientists researching embryonic stem cells justify the destruction of the embryos by promising great discoveries of cures for diseases. According to Ben-Yosef, Malcov, and Eiges, the value of embryonic stem cells is “Human embryonic stem (hES) cells carrying specific mutations can be used as a valuable tool for studying genetic disorders in human. One favorable approach to obtain such mutant ES cell lines is their derivation from affected preimplantation genetic diagnosed (PGD) embryos”.¹⁵⁵ Scientists are researching the use of pluripotent cells, which are

153 Lawrence J. Kaplan and Rosemarie Tong, *Controlling Our Reproductive Destiny: A Technological and Philosophical Perspective* (Cambridge: The MIT Press, 1996), 268.

154 Ibid., 275.

155 D. Ben-Yosef and others, “PGD-derived Human Embryonic Stem Cell Lines as a Powerful Tool for the Study of Human Genetic Disorders.” *Molecular and Cellular Endocrinology* 282 (2008):153.

found in embryos and have the potential to become “practically any cell in the body.”¹⁵⁶ Through human embryonic stem cell research, scientists have the potential to discover the exact make-up of genetic diseases then develop gene therapies to cure the disease.¹⁵⁷

The destruction of an embryo is equivalent to abortion to those who believe life begins at conception. It is the opinion of this group of people that regardless of whether conception happens in vivo or in vitro, as soon as the egg is fertilized with sperm the resulting entity should be revered and graced with the same moral status as humans. Therefore deliberately destroying an embryo, thus not allowing it the chance to develop to a full human, is tantamount to abortion. To these people, an embryo has the same status and should be given the same regard as a sentient human.

There are arguments that support the dissociation of the destruction of embryos with abortion. According to Reilly, the destruction of embryos should not be considered the same as abortion:

Because extrauterine fertilization creates a conceptus that cannot attain full humanhood unless it is placed in the womb, it is possible to argue that its destruction is not tantamount to abortion. Indeed, to argue that an unimplanted human blastocyst has the moral worth of an infant risks defining a human as nothing more than a diploid set of genes, for a frozen conceptus is little more than this.¹⁵⁸

Reilly’s argument makes the point that giving an embryo the status of a human minimizes the significance of what it means to be human. He is saying that humans are more than their genes.

Fenwick adds support to the argument that dissociates abortion with PGD by stating:

156 Ibid., 153.

157 Ibid., 157.

158 Reilly, *The Strongest Boy*, 242.

The arguments surrounding respect for human embryos in assisted reproductive technologies share many common points with those made in the abortion debate, but significant differences separate the two situations. Abortion is motivated by an intention to terminate a potential life; assisted reproduction is motivated by a desire to create a life that, in the absence of technologies to assist the couple, would probably not otherwise occur.¹⁵⁹

Fenwick's argument supports the destruction of embryos based on the motivation of the users not on the moral status of embryos.

For woman/couples who are known carriers of a genetic disease and are opposed to having an abortion, PGD is a much more acceptable method of having a healthy child. Cameron and Williamson's research found couples were more comfortable with discarding embryos than having an abortion. They concurred that there were two "major ethical distinctions"¹⁶⁰ between the two choices. The first distinction is choosing to transfer only healthy embryos; women/couples were choosing to create a healthy fetus while allowing the unhealthy embryos to "die".¹⁶¹ According to Cameron and Williamson, "In this decision positive balances negative."¹⁶² The second distinction "relates to the increasing status and attachment that a woman gives to an embryo in utero as it develops, as against an embryo in a laboratory".¹⁶³ The size and place of the embryo compared to the size and place of a fetus makes it much easier to discard than have an abortion. An abortion takes place through the woman's body making it a corporeal experience.

159 Fenwick, *Private Choices*, 185.

160 C. Cameron and R. Williamson. "Is There an Ethical Difference between Preimplantation Genetic Diagnosis and Abortion?" *Journal of Medical Ethics* 29, No. 2 (Apr., 2003): 92.

161 Ibid., 92.

162 Ibid., 92.

163 Ibid., 92.

Discarding an embryo takes place away from her body, in a laboratory, by some unidentified person. It is an impersonal process.

Association With Controversy

The marriage of genetics and assistive reproductive technologies that has been realized through the development of PGD provokes questions regarding how far is too far when assisting women with reproduction. With the advent of technology now playing an integral role in assistive reproduction, not only will conception be assisted but so to will heredity.¹⁶⁴ People no longer have to accept passing on their defective genes. Images of parents choosing and manipulating characteristics for their offspring are conjured up when the “designer baby” idiom is used to refer to PGD. According to Franklin and Roberts the “designer baby” idiom, “evokes very different images, from choosy parents seeking “genetic privileges” for their children to cautious parents who feel obligated to avoid future harm to their potential offspring.”¹⁶⁵ Both images provoke controversy, mostly from people not directly involved with PGD. Those who are directly involved with PGD know its uses, benefits, and limitations.¹⁶⁶

“Designer baby” is the term used to discuss PGD in public debates and the media. It is a provocative term that ignites passionate discussions. On March 3, 2009, Meredith Vera of the Today Show on NBC introduced a story about a New Reproductive Technology (NRT) by comparing it to Build-a-Bear Workshop Store where children put together their own stuffed

164 Franklin and Roberts, *Born and Made*, 218. Franklin and Roberts say that PGD inevitably poses difficult questions about conception and heredity because of the alliance of reproduction and genetics.

165 Ibid., 2.

166 Franklin and Roberts, *Born and Made*, 10. For further information regarding the debates of people who are not directly involved in PGD refer to Franklin and Roberts.

animal. Vera described the ways parents may use this technology to pick and choose traits for their children. She interviewed, Dr. Jeffrey Steinberg, a physician from California, who went on to say that soon parents would be able to choose eye and hair color, as well as the height of their child. Dr. Jamie Grifo, Director of the Division of Reproductive Endocrinology at the NYU School of Medicine, countered Dr. Steinberg's claim and said "I don't think this is what patients want."¹⁶⁷ Dr. Grifo supported the use of PGD by proclaiming its virtue in saving couples from the grief they would experience from passing on a genetic disease to their offspring.¹⁶⁸ The tactic of invoking sympathy for heart broken parents over the lost of a child who succumbed to a deadly disease is often used in public debates to justify the continued use of PGD.

PGD is a highly technical and discursively complex procedure that is reshaping human heredity. PGD is the first technology to bridge the gap between genetics and reproduction.¹⁶⁹ The association with genetics is what causes the biggest concern with PGD. According to Lori Andrews, genetics' alliance with any other medical field "heightens concern" because:

First, genetics often affects central aspects of our lives. Because genes are usually viewed as immutable and central to the determination of who a person is, information about genetic mutations may cause a person to change his or her self-perception and may also alter the way others treat that person. Second, there is a chance that people will get genetic testing or therapy without sufficient advance consideration of its potential effects.¹⁷⁰

The idea of changing genetic make-up is frightening because personal identity is so closely linked to one's heredity. To alter one's genes is to alter one's identity. It is the very idea of parents picking and choosing characteristics for their offspring that connects PGD to eugenics.

167 Celizic, Mike. www.Todayshow.com (accessed March 3, 2009)
Supplemental online copy of interview.

168 Ibid.

169 Franklin and Roberts, *Born and Made*, XV.

170 Andrews, *Future Perfect*, 5.

Currently, the selection of embryos is based on avoiding genetic diseases, but some say in the future the choice may be based on cosmetic or personality traits. That is the slippery slope that is of much to concern to the public and medical ethicists. According to Gina Maranto, "Preimplantation screening holds out the possibility of testing not just for disease-causing abnormalities but also for other characteristics."¹⁷¹ Maranto argues, "Indeed, it is hard to counter the contention that preimplantation screenings, like amniocentesis and sonography for purposes of aborting defective fetuses, partakes of eugenics."¹⁷² According to Bouffard there is no consensus on the definition of eugenics however, "the general agreement is that the term refers to practices aimed at improving the hereditary traits of the human species through deliberate intervention."¹⁷³ The Nazis practiced the most notorious use of eugenics during World War II. According to Ruth Schwartz Cowan there are "some left-wing intellectuals, who see genetic testing as a manifestation of biological determinism, and as inescapably linked to the evils of the eugenics movement, including the outrages committed by the Nazis in the name of eugenics."¹⁷⁴ Cowan would not agree with these left-wing intellectuals.

Cowan argues that genetic testing is the antithesis of eugenic. According to Cowan, "The reproductive goals of medical genetics are thus precisely the opposite of those of eugenics...Prenatal diagnosis was developed to assure those worried patients that they could have children free of the disease they feared. To put the matter another way: the practices of genetic

171 Maranto, *Quest for Perfection*, 270.

172 Ibid., 269.

173 Chantal Bouffard and others, "Genetic diagnosis of embryos: clear explanation, not rhetoric, is needed." *Canadian Medical Association Journal* 181.6-7 (Sept. 15, 2009): 389.

174 Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening* (Cambridge, Mass.: Harvard University Press, 2008), 7.

screening are inherently pronatalist.”¹⁷⁵ Genetic testing on embryos is currently used to determine which are the healthiest embryos to transfer, thereby placing value on producing a disease free, healthy baby.

PGD for eugenic reasons is impractical because it is a complicated and highly involved procedure that is not accessible to everyone. It is fraught with both physical and monetary demands. According to Bouffard “In short, this technique is too complex and humanly too exacting to be seriously considered ‘eugenic’. A society that would wish to rid itself of all embryos that did not satisfy certain criteria would resort to prenatal diagnosis, not genetic diagnosis of embryos, since diagnosing fetuses is more feasible, less expensive and more cost effective.”¹⁷⁶ The claims that connect PGD with eugenics are debatable, however at the present level of use, PGD does not present as a form of wide spread societal eugenics.

PGD is also associated with embryonic stem cell research. The controversy surrounding embryonic stem cell research stems from the destruction of embryos. During the process of research, embryos are destroyed and lose their potential to become human. The embryos used for research are obtained from fertility clinics. Women/couples can donate their unused embryos to embryonic stem cell research.¹⁷⁷ According to Ronald Green, “There are hundreds of thousands of these embryos in cryogenic freezers around the country, and around the world. Since few frozen embryos are made available for adoption, most of these supernumerary embryos will be

175 Ibid., 236.

176 Bouffard and others, “Genetic Diagnosis of Embryos...,” 389.

177 This information according to the National Institute of Health. Stem Cell Basics, <http://stemcells.nih.gov/info/basics/basics3.asp>, accessed March 12, 2011.

destroyed.”¹⁷⁸ There is great promise that embryonic stem cell research will develop effective treatment for currently untreatable diseases.¹⁷⁹ These promises are not yet realized.

Summary

PGD is a highly specialized and technologically involved procedure performed in conjunction with IVF. Embryos are biopsied and the genetic makeup is determined as a result of PGD. Women/couples select the embryos that will be transferred to the woman’s uterus based on the results of PGD. This decision is complicated when there are extra healthy embryos available. The woman and her partner must make a decision as to the fate of the unused embryos. The law considers the owners of the gametes as the owners and the ones responsible for the embryos.

There are four options for the extra embryo/s: freeze for later use, donate to another woman for use, discard, or donate to research. Discarding and donating the embryos to research come with an understanding that the embryo/s will be destroyed. The degree to which this decision is a moral dilemma is contingent upon the moral status given to an embryo. Generally people adopt one of three positions regarding the moral status of an embryo: either they give full human rights, no human rights, or some human rights.

There is controversy associated with PGD. The “designer baby” idiom used to refer to PGD conjures images of woman/couples picking and choosing characteristics for their babies. Concerns surround the idea of taking the technology to far and straying from using the technology for medical purpose to using it for personal gains. PGD is also associated to

178 Ronald Green. “Ethical Considerations” *Essentials of Stem Cells Biology, second edition*. Ed. Robert Lanza. (San Diego, CA., Elsevier, Inc., 2009), 602.

179 Ibid., 601.

controversial procedures because of its connection to genetics. Human embryonic stem cell research, eugenics, and abortion are all part of the controversial conversation involving PGD.

CHAPTER FIVE

THE LAST LINE OF DEFENSE: INITIATING A PGD CYCLE

The use of Preimplantation Genetic Diagnosis (PGD) as part of a fertility treatment plan is often not premeditated by the women/couples that use it. PGD is a relatively new procedure and not many people outside the medical community know that it even exists let alone what it is, what it is used for, or how it works. When women/couples are faced with an inability to have a child, PGD is not the first fertility treatment they think of, nor is it the first treatment physicians prescribe. There is a hierarchal order to fertility treatment.¹⁸⁰ Women/couples start out using less invasive procedures before moving on to more technologically involved procedures. Using the more technologically involved procedure indicates that the others procedures were unsuccessful and the fertility problem is more involved than originally thought.¹⁸¹

Seeking out medical assistance signifies two important aspects for the infertile woman/couple: 1) acknowledgment of the problem, and 2) acknowledgment that you are unable to fix the problem on your own. The first visit with a fertility specialist takes a woman/couple deeper into the medical system than they had previously gone for their infertility. This is the woman's/couple's introduction to the very sophisticated and highly technical world of fertility

180 In professional texts terms such as first-line therapy are used to indicate less invasive treatment as well as the treatment regimen first recommended for infertile women/couples. Macklon et. al. uses the term first-line therapy when discussing treatment for unexplained infertility on pages 450-451. Also Huang et al. uses the term first-line treatment when discussing medical intervention for treating infertility associated with endometriosis. 712.

181 Macklon et al gives a list of infertility diagnoses that are indicated for treatment with IVF as well as other diagnoses that other treatments, such as IUI, are indicated. His team cautions against the use of IVF to achieve "pregnancy at all costs". 447-449.

treatment. According to Arthur Greil, "...the medicalization of infertility implies that the infertile take on the role of patients, subject to the condition of doctor-patient interaction, including a passive role for the patient and physician dominance over face-to-face interaction".¹⁸² By going to a fertility specialist, the woman's/couple's inability to get pregnant moves from a personal failure to a medical diagnosis. In this chapter, I will explore the initiation into the world of using PGD as part of fertility treatment plan. What compels women/couples to engage with this highly specialized medical intervention? How did they learn about PGD? How did they choose to use PGD? What do they know about PGD? Is initiation into the world of fertility treatment seamless?

Infertility Induction

Infertility, most often, takes a person by surprise. Many American women and men follow a planned trajectory for their lives with a perceived notion of control prior to being diagnosed with infertility. According to Andrea Mechanick Braverman, "For many individuals, infertility is among the first life crises that they may face."¹⁸³ Many women and men assume they have the ability to procreate through coitus, and can do so whenever they choose. According to Greil, "From the vantage point of American infertile women, however, infertility is a major

182 Arthur L. Greil, "Infertile Bodies: Medicalization, Metaphor, and Agency" *Infertility Around the Globe. In Infertility Around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, edited by Marcia C. Inhorn and Frank Van Balen, (Berkley: University of California Press, 2002), 102.

183 Braverman, Andrea Mechanick. "The relationship between stress and in vitro fertilization outcome." in *Textbook of Assisted Reproductive Technologies: Laboratory and Clinical Perspectives*. Third edition. Edited by David K. Gardner, Ariel Weissman, Colin M. Howles, and Zeev Shoham, (London: Informa Healthcare, 2009), 877.

disruption in one's projected life course, a failure to live up to normative notions about what it means to be an adult woman in American society, and a challenge to the stability and quality of social relationships".¹⁸⁴ Having previously spent time and effort preventing pregnancy, women and men are often bewildered, frustrated, and angry when they are unable to produce a child. It is the loss of the perceived notion of choice and control that can cause these feelings. According to Van Balen and Inhorn, "[W]idely held and highly valued beliefs in individualism, free choice, and control over one's own life may cause frustration for infertile Western couples."¹⁸⁵ Infertile women and men never anticipate that they will not be able to get pregnant through coitus. Often there are no discernable indications that would lead them to believe they would not be able to get pregnant and have a child in the "natural" manner.

An infertile diagnosis is given when a woman has not conceived through coitus after one year of having intercourse without using contraception. The infertility may lie with one or both partners. Inhorn defines infertility as, "Primary Infertility means that infertility occurs in the absence of a prior history of pregnancy, while secondary infertility means that infertility occurs *following* a prior pregnancy (whether or not that pregnancy resulted in a live birth)."¹⁸⁶ Many women continue trying to get pregnant well after one year without intervention. Whether this is due to a denial of the problem, inability to afford medical intervention, lack of interest in consulting medical assistance, or a host of other reasons is unsure. In some cases, the chances of

184 Greil, "Infertile Bodies", 101.

185 Frank Van Balen and Marcia C. Inhorn, "Introduction" In, *Infertility Around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*. Edited by Marcia C. Inhorn and Frank Van Balen, (Berkeley: University of California Press, 2002), 9.

186 Marcia C. Inhorn, *Local Babies, Global Science: Gender, Religion, and In Vitro Fertilization in Egypt*. (New York: Routledge, 2003), 4.

a spontaneous pregnancy may be similar to the chance of getting pregnant with intervention.¹⁸⁷

When women and men finally seek out medical intervention, the appointment is fraught with optimism for answers as well as a solution.

Isabel and her husband George tried to get pregnant for four years before seeking medical advice. During those four years she had one miscarriage. She sought assistance from her gynecologist who put her on Clomid.¹⁸⁸ Shortly after being on Clomid she got pregnant but miscarried a second time. That was when they went to a new gynecologist in town who recommended they go to a fertility specialist right away.

Typically, women present their concerns about their inability to get pregnant to their gynecologist prior to seeking out more advanced assistance. The gynecologist may prescribe a treatment plan such as using hyperovulation medication to produce several eggs thereby increasing the likelihood that at least one egg will fertilize during coitus and implant in the uterus. A draw back of this plan is that the use of hyperovulation medication increases the likelihood of having a multiple pregnancy. The gynecologist may also prescribe the use of intrauterine insemination, which increases the likelihood of fertilization when the sperm count or

187 Macklon et al report that models for prediction spontaneous pregnancy in couples with unexplained infertility is 40% after 3 years of trying, and 20% after 5 years of trying. These models have been developed with the subfertile population in mind and may not translate to other populations, page 451. Silverberg and Turner define subfertile as patients whose deficiencies “may not be sufficient to prevent pregnancy from occurring: rather, they may simply lower the probability of pregnancy.” 40.

188 Clomid is used to induce ovulation. For more information refer to The National Center for Biotechnology at <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000752>

motility is low.¹⁸⁹ Addison's gynecologist started her on what she describes as "mild infertility treatment." Addison explains her treatment program with her gynecologist:

Addison: So he put me on Glucophage, he did the stereotypical first steps. Glucophage then when that didn't work he put me on Clomid. And then we started doing the testing to see if something was going on. I never had any issues as far as cycles are concerned or any other outliers. So it started with the HSG test to check my fallopian tubes and then they found there was ... some stenosis with my cervix. He said, 'Ah that might be an issue. We'll get it stretched out. We'll take care of that. We'll see if that should resolve it'. That didn't. So then it went into that following summer. So that would be the summer of 2006 that we started with the IUI's. My husband's sperm count was fine, everything was fine. They couldn't figure out why we weren't conceiving. So he thought it might be the cervical issues, so we started with the IUI's. We did them with Clomid. We did five rounds of those and no results. No pregnancies. I guess that was the end of September beginning of October of 2006. He said I can't help you anymore you need more assistance than I can give you. You need to see another doctor.

Addison's description of her treatment demonstrates the significant role relativity plays in experiencing fertility treatment. Her account may appear to be quite medically involved, however after going through a PGD cycle, her initial fertility treatment seemed mild to her. Depending on factors, such as the woman's age and medical history, as well as her partner's medical history, the gynecologist may prescribe a course of treatment similar to those described above or she may immediately refer the woman and her partner to a fertility specialist.

Most women/couples proceed to the fertility specialist hoping not only to have a healthy baby but also to discover the reason for their infertility. Classified as a specialist, the fertility doctor is armed with a different set of arsenal than the gynecologist. The fertility doctor, a Reproductive Endocrinologist, will perform a more thorough examination, specific to infertility,

189 Huang et al report that "Controlled ovarian hyperstimulation (COH), in combination with intrauterine insemination (IUI), has proven to be a cost-effective and appropriate first-line treatment for many infertility diagnoses." 712.

to determine a cause as well as the best course of action. Fertility treatment does not always follow a linear progression. Occasionally, during the examination, other issues are revealed that need to be addressed prior to starting fertility treatment, although, addressing these issues could be deemed as the start of treatment.

Isabel describes the procedures she had prior to the start of her PGD cycle:

The first thing he did was of course blood work. And we had already done a bunch of blood work, so there were some I didn't need to do. A couple of tests he did were to find out if I had one of those disorders to see if your blood is too thick. So he checked all that stuff. And he did some tests... he did an ultrasound and he thought that he could see a wall in my uterus. So he discovered that there was a problem inside my uterus. Then he did a surgery on that and fixed that and then ... then after that we did the IVF thing. We went through the whole process then just to make sure, because his thing was well we want to make sure we're putting a healthy embryo in a healthy uterus... you know eliminating any other gray area, so we decided to go ahead ... go ahead and try it.

The “it” that Isabel tried was PGD. In the hierarchal order of fertility treatment, adding PGD to an IVF cycle raised Isabel up the treatment ladder.

The Doctor's Appointment

A woman's/couple's initial appointment with the reproductive endocrinologist is fraught with excitement and anxiety. The reproductive endocrinologist can either fuel or extinguish the hope that the woman/couple bring to the office visit of conquering their infertility. The reproductive endocrinologist can offer this kind of hope because of her/his expertise and use of the most technologically advanced medical treatment. The couple understands that the specialist has more ammunition in his/her arsenal to combat infertility than the woman's gynecologist had. The purpose of seeking out the expertise of the specialist is to take advantage of the advanced technology she/he has at her/his disposal. The idea of seeking out the most advanced medical treatment available is pervasive in our society. Susan Sherwin found this idea to be true in her

research. According to Sherwin, “The pursuit of technological intervention in reproduction is part of a larger general pattern in our society in which a search for technological solutions is often the first response to the recognition of human problems.”¹⁹⁰ Rapp concurs with Sherwin. She argues that seeking a technological fix is, “deep-seated in the history of the United States.”¹⁹¹ People feel compelled to enlist biotechnology in solving their health problems.

The initial appointment is the first time the reproductive endocrinologist will hear the couple’s fertility history; therefore the woman/couple must be thorough in reiterating their past. Through a series of questions asked by the doctor, along with those on a medical history form, the woman/couple relives their past pregnancy losses, failed attempts at getting pregnant, and the pain associated with their infertility. Within the comfortable atmosphere of the doctor’s office, some uncomfortable questions are asked. The doctor must ask if there is or has been a history of drug abuse, alcohol abuse, or if either partner has a sexually transmitted disease. Patients often display outward signs of discomfort when answering these questions. During the initial appointment, the doctor and woman/couple begin the process of establishing a relationship. Their behavior during this appointment sets the tone for their relationship throughout the treatment process. The significance of the doctor-patient relationship on treatment outcomes will be discussed in a later chapter in this dissertation.

During the initial appointment, the doctor may suggest treatment options, but will confirm the best course of action after further tests are completed. Physicians consider many factors when planning a fertility treatment regimen for their patients. After reviewing the results from a thorough examination of the couple, along with looking at their fertility history,

190 Sherwin, *No Longer Patient*, 118-119.

191 Rapp. *Testing Women*, 3.

consideration is given to the benefits and risks of a regimen as well as the cost.¹⁹² The less invasive and technologically involved fertility treatments are also less costly and time consuming, but may also be less effective for some women and men. In vitro fertilization (IVF) is a highly technical form of fertility treatment and, prior to PGD, the last rung on the fertility treatment hierarchy. Macklon et al reports that IVF is seen as the “panacea for all those having difficulty in conceiving a pregnancy.”¹⁹³ Each tier on the NRTs hierarchy offers a greater chance of becoming pregnant because of an increase in the amount of medical intervention. After trying the less invasive procedures for several months to years unsuccessfully, many women/couples are willing to spend the extra money and endure the physical and emotional pain involved with more invasive and technologically involved procedures.

It is often during the second office visit when the doctor will discuss the results of the tests and plan the best course of treatment. This is when most patients hear about PGD for the first time. PGD is presented as the most advanced procedure available that can offer the greatest possibility of success for their particular situation. Upon first hearing about PGD, the patients may not recognize the ethical implications associated with the technique because the focus is often placed on the outcome of using PGD. In addition, PGD is presented as a technology that may allow them to have the child they desire. Their desire to have a healthy biological child overshadows their concern for any ethical debate associated with the procedure. It is only later in the process that couples come to realize that the procedure they are using is commonly referred to as the “designer baby” technique. The term “designer baby” signifies the ability to pick and choose physical characteristics. Although the women/couples of this study did not use PGD to

192 Macklon et al report that attention has been given to the “balance between benefits, burdens, and risks of IVF treatment.” 447.

193 Macklon et al, “Indications for IVF Treatment”, 447.

pick physical characteristics, other than the three women who used it for sex selection, they are all now associated with the “designer baby” debate because of their use of the technique. This was not a consideration when deciding to use PGD.

PGD offered Monica and Chandler the chance to carry a pregnancy to full-term. Monica had had two miscarriage from pregnancies conceived the “natural way”. A chromosomal analysis was performed on the second fetus. That is when they realized that there was a genetic problem and miscarriages could continue to occur. When the doctor told them about PGD, Monica said, “ We were happy.” She said they had no idea there was such a technology. Chandler said they were “pleasantly surprised, because otherwise we thought there was nothing we could do. Because if there is an issue [with the chromosomes] and it continues to happen, there is no way out of that.” The chromosomal problem Chandler refers to would only be detected through genetic testing.

Studies have shown that there are a number of reasons women experience recurrent miscarriages, however, those attributed to chromosomal abnormalities could benefit from using PGD. Munne et al report “50%-60% of all early losses show a number of chromosomal abnormalities. Conversely, 90% of chromosomally abnormal pregnancies abort, compared with 7% chromosomally normal.”¹⁹⁴ Therefore, by using PGD, pregnancy rates can improve by transferring only embryos that are chromosomally normal.

Hazel and Brad’s physician recommended PGD as part of their fertility treatment. Hazel had one failed cycle of IVF before using PGD. According to Brad, the doctor recommended PGD because “age had something to do... As well as a genetic thing... from what was in the blood clotting. I don’t know. He gave us some reasons but I don’t know that it was...” Brad did

194 Munne et al “PGD Reduces Pregnancy Loss”, 331.

not complete his answer because he did not know the true reason they used PGD. Neither Hazel nor Brad had heard of PGD prior to the doctor's recommendation. Brad said, "we would never have guessed." Referring to the availability of such technology, Brad and Hazel had no idea that genetic testing on the embryo could be done. Monica and Chandler's, and Hazel and Bill's discourses demonstrate that it is not necessary to fully understand the technology or all the implications associated with the PGD in order to take advantage of its benefits. By the time the women/couples of this study heard about PGD, and decided to use it, they were already committed to using the most advanced technology available to them. They were willing to rely on the expertise of their doctor and follow her/his recommendation.

PGD For Sex Selection

Women/couples who used PGD for sex selection went to their initial doctor's appointment specifically to use PGD. Fertile women/couples can enlist the service of PGD to assist them in conceiving the child of a specific gender they desire. They still have to go through the same process as infertile women/couples. Only embryo/s of the desired gender will be transferred to the woman's uterus. Women's activist groups have long been concerned with the practice of sex selection fearing that females will be devalued in the process. Liz Mundy cites Mark Evans as saying "selecting sex has traditionally been sought by parents from cultures where boys are valued more than girls",¹⁹⁵ to begin her discussion on this topic. However, according to Mundy, "in the United States and other first-world countries, most patients are not trying to get rid of girls, but to obtain one baby of whatever sex they don't have already."¹⁹⁶ While family

195 Liza Mundy. *Everything Conceivable: How assisted Reproduction is Changing Our World*. (New York: First Anchor books Edition, 2008), 318.

196 Ibid., 318.

balancing may be less problematic than sex preference there is still concerns that choosing an embryo based on sex sets up unrealistic expectations for the child as well as exemplifies biases. Neil F. Sharpe and Ronald F. Carter found that it is “suggested that it [sex selection for family balancing, *my insert*] is justified as long as one or more children are already born since this would not involve an inherent favoring of one sex over another.”¹⁹⁷ All the women of this study who used PGD for sex selection were looking to balance the genders in their family. Emma had four girls and no boys. Meredith and Janet each had two girls and one boy. All three women used PGD to conceive boys.

The women/couples of this study that used PGD for sex selection went to their initial doctor’s appointment specifically to use PGD. Emma and her husband wanted a gendered-balanced family. Emma said her husband first heard about PGD.

Actually my husband had read an article about it. We had always heard about the spinning of the sperm, and we always thought well that’s an option for us to do. He saw some advertisement when he was in Vegas, actually, for ... 100% guarantee sex selection. He came home and told me. And we were talking about it and I read an article in like a ... a family journal, of a family that actually went through PGD... I read that and thought wow you can actually do this?

Both Emma and her husband had a firm idea of the family they wanted. At the time, they had four daughters and wanted a son. Their first cycle of PGD produced one healthy male embryo and one healthy female embryo. They transferred the male embryo and discarded the female embryo. Currently, they are going through PGD again, hoping for twin boys. Emma said this time they will freeze the female embryos and use them at a later date. She wishes they had frozen the female embryo in the first cycle to use later.

197Neil F. Sharpe and Ronald F. Carter. *Genetic Testing: Care, Consent, and Liability*. (Hoboken, New Jersey: John Wiley and Sons, Inc., 2006), 199.

Meredith also wanted a gender-balanced family. She had one son and two daughters then used PGD to have another son. She discovered PGD through an Internet search. Meredith found the information on the Internet a bit misleading. She said she and her husband “did a lot of research online and it said 100% way of getting a boy”. Meredith and her husband latched on to the 100% guarantee and never questioned it farther. Meredith explains her initial understanding of PGD used for sex selection:

Everything says that you have the spinning, where they do the sperm spinning, is 80% and the in vitro is 100% and my physician said 100%. Which is accurate if you are going to get pregnant, you will get pregnant with a son 100%. But what they don't tell you is only if a boy ... you know after they implant the egg with a sperm, only if you have a boy embryo. They failed to kind of mention that part.

