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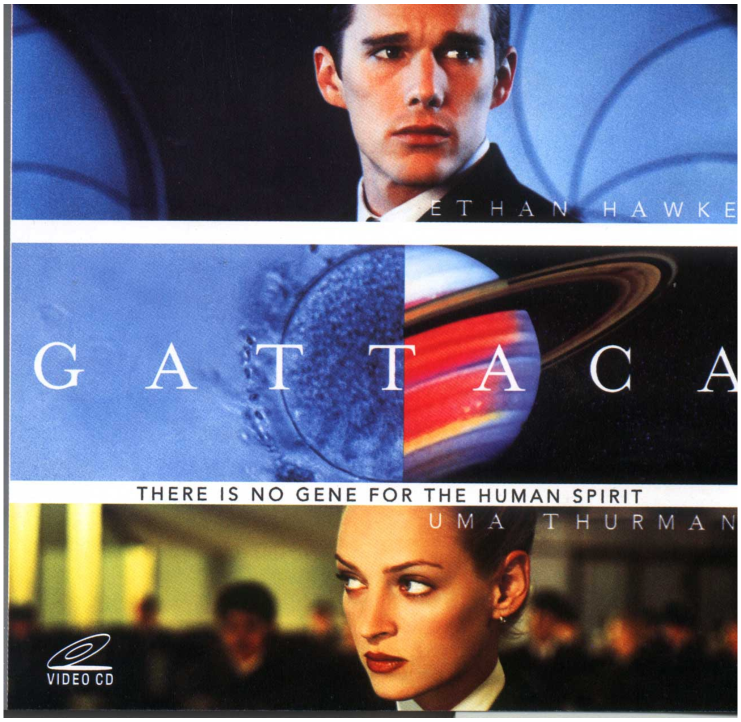
The Ethical Case Against the Use of Preimplantation Genetic Screening for Non-medical Enhancement



Introduction

Assisted reproductive technology for humans, namely in vitro fertilization (IVF), has been in existence since the late 1970s.[5] Since then, scientists have developed two technologies that aim to maximize the outcomes of IVF treatments.[4] Preimplantation genetic diagnosis (PGD), introduced in 1990, is a technology in which the embryos of couples known to be at high risk for a genetic disease are tested for the specific genetic disorder.[7] Only the unaffected embryos are transferred for implantation, thus ensuring that the children are at low-risk for developing the disease.[7] Currently, this technique can be used to prevent the implantation of embryos having at least 103 different inherited genetic disorders and chromosomal abnormalities, including cystic fibrosis, sickle cell anemia, and Huntington disease.[1] Preimplantation genetic screening (PGS), on the other hand, first used in 1995, aimed to improve pregnancy rates in subfertile couples who did not necessarily carry a known familial risk of genetic disease, by screening embryos for aneuploidies, which were thought more likely to result in failure of implantation or spontaneous miscarriage.[7,2] Recent studies have shown however, that there is no evidence of a beneficial effect of screening for aneuploidy in PGS on the live birth rate after IVF.[7] Instead, PGS has become a technology that allows parents to select for specific traits in their offspring.[6]

As our knowledge of the human genome increases, it will be feasible to select for things such as sex, height, IQ, susceptibility to disease, skin and hair color, personality traits, and much more. I remember watching *Gattaca* in my high school biology class, thinking that this piece of science fiction was far ahead of our time, and now only a few years later, it has become a pending reality.[8] What began as an attempt to prevent genetic disorders, has now become an instrument of genetically designing children. In the following paper, I hope to make a case against the use of genetic technology for non-medical enhancement, explaining the difficulty in making such a distinction, and exploring the possible repercussions of the free-market bioengineering of our children. I argue that the social implications of non-medical genetic enhancement are far too overreaching compared to the superficial gains that we would stand to achieve.

The use of PGS to prevent genetic disability

It is highly rational that parents would have a preference for their child to live a life without a debilitating medical condition, especially one that is potentially preventable.[1] Currently, in vitro fertilization with preimplantation genetic diagnosis (PGD) for couples with a known high-risk for certain genetic disorders would be the proactive choice in ensuring this for their children. If my argument is that preimplantation genetic testing (PGT) should only be utilized when medically relevant, the question then becomes what we consider to be a disability warranting intervention. Is it one that guarantees a shorter lifespan or is it one we subjectively deem to result in a lower quality of life? For example, while most people will readily agree that Huntington's disease, a disease that is both physically debilitating and leads to premature death, is a medical condition that should be avoided if at all possible, other conditions are not so clear cut.[1] What may be seen by many as a disadvantageous medical condition, may be seen by others as a socially desirable trait.[5] Take for example, deafness. While some people believe that deafness is a disability, others believe it to be an identity and not some medical affliction that needs fixing.[9] The subjectivity of the term disability is one that blurs the line between a condition necessitating medical intervention and a condition we simply deem inferior due to social conventions.

