Journal of Child Neurology
2015, Vol. 30(5) 547-550

DOI: 10.1177/0883073813511151
jcn.sagepub.com
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Ethical Challenges in Assisted Reproduction: The Place of Preimplantation Genetic Diagnosis in a Just Society

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Abstract

The purpose of this article is to provide an overview of preimplantation genetic diagnosis and identify the relevant moral questions it raises. In the course of this discussion, the scope of parental rights and the inherent difficulty in defining disease/disability will be considered.

Keywords

preimplantation genetic diagnosis, ethics, designer babies

Received August 28, 2013. Received revised September 26, 2013. Accepted for publication October 07, 2013.

Advances in the field of genetics seem to provoke our collective anxieties more than in any other scientific discipline. It is difficult to accurately assess the merits of novel reproductive technologies when terms like ''designer babies'' and ''genetic engineering'' are misused to distort a thoughtful dialogue. Fertility clinics do not genetically engineer ''designer babies,'' an unsavory term now catalogued in the *Oxford English Dictionary*. The term is frequently used by the media (to the great dismay of researchers) and is generally meant to convey the idea of children customized to meet the whims of parents. Selecting embryos that are free of certain diseases is possible, but scientists are far from having the capability to design an infant to any realistic specification. The ethical questions raised by the possibility of ''designer babies'' are spurred by a technique known as preimplantation genetic diagnosis, which is the focus of this paper.

Preimplantation genetic diagnosis is a technique that can only be used in combination with in vitro fertilization. After 3-5 days, typically when embryos reach the 8-cell stage, 1 or 2 cells are removed for testing. Preimplantation genetic diagnosis can determine sex as well as diagnose embryos with certain genetic diseases, or screen for chromosomal abnormalities. Preimplantation genetic diagnosis ranges in accuracy from 90% to 98% depending on what is being tested for. Because only 1 or 2 cells can be evaluated, the cells may not be representative of the entire embryo, which is referred to as mosaicism.[1] This is why the accuracy to determine Alper syndrome, for example, may be lower than determining sex.

Hundreds of genetic conditions can be tested using preimplantation genetic diagnosis, including Huntington disease, Duchenne muscular dystrophy, Fragile-X syndrome, and cystic fibrosis. Parents may seek preimplantation genetic diagnosis if they have a family history of genetic disorders, if they have unexplained pregnancy loss, or if they have a history of trisomies or monosomies.[2]

The idea behind preimplantation genetic diagnosis is not a new one. Humans have historically tried to select favorable traits for their offspring on the basis of partner selection. The social sciences have shown that when it comes to reproduction and the next generation, we pair with those who appear genetically healthy.[3] But the genetic lottery is capricious. In other words, looks can certainly be deceiving.

Choosing a partner with desirable physical and mental traits with no predispositions to major heritable diseases is an acceptable strategy. Likewise if someone attempts to choose the sex of their child by following a special diet, or by adhering to a calendar method to increase one's chances of having a boy or girl.[4] But preimplantation genetic diagnosis is now able to take some of the guesswork out of this endeavor and this is creating some intractable problems.

Historically, the primary goal of preimplantation genetic diagnosis has been to ensure a ''healthy'' fetus. By screening for embryos that are chromosomally normal and free of certain

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genetic diseases, fewer embryos need to be implanted, which lowers the risk posed by a multifetus pregnancy. Preimplantation genetic diagnosis also reduces the need for termination in the second trimester because embryos with disease would have been discarded at the outset. It also allows for exclusion testing where a parent may know they are at risk of a particular genetic condition—early-onset Alzheimer, for example—but do not want to know their own status.[5] Exclusion testing simply ensures that the implanted embryo is free of the affliction, but it does not address the parent's status. Sex selection was originally offered with preimplantation genetic diagnosis to avoid passing along sex-linked disorders, although it has evolved to also include sex selection for "family balancing." Having said all this, though preimplantation genetic diagnosis should increase the odds of implanting a "healthy" embryo, prenatal testing is still the standard of care and recommended to confirm its findings.

Discussion

There are a number of moral objections to preimplantation genetic diagnosis. One is rooted in the religious doctrine that considers embryos as persons, deserving the rights and protections afforded to all people.[6] According to this argument, creating embryos (persons) in which some will necessarily be destroyed, frozen, or donated to research, is morally illicit. Perhaps the most disturbing observation is that the use of this technique resonates with eugenics ideology.[7] The United States has a shameful history of sterilizing marginalized individuals or those who were thought to be a drain on society. This included Native Americans, African Americans, and the mentally ill, among others. Even those who do not have a theological objection to preimplantation genetic diagnosis may still reject the technology on secular grounds that it advances a genetic aristocracy.

Those who support preimplantation genetic diagnosis may address the religious objection by regarding the embryo as a cluster of cells that has the potential to become a person, but does not deserve special protections yet.[8] Others may propose the alternative view that we owe future persons the best life possible, and we have a moral obligation to use this technology to avoid passing on a debilitating heritable disorder (Tay Sachs disease, for example).[9] This perspective asks why we would subject children to disease that could be prevented? After all, we attempt fetal surgery to correct conditions in utero—why inflict such risk if it could be avoided?