During her first PGD cycle, Meredith and her husband produced only healthy female embryos. They were surprised and disappointed that they had not produced any male embryos. They did not transfer any of the female embryos. All were discarded. Although Meredith and her husband produced healthy embryos, they considered their first PGD cycle a failure.

Prior to using PGD, Meredith and her husband had set their goal to have a healthy baby boy. This was the only outcome they wanted from using PGD. Prior to beginning fertility treatment in general, PGD in particular, women/couples understand their reasons and set their goals for using this technique. It is understood by all who use PGD that there may be other outcomes than the one desired. There is no reason to use PGD if you are willing to compromise your goal. If Meredith and her husband were willing to take whatever they created, say for instance a girl or an unhealthy boy, then they did not need to use PGD; they could have conceived through coitus. The same holds true for women/couples that are using PGD to avoid a specific genetic disease. It would be imprudent for them to transfer an embryo that was affected with the disease, in the event no healthy embryos were produced, just so they could have a child.

If they were willing to accept a child with a genetic disease then they might as well have taken their chances conceiving on their own. This would have saved time, effort, and money.

The above circumstance does not hold the same conundrum for women/couples that have had multiple miscarriages or cannot conceive. Only the healthiest embryos will have a chance of surviving the transfer and implanting into the uterus in order to develop to a full-term pregnancy thereby reducing the risk of miscarriage. These women/couples are willing to have any healthy embryo transferred regardless of the gender. They have had unhealthy embryos implant during coitus, only to result in a miscarriage. For these women, using PGD is their only hope of having their biological child.

Becoming the Patient

The subjects of this study came to their doctor's appointment with long histories of pregnancies losses. Franklin and Roberts found similar histories in the women they studied that used PGD to avoid passing on a genetic disorder. According to Franklin and Roberts, "PGD patients frequently come to the technique with a significant history of reproductive loss and trauma behind them. They have often followed a lengthy and complicated path to its door, and have opted for its demanding regime out of a sense of obligation to avoid imposing harm on their potential offspring, or upon themselves, or both."¹⁹⁸ Abbey, Hazel, Tina, Monica, and Isabel all had two miscarriages prior to successfully having a child after using PGD. Janet had "several" miscarriages in between each of her three successful pregnancies. She used medical assistance to conceive all four of her children.

At 35 years old, Janet, a business owner, used PGD to conceive her fourth child because she was "tired of getting pregnant and miscarrying". Janet wanted a gendered-balanced family.

198 Franklin and Roberts, *Born and Made*, 220.

At the time she used PGD she had one son and two daughters. PGD met both her needs to have another child and to have a son. Janet was very comfortable enlisting medical assistance to meet her goals. She is in an ancillary medical profession and feels very comfortable using the latest medical technology to support her lifestyle. To paraphrase Janet's own words about why she used PGD she said she just wanted a healthy baby. She feels if a person has problems then they should reach out for assistance.

A history of miscarriages combined with advanced maternal age can also be the impetus for a woman/couple to seek medical assistance. The experience of having a miscarriage or multiple miscarriages is incredibly heartbreaking as well as frustrating. A miscarriage leaves women with unanswered questions: Why did this happen? Did I do something to cause this? How could I have prevented this? The first time a miscarriage occurs can be explained away as a mishap or as Derrick explains it "we thought it was a fluke." But as time passes, and still no child has been produced, the frustration and heartache remain, and the quest to find out why it occurred takes precedence. Tina and Brad spoke to Tina's gynecologist after her second miscarriage. That one occurred while she was on Clomid. Her gynecologist recommended that they go to a fertility specialist right away. Tina explains:

We had two miscarriages over the past two years and because of our age ...and they suggested... And prior to that, I was on Clomid maybe for 6 months and one of those miscarriages was during the period of taking the Clomid. One of them was prior to that. Because of that and the history between Brad and me, we did all the testing for blood work, he was good, I was good, between us... But there was no luck, we weren't getting anywhere and when we did we miscarried... so being at the age we were, we thought let's get some help.

Tina was nearing 40 years old at the time. A woman's ability to get pregnant decreases with age. According to Ariel Weissman and Colin M. Howles, "The decline in female fecundity associated with increasing age is well documented: the decrease occurs slowly through the 30s, and then

accelerates to reach nearly zero between the ages of 45 and 50 years old.¹⁹⁹ The quality and number of ovaries declines with age. In addition, there is an increase in aneuploid oocytes in women of advanced maternal age. Verlinsky and Kuliev found in their research that “half of oocytes from patients of advanced reproduction age undergoing IVF are aneuploid.”²⁰⁰ Their research found, “Aneuploid rates range from 39% at age 34 years old to as high as 72% for women ≥ 45 years old based on studies of up to 5 chromosomes (i.e. chromosomes 13, 16, 18, 21, and 22).”²⁰¹ An aneuploid oocyte is not likely to produce a healthy child; therefore PGD is indicated to screen the embryos prior to the transfer.²⁰²

It is no wonder after long histories with fertility issues that when physicians present PGD as a solution to their problem, the ethical issues are not the first thoughts of women/couples. The health of their baby was the most important consideration for the couples of this study. Hazel and Bill talk about their thoughts on the uses of PGD.

Hazel: We thought it was important because we weren't looking to pick eye color, or sex. We were looking for genetic disorders because of my age and my eggs were older. And to make sure that the embryos were going to be healthy.

Claudia: So what was your main reason for using PGD?

199 Ariel, Weissman and Colin M. Howles, “Treatment strategies in assisted reproduction for the low responder patient.” In *Textbook of Assisted Reproductive Technologies: Laboratory and Clinical Perspectives*. Third edition. Edited by David K. Gardner, Ariel Weissman, Colin M. Howles, and Zeev Shoham, (London: Informa Healthcare, 2009), 578.

200 Yury Verlinsky and Anver Kuliev. “Clinical application of polar body biopsy.” In *Textbook of Assisted Reproductive Technologies: Laboratory and Clinical Perspectives*. Third edition. Edited by David K. Gardner, Ariel Weissman, Colin M. Howles, and Zeev Shoham (London: Informa Healthcare, 2009), 375.

201 Ibid., 377.

202 Verlinsky and Kuliev. *Atlas of PGD*, 1.

Hazel: Health, that was all

Bill: We weren't trying to do anything mischievous or we weren't saying, OK what can I do ... hey if I can pick this, I'm going to do it.

Hazel and Bill's discourse demonstrates their awareness of the "designer baby" debate by alluding to choosing traits, but they dissociate themselves from the debate by explaining their reasons for using PGD. The importance of dissociating themselves from what is signified by the "designer baby" idiom is discussed in a later chapter.

Getting Answers

The inability to do something that presumably everyone was born able to do plagues these women but does not halt them. An explanation of their infertility becomes an integral part of the women's/couple's treatment plan. By using NRTs, they hope to shed the identity of being infertile and childless. So often when a couple is experiencing difficulty having a child, the blame is placed on the woman regardless of the cause. According to Inhorn and Van Balen, "[I]t is women who bear the burden of blame and social scrutiny for infertility...."²⁰³ The visible clue of not being pregnant is played out on the woman's body. Many of the woman's friends and family members might assume the onus of infertility lies with her because she has not gotten pregnant.

The discourse of the women of this study demonstrates their need for discovering a reason for their infertility. They wanted to determine their level of responsibility. PGD gave these women some answers about the culprit of their infertility. Paige understood this benefit of PGD. She explains, "Well, I'd have some answers... Knowing why I couldn't get pregnant. I knew it was my husband too. He has a low count." Marie also understood this value of PGD.

203 Van Bale and Inhorn, "Introduction", 18.

She said, “I just wanted to make sure there was nothing wrong with me. I wanted to make sure there isn’t anything else that I could have done that caused this miscarriage. Are there tests that you could run? Are there things that you can do? So I just begged and pleaded to put us through the whole gamut.” Sienna was also searching for answers. She explained her purpose for using PGD, “The purpose of doing it was to determine whether or not it was me, because if it was me, we would stop all this nonsense.” The nonsense she was referring to was the many cycles of IVF, the multiple doctor’s appointments, laboratory tests, and the hormone shots.

What is apparent in these women’s discussion is their need to determine their culpability in their inability to get pregnant. According to Inhorn,

[T]he burden of suffering generally rests on the shoulders of women....whether or not they are the infertile partner. Indeed, women worldwide appear to experience the major onus of infertility, in terms of blame for the reproductive failing; emotional responses such as anxiety, frustration, grief, and fear; marital duress, abuse, divorce, polygamous remarriage, or abandonment; and social stigma and community ostracism.²⁰⁴

In some cases, a reason cannot be found for infertility. Addison’s doctor diagnosed her infertility as “truly unexplained.” She said her doctor told her he could not say why she was not getting pregnant. None of the tests she and her husband had gave any reason for their infertility. Even though the tests were inconclusive, Addison’s doctor decided to treat her as if there was a genetic problem. He decided to do PGD after her first IVF cycle was unsuccessful. Addison became pregnant with twin girls on her first PGD cycle.

For some of these women/couples the answer explaining their infertility is so unanticipated that it shakes them to their core. That is what happened to both Marie and Natasha.

204 Inhorn, *Local Babies, Global Science*, 10.

The testing done prior to the inception of treatment revealed a balance translocation for both Marie and Natasha. This is something they were born with and had not known about. A balance translocation is not evident in a person's phenotype. A person can develop typically with a balanced translocation. It only becomes evident when this person procreates and even then it may not appear.

Being diagnosed with a balanced translocation means a piece of one of your chromosomes has broken off and attached itself to another chromosome. The person with the balanced translocation has all of her or his chromosomes therefore they develop typically. Their phenotype is typical but their genotype is not. The problem occurs when this person tries to procreate. Half of a person's DNA is present in either the egg or the sperm. The egg or sperm could end up with either too little genetic material or too much. For example if the tip of chromosome one breaks off and attaches itself to the bottom of chromosome nine then dividing the material in half will cause too much of chromosome one in the bottom portion and not enough of chromosome one in the top portion. Women with a balance translocation have a high rate of miscarriages. According to Verlinsky and Kuliev, "carriers of balance translocations have an extremely poor chance of having an unaffected pregnancy." They go on to say, "PGD provides them with a realistic option of having an unaffected pregnancy from the onset."²⁰⁵

Getting the news that she had a balance translocation devastated Marie. Not only did she not anticipate there being a genetic reason for her miscarriage, but also she was shocked to discover she had a genetic disorder. She describes her feelings after getting the diagnosis:

So he told me about the balance translocation, And that was just...I was just in a daze when he was telling me this. I thought that maybe there might be something

205 Verlinsky and Kuliev, "Clinical application of polar body biopsy", 375.

wrong, could the tests be wrong? What does this mean? What does a balance translocation mean? All these things. It was... it ... it was just not a good time.

Before Marie could embark on the next phase of her fertility treatment, she needed to come to terms with the new identity she now had of herself. When she started her fertility treatment, begging her doctor to run the gamut of tests to determine that there was nothing wrong with her, she never anticipated that there would in deed be something wrong. She said after receiving her diagnosis she felt “It’s bad enough that you had to deal with IVF. Then to lay this on us.” Marie was referring to her balanced translocation, which she later called “one more obstacle” to getting pregnant. After her diagnosis she said “I started doing some research about PGD and balance translocations and just the stats out there are just terrible, it wasn’t good at all in terms of ... success rates for those who have balance translocations and for those to actually have live births. So... so it was tough.”²⁰⁶

Along with her concerns about her chances of having a successful pregnancy, Marie was also concerned about telling members of her family about her diagnosis. A balanced translocation is a genetic disorder, which means other members of Marie’s family could also have the disorder. Marie told one of her brothers only that she was using IVF to get pregnant but did not tell him about her balanced translocation. She also did not tell her parents about her translocation because she said,

I believe if I were to tell them that I have a balance translocation and one of you could have passed it on, they would think they have a disease. That’s how they would look at it. There was no reason for them to know. Why would they need to

206 Results for Verlinsky and Kuliev’s study of PGD for translocation were as follows: 58 cycles, 667 oocytes studied, 62 resulting normal embryos transferred, 36 transferred, 11 pregnancies, 10 babies. For more information refer to Verlinsky and Kuliev, “Clinical application” page 378.

be tested? If anyone would need to be tested, it would be one of my siblings. And I think when the time comes I would have to tell them. So they can at least be tested to see...if they have normal DNA.

Prior to the testing Marie considered her DNA normal, but she can no longer do that. The testing revealed a genetic disorder that will become part of Marie's identity forever. All the testing Marie went through at the beginning of her fertility treatment gave her answers, just not the answers she was hoping for. Ironically though, it is those answers that would ultimately allow Marie to get pregnant and have a healthy child.

Natasha also has a balanced translocation. She gave birth to a son who died 11 days after birth because of a genetic disorder passed on from her balanced translocation. Natasha was unaware that she had a balanced translocation at the time of her son's death. The doctors told Natasha and Derrick their son died because of a heart defect related to chromosome number 9. Natasha and Derrick were devastated. It was not until after Natasha had a total of three miscarriages and one live healthy birth that they went in for further testing. Once the results were in, they were told about Natasha's balanced translocation. The news was upsetting but it was counterbalanced by the fact that they had one healthy daughter. So they decided to play the odds game and try to conceive a healthy child on their own. Derrick explains: "So we started piecing things together and thought, OK this is what probably caused all of this. You start doing the numbers in your head... there's a 50% chance you'd have a healthy baby, then let's try again because right now the odds are in our favor." Unfortunately, that pregnancy resulted in a miscarriage also. Natasha and Derrick went to see Natasha's gynecologist for advice after this miscarriage. Their disappointment was extremely high this time because the pregnancy had gone longer than any of the others. They both thought the pregnancy was going to go full term. The

explanation Natasha's gynecologist gave for the later term miscarriage was the impetus for Natasha and Derrick to seek the assistance of a fertility specialist. Natasha explains

After the fourth one because that one went longer than the others before I miscarried... 11 weeks. And... she said you know normally it's your body kind of rejecting it because there's a problem, when you get to ... where it just gets longer and longer your body may not know to do that... So you could have a child potentially with a lot of problems again. So that's when she said... if we wanted to have more children, we should see a fertility specialist.

Natasha and Derrick went to their fertility specialist armed with information about the cause of their miscarriages. This information, along with knowing that they were capable of having a healthy child bolstered their confidence that they would be able to have another healthy child. Natasha and Derrick had a healthy baby girl after using PGD. For Marie, Natasha, and people with a balanced translocation, PGD is used not only to rectify their genetically caused fertility problem, but also to produce a child devoid of their genetic disorder. Therefore in this instance, PGD "cures" two illnesses.

Choosing a Doctor

PGD is a highly technical procedure. A PGD cycle involves the collaboration of a team of highly specialized individuals. Because of its level of specialization and technicality, it was impossible for the women/couples to fully understand the procedure. It was also unnecessary to completely understand every aspect of PGD in order to make use of its service. These women/couples trusted the specialist and the system to work properly and deliver on their promise of giving them a healthy child. Monica trusted her doctor's answer when she expressed her concerns about the effects of removing cells from her embryos. Monica said, "When he [her doctor] told us ... he told us they would take out like two cells or something, to do the procedure,

that was a little concerning, but then he assured us.”²⁰⁷ Trust in the assurance your doctor gives comes only after feeling confident you have chosen the best doctor.

Choosing a fertility specialist can be as daunting as understanding fertility treatment. Couples want the odds of success to be stacked in their favor and that begins with choosing a doctor who has a high success rate. The Center for Disease Control (CDC) maintains the statistics on infertility treatment that takes place in the United States. Along with the number and types of procedures a clinic performs, the CDC posts the success rate of each clinic on their website. Perspective patients can go to the CDC website and discover the success rate of the clinic they are interested in as well as the number of procedures they have performed within any given year. Perspective patients can also discover the success rate of various procedures each clinic has performed based on a woman’s age. This information assists couples in choosing their fertility specialist. Clinics will post their success rates on their own website which can be verified with the CDC’s website statistics.²⁰⁸ Choosing a doctor is a means of gaining control in an

207 In 1999 Christine Munthe argues in *Pure Selection* “The urge to follow closely children who have come into existence by PGD is therefore very well founded indeed.” P. 162. He points out that “current standard view among specialists in PGD, the biopsy procedure by which the sample cells are extracted from the early embryo does not adversely affect the embryo’s potential for further development into a viable fetus.” He goes on to say, “However, some doubts have been expressed regarding the factual grounds for this view and, moreover, it is still unknown whether or not this procedure or the ICSI technique (when used) may have some other kind of impact on the embryo which in turn affects the constitution of the future child.” 160.

208 For more information refer to the CDC’s website at <http://www.cdc.gov/art/ART2007/index.htm> to get the latest posted report.

uncontrollable situation. For Natasha and Derrick the information online was very helpful in choosing their doctor.

Natasha: A lot of them, which I know [our clinic] had, put their success rates right on line. So that's mostly of course what we were looking for.

Derrick: Yeah who has the most live births? I think his [the doctor they went to] was like 85%...

Natasha: Yeah

Derrick: The other ones we looked at were like 50.

Natasha: 50-60.

Derrick: We were like hey, no thank you. Especially, you start looking into the finances and I would rather go where you have a better chance.

Weighing all the variables against each other, along with the odds of success, is a typical strategy used to pick a fertility specialist. This strategy gives a feeling of control as well as optimism by manipulating the numbers in your favor. Choosing a doctor is a very important part of the process. The participants of this study needed to feel confident in their doctor's skills in order to proceed with the suggested treatment plan.

In addition to finding the success rate of the doctors, perspective patients also use the Internet to learn more about their procedure. After learning about PGD for the first time at their doctor's appointment, many of the participants of this study went home and looked up PGD online. Monica went online to learn more about PGD.

Monica: I did read up a lot on the Internet... I was pretty comfortable with it (PGD) once we started the procedure.

Claudia: What sources did you use online? Did you Google it?

Monica: No, it was mostly like forums of people who have gone through the same thing. They had positive outcomes.

Claudia: Were there a lot of forums for PGD?

Monica: Yeah, there are quite a few... They were discussing it ... and even the doctors... about who to go to, who is rated well.

Claudia: How did they rate the doctors?

Monica: It's by success rate mainly. It's mainly people telling other people, I went to this doctor and was successful. ... This doctor is really nice.

Doctors are aware of their patient's propensity to go to the Internet for information. Hazel's doctor and nurses' told her to stay away from the Internet because the information online may "freak you out." She went online anyway and realized "it's better to just listen to your doctor."

Financial and Emotional Costs

The cost of using PGD is prohibitive to some couples. PGD adds approximately \$3,000-\$6,000 dollars onto the cost of IVF, which can cost anywhere between \$12,000- \$15,000.²⁰⁹ Health insurance does not fully cover the cost of the procedure. In most cases insurance only partially covers the cost of medication. For Natasha and Derrick, the cost of their treatment combined with the fact that their insurance was not going to cover treatment compelled them to find the doctor with the greatest success rate thereby giving them the greatest odds of success for the money. In Derrick's words, "Then we found out that our insurance wasn't going to cover IVF period. So at that point we wanted to go with who was the best... if we were going to pay for it".

The financial burden for women/couples who use PGD can be overwhelming and hard to manage, however for the women/couples of this study, who all have successfully had a child using PGD, the outcome supersedes any financial worry. For many of these participants the emotional costs far out weighed the financial cost. Abbey and Sam used PGD after two failed IVF cycles. They now have twins, a boy and a girl, as a result of PGD. They both said the

209 According to an article entitled "What can we do about the cost of fertility treatment in a recession?" on the American Fertility Association website, IVF can cost anywhere between \$12,000-\$15,000. The CDC estimates IVF costing \$12,000 based on the information from the American Society of Reproductive Medicine. The cost of PGD is based on Internet searches. Nova IVF lists their price as \$5,800 on their website. Fertility Proresgistry.com lists the cost of PGD as \$3,550.

emotional cost was far more than the financial cost. They had already invested in the process financially and were capable of making the financial commitment themselves. It is the emotional toll that they remember long after the birth of their twins.

Franklin and Roberts noted the emotional difficulties the women of their study experienced while going through a PGD cycle. Franklin and Roberts concluded:

Since it is impossible for anyone, however emotionally self-aware, to imagine going through all the myriad potentially distressing circumstances occasioning even a successful PGD cycle, no one can ever really know for sure how he or she will cope. It is for this reason, as with IVF, that the emotional and psychological demands of PGD are described, by patients and clinical staff alike, as the most challenging, and hardest, part of each cycle.²¹⁰

There is a strict regimen of medical intervention that must be followed when going through a PGD cycle. Medicine must be given in exact dosages, at exact times, in exact places on the body. The women in this study expressed concern about the unknown factors regarding the precision of taking the medication. What would happen if the placement was wrong or the timing was off slightly? Would these inconsistencies diminish their chance of getting pregnant? Suddenly, the women found themselves having control of factors that could contribute to the probability of meeting their goal. This realization added to the emotional toll they were feeling throughout the cycle.

The medication the women take during the cycle pump hormones into their body that have been known to alter emotions. Franklin and Roberts found in their study of PGD, the mood swings brought on by the hormones the women took were a source of “joking between partners.”²¹¹ The hormones can intensify the stress a woman already feels.

210 Franklin and Roberts. *Born and Made*, 138.

211 Franklin and Roberts, *Born and Made*, 142

There are concerns regarding the safety of the medication the women take during the cycle. If the wrong dosage of ovarian hyperstimulation drugs is given, a problem can arise causing ovarian hyperstimulation syndrome and other medical complications.²¹² Many of the women were concerned about the drugs. Abbey said she has a fear of the long-term effects of the hormones on her body. She says she took so many medications that she doesn't know what they might have done to her body. Emma, who used PGD to have a son, said she was very concerned about the medication she had to take. She had not anticipated having to go through the same regimen as women who were experiencing fertility problems since she was able to get pregnant on her own. Emma explains,

Um...yea... oh yea, it was very ... I was very leery about it [taking the medication]. But...you know I asked several times are you sure I have to do the whole thing? Because I know I can get pregnant... You would think that I could skip a few steps...no I had to do the whole thing.

Many fertile women who use PGD for sex selection or family balancing are under the impression that they will not have to go through the same regimen as infertile women. Franklin and Roberts cited a clinician in their study to explain the reasons fertile women need to use the same drug regimen as infertile women. The reason, Jenny Caller, the clinician, told Franklin and Roberts, is "[B]ecause what we're doing, we're taking everything out of the body and manipulating it, and using the drugs in the way that we do is so unnatural it doesn't make any

212 Adam H. Balen, *Infertility in Practice*. (London: Informa Health Care, 2008), 759. Balen claims that ovarian hyperstimulation syndrome, a "potentially fatal condition, can be avoided by the judicious use of gonadotropins and careful monitoring of stimulation regimens". According to Balen "the overall risk is estimated to be about 4% and that of severe form about .25%. Levine and Navot claim OHSS is "second only to high-order multiple birth on the list of adverse outcomes that need to be minimized or completely eliminated". 759

difference whether you're fertile or not.”²¹³ Women who use PGD for sex selection or to avoid passing on a genetic disorder are generally fertile. But because the fertilization of their oocytes is occurring outside the body and more oocytes are needed to improve the odds of creating healthy embryos and embryos of the desired sex, women must adhere to the drug regimen. Both Emma and Meredith thought their history of fertility would give them an advantage over infertile women when using IVF, but that is not the case. According to Franklin and Roberts, “For many couples, the fact that IVF success rates were not significantly higher for the largely fertile cohort of PGD patients was an unpleasant discovery, removing one of the few perceived “advantage” of PGD over “normal IVF”.”²¹⁴

The emotional toll of going through a PGD cycle is intensified by the demands of frequent doctors visits to monitor the growth of the follicles. Follicles are measured and counted to determine the date for the egg retrieval procedure. Fitting the many visits to the doctor's office in one's schedule causes a major disruption in one's life and adds a tremendous amount of stress. Suddenly these women find themselves asking for time off from work for something they would rather not talk about. Tina said she only told the girls she worked with because she needed the coverage for when she had to go to appointments, “just the girl... [in] human resources and then 3, or 2 of the girls I was working with. Mostly just so they could cover for me.” Many women going through fertility treatment sometimes have unexcused absences from work, which can jeopardize job security. The pull between responsibilities and desire can become overwhelming. According to Braverman, “Treatment for infertility places very concrete demands on the

213 Franklin and Roberts. *Born and Made*, 143.

214 *Ibid.*, 143. Franklin and Roberts' study looked at PGD used for couples that are known carriers of genetic disorders. Their subjects were considered fertile. None of their participants were using PGD for infertility treatment.

individual and couple, which adds to the stress and burden. For some, the time demands of physician consultation, monitoring, inseminations, or IVF may present real problems on patient's demanding job or upon an individual who is juggling childcare." She goes on to say, "Many individuals and couples may also feel that they are in limbo, foregoing new jobs or promotions due to concerns about access to treatment or even financial coverage (depending on the country)."²¹⁵ For the women of this study, going through fertility treatment was a very demanding experience.

With such a high emotional toll caused by fertility treatment, why do these women and men choose to participate? The primary reason they endure the emotional, physical, and monetary cost of infertility treatment is their strong desire to have their biological child. These women/couples feel it is their right to have a biological child and they deserve to be pregnant just as much as anyone else. The women feel that no cost is too great to expend if it results in a biological child. Diana Burgwyn explains,

Why do they go through it all with less than a fifty-fifty chance of success and with the risk that some treatments may end up worsening, rather than ameliorating, the condition? Because they want to have babies for all the reasons, healthy and neurotic, that fertile people want to have babies... Because they are angry at the removal of choice... And so they go on, spending years and large sums of money.²¹⁶

215 Andrea Mechanick Braverman, "The relationship between stress and in vitro fertilization outcome." in *Textbook of Assisted Reproductive Technologies: Laboratory and Clinical Perspectives*. Third edition. Edited by David K. Gardner, Ariel Weissman, Colin M. Howles, and Zeev Shoham, (London: Informa Healthcare, 2009), 879.

216 Diana Burgwyn, *Marriage Without Children*. (New York: Harper & Row, Publishers, 1981), 94.

Getting involved with NRTs demonstrates a strong commitment to getting pregnant and having a biological child. Infertility causes a major disruption in the planned trajectory of peoples' lives. This disruption can be disconcerting, causing women and men to feel out of control. Choosing medical technology to rectify this situation offers a means of exerting control.

Finding Support

The women/couples of this study felt the emotional burdens of going through fertility treatment, but did not feel compelled to seek support outside their marital relationship. The women consistently said they sought support from their husband to get through PGD. Many of them felt going through PGD was such a personal experience that they did not want to talk about it with anyone else. Knowing their husband was supportive and sympathetic was enough to get them through the experience. Comments such as "He was there," (Emma) and "there wasn't anyone else I wanted to share with. I wanted to keep it to ourselves" (Marie) were woven throughout the women's discourse when asked about getting support. Talking only to their husband and keeping this experience to themselves, goes along with Inhorn and Van Balen's findings. In their research they found that infertility "has long been a taboo subject, one that is not easily discussed with others."²¹⁷ They went on to say that often insensitive and incomprehensible comments are directed toward infertile women. According to Inhorn and Van Balen,

[C]omments such as 'There are already so many children in the world,' or 'You have to be glad that you have so much spare time,' or 'You can't have everything,' or 'You can always adopt.' ... may be especially difficult to accept when they are expressed by couples with children.²¹⁸

To avoid such comments, it is often easier to keep fertility problems to oneself.

217 Van Balen and Inhorn, "Introduction", 5.

218 Ibid., 9

Only one woman in this study sought out support for her emotional needs while going through PGD. Sienna wanted to talk to someone and get more information but did not want to attend a support group. So instead of meeting people face to face, Sienna made use of the Internet. She and Pierre discussed their ideas about support groups:

Pierre: Yeah that would have been a good thing... probably... I don't know the support groups part. I think we were still viewing it as being so private that... didn't really want to bring strangers into it.

Sienna: Yeah and yet I think I wanted that, to share information. I know I wanted that but I really didn't know how to go about it. Part of the problem for me is when you say support group it already has the stigma. If it's a bunch of ladies getting together for coffee to talk ... people who have a shared experience, that'd be different. So no I didn't do that. But what I did do was lurk on message boards on the Internet. I went to I-village and it made me feel more comfortable. Sometimes I'd put a question out there and I would read online stuff and of course I would take it with a grain of salt because it was the Internet. But the women online were really, really supportive of each other. They were just huge monster cheerleaders for each other. They would talk about their numbers, [success rates, hormonal levels etc.,] ... That to me was cool, but I watched. I didn't really get involved. I think once or twice I would ask a question.

Sienna was able to keep her anonymity by going online for support rather than meeting people face-to-face. The above discourse and comments made by the women/couples of this study demonstrate the perceived stigma attached to being infertile. The emotional toll was intense and yet the sorrow they felt about their situation, being infertile and going through treatment, eclipsed their ability to reach out for support. The stigma²¹⁹ attached to being infertile can be very difficult to overcome. According to Greil, the stigma attached to being infertile comes from

219 In "Deciding Whether to Tell children about Donor Insemination: An Unresolved Question in the United States", Gay Becker relies on Erving Goffman to define the experience of stigma as a negative sense of social difference from others that is so far outside the socially defined norm that it discredits and devalues the individual. 119

the “feeling that they have not lived up to norms which they strongly believe.”²²⁰ Infertile couples believe that they should be able to get pregnant and carrying that pregnancy to term without medical assistance. They are disappointed in their own inability and often want to keep their disappointment, and therefore their stigma, to themselves.

A person with a stigma is often separated, and distinguished as different from the norm. According to Erving Goffman a person with a stigma “might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated.”²²¹ The women/couples that used PGD had anticipated that they would be able to get pregnant through coitus on their time frame. When their bodies did not perform as anticipated they felt ashamed and defined their situation as a stigma. This stigma was the impetus for them to isolate themselves and not seek support outside of their relationship. For the women of this study, it was better for them to keep to themselves and deal with the emotional toll rather than open themselves up to public scrutiny for the possibility of finding some comfort.

Alternatives

If the last rung on the fertility treatment hierarchical ladder is unsuccessful, there are always alternatives to having a biological child. Using donor gametes is one such alternative. Women/couples could choose to use either a donor for sperm, or egg, or both. In addition, women/couples could choose to “adopt” another couple’s frozen embryo. With any of the alternatives, the embryo could be implanted in the woman’s uterus, or a gestational surrogate

220 Greil, *Not Yet Pregnant*, 134.

221 Erving Goffman. *Stigma: Notes on the Management of Spoiled Identity*. (New York: Simon and Schuster, 1963), 5.

could be used. These options are not initially looked upon favorably as evident in an excerpt from a Resolve meeting.