On one extreme, some ethicists argue that the only reason to select an embryo through PGD would be cases in which the potentially diseased child would be better off not being born.[5] I myself am uncomfortable with this statement as it suggests a value judgment of non-existence and any state of life. On the opposite end of the spectrum, the author of "The Case for Mandatory Preimplantation Genetic Selection" broadened the use of PGS to include the prevention of any type of "suffering," which he defined as "physical pain and psychological distress by victims of particular diseases” or “unhappiness” in which those afflicted with the condition would be happier without it.[1]

I personally am of the belief that PGT should be used to prevent conditions in which most patients afflicted with the condition are actively seeking medical treatment and are deemed by the government to be eligible for medical disability assistance. With this definition, things like sex, short stature, poor athletic ability, or cosmetic traits would not be justified for use of PGS. I believe PGT should only be used when the child’s health is at stake.

Interesting medically relevant case

Upon my research, I found an interesting case of performing PGD that challenged my conviction that PGD should only be used when the child’s health is in question. PGD can be used for couples who already have a child with a disease and want to conceive another child who can be used as a donor for their sick sibling.[5] Termed “savior siblings,” PGD is used to ensure the embryo is disease free and also to determine that the new child will be an optimal donor, principally through HLA typing.[5] In this case, the embryo will receive no perceivable medical benefit but the health of their sibling may be improved.[5] It becomes even more difficult to decide whether it is ethical as the level of invasion required of the donor sibling becomes higher, for example, a low invasive procedure such as using discarded umbilical cord blood versus donating an organ that requires invasive surgery.[5] In my opinion, the use of PGD is justified in this case because it confers an improvement of health, even if it is the health of someone else other than the child in question. However, I think it is important that in the cases that require invasive procedures, the donor sibling must be given a choice and deemed eligible to lawfully consent.

Reproductive autonomy and procreative beneficence

Julian Savulescu proposed two principles of reproductive ethics called reproductive autonomy and procreative beneficence.[9] Reproductive autonomy is the freedom of parents to make decisions regarding their reproduction.[9] In this respect, if abortion is allowed for any reason in a society, then women should be allowed to deny certain embryos with PGS, be it low intelligence, lack of a musical talent or short stature that prevents sport play, in favor of their genetic preferences.[11]

Procreative beneficence states that parents have a moral obligation to "select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information."[1] With procreative beneficence, the use of reproductive technologies for the avoidance of disability is not just acceptable, but even necessary, in order to fulfill the duty of a responsible parent.[1]

With these two principles, the use of PGS is justified for any reason the parents deem necessary, including those that are merely for enhancement. For this paper, I shall define enhancement as selecting for characteristics that would result in a non-medically-related improvement above average that would confer the individual an advantage. The distinction between utilizing genetic technologies for medically relevant cases versus enhancement is an important one because one restores a child to normal human function while the other aims to give the child an advantage.[10]

One could argue that in the autonomy of choosing a mating partner on the basis of above-average attractiveness, intelligence, and/or athletic ability is in a sense choosing a superior genetic pool from which one's children will be conceived, conferring the child an advantage over their peers.[10] Similarly, the proponents of enhancement, such as selecting for athletic ability or superior intelligence, argue that genetic engineering is no different to the heavily managed child rearing that is common now.[11] They argue that conferring advantages on their children through supplemental help, such as expensive schools, private tutors, basketball camp, piano lessons, SAT-prep courses and so on are no different to conferring an advantage through genetic engineering.[11] I agree with Sandel, author of "The Case Against Perfection," who argues that this similarity does not vindicate genetic enhancement but instead highlights the problem of hyperparenting.[11]

