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Pre-implantation Genetic Diagnosis and Selection: A Moral Vertigo

Pre-implantation genetic diagnosis (PGD), sometimes called embryo screening, is a process that was first developed in the late 1980s/early 1990s. It is a procedure that analyzes the DNA of recently fertilized embryos in women undergoing in vitro fertilization (IVF). The fertilized embryos are removed after about three days of growth and one or two cells are taken from each of the 5-10 cell blastocysts. (Greenbaum, King, and Shah) The cells are then either screened for chromosome abnormalities using florescent in situ hybridization techniques (FISH), or tested for certain genetic diseases using biochemical methods such as PCR. Only the healthy embryos are then reinserted into the mother in the hope that at least one will take, developing into a fully-grown fetus. PGD thus allows the selection for embryos that have, or lack, a certain genotype. While this technique was originally developed in order to prevent pregnancies that lead to babies with disabling, debilitating, or even lethal genetic diseases, PGD has opened the door to the creation of “designer babies,” where clinicians and parents can work together to select the gender and/or traits of the embryo so as to have the exact child they want. This process is termed pre-implantation genetic selection, or PGS. Combined, PGD and PGS are quite a controversial topic and there is much debate over the ethics and use of such procedures.

There are numerous arguments both for and against PGD and PGS, centering on the ethics, the negative ramifications (both realized and hypothetical), the costs, and the benefits of such practices. One of the main arguments regarding the ethics and morality of PGD and PGS relates to the idea of seeking mastery over nature. Though many would say that this argument is based solely on a religious foundation, the concept of PGS conjures up a feeling of uneasiness in

both believers and non-believers alike. That being said, it is true that there are people who maintain that only God has the right to choose our traits, be it something as important as our gender or something as minute as our eye color. PGD and PGS give doctors the power to “play God,” and control who is born and who is not, who gives birth to a boy and who gives birth to a girl, who has one set of traits and who has another. The prolife standpoint plays a role in this argument, for the belief that you are a human being from the moment of fertilization suggests that the choice to reinsert some of the embryos and discard others is a case of infanticide. Yet, the concept of seeking mastery over nature is one that transcends religion and prolife arguments. It speaks to the core of many individuals’ ambitions: the desire for perfection. While PGD puts control in the hands of doctors as to which embryos survive, PGS takes the process to an entirely new level. It allows doctors and parents to choose the traits of their offspring, selecting for anything from eye color to height to genes suggested to correlate with certain talents. PGS leads to the creation of “designer babies.” With the creation of these offspring with enhanced features and talents, the fear is that our society will become one in which the value of personal achievement is diminished, for our appreciation for achievement will be directed towards the clinician who selected for such traits rather than the individual themselves. In his paper entitled “The Case Against Perfection,” Michael Sandel argues that PGS reflects a “Promethean aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires.” He argues that it is not necessarily the mechanism itself that is flawed, but the underlying desire for mastery. Sandel says, however, that such a “promise of mastery is flawed. It threatens to banish our appreciation of life as a gift, and to leave us with nothing to affirm or behold outside our own will.” Thus, this fear of the negative consequences of our innate desire to seek perfection and mastery, combined with a moral conflict with the practice in general, leads many to stand against PGD and PGS.

Discrimination is also at the core of the ethical argument against PGD and PGS. Some clinics will allow parents to choose the sex of their baby, a process called sex selection. Only the embryos with the desired gender are reinserted into the mother. Though there are cases of mothers choosing a girl simply because they have only been able to give birth to sons, in many cases sex selection is an instrument of sex discrimination, typically against girls, as the unsettling gender ratios of China and India reflect. (Sandel) Some speculate that the tendency to select for boys will lead to less stable societies that are characterized by violence, crime, and general political and social unrest. (Sandel). Because sex selection can often be a form of discrimination, it is illegal in many countries, including China, India, Germany, the United Kingdom and Canada. Sex selection is also banned by the European Convention on Human Rights and Biomedicine. (Greenbaum, King, and Shah) Sex selection is, however, legal in the United States, though many clinics will not allow a patient to have pre-implantation genetic screening simply for gender selection. Discrimination also plays a role in PGS when couples select for other traits besides gender. Oftentimes, couples will select for genes associated with height or skin color, favoring some traits over others and discriminating against phenotypes such as certain skin types. There are even some people who argue that PGD is a form of discriminating against those with genetic diseases, suggesting that their lives are worth less, or not worth living at all. Therefore, the discrimination factor plays a role in the argument against the use of PGD and PGS.