Three days prior to a Resolve meeting, Kate had found out that at age 30 she no longer had any viable eggs to use for IVF. She was visibly distraught when she was telling her story at the meeting. She kept her arms tightly crossed in front of her chest and continually looked down. Occasionally, she became choked up and had tears in her eyes. She could not believe at thirty years old she no longer could produce eggs. She would now like to look for a donor egg that they could fertilize with her husband's, Alan, sperm. Alan is not so sure about using a donor egg. He feels if their child cannot have both their genes then their child should have neither of their genes and they should adopt. Kate feels she has already been "cheated" out of having a biological child and she at least wants to experience pregnancy. They both agreed that the news regarding Kate's eggs is too fresh and they need to give themselves some time before they make their final decision.

(Resolve Meeting)

Using donor specimens is initially thought of as settling for second best by women/couples who have met with continuous failure when trying to conceive a biological child. Mark and Jill felt that way initially. They said they would never have considered using donor egg or sperm. But at one Resolve meeting they advised others to look at all their options.

Jill and Mark had tried to get pregnant the "old fashion way" for many years. They have been married for 19 years. Infertility treatment was cost prohibitive for most of those 19 years. But two years ago, Jill turned 40 and realized she could no longer ignore her biological clock. The couple relented and tried IVF twice unsuccessfully. Jill was no longer able to produce eggs viable for fertilization after these two attempts. For the first time, Mark and Jill considered using a donor egg. This is an option they had previously never considered. However, after investing more than \$20,000 in the pursuit of having a child, Mark and Jill thought they should consider all options. Adoption was an option they considered, however Jill wanted to experience labor with Mark at her side. She wanted to bear Mark's child. Having a child with half its genes coming from one of them appealed to Mark and Jill. So they investigated using a donor egg. Jill is currently 17 weeks pregnant with a donor egg that was fertilized with her husband's sperm. She considers this child to be just as much a part of her as it is a part of Mark.

(Resolve Meeting)

Along with these options, there is always the option to adopt a child. The alternatives allow a woman/couple to have a child but not meet the goal of having her/their biological child.

Having a biological child is the preference for women/couples that chose to use PGD. After describing their multiple failings with IVF as arduous and painful, Pierre and Sienna, address alternate routes:

Pierre: Part of this is the emotional component. We were also looking into adoption and not just in terms of eggs but whole children. We hadn't gotten very far (long pause).

Claudia: But you considered that?

Pierre: Right

Claudia: And was that a viable option for you?

Pierre: It was not the preferred one.

Sienna: Right

Sienna quickly left this line of questioning without elaborating on her thoughts about adoption and went on to describe her desire to use PGD to find out why she was not maintaining a pregnancy. The alternatives were clearly not an option that Sienna wanted to consider. She was quite dismissive of the whole notion of adoption.

Hazel and Bill felt the same way as Sienna and Pierre did about the alternatives. After Hazel and Bill had two failed IVF cycles, the use of donor gametes was discussed during a consultation with their fertility specialist. They discuss their feelings about the alternatives suggested.

Bill: Because we weren't going to [long pause]. I wasn't going to start going to anything else like somebody else's sperm or somebody's egg. I wasn't going to do the donor. I mean if we weren't going to be able to have them on our own then we weren't going to have anymore.

Hazel: And that was one of the suggestions that [the clinic they went to] had suggested was a donor egg. That's where I said no we aren't comfortable with that. That's not where we wanted to go with this. It's either going to work... It's going to be us or it's not...

Bill: It's either going to be us or it's not going to be. Not that I'm against adoption or anything like that kind of stuff, but when you're dealing with this kind of thing, in my mind, it's got to be ours or it doesn't make any sense.

Not only does Hazel and Bill's discourse demonstrate their thoughts about using donor gametes, but it also demonstrates the way in which these couples view their fertility treatment as assisting them in getting pregnant on their own. Bill used the phrase "have them on our own" to describe the way in which Hazel got pregnant. When couples use their own gametes to get pregnant there is real ownership involved and as close to becoming pregnant the "natural" way as possible for them. Their discourse also demonstrates that getting pregnant is not the real goal here. Having their biological child is the goal. Because if the goal was just to get pregnant or just to have a child, the alternatives would not only be acceptable, but would be preferred because in some cases it would expedite reaching the goal. Having their biological child signifies the child as being "ours" as Bill refers to it.

PGD Initiation Conceptualized

The women's/couples' stories about their initiation into fertility treatment demonstrate the mediation with which their stories are framed. According to Hartouni, "there is and can be no unmediated account, no reading of the tale, or for that matter one's immediate surroundings, that does not depend on point of view or interpretation or a constellation of narratives that frames an otherwise random set of images (colors, lines, and objects) and makes them make sense."²²² The infertile women/couples came to PGD after long complicated histories of pregnancy loss and infertility. Their understanding of PGD is based on what PGD can do for them as an infertile patient. They took on the role and label of patient so they could have a biological child. The medical diagnosis legitimates the need for medical intervention. In our society, the only way to

²²² Hartouni, *Cultural Conceptions*, 16.

have a biological child if one cannot conceive through coitus is to seek medical assistance. The fertile women came to PGD with a strong desire to have a child of their preferred gender.

The knowledge and understanding these women/couples have of their situation is embedded in their embodied experience. It comes from a perspective of women/couples struggling to accomplish something that had been previously perceived by them as “natural” and something they should be capable of doing. It is from this perspective that these women/couples filter, organize, and classify the information they receive from their physician. This is what is meant when Donna Haraway defines “situated knowledge”. Haraway claims knowledge is positioned and it is from these positions that people can interrogate and construct conversations and ideas.²²³ People hold many positions that define them. The women/couples of this study hold many positions: race, class, gender, U.S. citizen, husband, wife, child, brother, sister, and professional to name just a few. They also hold the position of being people who are unable to have their biological child, for those who are experiencing infertility, and who cannot have a child of the desired gender without using medical assistance. This last position is the one that is holding most sway in their thinking and dominating their situated knowledge while going through fertility treatment. Haraway explains that situated knowledge is not a perspective that one merely adopts. It comes from a position and an embodied experience and therefore derives its power from a perspective shared by others.

Using an NRT to assist with procreation has become an acceptable means of treatment. By engaging in the use of NRTs and becoming successful, the women/couples of this study become part of the narrative Hartouni refers to when she says the stories of IVF were retold in

223 Haraway, *Simians, Cyborgs and Women*, 193.

“[A] highly sentimentalized story of heterosexual love, yearning, and procreative desire.”²²⁴ It is the fact that these women/couples were successful that they become part of this narrative about IVF with PGD. Their success stories of becoming a loving family will perpetuate the narratives that are working to make PGD acceptable. They have unwittingly become part of the “social relations” that work to render a new NRT part of the social fabric of medical intervention.

The reasons for the initial rejection of medical assistance by these women/couples needed to be reconceptualized when they were unable to reach their goal on their own. They needed to rework their definition of themselves as well as their ideas about medical intervention for infertility. Hartouni would define this process as “conceptual retraining”.²²⁵ Their thoughts on fertility treatment were initially based on the idea they had of themselves and their understanding of their bodies. By putting their goal of having their biological child ahead of their self-image as a reproducing able body, they were able to accept medical intervention. These women/couples reconstructed their identities on individual levels in order to engage with the NRTs. Hartouni discusses the reconstruction of identities on a societal level when she talks about engaging in developing NRTs, specifically cloning. According to Hartouni, “It requires the courage to take seriously the socially and technologically produced opportunity to invent ourselves consciously and deliberately, and in this to develop the practical, political implications of philosophical claim that “we” are only and always what we make.”²²⁶ It would appear that that sentiment “we are only and always what we make” compelled these women/couples to engage in the only technology that offered them the possibility to “make” their biological child.

224 Ibid., 20.

225 Ibid., 29.

226 Ibid., 50.

These women/couples felt that it was their choice to use PGD. Rapp investigates the idea of individual choice and how freely it is made. Not only did these women/couples reassign themselves an identity, from healthy person to patient, they became part of the market-driven choice in North American culture.²²⁷ The business of reproduction is a 3 billion dollar industry.²²⁸ These women/couples were fortunate enough to be able to pay for these services. Most treatments are not covered by insurance; however, some of the medications are covered under some medical insurance plans. The cost of NRTs has created a stratified reproductive society. Only those with the financial resources can afford to “reconceptualize” their identity to that of a patient in order to receive medical assistance.

In addition to becoming part of the market that drives choice, the mere fact that the technology is available is enough of a lure to take advantage of its service. Rapp concluded from the discourse of the women in her study, “[O]nce technology exists to provide the information, ignoring it constitutes deprivation. Such a structure of sentiment surely drives the proliferation of knowledge generation and consumption.”²²⁹ The women/couples that used PGD would be remiss in their responsibility to their unborn child if they had not taken advantage of the technology. Although in most of their cases, without the technology they would not have gotten pregnant. One could conclude that they owed the responsibility to themselves to try every

227 Rapp, *Testing Women*, 37.

228 This statistic is according to Debora L. Spar who compiled data in 2004. Also, according to Spar this figure does not include revenue from PGD procedures. Spar, Debora L., *The Baby Business: How Money, Science, and Politics Drives the Commerce of Conception*. (Boston: Harvard Business School Publishing Corp., 2006), 3.

229 Rapp, *Testing Women*, 122.

possibility available to reach their goal or they were succumbing to the pressures of society to do everything possible to become a mother.

The first decision the women/couples of this study made regarding the use of PGD was deciding to enlist the assistance of a specialist in combating their infertility. They put their trust in the specialist assuming that he would do everything within his ability to help them meet their goal. The women/couples discourse about this decision demonstrated that they had not thought much beyond that decision about any possible moral dilemmas that might arise from meeting with the specialist. The resolute trust the women/couples put in their doctor demonstrates their willingness to allow themselves to be vulnerable in order to have a child. Tong relies on Baier to discuss the importance of trust. “Realizing that trust entails risks, we must ask ourselves why we should willingly make ourselves vulnerable. Baier answers that we need to trust others because we are not self-sufficient. Without the help of others, neither the production of things and ideas nor the reproduction of persons could proceed.”²³⁰ The women/couples valued the potential relationship they would have with their child enough to subject themselves to the vulnerability they experienced in the hands of their doctor. However, as we will see in subsequent chapters, the women/couples did not relinquish their agency at the expense of vulnerability. The women/couples increased their agency with each successive PGD cycle but remained vulnerable to their doctor and the medical system.

The discourse of the infertile women/couples regarding their initiation into reproductive technologies elevated the conscious awareness of the painful and arduous fertility history the women experienced prior to gaining access to the most advanced fertility treatment. They told stories of their multiple miscarriages, failed attempts of getting pregnant, and loss of children

230 Tong, *Feminist Approaches to Bioethics*, 43.

that compelled them to ultimately enlist the assistance of a specialist. Some would question the emotional stability of the woman, after having many miscarriages, to make a decision to use NRTs. According to Tong:

Feminist critics of IVF counter that just because a woman knows cognitively what IVF's risks and benefits are, she is not necessarily emotionally able to make fully voluntary decision to use or not to use IVF. As they see it, Western society teaches women that their "fulfillment" depends on their mothering a child, preferably a child that is flesh of their flesh. To the degree that a woman is convinced that being a genetic and gestational as well as social mother is the *sine qua non* for her success as a human being, she will "want" to use virtually any reproduction-aiding technology to achieve her maternal goal.²³¹

Were the women who used PGD emotionally unstable and therefore unable to make an informed decision? They would argue that they knew what they were choosing. Tong argues that feminist advocates for the NRTs insist it is up to the users to decide, "whether the risks are worth taking".²³²

Discerning the risks to a woman's health is the most pertinent issue of a feminist's approach to bioethics regarding the use of NRTs. Feminists are concerned women are not always made aware of the health risks associated with IVF and PGD cycles. The women of this study will discuss their concerns regarding the long-term side effects of the drugs they took during their treatment in a later chapter. These women did not passively accept the use of the drugs without asking questions and doing some research on their own. However, they all felt the benefits far outweighed the risks.

Conclusion

The women/couples of this study had complicated fertility histories prior to seeking out medical intervention. They experienced several miscarriages and years of infertility. Some of the

231 Ibid., 182.

232 Ibid., 182.

women experienced failed cycles with medical intervention. Even after all their failed attempts and set backs, they continued with treatment hoping that they would eventually meet with success.

These women/couples epitomize the ideology that perpetuates the idea to seek out expert advice as well as a technological solution to medical problems. This type of attitude is not only financially costly, but as these women/couples discussed, emotionally costly as well. The emotional toll of fertility treatment far exceeds the financial. Going through a PGD cycle can be very isolating because of the stigma attached to being infertile. The women of this study did not want to talk about their infertility with other people.

The stigma attached to infertility not only isolates, but it also motivates women and men to find a solution to their problem and an answer to why they have the problem. PGD offered both ideas to these women/couples. For many in this study, this was the first time they had heard of such a technique. Not fully aware of all its complications, the promise that PGD offers made it very attractive for these women/couples.

The initiation into the world of infertility is wrought with pain and heartache, and one that is never anticipated. When suddenly women/couples are faced with the prospect of not fulfilling a desire of which they thought they had control, anger and frustration ensue. Disregarding a solution, such as PGD, regardless of its association with controversy, is not an option. By choosing to use PGD, women/couples are faced with a uniquely challenging experience.

CHAPTER SIX

ON THE FRONT LINE: USING PGD

Deciding to use PGD demonstrates a strong commitment to having a biological child. The process is demanding both physically and emotionally. The treatment protocol places high demands on a woman's body. She will be poked, prodded, and monitored to gauge her response to the treatment regimen.

After the initial phase of treatment is completed, the process is carried out in a laboratory. At that time the woman is not directly involved in the process. Her bodily contribution along with sperm is combined to create an embryo. Shortly thereafter, PGD will occur. The possibility of getting pregnant is contingent upon the outcome of the results of PGD. The results of this test will reveal the genetic health status of the embryo.

Using PGD requires decisions to be made regarding the fate of embryos. Decisions regarding which embryos should be transferred back to the woman's uterus as well as what to do with the remaining embryos need to be made. What criteria do women/couples use to make these decisions? What status do they assign to the embryos? Does this status change throughout the PGD process? How do they feel after they have made their decision? Do their decisions reflect their ideological beliefs? According to Kaja Finkler, "human beings themselves do not always recognize the consequences of their own ideological beliefs. Our subjectivity restrains us from seeing our existence in its totality".²³³ Do the participants of this study understand the consequences of their decisions?

The decisions PGD users must make are unique. Embryos are typically not separated from a woman's body and therefore no decision regarding their fate needs to occur. The users of PGD,

233 Finkler, *Experiencing the New Genetics*, xiii.

like the women in Rayna Rapp's study, could be considered "moral pioneers".²³⁴ They are making decisions that reflect cultural values about life. For the users of PGD, going through the process is a time full of contradictions, ambivalence, and acquiescence.

Committed

The commitment to having a biological child is never more greatly challenged than during a PGD cycle. The woman must commit to dedicating her time as well as enduring physical pain. Because the fertility treatment is carried out on the woman's body, she is more physically involved than her partner. Her body is injected with drugs that will produce hyperovulation and prepare her body for pregnancy. The hyperovulation shots are a big part of the memory of these women and their partner. Natasha and Derrick talk about their experience with the daily shot.

Natasha: At that point you do what you have to do... The medication didn't make me sick or anything so that was a plus. The only thing that was bad was the taking of the shot. The one we had to do in the hip every day. I can't remember how long we had to do that. Obviously, now it feels like it wasn't that long, but then it seemed like a long time.

Derrick: Your stressful time seemed to be every morning when I had to give you the shots.

Sienna and Pierre joke about the shots. Pierre gave Sienna her daily shots and they can now laugh about it because it is a distant memory.

Claudia: Let's talk about the procedure. Tell me about the shots.

Sienna and Pierre: (lots of laughter)

234 Rapp, *Testing Women*, 306. Rapp refers to the women of her study as moral pioneers because of the unique decisions they had to make. She says, "I came to think of the women who submitted to the discipline of new reproductive technology in order to reap its biomedical benefits as moral pioneers." 306

Pierre: One time the needle separated from the syringe in the middle of giving the shot. So she had it sticking in her... If there's anything a husband loves it is to give his wife pain.

Sienna: It was awful... it was intense... there were just so many.

Pierre: There were a lot of them.

Sienna: Just morning and at night.

Later in the conversation Sienna talks about the bruise the shots left at the injection site. Her bruise was exceptionally large because she had had multiple unsuccessful IVF cycles. She says it took two years for the bruise to heal.

The shots provide a daily reminder of the commitment the women have made as well as a means of actively participating in the process. In Isabel's description of her experience there is a note of realization and ambivalence about the amount of participation and control she had in the process.

Isabel: I guess there is a lot that is in your hands with the actual going through it because you have to give yourself all those little shots. And I kept worrying if I was going to mess up the medicine. The first couple of days I think I was really nervous ... I kept closing my eyes and stabbing myself ... I had never done anything like that before... the first couple of times I was very nervous, then... by the time it was over I was getting good at it. ... Those things ... it was a lot to have in your own hands... doing the actual administering the medicines when you're not a nurse, or a medical person, that was a lot.

Isabel points out that she gave herself the daily shots. Many women give themselves the daily shots even though they are trained to have a partner give the shot. During the training meeting at the doctor's office, the nurses give instructions as if a partner is administering the shot. This is typically a way for the woman's partner to actively get involved. However, several women said they gave themselves their daily shots. Janet gave herself shots using a mirror. She stuck the needle in her backside, because she did it quicker and caused less pain than her husband. Her

husband helped push the syringe to inject the medicine. “It’s not easy,” she said, “it was painful on my side. But it’s worth it.”

Emma also gave herself the daily shots. She found that mixing the medication was more difficult than giving herself the shots. Her dosage was so small that it was hard for her to mix the small amounts. She explains:

Emma: I was fine with the shots. And I did them all myself ... even the ones in the back... The hardest part with those is the mixing of the medication. I absolutely cannot stand that.

Claudia: What is it about that you can’t stand?

Emma: Oh it’s horrible... like I said I’m on my third or fourth day of starting my shots right now [Emma has just started the shots for her second IVF cycle with PGD to try to have another boy] and... It’s like I almost end up giving myself a shot of nothing because it doesn’t seem to be ... I’ll have like 6 vials and one saline and I’ll have to do 1cc of saline and then mix it into these 6 vials and pull it back out so it’s mixing all those medications together. But 1 cc... I mean ... it’s like nothing and trying to get it out of these vials, I barely end up with anything in that shot when I’m done.

Another challenge associated with the shots for Emma is scheduling them into her busy life.

Emma explains:

Claudia: How do you manage to fit everything in with a baby and other family responsibilities and work?

Emma: They tell me to take my shot between 6-8 at night ... I’m lucky if I get it before 9. It’s just impossible for me... and then it takes me a half an hour -45 minutes to actually mix it. ... So I’m lucky if it’s before 9.

Not only do the women get daily injections as part of the treatment regimen, but they also receive an important shot just prior to the egg retrieval. This shot is given to prepare the woman’s body to release her eggs. The shot is precisely dosed and timed in relation to the scheduled egg retrieval. Isabel talks about the stress associated with this one shot.

Isabel: The shot that is the really important one, the one that makes your eggs release, the one that had to be a certain time. That one is so important, the timing had to be right ... before they take the eggs out. It had to be done like 48 hours

before and it had to be done right at a certain time on that day. It was nerve wracking, that one shot, because then the medicine is ordered so if I was to do something that messed up the shot, then what was I going to do? And when it was done I felt like I could breathe. I felt like ok the shot's in me. I can breathe.

Isabel went on to talk about that one shot and the level of control she felt she had during the process.

Isabel: I was a wreck over that because there was no back up. The medicine is so expensive so you're not about to buy two of them. So there was no way that I knew of, that if I missed it... what was I going to do?

Isabel realized the direct correlation between her actions and the outcome of the treatment. If she did something wrong while administering this shot, then the whole procedure would be stopped and deemed unsuccessful. This amount of control over a very important part of the process gave Isabel reason to pause. She decided to enlist a friend of the family, who is a nurse, for assistance. Isabel felt more at ease knowing that someone with medical expertise was giving the shot. Isabel relinquished her control.

These discourses demonstrate the intensity of the regimen of a PGD cycle and the stress the women feel about their involvement. On one hand they want control of the process, especially demonstrated by the women who gave themselves their own shots, and at the same time having control produces stress. Regardless of the stress or any other difficulty these women faced, they remained committed to their PGD cycle. Arthur Greil says, "Thus, it is striking that the infertile are, as a rule, quite committed to pursuing treatment."²³⁵ Greil goes on to cite journalist Marsha Stamell to make his point, "[I]nfertility patients are surpassed only by cancer patients in their willingness to subject themselves to costly, painful, and sometimes hopeless

235 Greil, *Not Yet Pregnant*, 98.

medical procedures”.²³⁶ These women were willing to endure the pain of these shots because it was the only way to obtain their goal. Currently, there is no other way to stimulate ovulation than with injects.

There is always a risk of Ovarian Hyperstimulation Syndrome (OHS) occurring as a result of being injected with the medication. This syndrome can range in severity from being extremely painful to causing the death of the woman. According to Christian Munthe, “the probability of this condition occurring or taking a life-threatening course may today be significantly reduced by various means, the risk is till very much a reality in IVF. There are also some unclear risks of ovarian cancer which so far have not been sufficiently clarified”.²³⁷ To decrease the risk of OHS, the woman is frequently monitored at her doctor’s office to measure the growth and development of her ovaries.

The Biopsy

PGD occurs during the time the woman is not directly involved in the process. After the eggs have been removed from the woman, she is sent home and told to wait. Later she will receive a call informing her of the transfer date and the number of embryos created. She will not find out the number of healthy embryos until just minutes before the transfer. The transfer will either be three or five days after the retrieval depending on the progression of embryonic cell division. During these three to five days the woman does not need to come into the office. Nor does she have a need to be in touch with the staff at the doctor’s office. This is the time, she knows, when the egg and sperm are united, then the embryo/s develops in a dish to approximately the eight-cell stage and finally one or two cells are removed for analysis, and the health of the embryos is determined. A lot is happening in the process of her pregnancy during

236 Ibid., 98.

237 Munthe, *Pure Selection*, 170.

this time, of which she has no direct involvement. PGD is occurring in a laboratory. Thompson defines the significance of this aspect of a pregnancy in the following manner:

The embryology laboratory maintains an ontology of connectedness between patients and body parts during the time when the two are separated. This spatial separation between the patient and her gametes and embryos make possible events that would not otherwise occur but also increase the work that is necessary to mark and maintain a potential pregnancy trajectory.²³⁸

The pregnancies for women who use PGD are a discontinuous bodily experience. They do not have a continuous physical connection with their pregnancy. During the days that the embryos grow and PGD occurs, the woman is preparing her body for the embryos transfer.

PGD is often done in a specialized laboratory. The fertility clinic used by the women of this research project sent the removed cells to a laboratory in California to be biopsied. Abbey and Sam said they did not know their embryos would be shipped to California. They thought the testing was going to be done in the laboratory at the clinic where they had the egg retrieval. They took responsibility for not knowing about this aspect of the process. They felt it was their responsibility to ask all the right questions to get all the answers. As with most of the other couples, eventually Abbey and Sam knew that PGD was not performed in the clinic's laboratory and the cells were being shipped away.

Sienna and Pierre were well aware their embryos were being shipped to California for testing. Here is how they describe how they interpreted their experience.

Sienna: I think what I remember about it was it's just weird. That this little teeny thing was taking a trip to California to do this stuff and I thought it was weird that there wasn't any place near that could do it... I knew they were going to California. But I think... I don't think I worried about like, Oh my Gosh is somebody going to lose it? Is it in luggage or transport, or FedEx? Those thoughts never occurred to me. I had faith in the system that they would be handled

238 Thompson, *Making Parents*, 197.

appropriately. So I didn't think about any of that stuff. I really just kept thinking and maybe naively and maybe not, that it would be handled appropriately. So I didn't get all worked up about that.

Pierre: Yeah I think we just assumed that everything would happen the way that it was suppose to and not worry to much about the dramatic exception of there being any problems in transit.

Sienna: Which is kind of ironic for a couple who had been dealing with infertility for years. And had 5 failed IVFs and had a daughter through 2 years of other... We were just thinking, oh it'll work itself out.

Like Sienna, Tina also uses the term “weird” to describe her understanding of the process. She said, “Yeah... yeah I thought it was weird how they described how they take the embryos and send them off in shipped FedEx or something. I thought that was very strange. But I was comfortable with it.”

Sienna and Tina's use of the term “weird” suggests something they could not totally comprehend. The American Heritage Dictionary defines weird as “of an odd and inexplicable character; unusual; strange; fantastic.”²³⁹ The process of PGD was inexplicable to Sienna and Tina. The ability to extract a cell from an embryo without doing any harm moves beyond most people's comprehension; as does the information gleaned from PGD. Rapp concluded that knowing information that is not generally known could cause anxiety. She found, “The anxiety attendant upon amniocentesis may be linked not only to the content of the information it yields, but to the very process of choosing to know some ‘facts of life’ that are not conventionally revealed”.²⁴⁰ The information revealed through the use of PGD is unconventional and novel.

239 *The American Heritage Dictionary of the English Language*, New College Edition, 1453. s.v. “weird”. The definition of weird is suggestive of or concerned with the supernatural; unearthly; eerie; uncanny. Also of an odd and inexplicable character; unusual; strange; fantastic.

240 Rapp, *Testing Women*, 97.

These stories show that it is not necessary to fully understand a technology in order to engage with it. Participating in the latest, cutting-edge technology offered the best possible chance of obtaining their goal and also required a level of trust in the experts. Allowing the experts to lead and make decisions regarding treatment removed some of the burden from users. A passive patient can be exonerated from making difficult decisions. There are some decisions associated with PGD that are much more morally challenging than others.

Many of the decisions women/couples needed to make are based on the information obtained from the results of PGD. The calm attitude conveyed by Tina, Sienna and Pierre belies the anxiety associated with the outcome of the testing. The goal of having a healthy baby is highly contingent upon the outcome of the biopsy. Marie, a self-described “control freak”, was concerned about the cells being packaged and shipped to a laboratory in California. She had a difficult time waiting for the results. She wanted to understand more about the process. She describes her experience:

Things were going to be shipped out!... My child's cells are going to be shipped out? Were they going to package the cells right? Are they going to process it accurately in the lab in California? Are they reputable? Should I package it? Should I send it? Who are these people? The nurse gave me the number to Ted, I think he was the geneticist, from... whatever the place was called, and I talked to him, and then I really felt comfortable.

Ted, who Marie called, is the geneticist doing the testing in California. Marie needed the comfort and peace of mind brought about by having contact with the person actually doing the testing. Marie's behavior exemplifies the level of anxiety felt during these days of noninvolvement in the PGD cycle. It is very difficult to go from daily shots, and twice-weekly office visits, to sitting and waiting for the results of your efforts.

Abbey and Sam felt the anxiety during these “off days.” According to Abbey and Sam, there was a lot of tension during the five days of waiting. They both were concerned for the

embryos, the results, and wondered how many would survive. Abbey expressed her feelings toward the embryos, as if they were her “kids”. She felt that she had bonded with the embryos already and she said, her “kids were out in California.” The bonding she felt was based on the projected feelings she would have for the children her embryos would become. Abbey had not seen her embryos nor did she have any idea how many there were or the health status.

Both Marie and Abbey use possessive pronouns when talking about their embryos, indicating an attachment and a human identification. At the time after fertilization and before PGD results are known, all the embryos are considered healthy and potential children. Optimistically, Marie and Abbey considered the embryos they had created as the embryos that would ultimately produce their child/ren. Marie explains, “I didn’t consider myself a parent than but yeah I guess in some respects perhaps because here you’re taking a cell from an embryo that could potentially be a child and putting it out there and you hope they don’t screw anything up.”

Marie did not always assign human potential to all her embryos. She and her husband, Donald, had five frozen embryos from a previous failed IVF cycle without PGD. It was unknown if any of the five frozen embryos were genetically healthy, therefore their potential for becoming a baby was unclear. Marie and her husband did not want to take a chance by transferring any of the five embryos so they discarded all of them. Marie and her husband gave full human status to only healthy embryos.

What is most interesting in Marie and Donald’s discussion about their embryos is their ability to destroy unused embryo at the same time they considered their soon to be used embryos as potential children. Their behavior demonstrates the contradictory feelings experienced by these women/couples. These women/couples determine the definition and fate of their embryos based on their understanding of their situation and interpretation of their past reproductive

experiences. Barbara Rothman found in her study of woman who had an amniocentesis and had to make a decision about the fate of their pregnancy, also determined the definition of their pregnancy in a similar manner. According to Rothman, “If a woman defines the products of conception within her as accidental, then that is what they are to her. If she defines it as her baby, then she treats it as her baby.” She goes on to say,

The problem, or one of the problems, with the technology of amniocentesis and selective abortion is what it does to us, to mothers and to fathers and to families. It sets up a contradiction in definitions. It asks women to accept their pregnancies and their babies, to take care of the babies within them, and yet be willing to abort them.²⁴¹

The same contradiction is present in defining the embryos. Prior to PGD, all the embryos have the potential to become a healthy baby therefore the women/couples regard the embryos as potential humans. But once PGD is completed, then only those embryos deemed healthy are looked upon as potential children. Those that are deemed genetically damaged are no longer seen as potential children but are seen as mere cells and can be discarded. Charis Thompson discusses the manner in which embryos become waste. According to Thompson:

Making an embryo into waste is an outcome and not a by-product. Correspondingly, the word disposition is used to describe the various trajectories for embryos, including options that end up with embryos being discarded, and the related notion of disposal is rarely used, let alone coupled as “waste disposal.” There are thus only certain conditional outcomes by which embryos become waste, all of which involve conditions that cannot be known about before they occur, even if it is necessary to plan for their possibility.²⁴²

The definition placed upon the embryo is liminal and can change based on outcomes and timing within the PGD cycle. Some women deem even healthy embryos no longer as having potential for life once they have reached their goal and no longer need more embryos. The act of

241 Rothman, *The Tentative Pregnancy*, 6.

242 Thompson, *Making Parents*, 264.

discarding healthy extra embryos demonstrates a belief that considers embryos as a means to get to an end. Many of the participants in this study were willing to use the embryos in the manner they saw fit for their own purposes.