The case against sex selection

The use of preimplantation genetic testing for sex selection is medically relevant if it is utilized as a way to avoid passing on serious sex-linked diseases found in families at risk for these types of disease.[6] In cases of X-linked Mendelian recessive diseases, female embryos are selected because males need only one mutant X allele for the disease to occur, making it more likely that this male child will be afflicted by disease.[6] In cases of multi-factorial, non Mendelian disease, such as autism, Lupus, and mental retardation, the incidence differs markedly depending on sex, warranting a selection of the low-risk embryo, be it male or female.[5] However, in cases where the potential for sex-linked diseases are not present, the question for sex-selection becomes the justifying the use of a medical means for a non-medical end.[11] Most choose sex selection for social reasons, particularly citing "family balancing," where parents of children of one sex desire a child of the opposite sex.[12] The idea of creating an ideal family with a specified sex distribution of children based on the personal preference of the parents, is undistinguishable from sex discrimination.[12] When using PGS for sex selection, one sex is inherently valued over the other.[12] Particularly in societies that traditionally place a powerful preference towards male offspring, prime examples being India and China, one sex has the potential to be discriminated against, either by an individual basis or society as a whole.[12] In India and China, abortions of female fetuses are not uncommon and embryo sex selection is illegal.[5] The danger with sex selection in societies like these, in addition to sex discrimination, is the potential to skew sex ratios to an extreme.[6] The Stanford School of Medicine, an institution that performs PGD, contends that notwithstanding rare cases, PGD should not be used for gender screening.[5]

The case against superficial traits

Physical traits, such as body height, and cosmetic traits, such as hair color, eye color, and skin pigmentation, are determined by multiple gene and single-nucleotide polymorphisms.[6] With the recent advancements in genetic technology, it is now technically feasible to provide preimplantation genetic testing for these complex human traits.[6] The Stanford School of Medicine, an contends that notwithstanding rare cases, PGD should not be used for superficial trait (i.e. hair or eye color) screening.[5] In contrast to sex selection, where there may be a medically relevant reason for determining sex, the selection of superficial traits marks a complete departure of PGS from the medical realm.[6] As mentioned previously, the question we must ask ourselves is what justification exists of using medical means to achieve non-medical ends? If allowed, the selection of these aesthetic traits will not confer any benefit to the child's health. If one agrees with the principle of procreative beneficence or justifying PGS to prevent "suffering" or "unhappiness," one could argue that being short and unattractive could cause psychological harm and since attractive people tend to be more successful than their unattractive peers, superficial trait selection with PGS is justified.[1,9] However, the problem with that reasoning is that it embodies and exacerbates our societal preoccupation with the superficial. Similar to my argument against sex selection, discrimination against certain traits will likely ensue.

The danger with allowing such control over superficial traits is the potential of creating "designer babies."[6] The critics of genetic engineering argue that utilizing PGS for enhancement and creating "designer babies" is nothing more than "free-market" eugenics.[11] Those in favor of genetic enhancement argue that in the absence of coercion, freely made genetic choices are not really eugenic in the pejorative sense.[11] While it seems noble that eugenics aims at the improvement of society's genetic composition, I again am uncomfortable with the judgment we must make in order to achieve a superior genetic pool, valuing certain traits over others. Additionally, if we all subscribe to the same ideals of superior humans, we stand to lose a great deal of human diversity.

Consumerism run amuck

Currently the cost of undergoing PGD embryo screening is about $18000 dollars.[10] The sizeable cost of the procedure brings up questions of accessibility.[10] If enhancement through genetic technology is allowed, the wealthy will be given an additional edge through biotechnology over their poor counterparts.[10] This would serve to only widen the gap that currently exists between our nation's wealthy and poor.[10] Sandel commented on the unfair nature of having our nation's poor be not only economically impoverished, but also exaggerating the difference by having them genetically impoverished as well.[10]

The problem with "free market" eugenics, aside from the inherent problem with eugenics, is that it concedes to regarding our children as commodities.[10] Instead of accepting children as they come and unconditionally loving them as is the traditional role of the parent, conception based on consumerist ideals suggests children can be made into products that are tailored to meet our preferences and expectations.[10]

The effect of enhancement on children

The film *Gattaca* envisions a future world where genetic engineering is commonplace and designer babies are routinely ordered.[8] In the world of the film, the naturally conceived are discriminated against for being genetically inferior to those who were genetically engineered.[8] If the use of biotechnology in genetic selection becomes as widespread as it appeared in the film, it is logical to assume that a similar situation will occur in our society.

Additionally, this quest for genetic perfection will undoubtedly place an unprecedented amount of pressure on children, even more so than the extremely competitive environment they live in today. If children are genetically enhanced for certain traits such as athletic ability or athletic prowess, there would be an increased pressure for them to utilize their enhancements.[10] In this way, designer children will never be truly free and instead may be viewed as instruments to fulfill their parents' dreams.[10]

Conclusion

In his work *The Future of Human Nature: On the Way to Liberal Eugenics,* Habermas contends that widespread use of legal preimplantation genetic testing will inevitably lead from "practices concerned with preventing the transmission of severely disabling conditions to practices aimed at optimizing a child's makeup."[1] The incredible advancements in the field of genetics in the recent decades have presented our society with both a gift and a moral dilemma.[11] On one hand, we are able to treat and prevent a wide variety of debilitating medical conditions.[11]