Supporters of preimplantation genetic diagnosis further explore a particular paradox. Most parents, when asked, admit that all they really want is a healthy baby and will go to great lengths to achieve it. Pregnant women (usually) take prenatal vitamins, abstain from alcohol and tobacco, modify their diets, exercise, etc. Women who deviate from promoting fetal health are typically criticized or subjected to social pressures. This perspective would hold that it is hypocritical to reject preimplantation genetic diagnosis because we have already made a value judgment that healthy fetuses are preferable to unhealthy fetuses, and mothers who do not take measures to promote fetal/neonatal health are irresponsible. Further, statistics show (in some regions in the United States) a 90% termination rate based on the presence of Down syndrome.[10] Because preimplantation genetic diagnosis would ostensibly prevent Down syndrome (among other conditions), reduce terminations in the second trimester, and help ensure the healthy baby parents already hope for, this view would hold that it can be regarded like any other medical intervention.[11]

Though there seems to be no way to make preimplantation genetic diagnosis palatable to those with theological objections, perhaps there is a place for it without having to fully embrace a eugenics ideology. For those looking for compromise, the American Medical Association's code of ethics states it is "unethical to engage in selection on the basis of non-disease related characteristics or traits."[12] Accordingly, preimplantation genetic diagnosis could legitimately be used to prevent disease but not to select for eye color or hair color or even family balancing.

Though theoretically satisfying, this argument quickly becomes untenable because defining disease is ultimately a social construct, and what is socially undesirable is often cast in terms of illness.[13] For example, homosexuality was listed in the *Diagnostic and Statistical Manual of Mental Disorders* as a disease until the 1970s. Slaves were said to suffer from drapetomania, a mental illness that caused them to flee their owners. In addition, we are on a clear trend toward overmedicalization where we readily pathologize, diagnose, and treat conditions that previously would have simply been regarded as variations on normal behavior. Those who consume energy drinks may be at risk for "caffeine intoxication," which is now classified as a mental illness.[14] This expands our concept of disease and makes it quite difficult to set limits for the use of preimplantation genetic diagnosis.

It is easy to talk about sweeping categories of disease and conclude that preimplantation genetic diagnosis should be used to prevent them. Conditions like Krabbe disease and Lesch-Nyhan may stand as good examples. But what if the embryo carries trisomy 21, or cystic fibrosis—do these conditions cause such misery that screening to prevent such life is legitimate? What does it say to those individuals who currently have such conditions—are they socially devalued members of society if we determine that we want to screen our future embryos to avoid those conditions? Will funding to those programs that help the disabled be reduced if there is the option to have used technology to prevent them? Will parents be forced to use preimplantation genetic diagnosis if they are labeled as "carriers" and what are the implications for procreative liberties?

Equally troubling is screening embryos for genes that predispose one to disease but are not 100% penetrant, such as the *BRCA* genes, or for conditions that are truly devastating but might not afflict one for 30 years, like early-onset Alzheimer or Huntington disease. Is a good life determined only by longevity, or can one have a shorter but meaningful life? One might respond that we are faced with a multitude of hardships in life, why not use preimplantation genetic diagnosis to give a fetus

the best possible start? Again this forces us to examine what we mean by ''health'' and who is the ultimate arbiter of determining what is meant by ''normal.''

Additional thorny questions surrounding preimplantation genetic diagnosis involve nonmedical sex selection, donor siblings, and what constitutes culture versus disability. When nonmedical sex selection was offered in the United States, many feared that couples would use it to overwhelmingly choose boys. But in fact, there has been a small preference for girls.[15] Most fertility clinics only offer nonmedical sex selection for family balancing, which means only parents with a child can choose to balance the next child with the opposite sex. Sex selection is not typically offered in the United States as an option for first-time parents. Sexual discrimination may not be a problem in the United States, but this is clearly not the case in countries like India and China where female babies are regarded as less valuable.[16]

Parents can now use preimplantation genetic diagnosis to select an embryo to be a match for a sick child—sometimes called donor siblings or savior siblings.[17] The moral questions involve whether it is legitimate to create and use someone for the benefit of another, and to what degree parents can consent the donor child to undergo medical procedures that may involve some elements of pain or discomfort. The debate over donor siblings seem to be less contentious if a dying child can be saved through the use of a donor sibling's cord blood or other noninvasive measures. Less clear are cases when the donor child will be asked to donate tissues or whole organs.[18]

Another more hotly debated area of preimplantation genetic diagnosis involves the limitations of what parents can reasonably ask for when screening their embryos. The deaf community has made the argument that deafness is not a disability but a matter of culture. There tends to be a general resistance to cochlear implants for deaf children when the parents are also deaf. This has led some deaf parents to request preimplantation genetic diagnosis to screen and implant only congenitally deaf embryos.[19] The same argument has been extended to those with achondroplastic dwarfism. Although some have called it the ''deliberate crippling of children,'' others have cited parents' procreative liberty to maintain their community and reject the label of disability given by society.[20]

Conclusion

The broader concern is that nonmedical sex selection, donor siblings, and using preimplantation genetic diagnosis to promote cultural cohesion are all clear departures toward screening for what we said we do not do earlier in this paper: designer babies. This will create some very difficult questions as we learn more about the human genome and when parents may eventually have the option to select for an array of nonmedical advantages, including happiness, artistic ability, sexual preference, attractiveness, height/weight, life span and intelligence, among others.

In addition to questions of parental rights, the inherent difficulty in defining disease, and the role of eugenics in this debate, is that preimplantation genetic diagnosis is expensive. It can average between $4000 and $7500 per cycle above the basic cost of in vitro fertilization, which starts at $12 000 and can exceed $80 000. This has caused some to question whether or not we are commodifying embryos and if such a prohibitively expensive technology would be accessible to all.[21] Society could become more stratified between the wealthy/healthy and the other socioeconomic levels that would disproportionately be affected by disease. We ought to carefully consider these moral complexities now. Regulations and public policy guidelines should be implemented while the technology is in its relative infancy. There is currently little oversight in this rapidly changing area of assisted reproductive technology, which has the ability to dramatically impact our humanity.

Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

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