A third argument against PGS in particular is called the autonomy argument. It suggests that by choosing a child's genetic makeup in advance, parents deny the child's right to an open future. (Sandel) Children will become bound by the traits that their parents choose for them, thereby being forced in a certain direction without the freedom to define themselves. This argument, however, is not very strong, for it wrongly implies that without a parent designing

their offspring's traits, kids are free to choose their traits for themselves. In reality, none of us gets a choice; whether it is our parents choosing our traits or nature at work, we are bound by certain genetic constraints. Even without PGS, we are all "at the mercy of the genetic lottery." (Sandel) Thus, though some use the principle of autonomy to argue against the use of PGS, the argument ultimately does not get to the core of the issue. It merely suggests that we can now place the blame on our parents for our being given, or not given, certain talents, as opposed to blaming nature.

In addition to the ethical implications and negative consequences of PGD and PGS, the cost of such procedures serves to fuel the debate. IVF itself is very expensive, costing about \$3,500 per cycle, (IVF often requires multiple cycles due to its success rate of only 10-35%). In the U.S., PGD/PGS can add \$2,000-\$5,000 to this per cycle cost. ("Fertility Proregistry") The key question is who should pay for these costs. Should the government pay, using tax money as funding? Should insurance companies pay for part, or all, of the procedure costs? Or should the funding come entirely from the patient? As of now, there are some insurance companies that will cover a portion of the costs for PGD, but there are no companies that will pay for PGS, and many insurance companies will not even pay for PGD. There are benefits that the government and insurance companies get by paying for PGD, for if a mother at high risk for having an unhealthy fetus gives birth to a baby with a genetic disease requiring constant treatment and care, these institutions will be the ones covering a great deal of the expenses. Thus, there are incentives for the government and/or insurance companies to cover costs of PGD. Not everyone has access to insurance, however, and the fact of the matter is that PGD and PGS will always be more easily accessible to the wealthy. This inequality of access to such procedures suggests that, perhaps in the future, genetic diseases will become the stigma of the lower socioeconomic classes. (Botkin)

This brings up the issue of genetic equality and whether it is fair to maintain a procedure that gives a small portion of society the ability to have children free of genetic diseases. This argument is often rebutted, however, with the fact that wealthier people already tend to have healthier children due to their increased access to and ability to pay for healthcare. Therefore, the fact that not everyone has equal access to PGD and PGS does not necessarily mean that these procedures should be banned.

Yet another criticism of PGD and PGS is that the actual procedure itself, namely the process of removing the embryos from the mother, extracting cells, and then reinserting the desired embryos, can be harmful to the embryos. Having been growing for only about three days, the embryos are at a very delicate and crucial stage of development when they are removed from the mother for PGD/PGS. The physical disturbance that the procedure entails can interfere with or alter future growth and development of the embryo, which could ultimately result in future problems for the child after birth. (Greenbaum, King, and Shah) Though this possibility of harm to the embryo is not yet entirely understood, it is certainly a concern raised in the debate on the use of PGD and PGS.

Despite the numerous arguments that are raised in objection to PGD and PGS, these procedures, especially PGD, do have some important benefits. PGD can prevent debilitating diseases, thereby providing children the ability to live healthier lives, as well as preventing the stress, costs, and hardship that often greatly affect the families of those with genetic diseases. There are some who argue that we owe our children a “decent chance at a good life,” while there are others who argue that the only reason to select an embryo through PGD would be in instances where the potentially diseased child would be better off not being born at all. (Greenbaum, King, and Shah) Yet, despite whether one believes that we should prevent all genetic diseases or simply

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those that are extremely debilitating or lethal, one cannot argue with the fact that PGD leads to the birth of healthier children who have a better chance at living normal, long, fulfilling lives.

PGD also relieves the psychological burden of having an unsuccessful IVF, miscarriage, or abortion. A large percentage of the instances of unsuccessful IVF or early miscarriage (in both IVF and non-IVF patients) are due to chromosome abnormalities or other genetic problems with the fetus. This chance of miscarriage due to a genetic abnormality is further increased in women over thirty, and especially high in women over age forty. Having a miscarriage can have negative psychological affects on the mother, or the couple in general. The effects can often be quite severe and last for an extended period of time, leading to problems such as depression and a fear of trying to have a baby again. Similar psychological affects can occur after a mother, or couple, chooses to terminate the pregnancy mid-term. Today, doctors can perform multiple tests using techniques such as chorionic villus sampling (CVS) or amniocentesis at about four months' gestation. These tests screen for chromosome abnormalities and genetic diseases, and can inform the mother on the health status of her baby. These tests are invasive, however, and can sometimes lead to a spontaneous miscarriage. Furthermore, many couples choose to terminate the pregnancy if they discover that their fetus has a severe genetic disease or abnormality. Receiving such devastating news and choosing to have an abortion after having been pregnant for many months can be very tough psychologically, and can result in similar symptoms as previously mentioned for miscarriages and unsuccessful IVF. PGD reduces the number of miscarriages and abortions due to genetic abnormalities with the fetus, and thereby prevents such a psychological burden and trauma. Additionally, in response to the prolife argument against PGD, many will argue that PGD is justified for it prevents the abortions that would occur once the fetus is much more developed, after a couple receives a positive test for a genetic abnormality at about four months'

gestation. Thus, they argue, it is better to discard embryos that are only a few days old rather than terminate a pregnancy at four months.