Limbo

PGD requires one to two cells to be removed from the embryo at around the eight-cell stage of development. The idea that one or two cells can be removed without harming the embryo is sometimes difficult to imagine.²⁴³ Most of the women and their partners were reassured by their doctor that this procedure would not cause harm. Monica briefly discusses her thoughts. She said, “He [her doctor] did explain it and he said it would not affect the baby or child later on. When he told us ... he told us they would take out like two cells or something to do the procedure, that was a little concerning, but then he assured us.”

243 According to Christian Munthe, in *Pure Selection*, “Some arguments against PGD are linked to risks of damage to these children due to the use of micro-manipulation” (27). Munthe goes on to describe the concerns regarding the health of the children conceived through the use of PGD. He says children born from parents who experienced infertility may suffer a disability as a result of the micromanipulation used during PGD but will not be born with the genetic disorder which precluded their birth. Without the use of PGD, these children would not have been born at all. According to Dr. Serene Chen, “The risks of PGD include damage to the embryo during the biopsy procedure. Embryo damage is an “all or none” phenomena. If an embryo is damaged, it will stop growing. Embryos that continue to grow after the biopsy do not become abnormal as a result of the biopsy.” Chen, Susan, M.D. “Can Preimplantation Genetic Diagnosis (PGD) Reduce the Risk for Recurrent Pregnancy Loss?”

<http://www.inciid.org/printpage.php?cat=pgd&id=265> (accessed April 14, 2011).

Tina and Brad also were concerned about removing cells from the embryo. They were worried about the long-term effects. Here they talk about their concerns:

Brad: Yeah, would he come out with an arm missing? There are only 8 cells right? And they take one? I didn't really understand how ...

Tina: How is that? How it was there were 8? And they're taking one? Doesn't he need that? Yeah I thought about it, thinking well I guess if they've been doing this. So then is he missing something?... No, no we talked about it. Yeah that was a concern.

Tina and Brad's concerns were not enough to dissuade them from using PGD. Their trust in the advice of the experts coupled with their desire to have their biological child compelled them to continue with the procedure.

Marie also had some concerns about the removal of cells from her embryos. She did some research online and found that some embryos could be damaged in the process. She said, "When I was reading about the process of taking out a cell, in that process some could be damaged. They could damage them you know, that adds another obstacle." Marie was concerned that the embryo would be damaged in the process and would not develop into a viable, transferrable embryo. This outcome would add to the many obstacles she had already experienced in getting pregnant and reaching her goal of having a biological child.

Hazel and Bill were also concerned that removing a cell would damage their embryos.

Hazel: What kind of damage are you doing to the embryos?

Bill: Before we even went through it I watched kids of IVF going through wondering do they have a cell removed? I mean is there something wrong with that kid? You just don't know. I mean there are only 8 at the time they take it... that's 1/8th of the cells. What cell is that? ... Because you don't know what one cell does. I don't even know if anyone knows.

The genetic testing on the one or two cells is done in a laboratory away from the woman/couple. They never see the process occur. During this time, the woman/couple can plan

for the very complex decision they are going to have to make before the transfer. Just moments prior to the embryo transfer, they need to decide which embryo/s to transfer and what to do with the remaining embryo/s. The woman/couple are made aware of the number of embryos created from their eggs and sperm prior to their arrival for their transfer, however they do not learn the number of healthy embryo/s they have until just moments before the transfer. The possible scenarios regarding which embryos to transfer and what to do with the remainder are contingent upon the number of healthy embryos. In the worst-case scenario there would be no healthy transferable embryo.

The worst-case scenario may be difficult to consider but it is exactly what happened to Marie and Donald on their first PGD cycle. They had not discussed their decision regarding the fate of their embryo/s prior to the transfer. They had yielded 15 embryos all of which were tested using PGD. Marie knew that her balanced translocation would cause only a small percentage of those 15 embryos to be genetically healthy. She did not want to think about the endless possibilities of scenarios. She just wanted one healthy embryo to transfer. None of the 15 embryos were genetically healthy enough to transfer. Marie and Donald did not learn that their embryos were not transferrable until the morning of the transfer. Just prior to leaving their home for the clinic, they received a phone call telling them their transfer was cancelled. It was not until later when Marie spoke to the doctor that she found out the reason for the cancellation.

The second time [second IVF cycle, the first IVF cycle with PGD] we had...15 embryos ... so I didn't know until the day of, the day of the transplant, transfer, whatif any are good, normal, balanced. Let's rewind, ... actually I would say a few minutes before we left the house we got a phone call just saying, some guy, I'm not sure who it was, from [the clinic] called me to let me know they cancelled the transfer for that day. Ok, ok what do you mean you cancelled it? That was it; we were just left in the air. I didn't know why they cancelled it for the day. Are they going to have it for another day? That was our second time. Yeah that was pretty devastating.

That was Marie's second IVF cycle and her first cycle using PGD. Marie anticipated having at least one transferable embryo out of the fifteen created. She never considered that she would not have any healthy embryos to transfer.

On Marie's second IVF cycle with PGD she yielded 9 embryos. All were genetically tested and four were healthy and transferrable. Marie talks about the anxiety during the time the embryos were being tested.

Marie: Yeah I was more comfortable with the process, IVF, transferring. All this whole process was a little easier to manage and go through. I talked to Ted... I talked to Ted from the PGD lab a second time. I'm not sure why I called him... Oh I know why I called him...what was it?... The third time yielded, I think 9 embryos. I wasn't very happy with that number because before we had so many more. But I didn't know how many were sent out so that's what I called Ted about. To see how many were tested. He didn't know how many were good or balanced yet. I just wanted to know how many were tested. So all nine were tested. We didn't find out for a while. So the day of the transfer I didn't get my hopes up at all, we were on pins and needles.

Claudia: Because of what happened last time?

Marie: Yeah, we were driving to [the clinic] and I had the phone in my hand and the phone rang and it was my brother, wishing us well...It was kind of scary... and we found out that there were 4 embryos that were normal and balanced according to PGD. We were pretty happy about that. We transferred two. We put two in that resulted into him. [She refers to her baby boy she is holding]

The criterion to have an embryo transferred always includes health, but gender and number of embryos to transfer also play a role in the decision. The days between the egg retrieval and the embryo transfer provides an opportunity for the couple to discuss the possible scenarios that might occur once they learn the number of healthy embryos they have. Tina and Brad talk about the discussion they had prior to their embryo transfer.

Tina: Well at first ... we were nervous about it... we were fine ... we knew we had 6 [embryos]. We were like that's great... Well out of that 6 we at least have to have two good ones or something like that. And we were going to freeze the ones we weren't going to transfer or you know...

Claudia: So you talked about that. Had you come to some conclusion?

Tina: I believe at the very most we were going to put in two and we were going to pick I believe a boy and a girl wasn't that right?

Brad: If we had the option we were going to pick a boy and a girl

Tina: Right if we had the option. We were a little set on a girl I think ... in the beginning we thought about that but in the end we didn't care. We didn't mind at all. We just wanted a healthy baby.

In telling their story, Tina and Brad say they would have liked to have had all the information about their embryos prior to going to the clinic for the transfer. Having all the information would have made for a more informed discussion and decision.

Tina: We had to wait the weekend not knowing and we were like OK our babies are in California and we didn't know what we had. But maybe they do that for a reason. I think our ride down there [to the clinic for the transfer] was more talking about it then the weekend. I think we were a little nervous.

Brad: Plus there are such a variety of options, you have no idea of what to expect.

Tina: 2 boys, 2 girls, one of each?

Ultimately, Tina and Brad did not need to make a decision. They had only one viable embryo to transfer. They had a son as a result of PGD. Tina and Brad's discussion is quite typical of the extent to which couples consider the possibilities. Discussions typically go no further than what they desire to use without considering all the possible configurations of what they might end up with. Tina and Brad had discussed their plans prior to the embryo transfer and had come to an agreement.

Sienna and Pierre had also discussed their plan prior to the embryo transfer. They revealed that they were in agreement with what they would do. They had planned to "use what we could, if there were remainder, give them to research," according to Pierre. They ended up freezing their unused embryos and then later discarding them. Sienna and Pierre had a discussion prior to the embryo transfer but changed their mind once they had to make the decision.

These stories reveal the emotional and unique nature of the decisions regarding the fate of embryos. What appears to be an inconsistency between their intended decision and their actual decision reveals the uniqueness of this decision. The decision they must make is made in a short amount of time about an elusive entity. There is no contact with the embryos prior to making the decision. The women/couples have not seen the embryos, and only see the pictures representing their embryos in the moments they had to make their decision. It was difficult for these women/couples to grasp the magnitude of the decision they had to make and the long-term implications of that decision. Later we will hear about the regrets some of the women/couples have about the decisions they made.

The Embryo Transfer

The day of the embryo transfer is often eagerly anticipated. On this day, women/couples find out the number of healthy, transferable embryos they produced. Having at least one transferable embryo allows the PGD cycle to continue. If there is at least one transferable embryo, then the woman is prepared for the embryo transfer. She is dressed in a hospital gown and lays on a gurney before going into the surgery room. She is fully aware of the proceedings; no anesthesia is used. Once she is in the surgical room, with her partner by her side, she is presented with a list of genetic statistics and pictures of her embryos. The woman/couple is told of the genetic health, gender, and viability of her/their embryo/s. At this time, the woman/couple must decide which embryos to transfer and what to do with any remaining embryo/s.

There are evidence-based guidelines that suggest the optimal number of embryos to transfer. The American Society for Reproductive Medicine (ASRM) and the Society for Assisted Reproductive Technology (SART) have developed these guidelines.²⁴⁴ Doctors follow these

244 The Practice Committee of the Society for Assisted Reproductive

guidelines to maximize the likelihood of the woman delivering a healthy baby. A doctor can rely on the credibility of these guidelines when faced with a patient who wants to transfer embryos against her/his advice. Some women/couples want to transfer more embryos than is recommended by the guidelines because they think transferring more embryos will increase the odds of having a baby. This way of thinking is misleading. By transferring more than the recommended number of embryos, the odds of having a multiple pregnancy increases thereby increasing the chance of having medical complications that can compromise the health of the babies and mother.

Emotions run high on the day of the transfer. Addison was nervous on the day of her transfer. She was worried that none of her eight embryos would be deemed genetically healthy.

It was comforting knowing we were getting this testing, but I was still really anxious because we...you don't find out until the day of implantation... when you show up, if you are even going to have anything. So the whole time I was a nervous wreck on that morning going for implantation. A nervous wreck! And I just kept telling my husband we are going to show up and he's going to tell us, sorry you don't have anything, none of them were viable. And the first thing he did when he saw me, and he knew I was anxious and I told him about it, he said don't worry, you got two, you're good. So then I could relax... yeah you only need one. We would be happy with one.

Monica and Chandler talk about their experience on the day of the transfer.

Claudia: And how did you decide which embryos to use?

Monica: Dr. T suggested based on the rating ... so we went with what he said.

Claudia: How many did you transfer?

Monica: Two

Claudia: Were you disappointed that only one implanted?

Monica: A little, a little.

Technology and the Practice Committee of the American Society for Reproductive Medicine. "Guidelines on number of embryos transferred." *Fertility and Sterility* Vol. 86, Suppl. 4, (November 2006), S51.

Chandler: We were kind of on both sides. In one way it's good and one way it's not good.

Monica: One way were thinking if it's twins, then there would be a lot more issues medically... Actually, we were happy because we would have had a boy and a girl together.

Claudia: So the other embryo was a girl. Did you specifically transfer a boy and a girl?

Monica and Chandler: Yeah

Monica: Yeah we did.

Chandler: And Dr. T told us which ones were the best ones and so out of that we selected one girl and one boy.

Bill and Hazel had four healthy embryos on the day of their transfer. They did not have any difficulty deciding which to use. They knew they would eventually use all the embryos they created.

Claudia: So this past time you had 4 embryos and you transferred 2 and had the twins. How did you decide which two to transfer?

Hazel: Well that's when we decided to choose a boy and a girl.

Claudia: What are the other two?

Hazel and Bill: Girls!

Bill: But we also, we knew we were going back. If we didn't have... we weren't going to let the other two be discarded. That was something we already decided. When we selected a boy and a girl we said well let's start with a boy and a girl because we know we're going to end up doing the other two. And it's not like we were saying ok, we'll discard the girls because we want the boys.

Hazel and Bill's decision occurred without a conflict. But Bill contemplates the dismay he would have felt if their situation had been different.

Bill: I just don't know how you'd deal with 5 embryos. It's something we don't have to deal with. But some people have to. You don't know... although most women who are going through this have had long term issues with getting pregnant so the chance of people having ... other than unless you're donating eggs. What I'm saying is I don't know how I would have dealt with it [extra embryos] because I would have struggled with 5. I mean if I had 5 left it's like [heavy sigh].

Bill did not finish his thoughts. The situation would have challenged his beliefs and yet he would have had to make a decision. Many women/couples expressed their delight when the decision

regarding which embryo/s to transfer was made for them either by their doctor or “divine intervention”. Couples who did not have to make a choice to determine which embryos to transfer because they only had one or two transferable embryos referred to their situation as “divine intervention”. They were happy when they did not have to choose between embryos and decide the fate of unused embryos.

Brad and Tina had hoped to transfer one boy and one girl but on the day of the transfer they found out their options were limited. They talk about their experience the day of the transfer.

Tina: So driving down there it was a little stressful not knowing what we were going to have and then finally me getting in the room getting ready for this, getting in the gown, everything ... no one still told us until the doctor passed through and I'm laying on the table I was just going to get... at that one I don't get put under ... so I was very well aware of what was going on and we joked about it. We were like will somebody please tell us what we have ... 'well the doctor will be right in'. And then it was like I was sitting there ready for this... I was in the surgical room with a nurse.

Brad: Like 5 minutes before the implant

Tina: Oh it wasn't even that. It was just like ... the nurse was there got us ready, got me ready. Brad by my side and just kind of passing through and we were like what do we have. We still didn't know what we had...

Claudia: Because at that point you still didn't know if you were going to have to make a major decision.

Tina: Yeah, we were going to talk in a matter of... what a minute? (she looks to Brad for confirmation), and we were going to decide something? Because I didn't know what the doctor was going to do... come in and sit down and talk. It didn't look like it. Because I was laid right down on the table. So then it kind of made me wonder what was going on. Did I have a very limited choice here? Is there only a few that are normal? So I didn't know. So then Dr. G walked in and he said you had 6, ...you had 6 embryos, one did not develop, 4 were girls (the girls were genetically unhealthy which Tina had described earlier in our conversation), you have one healthy boy. We just looked at each other... Well I guess that's good.

Brad: It was actually kind of a relief that we didn't have to make a decision.

Tina: Yeah make a big decision

Brad: That was a relief really.

Brad and Tina were relieved to have the decision made for them. Emma had to make the decision about her embryos, but in her mind the decision was very clear. However, in hindsight, Emma regrets her decision. She used PGD to have a boy. She explains her decision:

Claudia: How did you decide which embryos to transfer?

Emma: We only had one boy, that we could consider, well, I mean and we had one healthy girl ... we only had two healthy ones, ... and the rest were all girls except for one unhealthy boy... So there were two boys out of the eight but only one was healthy.

Claudia: So there wasn't any decision that you had to make as far as what embryo to transfer?

Emma: No ... well there was a healthy girl embryo though... and now I look back and I wish we had frozen the embryo. And we will with this ... this time.

Claudia: Was it hard at the time to transfer the boy embryo and not the girl?

Emma: Yes

Claudia: How did you deal with that?

Emma: Well the whole purpose of us going through this was to conceive a boy...

Claudia: You were very clear about your goal?

Emma: Yeah, and ... I would have probably considered having both of them done if the twins weren't still so young... the twins that I had at home.

Claudia: How old were they? What are the age differences?

Emma: My oldest is 7 and then I have a 5-year-old girl then the twins are 3, and then our boy is 8 months, ... so they were so young still.

These stories demonstrate the relief these women/couples felt when the burden of making the decision about the embryos had been lifted as well as the regret some people had after a decision is made. In many cases, there were no options; there was only one or two healthy embryo/s. The embryos that did not survive the testing or did not develop properly were discarded. Thompson points out, "When the egg doesn't fertilize or when an embryo fails to develop normally, it is removed from the trail leading back to the uterus, an ontological bond is severed. Leaving the trail relaxes the legal moral, maternal, and political registrations of the embryos".²⁴⁵ The embryos that are found to be genetically unhealthy are not considered in any of the decisions during the PGD process. They are discarded.

245 Thompson, *Making Parents*, 198.

Many women/couples were grateful to follow the recommendation of their doctor. They were equally grateful when there was no option due to a low number of transferrable embryos. The gratitude and relief felt from having the responsibility of making a decision removed was also noted in Rapp's research. Rapp found that some of the women who received a positive diagnosis after having an amniocentesis did not want the responsibility of making a decision regarding the fate of their fetus. According to Rapp, "Some individuals and populations may not want what they perceive to be the burden of individual choice: To them, the doctor (or "his" stand-in, the counselor) is shirking responsibility by not directing the patient toward the appropriate choice".²⁴⁶ Similarly, the women/ couples that used PGD felt the decision to determine which embryo/s should be transferred was definitely a burden. They looked to their doctor for guidance and were relieved when the decision was made for them.

Numbers

Numbers and statistics play an important role in a PGD cycle. The women/couples of this study assigned meaning to numbers throughout their fertility treatment. As the women went through their PGD cycle, they began to focus on the numbers and statistics that their doctor and nurses define as important. The women began to understand that a high number of eggs extracted indicated that their bodies were cooperating with the treatment regimen. Producing many eggs gave these women a sense that bodies were performing properly. Having many healthy embryos provided reassurance that there would be at least one that was transferable. Having frozen embryos assured some women/couples that they would have another chance at an IVF cycle.

246 Rapp, *Testing Women*, 59.

Numbers played such an important role in these women's PGD cycle that years later they still remember the number of eggs retrieved and the number of embryos produced. Each woman knew exactly how many embryos she created and how many were viable. The emphasis with which they talk about their numbers indicates that they have assigned meaning to these numbers. What do these numbers mean? Do the numbers signify something directly about the woman?

Addison talks about her numbers:

I think we had 20 or 21 eggs extracted. Out of those I think like only 16 were mature and out of the 16 I think only like 12 fertilized and out of the 12 I think only 8 grew to blastocyst stage and out of the 8 we only had 2 genetically perfect embryos. ... These two. ... It makes me cry.

Tina also discusses her numbers. She explains her situation as the following, "What happened was I had six and the six... out of the six, 4 of them were girls and 4 of them had abnormalities and 1 did not develop and one was Dan. So out of the 6 all 4 were girls and for whatever reason they all had abnormalities and the fifth one did not develop properly and then the only good one we had was Dan." Having a high yield of healthy embryos indicates that the woman's body has cooperated with the medical intervention. Their bodies would not cooperate with nature, but now that nature had some assistance, they are fully cooperating.

Both Addison and Tina identify the embryos that resulted in their children. The direct association between the embryos and the resulting children only emphasizes the significance placed upon the embryos early on in the procedure. The embryos are identified and numbered, and then pictures are presented to the woman/couple for choosing.

For users of PGD, the number of embryos created becomes increasingly more important with each cycle especially if the previous cycles failed. All subsequent cycles will be measured against previous cycles. Marie's first IVF cycle with PGD yielded many embryos but none were transferrable. She talks about her experience and how this affected her other PGD cycle. Marie

explains, “He told me ...they tested 15 and 4 or 2 ... no 2 out of the 15 were normal and balanced. The PGD considered them normal and balanced but obviously the two weren’t good enough to transfer.” Marie also brings in percentages and research into her discussion. She goes on to say, “I knew that after doing some research going in that 78% of my eggs would be bad, I mean maybe the research now is worst but according to the journal articles, with balance translocation, 78% of my eggs would be bad.” Then Marie goes on to talk about her third cycle of IVF, the second cycle with PGD. “The third time yielded I think 9 embryos. I wasn’t very happy with that number because before we had so many more. So the day of the transfer I didn’t get my hopes up at all, we were on pins and needles.”

Having a high number of embryos feels as if there is a higher chance of success. When playing the odds with fertility treatment, it would seem that the more embryos produced the more likely one will be viable. That was not the case for Marie. Her two experiences demonstrated that the number of embryos does not directly correlate to the number of healthy embryos. And as Tina’s story demonstrates, you only need one viable embryo to go all the way to having a healthy baby.

Persistence

Tenacity and perseverance, as well as a strong conviction, are necessary attributes to possess when going through fertility treatment. A PGD cycle is fraught with potential for disappointment. A live birth is not always realized on the first cycle. As demonstrated by the women of this research project, many went through two or more cycles before giving birth to a healthy baby.

Knowing when to accept failure and discontinue fertility treatment has been researched in many studies of IVF. According to Franklin and Roberts “many couples found the question of

when to end treatment confusing, in large part because of changes that affected them during the course of treatment.”²⁴⁷ They go on to say that “such a clear cut end point is not clinically determined in the majority of cases, and even in the most apparently unlikely cases, clinicians will have seen the exceptional successes against all odds.”²⁴⁸

Tina and Brad had no clear-cut plan to discontinue treatment if they were unsuccessful. They discussed options but nothing was definite. They explain:

Tina: And that was one of our thoughts, OK, so we’re definitely... if it doesn’t work this time, which you know he [her husband] kept telling me if it doesn’t work we’re going to keep trying again. We’re going to try it again, don’t worry. It probably won’t work the first time. The odds of that and my age weren’t very good so we were kind of ready for that. The second time, so the third time around yeah maybe it will take, so we were kind ready for that.

Claudia: Did you have a certain number of tries set in your mind?

Tina: Well I know that we were going to try again if it didn’t work the first time. We were going to do it again a second time then I don’t know about after that. You know yeah we really wanted to keep trying, keep going with this. But I don’t know how much of that I could’ve taken. I guess...

Brad: I think that’s what I was going to say. It would have been based really on how Tina was emotionally because after the first two miscarriages... it was pretty devastating to her.

Tina and Brad’s discourse demonstrates the ambiguous nature of determining when to stop fertility treatment.

Several of the women in this study had several failed IVF cycles before meeting with success. Sienna had tried IVF 3 or 4 times (She couldn’t remember but probably four times she said, however later in the conversation she made reference to going through 5 failed IVF cycles to get the twins and two IVF cycle to conceive her older daughter.) without ever getting pregnant

247 Franklin and Roberts, *Born and Made*, 165. To read more about the difficulties associated with discontinuing fertility treatment refer to Margaret Sandelowski (1993), Sarah Franklin (1997), Gay Becker (2000), and Karen Throsby (2004).

248 Ibid., 166.

before having twins using PGD. Marie had been trying to get pregnant for about a year and couldn't. After that is when she and her husband decided to consult a fertility specialist. She then miscarried after one cycle of IVF without using PGD. Hazel went through one cycle of IVF without getting pregnant. Then she went through one cycle of IVF with PGD and miscarried. She was successful on her second cycle of IVF with PGD. And Addison was unable to conceive using "mild infertility treatment" then miscarried on her first IVF cycle. These failed attempts did not dissuade these women to abandon their goal and stop treatment. Their previous investment of time, money and pain persuaded them to keep going. Sienna describes it as "we just went all in" when she discusses why they continued with the medical assistance after having multiple miscarriages and several failed IVF cycles. From Pierre's point of view, they continued on after so many failed attempts because, he says, "look we've invested all this money, emotionally we really wanted this to happen." After being in the fertility treatment program for so long, having a child not only satisfies reaching the goal but also serves as a justification for their efforts and expense of previous fertility treatment. Meredith commented on how she felt about going through IVF with PGD a second time after the first cycle did not produce any boys "We were very reluctant but we already invested all this money. So it's like you're forced to do it. And I'm glad we did because we got our... our... the outcome we wanted." These women/couples wanted to continue until they met with success to justify all the money they had already invested. Quitting before they met their goal would have negated their effort.

Their financial investment as well as their desire to have a child may have compelled these couples to continue fertility treatment after so many failed attempts, but failed attempt also provided its own impetus for continuing. There is always the feeling that the next attempt will be the one that is successful. According to Elaine Taylor May, "For many of those who decided to

pursue treatment, the baby quest took on a momentum all its own, and it became difficult to know when to stop...the greater the investment and loss, the more desperate the need to keep trying for success so the sacrifice would not be in vain”.²⁴⁹ Sienna and Pierre explain why they continued to treatment after so many failed IVF cycles.

Sienna: This is the way I was thinking about it to myself. We're a science experiment. You do it the first time you get more data. You do it the second time, you look at all the factors and the variables you get more data. So then the third time, we have plenty of data here, this is ridiculous.
Pierre: Good question about why did we keep trying. I think I was still... the pulling out... that this time it will go right.

Each successive cycle provides more diagnostic information than was known prior to starting that cycle. According to Kaja Finkler, “to be human is to impose an order on what otherwise seem to be senseless, chance experiences. Human beings pursue explanations for their afflictions in order to ascribe a naturalness and regularity to otherwise meaningless adversity by removing a sense of randomness from their suffering”.²⁵⁰ These women/couples were trying to make sense of their situation by continually using medical intervention to rectify and explain their infertility.

Information gleaned from a failed cycle can sometimes explain the reason for the infertility and or point out the direction for future success. Therefore, the experience of the subsequent IVF and PGD cycles is different from the initial cycle. Armed with new information, women/couples take on a more proactive role in determining the direction of their treatment. Sienna describes it as “turbo charging our involvement” and tells of an incident where she had to

249 Elaine Tyler May, *Barren in the Promised Land: Childless Americans and the Pursuit of Happiness*. (New York: Harper Collins Publishers, 1995), 236.

250 Finkler, *Experiencing the New Genetics*, 76.

“push for that medication” which Pierre says was heparin. Sienna had read that Courtney Cox had fertility issues and was successful using heparin.

Hazel and Bill describe the difference between their first cycle of fertility treatment and their second.

Hazel: The first one we were basically blind going into it.

Bill: We heard things from other people.

Hazel: We really didn't know much about IVF. And then as we were going through the cycle we met some people who were going through it as well. They had done it prior and they had a lot of information. So we started talking to these people, getting information, and then exploring it a little farther online. Starting to understand it more. So the second time we went into it we were a little bit more educated. We knew about 5 day blastocysts. We knew more of what we wanted to achieve. Rather than just doing a 3-day, we knew we wanted a 5-day. Just to make sure that we weren't just transferring anything.

They later go on to explain their thoughts on the reason for the success of their third cycle.

Bill: But on the third time it was more so than the first. The first time we were like whatever you say.

Hazel: Totally blind

Bill: The second one we had a better idea and the third one we were like hey this is what we're doing. And I think that that... I think that's part of the reason it doesn't work earlier is that people don't know what's going on. They don't know what to expect. So they don't go in fully prepared. You just go in with a \$20,000 check, or whatever it is, and say here go ahead and make me pregnant.

Hazel: And when it doesn't work you're like wait a minute. Let me research this a little more and figure out how to make this work.

Hazel and Bill's story demonstrates a perceived sense that the woman/couple must take control of their treatment in order to be successful. Hazel and Bill felt their lack of control and participation in developing their medical treatment plan contributed to their failed cycle, and that their successful cycle was only successful because they directed their course of treatment.

Thompson found the patients in her research defined the reason for their success in a similar manner. According to Thompson, “Patients who have a successful cycle are more likely to say

that previous unsuccessful cycles were unsuccessful because the women lacked agency, insufficient attention was paid to her specific situation, or she was unable to serve as an expert witness about her own treatment”.²⁵¹ Thompson goes on to say, “There personal comments tend to be highly specific to themselves rather than to their diagnosis: something amorphous made the difference between a protocol on which a particular woman would get pregnant versus a generic protocol for other patients with her diagnosis”.²⁵² The women/couples in this study became more knowledgeable about their own situation and gave input into determining a protocol that was specific for their treatment.

Hazel and Bill’s behavior also demonstrates the power struggle between patients and doctors. Their new knowledge, based on information from their previous IVF cycles and from people who have used the same treatment protocol, gave them power to negotiate their treatment plan with their doctor. They were working to balance the power differentiation between a doctor and patient, as well as demonstrate their own agency in a biomedical system. Mamo found in her study that women were constantly renegotiating their position once in the biomedical system. Relationships within the system often changed based on acquired knowledge. According to Mamo, “Individuals or patients are able to selectively take on, resist, or negotiate its classifications and interventions. Biomedical knowledges and practices are not neutral social forces; they encompass power relations that define, shape, and control individuals and populations”.²⁵³

The balance of power is often negotiated between the doctor and patient. And in the case of the women who used PGD and their doctors, these negotiations took place throughout the

251 Thompson, *Making Parents*, 189.

252 Ibid., 190.

253 Mamo, *Queering Reproduction*, 12.

course of several cycles. Armed with information, these women and their partners were not passive patients. Greil discusses the importance of these negotiations. He says:

I believe that the relationship between doctor and patient can be characterized as a process of bargaining for control over the situation. The fact that one negotiator is in a weaker bargaining position than the other does not obviate the fact that a negotiation is taking place. Patients should be considered not passive role players but strategists who seek to overcome their limited roles to obtain the best possible outcomes.

Hazel and Bill felt they took control of their treatment plan. They felt as if their active involvement is the reason they met with success. According to Tong, “what the patient typically sees is not what the physician typically sees; and for this reason both patient and physician are blind to each others’ vision and will remain so unless they reveal in words their guarded thoughts and hidden feelings”.²⁵⁴ By communicating with their doctor, Hazel and Bill worked together with their doctor to create a treatment plan that they felt tipped the odds of success in their favor. Having a successful outcome from the cycle where the patient takes a more active role in planning the treatment perpetuates the idea that a more controlling and active roll by the patient in the treatment plan contributes to a successful cycle outcome.

Maternal age is the factor that is most often held responsible for determining the success of IVF and PGD cycles. Therefore timing is very important when considering using these treatments. Each failed attempt adds more time onto the maternal age. Waiting long periods of time in between PGD cycles to either recover physically or emotionally is just not an option. In this situation, months matter. The pressure to minimize the maternal age is always present.

Hazel and Bill talk about age being the impetus to go through another cycle of IVF fairly quickly after the first cycle.