On the other, we have this profound knowledge that could potentially enable us to manipulate our very nature, from our intelligence to our athletic ability to our personalities to our appearance and more.[11] Simply because we have the ability does not necessarily mean we should use it. I think Sandel said it best when he stated that science was moving faster than our moral understanding.[10] Sandel also speaks of the Promethean aspiration to remake and conquer nature to serve our purposes and satisfy our own desires.[10] I think the problem with allowing PGS for non-medical selection is that it speaks more about our desire to have our children fulfill our preferences and become instruments of our own ambitions, rather than focusing on ensuring a healthy future for our children.[10]

References

1. Appel, J. "Toward an Ethical Eugenics: The Case for Mandatory Preimplantation Genetic Selection." JONA's Healthcare Law, Ethics, and Regulation. January/March 2012, 14(1): 7-13. http://www.ncbi.nlm.nih.gov/pubmed/22367014
2. Checa, M., et al. "IVF/ICSI with or without preimplantation genetic screening for aneuploidy in couples without genetic disorders: a systematic review and meta-analysis." J Assist Reprod Genet. 2009 May; 26(5): 273-283. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2719075/
3. Diekema, D., et al. "Clinical Ethics in Pediatrics: A Case-Based Textbook." http://books.google.com/books?hl=en&lr=&id=C1T6NrSPD_AC&oi=fnd&pg=PA68&dq=preimplantation+genetic+screening+ethical&ots=9_4lKoHPgf&sig=1Zw1J3I7HtzhyoVlb742Q4sM4zo#v=onepage&q=preimplantation%20genetic%20screening%20ethical&f=false
4. Ginsburg, E., et al. "Use of preimplantation genetic diagnosis and preimplantation genetic screening in the United States: a Society for Assisted Reproductive Technology Writing Group paper." Fertility and Sterility, October 2011; 96(4): 865-868 http://www.sciencedirect.com/science/article/pii/S0015028211022552
5. Greenbaum, D., et al. "Preimplantation Genetic Diagnosis: Scientific and Ethical Considerations." https://mail-attachment.googleusercontent.com/attachment/u/1/?ui=2&ik=ccea47946d&view=att&th=13b590250783c09b&attid=0.1.3&disp=inline&safe=1&zw&saduie=AG9B_P9lOgfQayeWv1HlcHo666zP&sadet=1354942270848&sads=e6PsgHfVMw4OfdFhVbQZaFSr2J4

6. Lau, E., et al. “Preimplantation Genetic Testing: Current Status and Future Prospects.” http://cdn.intechopen.com/pdfs/35170/InTech-Preimplantation_genetic_testing_current_status_and_future_prospects.pdf

7. Mastenbroek, S., et al. “Preimplantation genetic screening: a systematic review and meta-analysis of RCTs.” Hum. Reprod. Update 2011; 17(4): 454-466. http://humupd.oxfordjournals.org/content/17/4/454.full

8. Niccol, A., et al. “Gattaca.” Special ed. Culver City, Calif.: Sony Pictures Home Entertainment, 2008. http://searchworks.stanford.edu/view/7593698

9. Parker, M. “The best possible child.” J Med Ethics 2007 May; 33(5): 279-283. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2598117/

10. Sandel, M. “Michael Sandel: Genetic Engineering.” Forum with Michael Krasny. May 7, 2007. http://www.kqed.org/a/forum/R705070900

11. Sandel, M. “The Case Against Perfection.” April 2004. The Atlantic Monthly. https://mail-attachment.googleusercontent.com/attachment/u/1/?ui=2&ik=ccea47946d&view=att&th=13b590250783c09b&attid=0.1.1&disp=inline&safe=1&zw&saduie=AG9B_P9lOgfQayeWv1HlcHo666zP&sadet=1354942257857&sads=PjSjLqliQmEZv8nECaD3j4OrK8E

12. Talbot, M. “Jack or Jill? The era of consumer-driven eugenics has begun.” March 2002. The Atlantic Monthly. http://www.theatlantic.com/past/docs/issues/2002/03/talbot.htm

13. Wang, C., et al. “Ethical, legal and social implications of prenatal and preimplantation genetic testing for cancer susceptibility.” RBM Online. 2009; 19(2): 23-33. http://web.ebscohost.com.ezproxy.stanford.edu/ehost/pdfviewer/pdfviewer?sid=40184b23-c620-46c1-971f-1dc5909b00ec%40sessionmgr13&vid=2&hid=11