Finally, PGD gives more couples the opportunity to have healthy kids. As previously mentioned, women over a certain age are at a much higher risk for having a baby with a chromosome abnormality or genetic disease. Couples in which the potential mother and father are both carriers for a certain genetic disease, or in which just one parent is a carrier if the disease is autosomal dominant or sex-linked, are also at high risk for having an unhealthy fetus. PGD allows these couples that might otherwise not try to have children, or get pregnant and then end up having a miscarriage or terminating the pregnancy, the opportunity to have a healthy child. Thus, PGD provides such couples that might not be able to have healthy children on their own, the chance to have a normal family.

It is clear that there are numerous pros and cons to the controversial PGD and PGS procedures, and it is difficult to outline the exact solution or plan of action that should be taken with regards to banning, continuing, or regulating such procedures. In Greenbaum, King, and Shah's paper on PGD, they uphold that PGD confers too strong of a benefit to society to be banned, and that governmental regulation of such a novel practice would "chill" the procedure in the United States and force couples to look internationally for similar, yet possibly less-developed and more risky, procedures. Thus, the authors suggest that a series of tests should be established to allow doctors and clinicians to better regulate how they use PGD and to whom they provide the service. Doctors and clinicians would evaluate each couple on a case-by-case basis, using two factors as their guide: the scientific reliability of the test and the ethical implications of providing the test. This proposed solution suggests that PGS should not be provided to any couples, and that PGD tests should take into account the information known on

the inheritance of the genetic disease in question. Mendelian diseases, such as Tay Sachs, Huntington's disease, Sickle Cell Anemia, and Cystic Fibrosis, are much easier to diagnose than non-Mendelian diseases, due to their simple patterns of inheritance, (the gene is either dominant or recessive). A vast number of diseases, however, do not follow simple patterns of inheritance and can be difficult to diagnose. For example, in many diseases one's genotype only influences the probability of developing the disease, as opposed to being a concrete indicator that one will get the disease. Genome-wide association studies (GWAS) can help increase our understanding of the correlation between certain genes (SNPs) and the probability of getting a specific disease. Greenbaum, King, and Shah propose that PGD clinics should only test for diseases with concrete patterns of inheritance or for genes whose correlation with a disease is quite strong, and has been substantiated by a multitude of reliable GWAS. Furthermore, the clinics should fully inform parents about the gene they are testing for so as to prevent them from developing unrealistic expectations of a disease-free child. This proposed solution thus works to maintain PGD while reducing possible ethical concerns.

I believe that PGS should not be legal, for it uses an expensive, and possibly harmful, technique to allow parents to selfishly design their baby to their hearts' content. That being said, however, in my opinion PGD is a procedure that is beneficial to society and should not be banned. It provides more couples with the ability to have healthier children and reduces the prevalence of debilitating diseases in our society. It also reduces the number of abortions that occur mid-term and relieves the psychological burden that many couples face after having a miscarriage, or terminating a pregnancy, due to a genetic abnormality in the fetus. I am concerned, however, that PGD is currently not well regulated, which could pose problems for those who seek PGD, as well as for our society as a whole. I believe that healthcare programs,

either through insurance companies or through the government if one cannot afford insurance, should cover some of the costs of PGD in couples at a high risk for having a child with a debilitating genetic disease. For those who want to undergo PGD to test for less severe genetic diseases, or simply just in case they might have a child with some sort of genetic disease, I believe that they should have to pay for the procedure themselves, or convince their private insurance to cover some of the costs. I do not necessarily agree with Grennbaum, King, and Shah that government regulation of PGD would prevent it from providing a positive service to our society. Yet, I find their proposed solution to be reasonable, mitigating as best as possible the ethical concerns that many have with the procedure.

Ultimately, PGD and PGS are, and will most likely remain, quite controversial topics and I believe that it is important to inform the government, scientists and doctors, and the public as a whole, on the numerous pros and cons of the issue so that the procedures can be regulated in the best way possible. In my opinion, however, PGD and PGS are simply the tip of the iceberg of issues in science and medicine that will lead to a host of ethical dilemmas and debates. As Sandel wrote in his paper, we have reached a point where “science moves faster than moral understanding,” leading to a “genomic revolution [that] has induced a kind of moral vertigo.” It is therefore imperative that we approach the new scientific and medical techniques arising from our ever-expanding knowledge of the human genome with caution, making sure to fully understand the ethical implications and consequences that they could have on our society. **Bibliography:**

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