254 Tong, *Feminist Approaches to Bioethics*, 244.

Claudia: And how long did you wait in between the first and second times?
Hazel: Not long it was from like... December to February, was it?
Bill: I couldn't tell you.
Claudia: Did you feel you chose to do it a second time because you were armed with more knowledge?
Bill: And age.
Hazel: Yeah age.
Bill: It was age.
Hazel: We didn't have much time to wait. It was either do it now...
Bill: One thing we did look at online is the success rates as you get older and they go down dramatically. And we saw after 40 it's like good luck.
Hazel: So we knew we didn't have much time. So we knew if we wanted to do it again we needed to do it fairly soon and just try and see what would happen.

Maternal age is a contributing factor that cannot be manipulated or negotiated. The lower the woman's maternal age at the time of an IVF cycle, the better the chance of success regardless of the level of involvement in the treatment plan.

Patient- Doctor Relationship

Women spend a great deal of time at their doctor's office as they go through a PGD cycle. Relationships between the woman and the medical professionals begin to form as the doctor directs and oversees the treatment. Bill describes his feelings about the doctor, "Once you're in the procedure he's the boss. Before you start you can choose what you want, he'll execute it, but you have to listen to him."

Meredith appreciated the care she received from her doctor.

She explains:

It was just...Dr. G was absolutely wonderful ... he was very understanding and when I was there he tried to reassure me. Tried to listen, he was very understanding, he never questioned me even sometimes when I would rant and rave, especially after the first time it didn't work. He was wonderful.

A doctor's style of handling the care of his patients is important to the overall experience when using NRTs. Isabel talks about her first conversation with her doctor and how his confidence encouraged her to go through with the procedure.

We were concerned at first because there was a pamphlet we got from his office that said 30% success rate. And we were like only 30% success rate? That's a lot of money and a lot of emotional trauma to go through for a 30% chance. And he goes where did you read 30%? We have a 70%. Where did you learn 30%? We're like a pamphlet from your office. He's like what pamphlet is that? (Isabel laughs out loud) He seemed very proud of his success rate. So then we were like you know that's a lot better. That was kind of a sigh of relief that it was 70% not 30% ... so that was another thing that helped us decide. It was like this guy really seems to know what he was doing. He wanted to be real thorough and not do anything half way.

Isabel's conversation with her doctor set her mind at ease. She and her husband decided to use IVF with PGD as part of their fertility treatment because of the conversation with her doctor. The doctor's success rate and thoroughness instilled confidence in Isabel and George.

It is only after the procedure is unsuccessful that women/couples start to doubt the capabilities and intentions of their doctor. Meredith talks about her doubts after her first unsuccessful cycle, "I started questioning things, the anxiety and stress... are they telling me the right things? And then when it didn't work the first time, here I go. Oh I knew it, they weren't telling me the right meds or they weren't following... and it's all their fault." Meredith blamed the doctor for her unsuccessful PGD cycle. She used PGD for sex selection. In Meredith's case, her lack of success happened because Meredith and her husband did not produce a male embryo. Her PGD failure had nothing to do with the procedure; however, fertile women who use IVF have the same odds of success as their infertile contemporaries. Franklin and Roberts noted in

their study that the failure rate for IVF “appears not to be substantially altered when it is used for fertile, instead of infertile, couples”.²⁵⁵

Meredith’s projection of blame onto the doctor demonstrates the need to have a reason for a failed cycle. Women who go through fertility treatment want answers for their infertility. And although Meredith is not infertile, she found herself unable to accomplish a pregnancy that she desired. Her behavior mimicked that of an infertile woman using NRTs. It is only when a cycle fails that women/couples question the motives of their doctor. After several failed attempts, Sienna was a bit leery about her doctor’s motives. The line between business and medical assistance became questionable in her mind. She says, “Part of me was feeling like now we’re just in a money thing, now I feel like I’m part of a business. I think that was after the 3rd time that this was just a business. You guys just want my money.”

The high cost of the procedure also had Isabel questioning her doctor’s motives. She and her husband had already invested a large amount of money in lesser medically invasive techniques to get pregnant. None had worked. This was their first attempt PGD cycle. She talks about her feelings when she initially heard the cost; “A part of me felt like, is this guy just out for the money? But... there... it’s really expensive.”

The suspicions regarding the doctor’s motives are more prevalent after failed attempts. It is easier to blame the doctor’s misplaced motives saying she/he was more interested in making money than a successful outcome, than accept defeat. A woman/couple can overcome a doctor’s misplaced motives simply by changing doctors. Changing doctors is a strategy women/couples use to gain control over their treatment. According to Arthur Greil:

255 Franklin and Roberts. *Born and Made*, 104.

One strategy women commonly used to exert more influence over the treatment process was to change doctors. Switching physicians [is] a “big step in gaining some control.” Women who were unable or unwilling to persuade their physicians to modify the treatment regimen in accordance with their wishes often voted with their feet. On frequently cited reason for switching was dissatisfaction with the slow pace of progress of the treatment process.²⁵⁶

Getting more involved in determining the treatment plan and having more control of the treatment process circumvents any of the suspicions directed toward the doctor. If the PGD cycle fails when the couple feels they had more control over the direction of their treatment, then the couple cannot blame untoward motives by the doctor as the cause. They need to assume more of the responsibility for the failure.

The success or failure of a PGD cycle may be impacted by the relationship the woman/couple have with their doctor, but their attitude about their overall experience with their fertility treatment is highly contingent upon their relationship with the nursing staff. The nurse is the person who guides and instructs the woman/couple throughout the treatment process.

Women/couples come into the office anxious about learning the tasks they need to perform.

They want to be exact in their roles. They do not want their actions to cause the cycle to fail. For many of them, this is their first experience administering such an elaborate treatment regimen.

The novelty of the procedures, coupled with their strong desire to get pregnant produces a high level of anxiety.

256 Arthur L Greil, “Infertile Bodies: Medicalization, Metaphor, and Agency.” *Infertility Around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*. Ed. Marcia Inhorn, and Frank Van Balen. (Berkley: University of California Press, 2002), 112.

It is the role of the nurse to reduce the women's/couple's anxiety and assist them throughout their treatment. Women/couples often described the attitude of the nurse who instructed them as being condescending. They attribute this condescension to having given these instructions countless times. The first time a woman and her partner hears these instructions can be very overwhelming. Hazel and Bill talk about their experience.

Hazel: That's one thing we found ... talking to the nurse... she talked to us like we were dummies. Like how do you not know this? Whenever we asked questions she would answer back like... you know... like we were suppose to know what was going on. We were like no we're asking you; we need the information from you. You're the expert. And we just feel like ... some of the nurses...

Bill: We were putting them off. And it's like well wait a second we are spending a ton of fricking money, you just better kiss my***, oh sorry. No but it really is... I may drive them... and I drove them crazy. I can guarantee you that K (a nurse) thinks I'm an idiot. But I asked questions and I asked a lot of questions. And they may not like it, but I think they owe us an answer. Whether it's a stupid question or not.

Meredith also had an issue with a nurse, which was complicated by the fact that she is a nurse. She explains:

Meredith: You have to realize as a nurse I care for a million people and I know my job. It becomes repetitive and I imagine in this setting, where you're in a specialty, there is nothing new to you. You do it, you do it, you do it ... I always felt like she was going through the process like, "Oh you're just another woman let's go". Not realizing that just because you've done this a thousand times, I've never done this before. Just because this is not new to you, this is new to me. And this is stressful to me and it's emotional to me.

Later she goes on to say:

Meredith: And you wanted to know that you're getting competent care and that everyone is on top of his or her game and everybody knows exactly what they are doing. This whole process is very different... very difficult for some one to go through, for me it was at least.

The process of going through a PGD cycle is very emotionally and physically demanding. These women/couples felt the strain. Their discourse demonstrates the vulnerability they felt while in

the system. It also demonstrates the impact the interactions with the staff have on the experience of using NRTs.

God

In an effort to find meaning and come to terms with their infertility many women expressed a sense of being part of God's plan. Somehow they felt their infertility was part of a larger life plan that God had for them. Addison describes God's plan as being one that may be different than the one a person has for herself. She explains her feelings as the following:

Yeah... in the fact that I feel God has his plan and it might not be the plan we have for us, and he might work his plan through different ways that we don't see. But I do feel comforted that God was on my side and what was meant to be was meant to be.

Sienna also believed she was part of God's plan. She says,

Religion as it's ... in it's basic form that it just meant to me that there is a plan that God will take care of this, that there will be... it will be OK. Something... there's a path here, I have faith that something's going to happen here. That's why I felt if... in the end, if the babies had, if there was an issue with them, this was God's plan and we'll sort it out.

Hazel also believed she was part of God's plan.

I'm a big believer in higher power. Our path is already laid out and it's ... you know you just got to have faith and everything good will come to you so I knew that whatever was going to happen was going to be the best for me. It's just you know... it's still hard to take the news at that point in time but when you sit down to think about it. It's comforting to know this is God's plan and this is what is meant to happen to me. So this is OK... So yeah it was comforting...

In addition to knowing they were part of God's plan, many women felt God's presence throughout their fertility treatment. Some felt God gave them signs to know he was present.

Isabel talks about the signs she saw:

There were things that God was there, showing me that he was with me. Well only six of them (ovum) were fertilized, I was kind of upset that they all didn't fertilize. But they didn't tell us, which I'm glad, I guess, that they didn't tell us. But the day we went for the procedure, they told us that only one was healthy. (A

very long pause) And I started crying right away because they said they were going to put in two to ensure that at least one takes ... So I was crying right away, I was so upset. But when they were doing the procedure, I was just crying, there was just so much at stake and all your hopes are up so high. But it was funny because the healthy one, which was him, was embryo number seven. They had him listed down the line and he was number seven. (laughs) So that was kind of a cool thing like God was in it... One other thing that I felt that God was there with me was because how they always go by the first day of your last cycle well it was January 8, 2008 and we believe that 8 is the number of new beginnings. So that was another kind of a cool thing. It was 8, 8 and then he was embryo number 7.

Isabel explained that Christians consider number 7 to be the number of completion and she felt she was going to be complete once she had her baby.

Many of the women identified themselves as a participant in an organized religion but none said they went to their religion for guidance. No one looked to their religious doctrine exclusively to make their decisions. In her research, Rapp also found that the women who used amniocentesis did not exclusively go to their religion for guidance. She explains:

Religion provides one resource in the complex and often contradictory repertoire of possible identities a pregnant woman brings to her decision to use or reject amniocentesis. There is no definitive “Catholic”, “Jewish”, or “Protestant” position on reproductive technology, when viewed from the pregnant woman’s point of view. Rather, each concrete, embedded pregnancy is assessed in light of the competing claims on maternity the individual acknowledges and to which she responds. Religion constitutes one powerful arena for such identity claims.²⁵⁷

Religion is just one of the many ideologies women/couples use to help them define their situation. Bill talks about the conflict he had between his decisions and his religious beliefs.

And that’s what I keep telling her, what if we would have had 5 and she says well God wouldn’t give us more than we could handle so. We figure it is one of those ... because you’re torn as a Christian you’re torn as do you do it or don’t you do it? Is it ethical or isn’t it ethical?

The ethical decisions inherent in using PGD were not enough to stop these participants from using the procedure. Feeling as if they were part of God’s plan may have made using PGD

257 Rapp, *Testing Women*, 159.

less problematic. Believing their fate was in God's hands brought some comfort, however many did not want to leave their fate totally in God's hands alone. Some women describe things they did that they felt tipped the scales of fate in their favor. Addison believed her experience was part of God's plan but she felt she might have to make decisions on her own without giving over to God completely. Addison used intrauterine insemination (IUI) prior to using PGD. She talks about the decisions she and her husband considered making during that process.

But I didn't take it to the extent where some people take who go through the IUI's and get pregnant with 6-8 embryos and say well it was God's will, this is what God wanted. You know I think at some point you do take it out of God's hands and put it into your hands and then you are ultimately the one that has to make decisions and not just say, 'Oh this is what God planned'. It is one of those tricky things... A lot of gray area... and my husband and I had to deal with that selective reduction issue when we were going through IUI's and what we would do. And we both have our views on prochoice, right to life ... they are a little different. I tend to be a little more liberal; he tends to be a little more conservative.

Addison and her husband were prepared to make decisions in case they were not pleased with God's plan. Isabel describes a situation where her mom decided God needed a little incentive to work on her behalf. She explains:

And then another thing that happened, was my mom, she believes in giving to God and God will give back in the area where you want him to. And she gave to God in a...she didn't tell me about it,... she gave to God in a children's thing, this feed the children program and she's like 'God I'm giving this money to this Feed the Children program believing that we're going to have a healthy grandbaby'.

These discourses demonstrate the ambivalence the women feel regarding their beliefs and their situation. On one hand they want to believe God sanctions their situation. They want to believe they are experiencing infertility as part of a bigger plan for their life. They also want to believe that they will have a positive outcome although they are hoping their positive outcome will also be the one they desire.

Like the women of Rapp's research, religion and God are central to these women's experiences of infertility and trying to have a child. According to Rapp,

Religious beliefs and practices, and the concrete social resources that churches provide, are thus central to many pregnant women's orientations...the women with whom I have spoken rarely "toed the line" of any particular church; they were more likely to describe the complex accommodations through which they tested and negotiated their faith.²⁵⁸

The women who used PGD also negotiated their faith as they went through the process of PGD and had to make sense of their situation. At times they "suspended" their religious beliefs in order to get through the process and justify their decisions.²⁵⁹

A PGD Cycle Conceptualized

The stories of the women/couples tell about their experience of going through the treatment regimen during the time PGD occurs demonstrates the many nuances of the treatment they need to consider. The information gleaned during this part of the PGD cycle is novel and must be placed within the context of an experience that is typically thought of as natural. The women/couples are dealing with information that is typically not known when pregnant and yet

258 Ibid., 178.

259 Rosalind Pollack Petchesky, *Abortion and Woman's Choice: The State, Sexuality, and Reproductive Freedom*. (Boston: Northeastern University Press, 1990), 353. This goes along with Petchesky's claim about abortion and women's choices. She says, "This might be called the "ethic of people being allowed to work out their own ethic," to take their own moral judgments seriously. In this regard, a feminist morality of abortion cannot totally separate the political question of who decides from the moral question of what decision to make, any more than it can prejudge what is "right" in a particular case by reference to some holy writ".

their pregnancy is highly contingent upon this information. Their stories make visible the liminality and disconnectedness of a pregnancy conceived through PGD.

Their stories also make visible the way in which they approached making the three decisions regarding their embryos. At the time of the embryo transfer the women/couples must decide the number of embryos transferred, which embryos to transfer, and what to do with the unused embryos. These decisions are life altering. They had days before the embryo transfer when they could have ruminated over their possible options, but most women/couples did not do that. The range of possibilities was too vast for them to comprehend. Some women/couples made a tentative decision during that time found that their decision made during their rumination did not feel right once it was time to make the actual decision. Rapp found that to be true with the women in her study. According to Rapp, “Women and their supporters may respond to an interviewer “as if” they had a rational plan (or an ability to avoid having to have one) for confronting bad news. But the resources and concerns that influence a real decision may be significantly different from a description offered in response to a hypothetical probe.”²⁶⁰ The decision the women/couples had to make regarding the embryo was made while anxiously awaiting the embryo transfer. They had only a few minutes to make a decision that was going to change their life forever. The embryo/s they transferred would eventually become their child/ren. The knowledge they had to make their decision was situated in their perspective of their situation based on everything that they had previously experienced regarding their fertility and the anxiety they were feeling at that very moment.

Making a decision about the fate of their embryos is one of the most prevalent aspects occurring during the time after the egg retrieval and before the embryo transfer. These women/

²⁶⁰ Rapp, *Testing Women*, 135.

couples may be unwittingly participating in a process that changes the way embryos are thought of. Embryos are most often only considered when they are attached to a body. Hartouni describes the manner in which embryos are currently thought of: “To the degree that we think of them as being ‘in the world’ at all, it is as attached and ‘embodied’— in a body, part of a body, and a body that is, still, necessarily and exclusively female.”²⁶¹ Now that embryos can be separate entities from a female body, will consideration for their wellbeing be privileged over the wellbeing of the woman who may carry the embryo? Will the status of the embryo follow the same trajectory as the fetus? Will the embryo become personified as the fetus has?

The fetus became personified through the use of ultrasound. As medical professionals began to “gaze” at the fetus, they attached human characteristics to the fetus’ movements.

According to Hartouni:

‘[P]eering’ is not itself a benign, impartial, and disinterested, or disembodied activity, but is both mediated and situated within interpretive frameworks, point of view, sets of purpose. The question, then, is who is peering, what are they looking for and why, with what predispositions, assumptions, expectations, and predilections?²⁶²

Who will be looking at the embryo? What will they be looking for? What will be the interpretive framework used to explain the view of the embryo? Currently, PGD is the technology peering at embryos. The interpretive framework is based on genetics. Fertility specialists are peering at the embryo to improve the outcome for their infertile patients as well as couples who are known carriers of genetic diseases. If the ideology that embraces genetic determinism becomes more prevalent, embryos could be given human characteristics based on the results of genetic tests. The personification of embryos could have already begun with the inception of PGD.

261 Hartouni, *Cultural Conceptions*, 27.

262 Ibid., 38.

Considering the status of the embryo is not always the first consideration when making the decision about the disposition of embryos. According to Tong, “Although there is no uniform feminist position regarding in-vitro fertilization, it is accurate to say that, unlike nonfeminist bioethicists, feminist rarely discuss the moral status of the pre-embryo.”²⁶³ The main concern of both feminist critics and advocates of IVF is the woman. At the moment the decision regarding the disposition of the embryos needs to be made, the woman is prepared and made ready for the embryo transfer, which is a surgical procedure. She has to consider the immediacy of her situation, the best option for getting pregnant, and the health of her future child. These women demonstrated a feminine ethical decision making approach by considering multiple perspectives.²⁶⁴ The health of their child and their desire to be a mother took precedence in their decision-making.

The discourse of these women raises the consciousness regarding their commitment to having their biological child. They tell stories of going through the process several times before meeting with success. And they endured trying relationships with the medical staff as well as they questioned the motives of their doctor. Their stories of the steps they took to maintain control of their treatment regimen do not read like stories of passive patients. These women/couples took hold of their agency and rose to higher levels of involvement to get what they wanted.

Conclusion

263 Tong, *Feminist Approaches to Bioethics*, 181.

264 Justice and autonomy are what Tong refers to as “ethical implications of allegedly masculine concepts”. For further explanation refer to Tong, *Feminine and Feminist Ethics*, 10.

The women/couples of this study demonstrated their willingness to wage war against the forces that came between them and their goal of having a healthy biological child. They learned to find a perfect balance between taking and giving up control of their treatment. This balance occurred between them and their doctor as well as them and their God. The experience of using PGD is replete with life-changing decisions.

Made on an individual basis, the choices made are socially mediated and reflect cultural values. According to Petchesky, “the very nature of reproduction – is social and individual at the same time; it operates ‘at the core of social life’ as well as within and upon women’s individual bodies.”²⁶⁵ Most fertility treatment is carried out on the woman’s body, however PGD actually occurs in a laboratory away from her body. The results of PGD will provide the information used to make the decision about the fate of the embryos. These results, along with the understanding of their particular situation, and their desire to reach their goal, influence the decisions a woman/couple makes regarding her/their embryos and treatment regimen.

²⁶⁵ Petchesky, *Abortion and Woman’s Choice*, 2.

CHAPTER SEVEN

TRIUMPHANT: COMPLETING A SUCCESSFUL PGD CYCLE

A successful PGD cycle culminates in the birth of a healthy child. The journey from the beginning of the cycle to the end is long and arduous. Many things must occur to make the goal a reality. A woman's body is monitored to measure, regulate, and observe these occurrences. One such occurrence is the implantation of the embryo on the wall of the woman's uterus. An embryo implanted on the uterine wall marks a successful embryo transfer and the beginning of a pregnancy.

The confirmation of a pregnancy is a jubilant moment. But shortly after that moment, the woman must begin to navigate her way through the systematic medical care of her pregnancy. Her fertility specialist will hand over her care to her obstetrician after the first trimester. At that time, her obstetrician will monitor her pregnancy as any other pregnancy and the focus of care will be shared between the woman and her fetus. The pregnant woman must now navigate another medical regimen different from the one she used for conception while still keeping her goal in sight. How does a conceiving a pregnancy through the use of PGD affect the pregnancy?

By using PGD, and meeting with success, the women/couples of this study were able to experience the pregnancy they never thought they would. For eight of the women, this was the first pregnancy they carried to term. The experience of pregnancy and delivery was not always what they had anticipated. And for some of the women who had carried a previous pregnancy to term, this PGD pregnancy was different than any of their other pregnancies.

Women/couples that use PGD as part of their fertility treatment will forever be associated with the conversations about IVF and PGD. IVF was initially referred to as the "test tube" baby technique. That dysphemism slowly vanished as the technology became acceptable and more

widely used. The initial alarmists came to realize their fears about the products of IVF, mostly abhorrent babies, were never realized. According to Hartouni,

Over the course of the past twenty-five years, these new reproductive and genetic practices have been assimilated into the order of nature or brought into the service of precisely those institutions, relations, and relationships or ways of life they seemed destined to raze, their transgressive potential at least temporarily contained.²⁶⁶

If it takes approximately twenty-five years for a new reproductive technology to be assimilated into the culture as an acceptable practice, then will the fears and concerns associated with PGD be expunged in five years?

The main fears and arguments against the use of PGD are that the technology is progressing too quickly without the consent of society, and that it will change human identity.²⁶⁷ These arguments usually reference PGD by using the “designer baby” idiom. Many of the women/couples in this study were not even aware they were using the “designer baby” technique when they first started their fertility treatment.

Their understanding of the value of PGD as it applied to their needs and what they understood the “designer baby” idiom to mean were diametrically opposed. They felt very disconnected to the “designer baby” label even after they realized that that idiom refers to PGD. They understand the controversies associated with PGD, but their close proximity to the issue allowed them to discern the nuances and benefits of the procedure. They were able to weed out the exactness of the procedure that pertained to them and distance themselves from the generalizations and inaccurate portrayals of PGD.

266Hartouni, *Cultural Conceptions*, 114.

267 Franklin and Roberts. *Born and Made*, 30. Refer to Franklin and Roberts for an in-depth discussion of the opposition toward PGD.

It is only after these women/couples have completed the whole process, given birth to a healthy baby, that they could distance themselves from the experience and talk about their feelings about the decisions they made. How do they reflect upon their experience with PGD? How does the “designer baby” idiom affect the users of PGD? Do they feel a need to justify their use of PGD? And if so, how do they do that?

The women/couples of this research project were all successful users of PGD. Many were talking about their experience while holding their PGD conceived baby. For them, the baby in their arms contextualizes PGD. For these women/couples, PGD was the technique that gave them their “miracle”.²⁶⁸ It is from this perspective that they discuss their final thoughts on PGD.

You’re Pregnant

PGD is a multistep procedure with many directives. After the embryo transfer, the woman is sent home and told to rest for the remainder of the day. She is also told that she should not use a home pregnancy test. At this point in the procedure, a woman’s body is full of the hormones that were used to prepare her for the egg retrieval and embryo transfer. These hormones cause a home pregnancy test to give a false reading. This directive, to avoid the use of home pregnancy tests, brings to consciousness the many drugs the woman has pushed into her body and the fear about the long-term effects of the hormones. Currently, there are no conclusive studies that indicate the hormones cause any long-term effects. According to the American Society for Reproductive Medicine (ASRM), “Although initial reports suggested that women who use fertility drugs have an increased risk for ovarian cancer, numerous recent studies

268 Marie often referred to her baby as her “little miracle”.

support the conclusion that fertility drugs are not linked to ovarian cancer. Nevertheless, there is still uncertainty whether a risk exists and research continues to address this question.”²⁶⁹

Women who go through an IVF cycle take ovulation-stimulating hormones and can feel the dramatic effects these drugs have on their body. The concerns about the long-term effects are part of their thinking, however the drugs cannot be avoided if they want a child. Hazel talked about her concerns and how she dealt with them.

Hazel: It's a tough procedure and it's tough on your body too. And you don't know what you're doing to your body in the end. What kind of harm you're doing.

Claudia: How do you feel about that?

Hazel: It worries me. I mean I don't know the long-term effects it's going to have on my body. I mean you read things and you worry. And I went for a mammogram and they found something. And it's like ah is it from the IVF drugs? And you just... you just don't know what you're doing to yourself. But it is all things that play in the back of your mind. Because you don't know the long-term damage you're doing to yourself with all these drugs. But you want a baby so you do it.

Abbey and Emma had the same concerns as Hazel but the women assuaged their worries by knowing that they were doing it for their child. Their use of the drugs, and acceptance of the possibility of harm, is an example of the maternal sacrifice these women made for their children. Rothman describes the way women are judged as being good mothers by the level they sacrifice for their children. According to Rothman, “The more she gives of herself to her children, the better a mother the society says she is.”²⁷⁰ Hartouni concurs with Rothman regarding the value

269 American Society for Reproductive Medicine, “Assisted Reproductive Technologies: A Guide for Patients.” *A.R.T. Guide for Patients*, 2008, 13. <http://www.reproductivegenetics.com/ivf.html> accessed 2/2/2011.

270 Rothman, *The Tentative Pregnancy*, 241.

society places on maternal sacrifice and commitment.²⁷¹ A good mother dedicates her life to her children. The women who used PGD may have sacrificed their future health as a demonstration of their maternal commitment.

Each step of the process in a PGD cycle is marked by milestones that when reached can make the sacrifices appear to be well worth making. One such milestone is the pregnancy test. After the embryo transfer, a woman must wait two weeks until she can go to the doctor's office for a pregnancy test.²⁷² The results are not immediately known like the results of a home pregnancy test. Monica was tempted to take a home test. She describes her feelings during the time she waited for her test results.

Claudia: How did you handle the time between the embryo transfer and getting the results?

Monica: Oh that was the worst time... Those are the longest two weeks I've had.

Claudia: How did you deal with that? Did you do special things on those days?

Monica: No, I was very tempted to start using the home pregnancy tests. But Dr. T told me not to do that because it will always come back as positive because of the hormones.

Isabel agrees with Monica that it was difficult during the two weeks she had to wait to take a pregnancy test. She was not tempted to use a home test but, she says, "Even after the procedure, at that point when your waiting to find out whether or not you pregnant, that week or two that there, that's the longest couple of weeks of your life." Isabel's experience was not typical of women who wait for the pregnancy tests results. She describes her experience:

271 Hartouni, *Cultural Conceptions* 32. Hartouni uses the example of a pregnant woman who was kept alive on life support so her fetus could grow to full term. Hartouni uses this to demonstrate society's idea of the ultimate maternal commitment: giving birth after death.

272 This information acquired from observing in the fertility clinic and also reported from women who went through procedure.

We did the pregnancy test, where they draw the blood, they were suppose to let us know that day whether or not it was positive or negative... Of course that's a huge step. And well we waited and waited and waited and they didn't call, and they didn't call, so we called them. And "Well our machine is broken" ... They weren't going to be able to tell us until Monday and this was Friday. They said they couldn't tell us until Monday because their machine was broken. I was like you've got to be kidding. They made me wait and wait and wait. And another thing that we did, that day... I took that day off from work because I thought if they call me and tell me yes, I'm not going to be worth anything at work. And if they tell me no, I'm going to need medical attention. So I took that day off from work and everything and then they tell me they can't tell me until Monday. I was upset, George was livid. And we... I think he called them again and said why didn't anyone tell us sooner, tell us that thing was broken. You couldn't tell us? Then they ended up calling us Saturday morning. A nurse from the hospital or Ann Arbor, whatever, and telling us it was positive. I was so excited to get that phone call Saturday morning, because I was so upset before, saying what are we going to do? We had to wait and the waiting was already so hard. And then I thought should I go into work Monday? Should I call in sick? Because if it's no... Then we got that call that it was yes.

Isabel had altered her work schedule in anticipation of her reaction to the results. This is a very important moment in a PGD cycle. It is the moment that offers so much hope that all will end as planned. If the results are positive then the process continues in the direction that will fortify a pregnancy. A negative result ends the cycle.

Tina's experience of getting her pregnancy test result was also not typical. The results of Tina's pregnancy test indicated that she was indeed pregnant. But subsequent tests that checked her hormones indicated her hormonal levels were increasing but not at a rate that could support a pregnancy. It was recommended that Tina discontinue taking the supplemental hormones because she was no longer pregnant. Tina was not ready to give up. She noticed her hormone levels were rising, just not at the rate the medical professionals desired, so she continued to take the medication. Tina tells her story:

Tina: Yeah, so I told her [the office nurse] that I was still going to keep taking it [hormonal medication]. And she got a hold of Dr. G who was down in the Detroit area and he requested I stop and I said no I'm not going to, and she said OK I'll tell him but come in on Monday and we'll have you do an ultrasound. I

felt... I'm not going negative [her hormonal levels], I'm not going backwards but I'm just not climbing like they wanted me to. I was climbing a little bit but not as much as they said I should have been. So then you know, Brad said just stay on the medicine. Let's just wait until we do the ultrasound. So when I went in at 5 ½ weeks we did an ultrasound and at that point there was... I don't believe there was a heartbeat. And yes it was there... When we both went in. The doctor came in and I had never met Dr. T and we really liked him. And he just held my hand and he says "I'm here to tell you that you have zero percent that anything is going to be there So just prepare yourself for that". And so here I'm being told I am, then I'm not, I should go off my medicine and then I'm still on it and then he comes in tells me no... I mean this is just week-to-week. So I'm so drained from it all. So we were prepared for no it's not there. And he ran the ultrasound and yes it was there and there was a heartbeat. And he couldn't believe it.

Brad: Yeah, he said this is a miracle. I've only seen this ever happen one other time since I've been doing this. It's just a miracle.

Tina: And it's all because of that number and I thought well obviously I have a problem because that's why I'm here. Maybe there is something wrong with my hormone producing... pregnancy-producing hormone. Maybe there is something wrong... why I'm here. And he said it has only happened one other time back in the 80s that he remembered with twins. And the woman, he still remembers the woman that he helped. Anyways we walked out of there...

Brad: Everybody's all crying

Tina: Yeah the nurses were all crying and I'm just like going yep, yep. Thank God I choose to stay on the medicine because maybe not taking that progesterone would have... he may not have attached.

The medical monitoring that ultrasounds provide proved to be helpful to Tina. Without peering into her uterus and seeing the heartbeat, she would not have known she was indeed pregnant.

Although the ultrasound has come under fire for personifying the fetus, which led to privileging the fetus over the woman²⁷³, it is also seen as beneficial in monitoring the health of the fetus. The ultrasound confirmed Tina's maternal instincts were correct. She knew she needed to keep taking the medications to support her pregnancy. She went against medical advice and listened to her own body.

273 For further discussion regarding the personification of the fetus refer to Hartouni, Rothman, Petchesky, Rapp, Thompson as discussed in chapter two of this dissertation.

Monica, Isabel, and Tina's discourses demonstrate the level of anxiety and jubilation associated with finding out the results of the transfer. This anxiety and anticipation is similar to the way the women of Rapp's study felt when awaiting the results of their amniocentesis. According to Rapp, "The liminal period awaiting test results intersects anxiety on many levels."²⁷⁴ There are many levels of anxiety felt when awaiting the results of a pregnancy test. Receiving the news that you are not pregnant means your body has failed again and you may never meet your goal. Getting a positive result marks the beginning of your pregnancy as well as the trajectory to "normalcy". However there is always fear that your body will reject the embryo and you will miscarry later in the pregnancy as you had in the past. Certainly, a positive result is hoped for but it does not come without worry.

A positive result means the rigors of getting pregnant are subsumed by the job of maintaining the pregnancy. The worry about maintaining this pregnancy to full term was first and foremost on these women's minds. However, having used PGD provided some comfort for some of the women. Hazel said, "PGD really put my mind at ease" when discussing the health of her fetuses. However, there is one concern with the pregnancy that is uniquely associated with IVF that loomed in the back of some of the women's mind and that is the thought that the wrong embryo could have been transferred. The concern is that either some other couple's embryo was transferred or an unhealthy embryo was transferred.²⁷⁵ Each fertility clinic institutes systems to

274 Rapp, *Testing Women*, 104.

275 There is always a possibility of the wrong embryo being transferred to the woman's uterus, because the embryo is formed outside of her body during a PGD cycle. I witnessed the procedure put into place by IVF Michigan to prevent this from happening. Many people match the identification of the embryos with the corresponding identification of the woman before the transfer occurs. The women are completely awake

assure this does not happen. However, even with systems in place it can happen.²⁷⁶ Several women/couples voiced their concern. Meredith describes her concern:

To be silly, this was just another worry of mine even though I knew that it wasn't realistic, but I always just worried that, and this was one of my biggest issues before we even did it was, you know what if there's a mistake or what if they implant the wrong baby or... I always worried about that so I kind of had that stress throughout too. Just wondering if is it even...even my baby? All kinds of things ran through my mind. Until I saw him and he looked 100% like my husband.

Janet also said the idea came up during her pregnancy. Jokingly her husband asked what they would do if they baby came out not looking like them. She said it really was not a concern but it did come up in conversation.

The stories these women tell of their concerns and anxieties, once again demonstrates their unwavering commitment to having a healthy child. Now that they are pregnant, they have the opportunity to have a “normal” pregnancy experience. For some of the women it will be the first time they have carried a pregnancy to full-term. For others, it will be a pregnancy conceived

and alert during this procedure; therefore they are witnesses to this safety measure as well. There is always the potential for human error to dislodge this safety measure. Having the wrong embryo transferred is just an example of one of the many things that the women worried about when they thought about things that could go wrong with their pregnancy.

276 While doing this research, this very publicized case of an embryo transferred into the wrong woman was frequently in the news. The pregnant woman gave birth and gave the child to the biological parents. Carolyn Savage was the carrier, and Paul and Shannon Morell are the biological parents. For complete details refer to book written by biological parents. Shannon and Paul Morell, *Misconception: One Couple's Journey from Embryo Mix-up to Miracle Baby*. (New York: Simon and Schuster, Inc, 2010).

in a different manner from their other pregnancies. For all the women, the use of PGD affected their pregnancy in ways they did not anticipate.

Medical Monitoring

Once a woman becomes pregnant from a PGD cycle, she will continue to be seen by her fertility specialist until the end of the first trimester. At that time, the pregnancy is regarded as any other pregnancy and the woman's care is transferred to an obstetrician who follows her through the birth of her baby. There are no inherent risks for pregnancies conceived through PGD other than there being a greater chance of having a multiple pregnancy with the use of IVF.²⁷⁷ Even then, it is no different than a multiple pregnancy conceived through coitus. Maternal age continues to be a factor that affects a pregnancy, but again no differently than one conceived through coitus. Obstetricians monitor pregnancies conceived through IVF as they would any other pregnancy. They prescribe a treatment program based on the individual needs of the woman.

The medicalization of the pregnancies of the women who used PGD is no less or no more rigorous than what these women experienced while trying to conceive. However, now they find themselves in a system that monitors their fetus more than they themselves are being monitored. The fetus will be monitored through the use of ultrasounds. According to Hartouni, "The use of ultrasound for monitoring early fetal development as well as labor and delivery has become regularized in the United States-- over one third of all pregnant women can expect to undergo the procedure at some point in their pregnancies..."²⁷⁸ It is the use of ultrasound that, according to

277 For more information regarding the statistics on multiple pregnancies as a result of using IVF refer to R. P. Dickey and B.M. Sartor.

278 Hartouni, *Cultural Conceptions*, 36.

many scholars, personified the fetus and privileged the status of the fetus above the pregnant woman.²⁷⁹ The use of medically monitoring technologies, including ultrasounds, is highly contested as controlling women's choices and undercutting their authority regarding their pregnancy. However, these technologies can also provide information that is useful for a woman in making decisions regarding her pregnancy. According to Rapp,

Although the biomedical technology I was tracking produces universal and uniform claims about the advantages of prenatal testing, my research increasingly revealed alternative and sometimes competing rationales through which members of different communities made sense of its burdens and benefits.²⁸⁰

Rapp points out that there can be no universal claim regarding the advantages and disadvantages of any NRT. The women who engage in these technologies determine the benefits or burdens based on their understanding of their situation.

The women in this study relied on their understanding of their pregnancy to make a decision to refuse an amniocentesis as part of their medical care. Several of the women of this study were asked if they would like to have an amniocentesis because their age put them within the range where having an amniocentesis is part of the standards of practice. All the women refused to have the test.

An amniocentesis is routinely done on pregnant women who are over the age of 35.²⁸¹ It has become one of the most invasive means of monitoring a pregnancy and most accurate means

279 Refer to Hartouni, Petchesky, Rapp, Rothman, and Thompson.

280 Rapp, *Testing Women*, 10.

281 Keith Eddleman and others, "Pregnancy Loss Rates After Midtrimester Amniocentesis." *Obstetrics & Gynecology* 2006. Vol. 108, No. 5, (November 2006), 1067-1072. In their research, Eddleman et. al. argue that the practice of routinely offering amniocentesis to women after age 35 years has become arbitrary and archaic.

of fetal diagnosis. The amniocentesis is performed to diagnosis the health of the fetus with the understanding that in the event the results indicate a genetic disorder is present; the woman will abort the fetus. PGD was originally used to test the embryos of couples that are known carriers of genetic diseases so that they could transfer only unaffected embryos. Testing the embryos, as opposed to testing the fetus through an amniocentesis, eliminated the difficulty associated with aborting an affected fetus. Using PGD preempts the use of amniocentesis. The information gleaned from an amniocentesis has already been obtained during PGD.

All the participants of this study refused to have an amniocentesis for similar reasons. Natasha and Derrick chose not to have an amniocentesis because of the risks involved with the procedure. They were comforted by the results of the ultrasounds that Natasha had throughout her pregnancy.

Claudia: Were you asked if you wanted an amniocentesis?

Natasha: Ummm... I think yes by my OB. I think she did and we declined. We had ultrasounds ... they specifically checked things, especially because of our son. And we had a level two ultrasound. And at that point they said everything was good so we declined. Amnio has risks in itself so...I think that we were fortunate to have the level two, which of course by then is covered by insurance, so that we would, they would specifically look at those things. Because they looked at not just the structure, but they looked at the blood flow through the heart and everything, because of our previous experience.

Derrick: I don't think we breathed up until that point.

Previous conception experiences contributed to the concerns the women who used PGD have during their pregnancies. Natasha and Derrick lost a son shortly after he was born due to a heart defect.

Some women refused an amniocentesis because of the risk of miscarriage associated with the procedure. Tina explains her reasons for not having an amniocentesis:

Tina: They asked me if I wanted one and I said no because I felt why risk something happening at that point. Because you could possibly miscarry at that point. I said no way. What I have is what I have.

Brad: Especially after doing the PGD

Tina: Yeah, so I felt he [her son] was OK and when I told my doctor that, he says, I know they both told me, him and his assistant, both told me that that's exactly what they'd do. It's a good decision. ... because what was I going to do? If they told me either way. You're not going to give it up at this point. No I'm going to take what I have. No that wasn't... there wasn't any thought into that. Nope I won't go through it to risk a miscarriage if something happens. ... that's it.

The implication of aborting an affected fetus was not something Tina was willing to consider. Hazel and Bill felt the same way. They also said abortion was not an option for them.

Claudia: Were you asked to have an amnio?

Hazel: No once we told our doctor that we had done PGD ...

Bill: She still gave you the option.

Hazel: She basically said it wasn't necessary.

Bill: I don't think, well this is just my opinion. I don't think we would have done it anyway because I don't know that an option would have been aborting. So if you're not going to abort then why get an amnio. I mean that's my opinion. It may not be the one everyone has but...My opinion is if you find out early then you're stressed out wondering if the baby's going to have 16 fingers... you might as well... if whatever happens, happens. I mean it would be tough.

Isabel also said she declined an amniocentesis because she would not have been able to abort her fetus. She said, "No, because I wouldn't have been able to abort him if it would have come up with something. That is against my religion. So I wouldn't have been able to do it".

The women who used PGD to combat their infertility just wanted a biological child. They did not use PGD to have a specific child. The only way for these women to get pregnant was to use PGD. Now that they are pregnant and past the time where they had miscarried their previous pregnancies, they were not about to do anything that might jeopardize their pregnancy. There is a

miscarriage rate of nearly 1% associated with having an amniocentesis.²⁸² Any possibility of losing the child, that these women worked so hard to get, was unacceptable.

Another reason women who use PGD reject having an amniocentesis is because they understand that they already got the information gleaned from an amniocentesis. PGD already determined the genetic makeup of this fetus when it was an embryo. Amniocentesis is a redundant and unnecessary procedure for these women.

Having an amniocentesis comes with an implied set of behaviors based on the results. The women who used PGD understand this implication. They understand that if the results come back positive, indicating that a genetic disease is present, they would be expected to abort their fetus. This was not something they were willing to do. They had worked hard to have this fetus and they were not going to destroy it for any reason. Abortion was not a consideration for them for two reasons: 1) they were willing to accept the child regardless of the genetic health and 2) it was against their religion to have an abortion. Their use of religion to justify their condemnation of abortion is in stark contrast to their disregard of their religious values when it comes to choosing to use IVF with PGD.²⁸³

Many of the women/couples commented on the association of discarding embryos with abortion.²⁸⁴ There were two contrasting opinions about this association. One group felt that discarding embryos was not the same as an abortion. They felt embryos were just a group of cells. This group does not assign human status to embryos. Sienna and Pierre's discourse follows this line of thinking.

282 Ibid., 1071.

283 Refer to description of participants' religious affiliation in chapter three of this dissertation. Also, further discussion of subjects' religious beliefs and religions views on NRTs later in this chapter.

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Sienna: That's a great question.
Pierre: I think emotionally it's an easier decision.
Sienna: Yeah because it's just chemistry
Pierre: Yeah at that point definitely, chromosome assembly.
Sienna: Yeah kind of like the "thing".

Sienna and Pierre refer to the embryo as "chemistry" and "chromosome assembly" which are very technical, detached terms. They are not referring to the embryo possessively or as if they recognize its potential for human life. However, later in the conversation, there was a hint of ambivalence in Pierre's conviction about the status of his embryos when he said he considered all their embryos as "potentially" their children. The word "potentially" allows Pierre some leeway to change his mind about the status of his embryos. The ambivalence demonstrates the ability of these women/couples to shift their values regarding their embryos as they progress through their PGD cycle.

Meredith also believes discarding embryos is not the same as an abortion. However, she struggles with coming to terms with the decision she made to discard all her female embryos.

Claudia: Do you feel it is the same as an abortion?
Meredith: I don't feel it is, I guess until it's ...I guess until it gets to a certain... I didn't view it that way, I don't know how I feel, but I didn't view it as an abortion. I mean we're ... This was the hardest decision that we ever, ever had to make. I never thought I would go this route in getting pregnant or that in a million years we would ever do this. I guess it came where we had a boy and two girls, the decision came up and we made it. I never viewed it as an abortion. I would never have an abortion of a child... if I conceived... I would never... I would never abort the baby but I didn't view it as an abortion, I guess you'd have to get pretty deep into it.

Meredith's discourse reflects a hint of ambivalence in her voice about her decision to discard all her female embryos. She is not clear how she would define her act of discarding her embryos. Although she does not regard the embryos as having the same status as a human as she would a fetus, she does acknowledge that the decision to discard the embryos was hard.

All the women/couples regarded the embryos as having potential for human life early on in their PGD cycle. At one point in time, their embryos signified the strongest connection to obtaining their pregnancy goal. Their embryos represented the life they wanted to bear. That representation, along with the fact that they can now identify the embryo that resulted into their child, causes difficulty in considering embryos as only cells.

There are some women/couples who viewed discarding their embryos as tantamount to abortion. People of this opinion assign full human status to an embryo once it is formed either in vivo or in vitro. Two couples held this opinion and did not discard their embryos. Both have frozen embryos and plan to use them in the future. Bill describes how he feels about discarding embryos. He said, “Well I think it’s ... from my stand point alone it’s ... you know ... I believe at conception it’s a human so I don’t ... discarding is just like an abortion. So that’s the way we viewed it and I wouldn’t support an abortion so that’s kind of...” Bill starts off by presenting this as his opinion and then states that it is both he and Hazel’s opinion. Hazel agrees that they should transfer the two frozen embryos, but she was able to put it into the context of their lives as to what it would mean to have another set of twins. In Hazel’s words, “And now it is going to start all over again. To have twins again, it’s going to be difficult. We have a set of twins and to have another set of twins... it’s going to be difficult to have four children, two and under”. Hazel is able to consider many aspects other than just the human status she assigns to her embryos when deciding to use her frozen embryos. She considers how this will affect her live and her relationships with those in her life. She also understands that the burden of care for four young children will fall primarily onto her. Hazel demonstrates moral decision-making that reflects woman’s values.

Derrick is also against the idea of discarding embryos. He and his wife, Natasha, disagree on this point. They explain:

Derrick: I think the only religious thing, and again you [he looks to Natasha] and I were talking about this a few weeks ago. Just my feeling on the embryo that's in the freezer is that we got to do... you know because again I guess that would be my viewpoint is that if you are doing this for ... everybody to each their own. But if you are doing this for other reasons, you know um... and then if it is like OK here's 8 fertilized eggs and we got the 2 we want and throw the rest out... That's not right.

Claudia: And do you feel the same way about the frozen embryo?

Natasha: Yeah, I feel like we should discard it but I'm not sure I feel as strongly as he does.

Claudia: So you're not sure if you want it implanted?

Natasha: Oh no I want it implanted... but I'm saying if there were 8, I wouldn't want to just keep going and going and going. Like if there is 8 you have 8.

Derrick: Well...

Natasha: I don't feel quite the same as him

Derrick: Well not necessarily if there are 8 she has 8. But if there are 8 somebody has to have 8... Something, that now it's a child and it needs to have a home.

Natasha is willing to go along with her husband's view and transfer their frozen embryo to her uterus at a later date. She said she does not feel the same as her husband about discarding an embryo, however she feels he feels more strongly about his opinion than she does about her opinion. Derrick's opinion does not appear to be clearly formulated. He does not use complete sentences when expressing his opinion and he implies that his opinion is contingent on the fact that they only have one frozen embryo and if they had eight frozen embryos he would rethink his opinion.

Both Hazel's and Natasha's discourse suggests they understand their limits in mothering. They are able to consider all aspects when formulating their opinion about the status of their embryos. In her study, Rapp found similar thinking in regards to aborting a genetically diseased fetus. The women in her study struggled with the discourse that defined their behavior as selfish. According to Rapp, "Too often, the politicization of abortion is inscribed in a discourse of

individual ‘selfishness’. But in the interviews I collected, women usually positioned their abortion decisions in relation to the way they imagined their intimate others would be affected. The most salient of these were their other children.”²⁸⁵ Later Rapp explains the significance of their discourse; “This important corrective then performs invisible work of its own, muffling cultural attitudes toward disability and the voluntary limits of maternity.”²⁸⁶ Natasha and Hazel understood their maternal limits when considering what to do with their frozen embryos. However, both women plan to transfer their embryos to their uterus in hopes of a resulting birth. Their husbands voiced only concerns of their moral obligation to the frozen embryos as their reason for wanting to use the embryos. The difference in the women and men’s perspectives may be teasing out a deeper value of our society. The men may lean toward a patriarchal ideology that says a man should spread his seed, but are uncomfortable voicing that directly. It may also be indicative of the difference in the levels of responsibility of parenting between mothers and fathers. Traditionally mothers bear more of the responsibility for caring for the children than fathers. It may be easier for the men to have more children using the frozen embryos because it will have less of a direct impact on their daily lives than on the women’s lives.

The Delivery

Fertility treatment is not deemed a complete success until a baby is born. That means carrying the transferred embryo through a full-term pregnancy to delivery. It is not until the baby takes its first breath that women who use fertility treatment can truly breathe a sigh of relief. The pregnancy created through the use of PGD was the first pregnancy many of these women carried to full term or near enough to full term to deliver a baby. The delivery was much anticipated with excitement and anxiety. All anticipated and planned to have a typical vaginal delivery. However,

285 Rapp, *Testing Women*, 246.

286 Ibid., 247.

several of the women delivered their baby via cesarean section. According to M. Singer et al., “Patients older than 40 undergoing IVF or donor egg cycles are at a much higher risk to have a cesarean section when compared to non-IVF patients. This trend remained among the different age groups and even at an advanced age, IVF further increased the likelihood of patients to deliver via cesarean section.”²⁸⁷ A cesarean section is typically performed to avoid a complication that may have developed as a vaginal delivery progressed. It is often precipitated by an emergency situation. Meredith, who used PGD for sex selection and had given birth to three other children, describes the difference between her PGD pregnancy and delivery, and her other three pregnancies and deliveries.

It was 150% different. The whole thing was quite an ordeal. I had a very easy time with all my pregnancies. I was like the ideal pregnant woman. I never had any kind of complications, I gained very little weight, I was always light on my feet And the pregnancies... I delivered all of them within an hour, no problem. It was just... no problem, if you had to go through labor; it was just very pleasant labor. This one, it was... from the beginning... and of course it's the fourth kid and I was older, and I take that all into account, and working and taking care of three kids. I knew this wasn't going to be an ideal ... but I ended up having a C-section with this one, my fourth one and it was quite an ordeal just the whole thing.

Tina describes her delivery. This was her first delivery.

I had a C-section. What happened was... my delivery... I was going in on a Friday afternoon and having him the next morning by 8:00. My water broke, but not all the way when I was at home so what happened was when I was at the hospital they tested it and... tested the water that I was still carrying and he had had a bowel movement ... so he had to...if I wasn't going to start going into labor soon then they had to do that, but I didn't know that until like 15 minutes before I had him so ... the labor was, prior to that was no problem for me. As a matter of fact we were home and just kind of getting ready for work. I was working and

287 T. Singer and others. “A Comparison of the Cesarean Section Rates Between IVF and Non-IVF Groups and Between Donor Eggs and Non-donor Eggs Groups in Singleton Pregnancies in Patients Older Than 40.” *Fertility and Sterility* Vol. 90, Suppl 1, (September 2008), S402.

though I would work one more week and I was actually on week 36 and that's when we had him ... so I was going to work until week 37 so I was pretty big and it was getting uncomfortable at work, sitting and walking around ... but the labor part I don't really even remember it because it was a quick decision. My doctor was not in. He was on vacation. So I had his associate and she came in and said we got to get him [her baby]. Just get him; I wanted him to be ok. I didn't care to sit and wait and prolong it so I could have him naturally. I just wanted him healthy because there was that risk of him swallowing [meconium]... then it can get into his lungs and there might be danger there ... so I said just take him and that was it. ...I didn't even care. I didn't think twice of it. And you know that part where you're getting ready and start to do research on C-section, I just avoided it. I never even looked at it before, didn't know what was involved and maybe through one class that I took, what could happen. But it didn't even bother me a bit.

Tina did not even consider the possibility that she would need a cesarean section. She did not do any research on the topic or any preparation. As her pregnancy progressed, she felt as if it was a typical pregnancy and she would have a “natural” delivery. Hazel too did not plan for a cesarean section. She talks about her experience:

Claudia: How was your delivery?

Hazel: It didn't go as planned. We were hoping for a natural delivery and we had a C-section. We went to 38 weeks; they had to induce because I would have kept going. I was huge and I was completely retaining water. And I was nauseous the whole pregnancy. It wouldn't go away. But it was worth it.

Hazel concludes her story by resigning to the fact that having a cesarean section was necessary in order to have her healthy twins. Isabel comes to the same conclusion. Here she tells her story about her cesarean section:

Isabel: I started having the Braxton Hicks, which I had been having those, but I was ignoring them and they were coming a lot more at the time and then I started bleeding again so I called the hospital and I'm like I don't know if this is normal because this is my first baby and they had me come in and they said they didn't know why I was bleeding they didn't know where it was coming from. And they were kind of concerned about that and they did another ultrasound and Dr. H said you can't tell enough from the ultrasound whether or not the placenta is tearing or anything like that. So he was concerned and he was like I wouldn't send you home ... so they went ahead and took him [her baby] ... and the cord was around his little neck twice. I know he did a lot of moving around in there. He got

himself all wrapped up. Dr. H came in and said we're going to take him and they were rushing me down the hall and my head was spinning.

Claudia: Everything changed in an instant.

Isabel: Yeah it was fast. He told us that and it was like 20 minutes... He was born at 1 o'clock or like 1:05 they put down. And it was like 20 minutes to 1 when the doctor came in and by 1:05 there he was.

Claudia: So it was a C-section?

Isabel: Yeah it was a C-section, because I still wasn't at that point... no dilation or nothing. My body wasn't ready to deliver him at all so the doctor said he couldn't even induce me or whatever I guess... But anyhow it worked out. It was worth it.

Having to have an unexpected cesarean section mocks the perceived control these women felt they had at this point in their pregnancy. Rapp talks about the illusion of white middle-class American women who feel they have control over their circumstances. Rapp attributes this illusion to "transformation in education, labor-force participation, postponed marriage and childbirth."²⁸⁸ These women were on a life trajectory where there is perceived "individualism, free choice, and control over one's own life".²⁸⁹ Infertility can typically be the first indication that this control over one's life is just an illusion. But this illusion of control can come back, as the discourses of these women indicate, once they perceive that they are back on their planned trajectory.

The women of this study are constantly reminded of their lack of control over their bodies, first with not being able to get pregnant on their own then the monitoring of their pregnancy, so it is surprising that they did not even consider the possibility of having a cesarean section. The illusion that their bodies were back on the "natural" path once they got some assistance with getting pregnant is very strong. Therefore, the expectation of having a "natural" delivery seems natural.

288 Rapp, *Testing Women*, 140.

289 Van Balen and Inhorn, "Introduction", 9.

The dedication to their children and giving them the best possible start to life obliged both Hazel and Isabel to use the phrase “It was worth it” to denote their acceptance of level of pain, stress, and disappointment brought on by having a cesarean section instead of having a vaginal delivery. To ensure having a healthy child, these women subsumed their own desire of having a “natural” delivery to the needs of their child. However, in their cases, perhaps subsumed is not the appropriate term. In these cases perhaps the correct term is denied. These women were denied their desire to have a “natural” delivery by their bodies. Their bodies once again did not cooperate with their desires. Just as they wanted to get pregnant the “natural” way and could not, they could not give birth the “natural” way.

A cesarean section is more medically managed than a vaginal delivery and an example of the medicalization of reproduction. Some cesarean sections are planned in advance of delivery and are not precipitated by an emergency. A cesarean section could be planned in advance for a high-risk pregnancy or for a woman who previously delivered via cesarean section. The medicalization of reproduction gives more power and control over reproduction to doctors than women. Greil cites sociologist Catherine Kohler Riessman’s explanation of why this shift in power and control occurred. According to Greil, Riessman has suggested, “that the medicalization of reproduction has occurred when doctors’ interests to maximize their professional power has converged with women’s perceptions of their own medical needs, especially among relatively affluent white women.”²⁹⁰ Greil adds, “But the medicalization of reproduction, according to Riessman, is ironic: at the same time that it has promised women more control over their bodies, it has strengthened the control of the biomedical interpretation of

290 Greil, *Not Yet Pregnant*, 37.

their experience.”²⁹¹ These women’s doctors determined the need for a cesarean section based on his/her expertise and interpretation of the situation. These women were willing to acquiesce to their doctor’s recommendation based on their interpretation of their situation and medical needs.

Parenthood

Much of the focus when using PGD is about getting pregnant and having a healthy child. There is little discussion of the resulting motherhood/fatherhood. Although motherhood/fatherhood is tacit as an outcome, it is not until the procedure has been deemed a success that the joys of parenthood can be realized. Hazel and Bill had twins as a result of using PGD. The twins are Hazel’s first biological children. Bill has three children from a previous marriage. Hazel and Bill talk about Hazel’s thoughts about motherhood after the twins were born:

Claudia: Did you anticipate parenthood being like it is?

Hazel: You know I never thought of what it was going to be like. I thought whenever you get there you handle it and that’s it.

Bill: No you never thought...Oh you were just so matter of fact. ‘Oh I’ll just have them then go back to work. No big deal’. And now it is like ...

Hazel: Now it is like... I want to stay home. I can’t leave them.

Bill: She has a completely different outlook.

Isabel feelings about motherhood also changed after the birth of her son. For her, motherhood is like nothing she has ever experienced. She talks about the unexpected feelings she has toward her son.

Isabel: Well there have been a lot of things that I’ve learned that I didn’t know, but yeah it’s awesome. I just love him so much. I never ... It’s just hard to believe that you could love some one that much and ... you know at one point in my life I was a baby and it’s hard to believe that my mom or anybody could love me this much. I just love him so much it hurts. I just feel like I’d do anything for him.

291 Ibid., 37.

Isabel and Hazel's children created through the use of PGD were their first. It is understandable that their feelings would change once their children were born. The experience of motherhood was novel to them. Meredith and Janet each had three children, and Emma had four children prior to using PGD for family balancing/sex selection. Meredith talks about the joy this child brings to their family. She said, "Now I wouldn't change it for the world. He's perfect in every way. We are complete. When I look at him I forget about everything. The kids just love him ... it all worked out". Meredith felt that having this boy completed her family. Janet reiterated the same sentiment when she said her second son, fourth child, completed her family. Emma wants at least two more boys to complete her family. She is currently using PGD and is hoping to get pregnant with twin boys. She would like to have at least eight children. She currently has four girls and one boy.

These women have experienced what Franklin refers to as "achieved" parenthood. Women who conceived through the use of NRTs felt that this was a greater accomplishment than getting pregnant through coitus. According to Franklin,

Whereas most couples 'take for granted' their ability to reproduce, women who undergo IVF can feel that achieved parenthood is special because it is different: a unique accomplishment. In this too lies an important component of the meaning of 'achieved' conception. It is different, it 'makes something of you', and it is all the more valued as a result.²⁹²

Along with the joys of becoming a parent comes the responsibility of raising your child. Parents have to choose how much of their child's conception they will reveal to their child. Some children curiously ask their parents about their conception and birth. When asked if she would tell her son how he was conceived, Emma responded as follows:

292 Sarah Franklin, *Embodied Progress: A Cultural Account of Assisted Conception*. (New York: Routledge, 1997), 164.

I think I will because my whole family knows... I'm not one that ... you know if someone asks me about it I'm going to tell them about the whole thing... there's no reason for me to hide it. I wouldn't have done it if I felt like I shouldn't be doing it. I will tell him... it will be down the road obviously.

Hazel and Bill are not sure if they will tell their children about their conception. Bill said he has “no idea” if he will tell the children. Hazel said, “I don't know” if she will tell the children. Then Bill added, “There would never be a reason for it to come up. Unless ... it would only be something the older kids would put in their heads.” The women/couples who told people about their use of fertility treatment felt they might have to tell their children about it because they may hear about it from someone else. But the women/couples who did not tell anyone about their use of fertility treatment were not sure if they would tell their child about their conception.

Rationalizing

As these women/couples progressed through their fertility treatment regimen, they came to understand that they were using a procedure that is associated with controversy. PGD is commonly referred to as the “designer baby” technique. It is referred to in this manner because of the ability of users to pick and choose the embryos they want transferred. The “designer baby” idiom also implies the ability to choose personality traits and physical characteristics. According to Franklin and Roberts, “Like the figure of the clone, the designer baby has become an iconic signifier within this genre of dilemmas and risks posed by new genetic technologies”.²⁹³ Franklin and Roberts summarize the arguments against the “designer baby” technique. According to Franklin and Roberts, people against the use of PGD argue that PGD, “is moving too quickly, without our consent, and that it is not something we really want, because it will

293 Franklin and Roberts, *Born and Made*, 25

destroy who we really are”.²⁹⁴ Medical ethicist Guido deWert presents what he calls the slippery slope argument against PGD. The main concern from a slippery slope argument point of view is that a situation will get out of control and move to quickly on its own. According to deWert,

If you permit an exception to the guideline that PGD may only be used to select for characteristics related to the health of the future child (in other words if you make an exception to the medical model) and accept PGD/HLA-typing, then you no longer have any convincing arguments for the rejection of the ‘designer’ model, which allows parents to select embryos however they please, including selection for non-medical characteristics such as predisposition for special talents.²⁹⁵

deWert counters his own slippery slope argument by stating “the complexity of the genetics of the desired characteristics is underestimated and because the burdens and stress of IVF, the limited chance of success and the availability of just a very few embryos, all provide obstacles to the use of PGD ‘for trivial reasons’”. deWert is assuming that choosing physical traits or personality characteristics are considered trivial and that the success rate of PGD will not improve over time.

The arguments that support the use of PGD primarily speak to the significance of eliminating the pain and suffering of infertile people. In addition to eliminating the pain and suffering of infertile people, supporters of PGD argue that the technique gives some children a chance at a having a healthy life.²⁹⁶ These supportive arguments for PGD work to “rescript” the

294 Ibid., 30. Franklin and Roberts cite the arguments made by Francis Fukuyama, a professor of political economy, Jurgen Habermas, a philosopher, and Bill McKibben, author.

295 deWert, Guido. “Preimplantation Genetic Diagnosis: The Ethics of Intermediate Cases.” *Human Reproduction*, v. 20, n.12 (2005), 3261-3266.

296 Franklin and Roberts, *Born and Made*, 31. Franklin and Roberts use Roger Gosden, reproductive biologist and Gregory Stock, director of the

scary and unacceptable aspects of PGD, in the same manner supportive arguments for IVF worked to make IVF acceptable. Those who speak about the benefits of PGD, assisting nature and allowing infertile couples to become pregnant, work to make the procedure more acceptable. According to Hartouni,

They [new reproductive and genetic practices] are no longer regarded as contrary to the work of nature, but rather as instruments that promote or assist nature's work, enabling, correcting, or improving natural processes that have gone awry and that, in any event, apparently, are highly mercurial and inefficient.²⁹⁷

Hartouni goes on to say, "In this respect, they are now part of what Sarah Franklin, among others, terms a new "conception narrative," a highly sentimental narrative of biological desire and drive that displaces the image and threat of technoscientists playing god with portraits of the happy, heterosexual, white nuclear family..."²⁹⁸ Discussing PGD in the context of its ability to assist infertile couples creates a better understanding and appreciation for its use. It moves away from the image of a technology out-of-control to a more acceptable medical procedure.

The "designer baby" idiom signifies the concerns society has regarding the challenges NRTs inflict on human identity. The ability for parents to pick and choose traits and characteristics they desire has not yet been realized by PGD. The women/couples who used PGD wanted to distance themselves from what is signified by the "designer baby" idiom. They distanced themselves by arguing that their use of PGD was altruistic. They used PGD to give their child the best possible chance of being born healthy.

Program on Medicine, Technology and Society at UCLA School of Public Health arguments to demonstrate support for PGD.

297 Hartouni, *Cultural Conceptions*, 115.

298 Ibid., 115.

Sienna and Pierre understand the assumptions associated with the “designer baby” technique. They had no thoughts of choosing physical characteristics or personality traits. They explain the ways in which their use of PGD differs from the common perception of “designer baby” uses and their thoughts of people using PGD in the future:

Pierre: I think people should be allowed to make those decisions for themselves. I may not agree with their decision, I think it’s pretty shallow but ultimately it is their decision. I think from the emotional pain that we had to go through; it was especially rough on Sienna... I don’t think anyone who goes through it takes it lightly. But I still reserve the right to think that someone is pretty shallow to make a decision once you’ve gone the steps to do this to exclude a potential child just based on what the gender outcome is going to be... or IQ or athletic prowess.

Sienna: Right designer babies. For us I look at it that we were using for the good of it because we were using it as a tool to determine... because really what was next was are we using somebody else’s egg that I’m carrying or are we going to adopt. So it was a tool for us to assess what our next step was... It’s not an easy decision to make.

Monica and Chandler concur with Sienna and Pierre. Their use of PGD was not for reasons that are typically associated with the “designer baby” idiom.

Chandler: In our case it is not like a designer baby. If it is a good embryo, it has a better chance of survival. In our case, well we can pick the sex of the baby. But we are not really saying it’s a tall gene or this complexion... in our case it is only that aspect ... it has to be a good ... healthy..

Monica: If people are doing this for picking the sex or parameters... I don’t feel to good about that.

Sienna and Pierre, and Chandler and Monica actually use the term “designer baby” to distance themselves from that model. Tina and Brad do not use the term “designer baby” but they give their opinion about the implicated uses signified by that term. They also comment on people creating their families through the use of NRTs instead of coitus, the “natural way”.

Tina: Yeah ... Some of it, that I read, was people doing it [PGD] for reasons of picking a certain sex in their family and I couldn’t believe that. I thought... I was really against that. I would never do that for that reason alone, because if you’re having problems having a baby... I just couldn’t imagine that somebody would be

given this opportunity and they say OK you've got 5 girls and no boy and they say no we don't want them. I read a lot on that. I thought that was wrong.

Although Tina condemns the use of PGD for sex selection purposes, she and Brad were quick to justify their use of PGD.

Brad: Another thing is we never... we both were raised Catholic, I was an alter boy, my parents were strict Catholics. I think in the early days when you heard about in vitro or that kind of thing, people talked about like you were playing God and all that, we never thought of it that way.

Tina: No, I never did... I never did. And... but when I started hearing about picking and choosing gender, I didn't like that. I would have never done that. And ... and then the freezing of the embryo, that was kind of... that was weird for me.

Claudia: Tell me what was weird about that.

Tina: I guess it was kind of weird for me at first to think it could happen, but we were going to do it.

Brad: Yeah it just seems like something that is really out there.

Brad relies on his religion to set the parameters of what he found to be acceptable uses of PGD.

Meredith also leans on her religion when talking about her moral dilemma with using PGD. She describes the struggles she experienced from her choice to discard all the female embryos.

Meredith: That... Yeah that is...that is something we spoke about. I knew that that would come today and that was something we prepared ourselves for. It was hard, I really tried to not... you know... And I'm Catholic, and we tried to not to think of this as becoming an ethical issue or I don't know, I can't even tell you what I thought, I just tried to make it seem like it wasn't ... I thought it's all in God's hands. If this is what he wants it will work, and it will happen, and we'll get what we want. And if it's not ... It was meant to be ...so I thought that way. I was not ... I did not want to donate the eggs ... I didn't feel comfortable with another woman using them or...I don't know. I just thought of all these weird things of having another child out there and not knowing about it... I didn't want to go that route and then I didn't get pregnant with a daughter so that really was, I guess, my only option.

Claudia: Did you anticipate the decision of what to do with the unused embryos prior to using PGD? Is that something you and your husband discussed?

Meredith: Yeah... that was something we did discuss. And we decided that if there were ... we would because he mentioned that they would be discarded. That is something we knew about but I guess you try not to focus on it.

There appears to be a real disconnect between the manner in which some of these women/couples view their use of PGD and their religious values. They identify as a member of a religion, and yet their behavior goes against that religion's doctrine.²⁹⁹ Brad and Tina identify themselves as Catholics. According to Joseph Schenker, "The Vatican's statement on IVF is very clear. It does not accept IVF as a method for procreation."³⁰⁰ Schenker goes on to state the position of several religions on the use of fertility treatment. Judaism, Hinduism, and Buddhism all support the use of IVF. Islamic, Protestant and Anglican all support the use of IVF provided the gametes used come from the husband and wife. Eastern Orthodox doctrine does not support the use of IVF.³⁰¹ For many of the women/couples, using IVF was in deviance of their religion. Their discourse demonstrates the difficulty they had with coming to terms with the disparity between their religion and their use of PGD.

Meredith had difficulty finishing her sentences and saying out loud what she actually did. She was struggling to find acceptable words to describe her behavior. Her discomfort with her decisions was evident in the manner that she discussed her choices. She is not fully convinced of the righteousness of her use of PGD. However later in the conversation she was able to articulate justification for the use of PGD as a treatment for infertility.

Meredith: That is getting into a different level of what a person wants and what a person, I guess needs. If a woman can't get pregnant, it is the same thing as if you needed a heart you would get a heart transplant even though that's scientific... I

299 Several participants in this research project identified as being a practicing Christian. Some specifically said they were Catholic. Only one couple identified themselves as practicing Hinduism.

300 Joseph Schenker, "Religious Views Regarding Treatment of Infertility by Assisted Reproductive Technologies." *Journal of Assisted Reproduction and Genetics*, Vol.9, No. 1, (1992), 3-8.

301 For more details on the religious views of all the new reproductive technologies, refer to Schenker.

don't know. I think if you are being medically treated for any disease that you have... If you can't get pregnant this is the treatment. If you had a heart attack or needed a new heart your treatment would be to get a new heart. That's how I view it.

Her justification takes only into account the desires of an infertile woman who wants to get pregnant. Meredith's argument does not justify her own use of PGD because she was quite capable of getting pregnant without intervention.

Bill and Hazel take issue with what they consider abuses of PGD. They explain:

Bill: We know people who have been through it... that did...and they were...well she [Hazel] talked to them. Well she [the other women who used PGD] was pretty... 'I got what I wanted so whatever... so throw them away'.

Claudia: How did you feel about that?

Bill: I didn't feel so good. I just thought how could people think so little...

Hazel: I didn't want to judge...everybody's got their own...

Bill: I would have never said anything to her.

Hazel: That's her choice and we can't do anything about it.

Bill: But at the same time some people are going to have 5, 6, 7, 8...

Hazel: People are going to have abortions and there is nothing I can do about it. I try... I choose not to. I can only act for myself. I can't act for other people and I can't tell them what to do. So...

Bill: I definitely think it can be abused.

Claudia: How do you think it can be abused?

Bill: Well ... the girl who had six, or who had 8, and the doctor who ... that's ridiculous, she did it just for whatever... she wanted to get millions of dollars... I don't know what she wanted, but it just made no sense. And the doctor, as far as I'm concerned, was unethical by putting so many in as he did.

Like Meredith, Bill had difficulty completing his thoughts. He could not fully articulate his feelings about what he considered the misuses of PGD and IVF. Having first hand experience with the technology and being aware of the abuses showcased in the media, Bill is sure the technology "can be abused". Hazel feels it is not her place to judge others' behavior. She cannot tell anyone what to do; she can only "act for myself". Hazel implies that she is comfortable with

her decisions and would not like anyone judging her. Bill and Hazel point out that they acted ethically by not abusing the technology.

Bill: Well they [the fertility clinic] only put 3 [embryos] in because they were 3 days. They would never put 3, 5 days in. The max is 2. I'm OK with that. And I think that's from an ethical standpoint, that's the right thing to do. But when you start messing with that kind of stuff or using PGD for ... for other purposes...
Hazel: eye color selection, gender selection...

Hazel and Bill compare their use to the uses they consider abusive to demonstrate that they did not cross the line of anything that might be unethical or a misuse of PGD. Couples who used PGD to rectify their infertility often condemned the use of PGD for sex selection. To them this was a use that belittles its medical significance. Meredith who used PGD for family balancing/sex selection twice, found her moral compass to be farther down the use scale of PGD. She described where she thinks the line should be drawn and what she considers an abuse of PGD. She said,

Of course it has to stop at some point. As far as ...they had mention that you could pick the color of your child's eyes, the color of their hair. To me that is like a whole different level. I don't think... I don't believe in cloning and all of that. I think there has to be a point where it stops". She also discussed her thoughts on regulating PGD. Meredith believes, "There needs to be a certain level of government involvement. The law has to be involved. But then I think that each person doing it... I should have a right if that is something I want to do. But it should be the law to be able to do it.

Rationalizing helped these women/couples make sense of their use of PGD and how their use fit into the discussions about PGD. Their personal situations contextualized their use. In her study, Rapp had similar findings about the rational women used for having an amniocentesis. Rapp explains, "Although the biomedical technology I was tracking produces universal and uniform claims about the advantages of prenatal testing, my research increasingly revealed alternative and sometimes competing rationales through which members of different communities made

sense of its burdens and benefits”.³⁰² The women/couples who used PGD made claims about the benefits of PGD based on their specific needs and goals.

The users of PGD came to terms with their use of a controversial and morally complex technology. They contextualized their values by framing their situations as they understood it to be at the time. This is similar to what Petchesky calls “the ethic of people being allowed to work out their own ethic.”³⁰³ Examining PGD from the vantage point of a successful user puts the procedure in a very acceptable perspective. PGD gave these users their healthy child. It would be difficult for these women/couples to be anything other than supportive of the technology.

Octomom

About the same time the women/couples of this study were going through their infertility treatment, Nadya Suleman, commonly referred to as Octomom, was also going through fertility treatment. Suleman was the subject of a “media frenzy”³⁰⁴ after the birth of her octuplets. Suleman had six frozen embryos transferred during an IVF cycle that resulted in eight live births. The children were born with medical complications and required hospitalization after birth. Suleman, a 33-year-old divorced mother, had six children at home prior to the birth of her

302 Rapp, *Testing Women*, 10.

303 Petchesky, *Abortion and Woman’s Choice*, 353. Petchesky refers to this ethics when discussing women working through their decision to have an abortion.

304 Josephine Johnston, “Judging Octomom”, *The Hastings Center Report* Vol. 39, No. 3 (May/June 2009), 23-25. Johnston says Suleman was part of a frenzy because, “first because the babies were only the second set of octuplets born in the United States, and later because of the irregularities of their conception by in vitro fertilization and the personal details of the mother’s life.” 23.

octuplets. All six children were conceived through IVF, and her ex-husband fathered none of her fourteen children.³⁰⁵

The women/couples of this study had strong opinions about Suleman's experience because they also used IVF to treat their infertility. Suleman's use of IVF epitomized some of the concerns society has with biomedical technology. Having eight children at one time through the use of IVF is emblematic of a technology out-of-control with no safeguards in place to prevent abuses from happening. Currently, assistive reproduction is not regulated in the United States.³⁰⁶ The ASRM offers guidelines for embryo transfers, however physicians are not obligated to follow those suggestions.

Suleman's pregnancy not only put her life in danger, but also put the lives of her children in danger. Josephine Johnston of The Hastings Center Report cites the Center for Disease Control to explain the dangers associated with multiple births. According to the CDC, "Multiple birth is associated with poor infant and maternal health outcomes, including pregnancy complications, preterm delivery, low birth weight, congenital malformations, and infant death."³⁰⁷ Suleman's doctor transferred all six of her embryos at her request. He disregarded the guidelines set up by the ASRM.

In addition to the concerns about Suleman's and her babies' health, there was outrage directed toward Suleman because of her lifestyle as a single parent with many children. Suleman's ability to provide for all her children was called into question. According to Johnston, "Many feel she [Suleman] has irresponsibly created more mouths than she can possibly feed, and

305 American Woman Gives Birth to Eight Babies. Voice of America News / FIND (2009, February). Retrieved January 29, 2011, from Research Library. (Document ID: 1639806671).

306 Johnston, "Judging Octomom", 24.

307 Ibid., 23.

that the taxpayers of California are going to be left holding the babies, as it were.”³⁰⁸ The idea that the taxpayers would be responsible for subsidizing the care for these children created a societal connection to this situation and fueled the debate about the abuses of IVF.

Suleman’s situation often came up in conversation with the women/couples of this study. They wanted to dissociate themselves from this abuse of IVF by explaining the differences between their use of IVF and Suleman’s. They pointed out that they would never have had the same experience as Suleman because they were more conscientious in their use, and they went to a reputable doctor.³⁰⁹ Addison talks about her feelings toward Suleman’s situation:

Exactly, and it angered me so ... her [Suleman] situation...everybody was getting on her and getting on her at first and I’m like what the heck about the doctor? He is not following any set protocols that are set by all these associations and reproductive endocrinology. I remember being in the operating room and Dr. S has a poster there that says if your this age and you’re getting this done with this, that, or the other procedure, this many embryos will be transferred... The fact that he [Suleman’s doctor] didn’t follow them with her and subsequent patients... It’s just, how is he allowed to practice? It just seems so wrong.

Addison goes on to talk about her friend’s reactions to her use of IVF:

308 Ibid., 23.

309 Rita Rubin “Fertility Expels doctor of ‘Octomom’.” *USA Today* (October 19, 2009)

http://za2uf4ps7f.search.serialssolutions.com.proxy2.cl.msu.edu.proxy1.cl.msu.edu/directLink?&atitle=Fertility%20group%20expels%20doctor%20of%20%27octomom%27&author=Rita%20Rubin&issn=07347456&title=USA%20TODAY&volume=&issue=&date=20091019&spage=D.9&id=doi:&sid=ProQ_ss&genre=article&lang=en, accessed February 7, 2011. Rubin of USA Today reported on October 19, 2009 that the American Society for Reproductive Medicine (ASRM) expelled Nadya Suleman’s doctor from the organization. This organization has no jurisdiction over the physician’s medical license but reports that some medical insurance policies will only cover treatment by a physician who is a member of ASRM.

They think that since you went through IVF... they say ‘oh you could be Octomom’. And it’s like ... and I don’t know how many people told me that, because... There were a few people who knew we were going through IVF after the fact... we kept it quiet this time because if it was unsuccessful... but they said ‘oh you could have been Octomom’. No I couldn’t. The most there could have been were 4 if they both had split into identical twins, and that’s not the fault of the doctor that’s just what could happen. So Octomom really irritates me, and even Jon and Kate plus eight irritates me.

Bill feels the same way Addison feels about Suleman’s doctor. Bill feels both Suleman and her doctor are responsible for her situation.

Bill: Well ... the girl [referring to Suleman] who had six, who had eight and the doctor who ... that’s ridiculous, she did it just for whatever... She wanted to get millions of dollars... I don’t know what she wanted, but it just made no sense. And the doctor as far as I’m concerned was unethical by putting so many in as he did.

Paige also referred to Suleman when she was talking about the potential abuses of IVF, “Well just like Octomom. She should have never been able to put that many in. You know they [the doctor and staff at her fertility clinic] had a list stating if you’re this age or this age you can put this in.” Paige and Addison are referring to a chart hanging on their doctor’s office wall that lists the guidelines developed by the ASRM specifying the number of embryos to transfer based on maternal age and medical conditions.

Derrick feels that it is a person’s intent that should define the morality of a situation. He explains using Octomom as his example.

Derrick: I think intent is the biggest thing in any morality. With her if the intent is she wanted to have 8 kids because she really loves kids, God bless her go have 12..

Natasha: She has 14

Derrick: Well, have a clan, but if it’s just because, I don’t know why she did it, does she want the money or fame, whatever... that’s the wrong reason to do it But how do you legislate morality and intent ...

Natasha: I think at some point... like Dr. S was specific that he wasn’t going to implant that many embryos. So at some point it comes down to the doctors.

Later when asked who should be responsible for determining who gets to use IVF and the number of embryos transferred Derrick responded, “If you can pay then you should receive it.”

Later he and Natasha got into a discussion saying:

Derrick: If you say well the doctor should be in a position where he should explain the risks to them. I don’t know putting... the DR in that place where he has to make the decision of what’s right or wrong because...

Natasha: Well he never said he wouldn’t implant 8 eggs, he just said he wouldn’t do it at once because it gets risky.

Derrick: Well no, I guess my point was ... then how much do want a doctor telling you what you can and can’t do?

These women/couples reiterated the concerns discussed in the media directed toward the Suleman case. The representations in the media of atypical uses of IVF depict the practice in a critical manner. These women/couples are aware that many people will come to understand IVF only through what they see and read in popular media. Rapp found that what some of the women in her study knew about amniocentesis was obtained through what they saw on television or read in popular magazines. According to Rapp,

Well-educated women often arrived at counseling sessions with new questions on Wednesdays after the Tuesday science section of the New York Times reported on advances in genetic technologies. But women without privileged educational backgrounds were likely to remember and to mention specific media sources when I asked about their first encounters with this technology.³¹⁰

Popular media is a representational system that depicts “real life”. Representational systems, such as music, movies, television, and novels, present images of contemporary ideologies of human identities. These images are infused with cultural values. According to Kath Woodward, representational systems “are part of culture. Culture includes all the ways we have of making

310 Rapp, *Testing Women*, 114.

sense of our lives.”³¹¹ Culture produces signifiers through images and ideas that provide a means of understanding our lives. Woodward sites Raymond Williams who describes the importance of culture when he says culture is “the signifying system through which ...a social order is communicated, reproduced, experienced and explored... Culture does not simply reflect meanings, it produces them.”³¹² Representational systems produce meaning by providing a place for identity negotiation, assimilation, and rejection. The representation of Suleman in popular media is not a portrayal of IVF that these women/couples identify with. Nor do they want others to associate them with this identity. The close proximity of these women/couples to IVF with PGD created a great respect for the technology and understanding of possibilities of abuse.

PGD Success Conceptualized

These women’s/couple’s stories reflecting upon their use of PGD is informed by the feelings they have for their child/ren created by PGD. They are now “seeing” their PGD experience from eyes that have gone through the process and have met with success. For these women/couples, the technology did what it claimed to do. For them PGD has become part of their “naturalized” conceptual story. Their personal stories will contribute to the “rescripting” of the discourse about PGD. Their stories take PGD from a technology out of control, changing human identity to a technology that creates happy, loving families. Their stories work to make PGD acceptable in the same way personal narratives contributed to making IVF acceptable.

The women/couples chose to genetically test their embryos in order to select the best embryos that would have the greatest possibility of resulting in a pregnancy. Not only did the

311 Kath Woodward, “Representations of Motherhood.” *Gender, Identity and Reproduction: Social Perspectives*. Ed. Sarah Earle and Gayle Letherby. (New York: Palgrave Macmillan, 2003), 19.

312 Ibid., 19.

healthy embryos allow the women to get pregnant, but it also allowed the child to have the best potential to a healthy start in life. The women/couples came to “see” the power of genes as a way of assisting nature and a benefit in helping them reach their goal.

The women who used PGD worked hard to conceive and give birth to their child. They remained committed to their goal throughout their pregnancy by navigating their way through the medical system while maintaining their agency. They made decisions based on their knowledge of their situation and their idea of outcomes. They rejected medical intervention when they felt it was unnecessary and accepted it when they felt it was beneficial.

The women’s efforts to conceive and their understanding of the benefits of PGD informed their decision to reject an amniocentesis. Rapp concluded “Thus, the “choice” any pregnant woman makes to take or reject the test, and to keep or end any specific pregnancy, flows from the way that both pregnancy and disability are embedded in personal and collective values and judgments within which her own life has developed.”³¹³ At the time the amniocentesis was recommended, these women were committed to give birth to the child/ren they conceived through PGD.

The women’s/couples’ justifications for using PGD reflect their ability to take into account many aspects when making moral decisions. They did not follow what constitutes the foundation of morality, “reason and rationality”.³¹⁴ Tong points out that reason and rationality are the foundations of morality in Kant’s estimation, but she says that is not always enough to make moral decisions. These couples relied on their emotions to make their decisions and used their emotions to justify their behavior. They reasoned their use of PGD was altruistic which set them apart from the media portrayals of the abuses of the technology. Tong argues that altruistic

313 Rapp, *Testing Women*, 91.

314 Tong, *Feminine and Feminist Ethics*, 73.

emotions are quite different than raw emotions in that altruistic emotions are “a tendency to do good to others that has been reflectively cultivated for many years, beginning with our parents’ admonition that we ought to think of other people’s feelings.”³¹⁵ The altruism these women/couples displayed was toward their unborn child.

Conclusion

The successful embryo transfer marked the beginning of pregnancy for the women who used PGD. Their pregnancy became monitored as a pregnancy conceived through coitus, however their decisions to engage with all forms of medical intervention were influenced by their conception experience and their understanding of their situation. They had worked hard to get pregnant and were not interested in getting the information that might be gleaned from a medical procedure if there was a chance that they would miscarry. Having a healthy baby was their number one priority and they were willing to endure physical and emotional pain to ensure a safe delivery. Many of the women endured an unanticipated cesarean section.

The women/couples were able to reflect on their experience of using PGD after they had met with success. They came to understand their association with the controversial uses of PGD and the reason for the “designer baby” idiom. While they understood the concerns associated with the “designer baby” technique, they were able to dissociate themselves from that signifier. The women who used PGD to combat their infertility were able to justify their use of PGD by pointing out their altruistic intentions. The women who used PGD for sex selection/family balancing purposes used their outcome of a “complete” family to justify their use. All the women/couples in this study were reflecting upon their experience of using PGD from the perspective of a successful user who had a healthy child/ren in her/their view.

315 Ibid. 74.

CHAPTER EIGHT

CONCLUSION

This dissertation follows a long trajectory of my interest in the new reproductive technologies (NRTs). In the preceding chapters, I have attempted to answer the question why a woman would subject herself to the arduous treatment regimen of a Preimplantation Genetic Diagnosis (PGD) cycle. I do this by presenting a picture of what some users of PGD experienced as they used this newest NRT. I began by explaining the process of PGD and its association with other biomedical technologies to demonstrate its complexity. PGD is layered with meaning derived from the medical professionals, society, scholars, and patients. These meanings shape the experience of women/couples who use PGD.

My research focused on the women's/couples' perspectives of PGD, however other perspectives of PGD constantly distracted me. A historical perspective of PGD and the expansion of its ability to tests for more genetic diseases would have broaden the understanding of the commercial influences involved in the practice of infertility treatment. This perspective would have also demonstrated the social aspects that contributed to the development of PGD. Analyzing policies and procedures within the medical system would have exposed any discriminatory and coercive practices that may exist within this system that might compel women/couples to use PGD. I stayed focused on the users of PGD because I was most compelled to hear their stories and understand this new technology from their perspective.

When I first began my research I only wanted to understand why women/couples chose to use PGD. I knew it was a complicated technique, but not quite the technique signified by the “designer baby” moniker. As I contemplated my initial question more I realized I had more questions to ask these women/couples. I wondered what would compel a woman/couple to use a

technology that was associated with controversy, that required making what I considered to be a difficult and morally challenging decision regarding the embryo, and that might compromise the health of the woman? How did they make the decisions regarding the fate of the embryos? How did they hear about the procedure? As I got further into my research, I realized that my questions came from a woman who never experienced any fertility issues and was able to realize my desire to be a mother without intervention. I was what some of the women in my first Resolve Meeting coyly referred to as those “bitches”. I knew that derogatory term came from their strong desire to have a child and their anger from not being able to do so on their own. Women like me were a constant reminder of their infertility.

My distractions were squelched once I began to interview the women/couples who used PGD. Their stories fueled my desire to learn more about what their experience entailed. They were making decisions that most people would never have to make. They were choosing the embryos they wanted to bring to life. They were deciding which embryos would be their children.

Through this research I came to understand three very important findings about the use of PGD from a user’s perspective. First, the reason women/couples use PGD and endure every aspect of the treatment regimen is a strong yearning to have the child they desire. Infertile women/couples desire their biological child. Fertile women/couples desire their biological child of a specific gender. Women/couples initially state the reason they are using PGD is to ensure having a healthy child. However, if they truly wanted only a healthy child they would have chosen to have an amniocentesis to ensure they were indeed having a genetically healthy and properly developing child. But all the women refused an amniocentesis and were willing to accept the child as he/she was born. These women/couples wanted the child they felt they were

entitled to have. Whether women are coerced into thinking they must be mothers, or they must have a biological child or they must use NRTs to achieve this goal, did not play a role in these women's consciousness. They considered using PGD to be a choice they independently made and a procedure that allowed them to reach their goal. I realize as a scholar, I needed to weed out the invisible coercion and oppressive practices, although other scholars have done this quite well, however, these women have convincing arguments supporting their use of PGD as an autonomous choice. They are not docile women. They are highly intelligent, fiercely strong willed women committed to reaching their goal who took advantage of reproductive choices and individual freedom.

The second finding of this research that was apparent to me is that if embryos were not destroyed or discarded in the process of PGD, there would be no remorse about using the technology. The women/couples who regret their decision to discard their unused embryos were the most vehement in justifying their use of PGD. Their guilt over destroying their embryos remains prevalent in their minds several years after the procedure. If the decision about the fate of the embryos could be taken away from its users then using PGD would become less complicated.

The third finding of this research is that using PGD imposes many physical and emotional challenges upon its users whether a woman uses it to combat infertility or for sex selection purposes. Much of the procedure is carried out on the woman's body and she endures all the physical pain, and because of this she endures more of the emotional pain than her partner, however, both the woman and the man experience emotional pain while going through the process of PGD. The yearning to have their desired child is strongly felt by both the woman and the man, and both partners also feel the roadblocks getting to their goal.

This study adds to the literature on the cultural and social aspects of the new reproductive technologies in two important ways. The first contribution this research project makes is to the discussions about the social mediation of decisions made while using NRTs. Because PGD is the latest NRT, implications of the unique information gleaned from PGD became evident by comparing the use of PGD with the use of other NRTs. Knowing the genetic makeup of the embryo is information that had not been previously known. It creates an imperative to consider the embryo as a separate entity to the woman. The users of PGD must make a decision about the fate of their embryos. This decision reflects their values. By making this decision, they are making a bold statement about the value they assign to embryos. Some women/couples went against their values and later regretted their decisions. Is this any different than the experience women had when using other NRTs? Does using PGD pose any more challenging decisions than those required by using any other NRTs? The findings of this study indicate that there are similarities to the experience of using any NRT however, the unique information PGD provides regarding the embryo, as well as the timing the woman/couple receives the information, makes the decisions required by using PGD different than other decisions required of other NRTs.

The second contribution this research project makes is to the discussions about biomedical literacy. Is it necessary to understand a biomedical technology in order to engage in its use? What impact does not fully understanding the procedure have on the experience of using a biomedical technology? This project demonstrated that it was not essential to fully understand PGD in order to engage in its use and benefit from the technology. The women/couples that used PGD ascribed understandings and definitions of PGD as it related to their situation. They came to understand the technology as they went through the process, and even after completing their PGD cycle they still did not fully understand all the nuances of PGD.

Salient Aspects

I initially wondered why women/couples would use PGD. They were able to explicitly explain why they used PGD as they told their stories. I also realized that their stories made visible the trials and tribulations of using an NRT as well as illuminated what was made visible to them during the process of using an NRT. The infertile women/couples had no intention of using PGD initially because they did not know of its existence. These women/couples come to PGD with long, complicated fertility histories. The women either had multiple miscarriages or could not get pregnant after multiple tries using various modes of conception. Initially, these women/couples understand PGD only as it relates to their situation. The women/couples in this study who used PGD to rectify their infertility first heard about PGD from their physician. It was slipped into the explanation of their treatment regimen as part of the arsenal that could assist them in getting pregnant. The women who used PGD for sex selection/family balancing purposes came into their physician's office knowing about the procedure, fully intending to take advantage of the technology. Neither group of women/couples fully understood the complexity of PGD. They relied on their physician to guide them through the process.

The women/couples who used PGD to correct their infertility were not only using the technology to get a healthy child but they also looked to the technology to explain their infertility. Their infertility went against the image they had of themselves; a body that was fully capable of doing what "nature" had intended. They wanted answers that explained why they were not able to get pregnant and/or carry that pregnancy to term. PGD was the technology that was going to explain their infertility and take the blame away from them. It was hoped by these women/couples that PGD would provide order to a situation that felt out of control and chaotic.

Gathering information about PGD, as well as using PGD, contributed to that sense of order. When first introduced to PGD, women/couples went online to get more information. Many were ambivalent about whether the information they found online was helpful. The women/couples went to online sources to learn more about the issues that concerned them the most. They wanted reassurance that removing one or two cells from the embryo would not cause any damage to their child. They also wanted to learn about the long-term effects of the drugs the woman took throughout her PGD cycle.

The women/couples also used the Internet to research the success rate of their physician. The Center for Disease Control posts all assistive reproductive procedures and success rates of all facilities in the United States. The procedures are broken down by type and woman's age. Some of these women/couples chose their physician based on the clinic's success rate. The success rate also instilled confidence that the physician would rectify their infertility.

The success rate of the clinic where the physician practices also provides a level of assurance of return on the financial investment that the women/couples are making in their future. A cycle of IVF with PGD is quite costly. The financial burden is high and patients want the best chance possible that their investment will pay off. They want to hedge their bets toward a successful outcome because not only is the financial cost high but also the emotional cost is high. For many of the women, the emotional toll far out weighed the financial toll.

Many women felt isolated during their fertility treatment. They did not want to join support groups because they felt the groups would not meet their needs. One woman joined a group online and enjoyed reading posts of other women going through the same experience. All the women commented that the support from their husband was most important in helping them get through the procedure.

PGD requires its users to make many decisions. Some of the decisions have potential to be morally challenging because they require the users to determine the fate of their embryo/s. The women/couples who used PGD demonstrated an ability to change the status they assigned to their embryos throughout the process. When women/couples were in the early phases of their PGD cycle, all their embryos had potential to be their child/ren. It is during this phase that the women/couple assigned full human status to their embryos. Some women/couples reassigned the status of their extra embryos from full human status to being merely cells. When the embryos were no longer needed, removing the human potential label and reassigning the embryos as merely a group of cells made discarding palatable. Some women/couples later regretted their decision to discard their healthy embryos.

Many women/couples felt a sense of relief when their situation resulted in not having to make a decision regarding the embryos. No decision needed to be made when all the embryos available were transferred. The clinic where these women/couples were seen follows the embryo transfer guidelines developed by the American Society for Reproductive Medicine. In the cases where all the embryos were transferred, many of the women/couples were convinced that God interceded and took the difficult decision away from them. When there was a decision to be made, some women/couples were happy to acquiesce to the recommendation of their physician when it came to choosing among several embryos.

During the time the biopsy of the embryo occurred, the women were not physically involved in the process. That time, between the egg retrieval and the embryo transfer, is a time that the woman/couple could consider possible scenarios that may occur when it came time to decide which embryo/s to transfer. Many of the women/couples said they did not consider all the options that could occur regarding the embryos prior to the transfer because the range of

possibilities seemed to enormous to consider. They generally had an idea of the number of embryos they wanted to transfer and the gender. They gave little thought to the disposition of the extra embryos. In hindsight many women/couples said they had not realized that they had to make such an important decision in such a short amount of time. Discussing the possible options prior to the embryo transfer could have been helpful with the decision making process as well as reassured them that they had made the right decision. Some of the women and their partners confessed to regretting the decision they had made regarding the unused embryos. They said they try not to think of the issue regarding the disposition of the embryos as an ethical issue, however that is exactly what plagues them now that they have been successful.

Many women/couples did not meet with success on their first cycle PGD cycle. And some had previously gone through IVF without PGD unsuccessfully. All increased their agency with subsequent PGD cycles. The knowledge they gained from previous cycles, informed their decisions and involvement during each successive cycle. They attributed their success during a later PGD cycle to their increase in participation in planning their treatment regimen. When they met with a failed cycle, they started to question the integrity of their physician wondering if he was more interested in his financial gains then their success.

The relationship between the physician and the PGD user is complicated by a power struggle inherent in any physician and patient relationship. The women/couple struggled between their desire to be actively involved in planning the treatment regimen and being the acquiescent patient. They expressed a desire to be led and reassured by their doctor, but they also wanted to have ample input into their treatment. All parties needed to find the perfect balance to facility the best possible outcome from the treatment plan.

Once a woman became pregnant from using PGD, her pregnancy continued to be monitored by her fertility specialist for the first trimester. After that time, her obstetrician followed her through her delivery. Outward appearances of a pregnancy conceived through a PGD cycle looks exactly like a pregnancy conceived through coitus. Although no one else may know how the pregnancy was conceived, the pregnant woman knows how she conceived and her conception experience informs her decisions throughout her pregnancy.

One of the main ways her experience informs her decisions is by refusing to have an amniocentesis. Many of the women's obstetrician suggested she have an amniocentesis as part of her obstetric care. All the women given this option refused this test. Some understood the results of the amniocentesis to be redundant of the information obtained through PGD and therefore found the test unnecessary. Other women quoted the statistics on miscarriages after having an amniocentesis as a reason to refuse the test. They felt they had worked too hard to get pregnant and they were not about to take even the slightest risk of losing the baby. Some of the women also refused an amniocentesis because of the implications of the test. These women were not willing to have an abortion if the results indicated a problem with their fetus. They wanted the baby they were carrying regardless of its health, which indicates their use of PGD, was never about having a specific child other than their biological child.

As they were discussing their experience of using PGD, the women/couples were compelled to justify their use of PGD into their narrative. Their need for justification stems from the ethical dilemma associated with choosing and discarding embryos. They wanted to point out in their discussion that they chose to use PGD for altruistic reasons. Their decision was not only to have a child but also to insure the child would be healthy. Their use of PGD gave their child the best possible start in life. Their justifications served another purpose besides explaining why

their use of PGD was acceptable. Through their justification they dissociated themselves from the implications suggested by the “designer baby” moniker. The infertile women/couples justified their use of PGD by arguing that it was the only way for them to get pregnant and carry the child to full term. Also PGD gave their child the best possible potential for a healthy life. The behavior implied by the “designer baby” moniker was completely different than their own behavior and not something they would ever condone. The women who used PGD for sex selection/family balancing purposes justified their use by referring to God in their argument. They argued that God made man capable of creating this technology therefore it was justifiable for them to use PGD for their own purposes.

Many women/couples referred to having a sense of God’s presence throughout their experience of using PGD. Some equated happenings throughout the process as signs of God’s presence and others felt they were part of God’s plans. None of the women/couples relied on their religious doctrine to support them through their cycle. All identified as Christians, some specifically stated they were Catholic. Currently, the Catholic faith condemns the use of any NRTs.

PGD Contributions

Discussions about the use of PGD now join the conversations regarding the use of all other NRTs. These discussions have the distinction of adding a new characteristic to the decision making process for women who use NRTs. Prior to PGD, decisions based on genetic information were done while the woman was pregnant. These decisions were made based on the result of either an amniocentesis or chorionic villus sampling. The decisions were complicated because many women had experienced quickening and began to bond with their fetus prior to getting the results of these tests. The genetic information about the fetus was used to determine the fate of

the fetus. The implication of using these tests is that if the results indicate that the fetus is afflicted by a genetic disease then the woman would terminate her pregnancy. This caused great hardship for many women. PGD determines the genetic makeup of an embryo long before the woman is pregnant. At that point in time she has not had a bodily experience or connection with the embryo as she had with a fetus. Her decision making could be more closely related to a man's decision making because the material is outside her body. However, the findings of this research show that men and women still have different ideas about embryos and come to their decisions differently. Some women considered the impact the embryos would have on their life if brought to human form. They understood that they would be the primary caregivers to any children that would come from their embryos. A couple of the men had very strong opinions that their frozen embryos should be transferred and every attempt made to bring them to life. Their wives felt differently but were not as convinced about their own opinions as their husbands, so they acquiesced and are preparing to transfer their embryos. One woman said she would like to donate their frozen embryo to science and but her husband was adamantly opposed to that. Since his feelings were stronger than hers, she went with his decision. Two women vocalized their regrets about discarding their embryos but felt it was in compliance with their goals. Two other women did not express any regret about discarding their embryos and did not want to go into details about their feelings on the issue. There was no consistent pattern of behavior when it came to determining the fate of the embryos other than staying consistent to reaching their goal of having the child they desire and the reason they used PGD. The determination of the fate of the embryo for these women and men may be as much about the status they assign to the embryo as it is about the fact that it is outside of the woman's body. The manner in which Sienna and

Pierre refer to their embryos, “just chemistry” and “chromosome assembly” demonstrates their lack of attachment.

Prior to PGD, the fate of embryos was based on their morphology determined through visual analysis. Embryos that “looked” healthy were transferred to a woman’s uterus or frozen for future use. Although this method still led to the disposal of some embryos, it was not known if these embryos were truly healthy. Embryos that looked healthy may indeed be genetically unhealthy and have not resulted in a pregnancy. Also, the criteria for choosing embryos based on vision did not include gender. Knowing the gender of the embryos can complicate the decision-making process by possibly requiring a woman/couple to choose one gender over another.

There are four propositions that are offered when determining the fate of unused embryos. The embryos can either be frozen and a decision about their fate will have to be made at a later date, they can be discarded, donated to research, or donated to another couple to use for a transfer with the intention of a resultant live birth. Donating an embryo to research comes with the understanding that it will be destroyed. Therefore, donating an embryo to research as well as discarding an embryo can cause a moral dilemma for some women/couples. To ease the moral dilemma and following Hartouni’s concept of rescripting through the use of discourse, there may come a time when women and couples will find donating their embryos to research acceptable.

The embryos used for embryonic stem cell research come from fertility clinics. Women/couples could consider donating their embryos to research as an altruistic gesture. The value on human kind that embryonic stem cell research is purporting to provide in the future could justify the destruction of the extra embryos. This would not take the moral implications totally out of the decision making process for some women/couples, because the potential for their embryos to become human is extinguished. However, considering the potential good their

embryos may do for future medical procedures and other humans' lives may assuage the conscious of these women/couples.

Future Considerations

The information gleaned from the experience of these women/couples leads to future research projects from patient perspectives as well as researching possible future applications of PGD. Future uses for PGD are still unknown. Will the technology lead to gene manipulation? Will potential parents be able to choose the genetic makeup of their offspring by having their embryos' genes manipulated? Will the implications signified by the "designer baby" idiom come to fruition? It is unknown whether any of these scenarios will occur, but for now PGD is increasingly being used to assist infertile couples become parents by determining the genetic makeup of an embryo.

The embryo plays a key role in the success of a PGD cycle. Every effort is made to care for and discern the genetic makeup of the embryo from the time it is created until it is transferred back to the woman. The genetic makeup of the embryo implies its viability to become human. If the results are interpreted that the embryo is unhealthy, then it is discarded in a manner similar to the abortion of fetuses that were found to be genetically unhealthy through amniocentesis. A future research project might focus strictly on the status of the embryo by comparing it to the status of the fetus.

PGD "peers" at the embryo by determining the genetic makeup. Peering at a fetus occurred through the use of ultrasounds. The physician and pregnant woman saw pictures and videos of the fetus as it moved around in the womb. Human attributes were given to these movements such as the fetus was waving or jumping around like a preschooler. Through the process of "seeing" the fetus and assigning human attributes the fetus became personified. The

personification led to the obstetrician considering the pregnant woman as two patients, the pregnant woman and the fetus. The care of the fetus became privileged over the woman's care. Could human attributes be assigned to the embryo because of the knowledge of the genetic makeup, thereby leading to the personification of the embryo? Could the care of the embryo become privileged over the care of the woman? The embryo plays a very vital role in fertility treatment; if the embryo is not genetically sound then there is no hope for a pregnancy. Hartouni suggests the interest in embryos is already on the road to becoming public domain when she says discourses have recasted "embryos as public entities".³¹⁶ She goes on to say that the genetic "blueprint" within the embryo may breathe "new life into once-discredited notions that social ills can be traced to genetic errors."³¹⁷ Connecting human characteristics to genes can lead to the personification of the embryo. The personification of the embryo could become an unintended consequence of PGD.

PGD is still in its infancy stage of use and research. There are many aspects regarding the use of PGD that need to be investigated. Further studies could include researching the experience of women/couples who rejected the use of PGD. Their stories may illuminate the more offensive aspects of PGD as well as the alternatives. Another research project could include researching the experience of women/couples who did not meet with success after using PGD. They would have had to make the same decisions as the women and men who were successful. Would they say all the challenges of using PGD were "worth it"? Their perspective on the benefits of PGD may be quite different than those who met with success.

Originally, this research project was designed to be a comparative study between the use of PGD by couples in the United States and those who live in Ireland. Couples from Ireland must

316 Hartouni, *Cultural Conceptions*, 18.

317 Ibid., 18.

travel to another country to use PGD. Most Irish couples travel to England or Belgium for this procedure. Doing a comparative study between two different cultures would have highlighted the cultural influences throughout the process of PGD and pointed out the similarities and differences between the most salient aspects of using PGD between the women/couples from each country.

APPENDICES

Appendix A

Glossary of Terms

Aneuploidy - One or a few chromosomes above or below the normal chromosome number.³¹⁸

Balanced Translocation- See Chromosomal Translocation

Blastocyst- An embryo which has developed to a hollow ball of approximately 60-100 cells after 5 days in culture.³⁰⁵

Cervix- The lower section of the uterus which protrudes into the vagina and serves as a reservoir for sperm.³⁰⁵

Chromosomal Translocation- A condition where a fragment of one chromosome is broken off and attached to another chromosome.³⁰⁵

Egg Retrieval- A surgical procedure to obtain eggs from follicles in the uterus for use in IVF/GIFT cycles.³⁰⁶

Embryo- A multicellular diploid eukaryote in its earliest stage of development, from the time of first cell division until birth, hatching or germination. In humans, it is called an embryo until about eight weeks after fertilization, and from then it is instead called a fetus.³⁰⁷

Embryo Transfer- Placing fertilized eggs (embryos) back into the woman's uterus or fallopian tube.³⁰⁶

Fallopian tubes -are two very fine tubes lined with ciliated epithelia, leading from the ovaries of female mammals into the uterus.³⁰⁷

Follicles- Ovarian Follicles- The basic units of female reproductive biology, each of which is composed of roughly spherical aggregations of cells found in the ovary. They contain a single oocyte.³⁰⁷

Gametes- Is a cell that fuses with another gamete during fertilization (conception) in organisms that reproduce sexually.³⁰⁷ (The egg and sperm in humans.)

Genotype- The actual genes that encode for the characteristics seen in an individual, or the genetic make-up of an individual.³⁰⁵

Gestational surrogate - An arrangement whereby a woman agrees to become pregnant and deliver a child for a contracted party.³⁰⁷

318 <http://reproductivegenetics.com/glossary.html> (accessed 7/21/2010).

306 http://www.arcfertility.com/infertility/infertility_glossary.html (accessed 7/21/2010).

307 <http://en.wikipedia.org/wiki> (accessed 7/21/2010).

GIFT- Gamete Intrafallopian Transfer- A procedure whereby eggs are surgically ‘harvested’ from a woman and combined with washed specimen of husband or donor sperm and placed in the fallopian tubes.³⁰⁶

Glocophage- An oral diabetes medicine that helps control blood sugar levels.³⁰⁸

HLA type- Human Leukocyte Antigen tissue. For complete details of procedure refer to http://reproductivegenetics.com/hla_matching.html.³⁰⁹

HSG- Hysterosalpingogram- A diagnostic image of pelvic organs through a radiopaque dye injected into the uterus and fallopian tubes. A common procedure in initial pelvic evaluation.³⁰⁶

ICSI- Intra-Cytoplasmic Sperm Injection - A breakthrough technique where a single sperm can be microsurgically injected into the cytoplasm of an egg to develop into a fertilized embryo.³⁰⁶

IVF- In Vitro Fertilization - A procedure whereby retrieved eggs are fertilized with washed semen in a petri dish outside of the body and re-implanted into the uterus after successful fertilization.³⁰⁶

IUI- Intra Uterine Insemination - A fertility treatment that involves placing specially washed sperm directly into a woman’s uterus through a small tube.³⁰⁶

Meconium- is the earliest stool of an infant. Meconium is normally stored in the infant’s intestines until after birth, but sometimes it is expelled into the amniotic fluid prior to birth or during labor and delivery.³⁰⁶

Morphology of an embryo- form and structure of an embryo.

Phenotype- Observable characteristics of an organism produced by the organism’s genotype (the specific genes possessed by an organism) interacting with the environment.³⁰⁵

Stenosis- Is an abnormal narrowing in a blood vessel or other tubular organ or structure.³⁰⁷

ZIFT- Zygote Intra-Fallopian Transfer - A procedure whereby retrieved eggs are fertilized outside of the woman’s body and returned to her fallopian tubes.³⁰⁶

308 <http://www.drugs.com/glucophage.html> (accessed 7/21/2010).

309 http://reproductivegenetics.com/hla_matching.html (accessed 3/14/2011).

Appendix B

Research Participant Information and Consent Form

You are being asked to participate in a research project. Researchers are required to provide a consent form to inform you about the study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Study Title: A Comparative Study of the experience of using Preimplantation Genetic Diagnosis between the United States and Ireland.

Researcher and Title: Dr. Robert McKinley, Associate Professor, and Claudia Cassidy Bennett, PhD candidate

Department and Institution: American Studies Program, Michigan State University

Address and Contact Information: Ms. Bennett e-mail: benne272@msu.edu, phone number: 734-395-2305, regular mail: 117 S. Main Street, Ann Arbor, MI 48104. Dr. McKinley, phone number 517-353-2930 or regular mail at 116 Morrill Hall, East Lansing, Michigan 48824.

1. PURPOSE OF RESEARCH:

- You are being asked to participate in a research study regarding the experience you have had using Preimplantation Genetic Diagnosis. This study is being conducted collaboratively by Michigan State University in East Lansing, Michigan; IVF Michigan in Ann Arbor, Michigan, and Lister Fertility Clinic in London, England.
- You have been selected as a participant in this study because you have used PGD as part of your fertility treatment.
- From this study, the researchers hope to learn about the real life experience of PGD. The survey you will be asked to complete focuses on general demographics, opinions about PGD, the logistics of using PGD, and the decision making process. The personal interview will consist of open ended questions that will allow you to discuss your experience in more detail.
- Your participation in this study will take about 15- 20 minutes to complete an online survey and about an hour for a personal interview. The interview will be conducted at a time and location of your convenience.
- If you are under 18, you cannot be in this study without parental permission.

2. WHAT YOU WILL DO:

- You will be asked to complete a survey online and participate in a face to face interview answering questions regarding your experience with PGD.
- The interviews will be audio tape recorded and transcribed. The interviews will be held at your convenience. Ms. Bennett will contact you to arrange a convenient time for the interview and answer any questions you might have. At the completion of your interview, you may request a copy of the transcript.

3. POTENTIAL BENEFITS:

- You may not directly benefit from your participation in this study. However, your participation in this study may contribute to a better understanding of the needs of patients who use PGD.

4. POTENTIAL RISKS:

- The potential risk of participating in this study is associated with sensitive questions that may cause distress or discomfort. Remember, you may choose not to answer any questions on the survey during the interview and you may terminate your participation in this research project at any time. This will not affect the care you receive as a patient at your clinic.

5. PRIVACY AND CONFIDENTIALITY:

- The data for this project will be kept confidential to the maximum extent allowed by law.
- Although it may be useful to reproduce extracts from transcriptions from interviews and data from the surveys for the purpose of scholarly publication, no identifying details will be revealed. The very strictest levels of confidentiality will be maintained.
- Data with identifying information (patient consent forms) will be stored in a locked filing cabinet and kept separate from surveys and transcripts of interviews. All tapes will be erased once transcribed. All information stored on a computer will be password protected.
- Dr. McKinley, Ms. Bennett, and the Institutional Review Board will be the only people who have access to the data.
- The information collected on the online survey will be kept confidential. Survey results are sent directly to Ms. Bennett. IP addresses will not be collected.
- Due to federal regulations, data collected will be kept for at least three years.

6. YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW

- Participation in this research project is completely voluntary. You have the right to decline participation.
- You may also change your mind at any time and withdraw. You can simply stop filling out the survey or contact Ms. Bennett to cancel your interview.
- You may choose not to answer specific questions or to stop participating at any time. You may stop the interview at any time you feel necessary.
- Choosing not to participate or withdrawing from this study will not make any difference in
 - the quality of any services you may receive.
 - benefits to which you are otherwise entitled.
- You will be told of any significant findings that develop during the course of the study that may influence your willingness to continue to participate in the research.

7. COSTS AND COMPENSATION FOR BEING IN THE STUDY:

- You will not receive money or any other form of compensation for participating in this study. Nor will you incur any cost for participating in this study.

8. CONTACT INFORMATION FOR QUESTIONS AND CONCERNS

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researchers Claudia Cassidy Bennett at 734-395-2305 or email benne272@msu.edu or regular mail at 117 S. Main Street, Ann Arbor, MI 48104 and Dr. Robert McKinley at 517-353-2930 or regular mail at 116 Morrill Hall, East Lansing, Michigan 48824

If you have questions or concerns about your role and rights as a research participant, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 202 Olds Hall, MSU, East Lansing, MI 48824.

9. DOCUMENTATION OF INFORMED CONSENT.

Your signature below means that you voluntarily agree to participate in this research study.

I agree to participate in filling out the online survey. Yes _____ No _____ Initials _____

I agree to participate in a face to face interview. Yes _____ No _____ Initials _____

I agree to allow audio taping of the interview. Yes _____ No _____
Initials _____

Signature

Date

Print Name

Signature

Date

Print Name

Contact information:

e-mail address:

phone number:

address:

You will be given a copy of this form.

Appendix C

Preimplantation Genetic Diagnosis Survey (First Survey)

Preimplantation Genetic Screening (PGD) is a relatively new technology now being offered in conjunction with In Vitro Fertilization. This survey is designed to understand the experience of using PGD from a patient's perspective.

Age: _____,

Female _____, Male _____.

Marital status: single _____, married _____, with life partner _____, other _____.

Do you have a partner going through this experience with you? Yes _____, No _____

(Please have your partner fill out survey 2).

Education level completed: high school _____, undergraduate degree _____, graduate degree _____, post graduate degree _____.

Average household income: up to \$25,000 _____, \$26,000 - \$50,000 _____, \$51,000 - \$75,000 _____, \$76,000 - \$100,000 _____, \$101,000 - \$150,000 _____, \$151,000 - \$200,000 _____, greater than \$201,000 _____.

Profession: _____

What is your religious affiliation? _____

Do you currently consider yourself a practicing participant in your religion? Yes _____, No _____.

Reason(s) for using PGD (Check all that apply. If more than one, please rank in order of importance with 1 being most important and so on.)

- _____ Improve fertility
- _____ Decrease the risk of passing on a genetic disease
- _____ Tissue matching to create a donor sibling
- _____ Sex selection or family balancing
- _____ Decrease the chance of pregnancy loss

How did you hear about PGD?

- _____ Physician
- _____ Friend

- _____ Family member
- _____ Internet
- _____ Book
- _____ Support Group
- _____ Other _____

Why did you choose this clinic? (Check all that apply. If more than one, please rank in order of importance with 1 being most important and so on.)

- _____ Close to home
- _____ This clinic had the soonest appointment available
- _____ Physician referral
- _____ Reputation of clinic
- _____ Friend used clinic
- _____ Most cost effective
- _____ Other _____

How far did you travel to get to your PGD clinic? _____

Have you told any of the following people that you are using PGD?

| | Yes | No |
|------------------------|-------|-------|
| Your partner | _____ | _____ |
| Your parents | _____ | _____ |
| Your partner's parents | _____ | _____ |
| Friends | _____ | _____ |
| Your siblings | _____ | _____ |
| Your children | _____ | _____ |
| Religious leader | _____ | _____ |
| Colleagues | _____ | _____ |

Have you recommended PGD to anyone? Yes ____, No ____.

Have you recommended this clinic for PGD to anyone? Yes ____, No _____. If yes, how many people? _____.

| How much do you agree with each of the following statements? | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|--|-----------------------|--------------|----------------|-----------------|--------------------------|
| I knew I wanted to use PGD when I started with my fertility treatment. | | | | | |
| I followed my doctor's recommendation to use PGD. | | | | | |
| I did not know about PGD prior to meeting with my doctor. | | | | | |
| I felt I had no other choice but to use PGD in order to ensure the best possible outcome. | | | | | |
| I knew that by using PGD there was a possibility of having left over embryos that would not be used. | | | | | |
| I received professional counseling prior to making my decision to use PGD. | | | | | |
| I consulted other people before I decided to use PGD. | | | | | |
| Cost was not a factor in my decision to use PGD. | | | | | |
| I believe I made an informed decision. | | | | | |
| I would use PGD again. | | | | | |

Please tell us anything else about your PGD experience that you think would be helpful for this research project. Also, your comments regarding this survey would be greatly appreciated.

Thank you for taking the time to fill out this survey. Your participation in this research project is greatly appreciated.

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Appendix D

Preimplantation Genetic Diagnosis Survey (Second Survey)

Preimplantation Genetic Diagnosis (PGD) is a relatively new technology now being offered in conjunction with In Vitro Fertilization. This survey is designed to understand the experience of using PGD from a patient's perspective. For the purposes of this research project, we ask that both you and your partner fill out separate surveys.

Age _____, Female _____, Male _____.

Marital status: single _____, married _____, with life partner _____, other _____.

Do you have a partner going through this experience with you? Yes _____, No _____

Education level completed: high school _____, undergraduate degree _____, graduate degree _____, post graduate _____.

Average household income: up to \$50,000 _____, \$51,000 - \$75,000 _____, \$76,000 - \$100,000 _____, \$101,000 - \$150,000 _____, \$151,000 - \$200,000 _____, greater than \$201,000 _____.

Profession: _____

What is your religious affiliation? _____

Do you currently consider yourself a practicing participant in your religion? Yes _____, No _____.

How much time has passed since you used PGD? _____ months.

Reason(s) for using PGD (Check all that apply. If more than one, please rank in order of importance with 1 being most important and so on.)

- _____ Improve fertility
- _____ Decrease the risk of passing on a genetic disease
- _____ Tissue matching to create a donor sibling
- _____ Sex selection or family balancing
- _____ Sex selection for personal reasons
- _____ Decrease the chance of pregnancy loss

How did you hear about PGD?

_____ Physician

- _____ Friend
- _____ Family member
- _____ Internet
- _____ Book
- _____ Support Group
- _____ Other _____

Why did you choose this clinic? (Check all that apply. If more than one, please rank in order of importance with 1 being most important and so on.)

- _____ Close to home
- _____ This clinic had the soonest appointment available
- _____ Physician referral
- _____ Reputation of clinic
- _____ Friend used clinic
- _____ Most cost effective
- _____ Clinic's successful birth rate
- _____ Other _____

How far did you travel to get to your PGD clinic? _____

Have you recommended PGD to anyone? Yes ____, No ____.

Have you recommended the clinic you used for PGD to anyone? Yes ____, No ____. If yes, how many people? _____.

Have you told any of the following people that you used PGD?

| | Yes | No |
|-----------------------|-------|-------|
| Your partner | _____ | _____ |
| Your mother | _____ | _____ |
| Your father | _____ | _____ |
| Your partner's mother | _____ | _____ |

Your partner's father _____ _____

Friends _____ _____

Your siblings _____ _____

Your partner's siblings _____ _____

Your children _____ _____

Religious leader _____ _____

Colleagues _____ _____

| How much do you agree with each of the following statements? | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|--|----------------|-------|---------|----------|-------------------|
| I knew I wanted to use PGD when I started with my fertility treatment. | | | | | |
| I followed my doctor's recommendation to use PGD. | | | | | |
| I did not know about PGD prior to meeting with my doctor. | | | | | |
| I felt I had no other choice but to use PGD in order to ensure the best possible outcome. | | | | | |
| Cost was not a factor in my decision to use PGD. | | | | | |
| I knew that by using PGD there was a possibility of having healthy embryos which were not used. | | | | | |
| I knew that I would have to decide what to do with any unused embryos. | | | | | |
| I knew that I would have to decide which embryo/s to have transferred/inserted. | | | | | |
| Prior to the embryo transfer date, I considered all the possible scenarios that may occur regarding the decision | | | | | |

| | | | | | |
|---|-----------------------|--------------|----------------|-----------------|--------------------------|
| of which embryo/s to transfer/insert. | | | | | |
| How much do you agree with each of the following statements? | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| I followed my doctor's recommendations regarding which embryo/s to transfer/insert. | | | | | |
| I know the position my religion has on using PGD. | | | | | |
| I received counseling from a religious leader prior to making my decision to use PGD. | | | | | |
| I had no personal religious conflict using PGD. | | | | | |
| I consulted other people before I decided to use PGD. | | | | | |
| I received psychological counseling prior to making my decision to use PGD. | | | | | |
| I received genetic counseling prior to making my decision to use PGD. | | | | | |
| I primarily used online sources to learn about PGD. | | | | | |
| I believe I made an informed decision to use PGD. | | | | | |
| I plan to tell my child that she/he is a product of PGD. | | | | | |
| I plan to raise my child according to my religious beliefs. | | | | | |
| I would use PGD again. | | | | | |
| I am concerned that people may misuse PGD. | | | | | |
| I feel it is the responsibility of doctors | | | | | |

| | | | | | |
|--|--|--|--|--|--|
| to make sure PGD is not misused. | | | | | |
| I feel it is the responsibility of the people who use PGD for their fertility treatment to make sure PGD is not misused. | | | | | |

Please give us your ideas of how you think people could misuse PGD:

Please check all that apply:

_____ I had no unused healthy embryo/s as a result of my procedure.

_____ I had unused healthy embryo/s as a result of my procedure.

_____ The unused healthy embryo/s were discarded.

_____ The unused healthy embryo/s were frozen.

_____ I plan to use the frozen embryo/s in the future.

_____ I plan to donate the frozen embryo/s to research.

_____ I plan to allow another couple to use the frozen embryo/s.

_____ I plan to have the frozen embryo/s discarded.

_____ I do not know what I plan to do with the frozen embryo/s.

I thought the process of using PGD was ... (please use your own adjectives to describe your experience).

Please tell us anything else about your PGD experience that you think would be helpful for this research project.

Thank you for taking the time to fill out this survey. Your participation in this research project is greatly appreciated.

Any questions or comments regarding this survey can be directed to: Ms. Claudia Bennett at benne272@msu.edu.

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