

The Ethics of Pre-Implantation Genetic Diagnosis in Practice: An Analysis of the Feasibility and Ethical Considerations of Applying and Regulating Genetic Enhancement

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Résumé :
(traduction)

Le diagnostic préimplantatoire (DPI) compte de nombreuses applications pour entreprendre une thérapie et pour augmenter le potentiel humain. Dans un article précédent, j'ai présenté des arguments en faveur de tous les types de DPI, qu'il s'agisse de traitements médicaux ou d'interventions pour augmenter le potentiel humain. Ces arguments étaient fondés sur l'absence de distinction morale entre la thérapie génique et l'amélioration génétique.

Par conséquent, si on ne peut établir de distinction entre la thérapeutique et l'amélioration génétique sur le plan moral, on ne pourra définir le caractère moral des applications du DPI qu'en fonction de leur processus et non de leur finalité. Bien que cet argument semble logiquement vrai, on croit qu'il est possible et nécessaire de faire une nette distinction, sur un plan pratique, entre ce qui est moralement admissible et ce qui ne l'est pas, dans le cadre des applications du DPI à des fins d'amélioration génétique.

Afin de bien faire cette distinction, cet article passe de l'analyse de la substance morale du DPI en tant que technologie à l'étude des agents moralement concernés employant le DPI. En tant qu'êtres humains, nous sommes probablement à la fois responsables et peu fiables sur le plan moral en tant que consommateurs du DPI : ce qui constitue la base de la délimitation de pratiques acceptables en matière du DPI.

Mots-clés :

la bioéthique, la fécondation in vitro, le diagnostic préimplantatoire, l'amélioration génétique, le biolibéralisme.

Abstract:

Pre-Implantation genetic diagnosis (PGD) has many therapeutic and enhancement applications. In a previous work, I presented arguments in favour of all types of PGD, whether for medical therapies or human enhancement. These arguments were based on the absence of moral distinctions between genetic therapy and genetic enhancement.

The implication of these arguments is that, if one cannot distinguish between therapy and enhancement on moral grounds, then all PGD applications must be either moral or immoral. Although logically speaking this argument may be true, in practice I believe that it is possible and necessary to draw a line between what is morally permissible and what is not with respect to applications of PGD for genetic enhancement.

In order to draw this line, I move away from analyzing the moral substance of PGD as a technology and focus instead on the moral agents that will employ PGD. As humans, I believe we are both morally accountable and morally unreliable as agents for the use of PGD, and this feature forms the basis of the delineation of acceptable PGD practices.

Keywords:

bioethics, in vitro fertilization, pre-implantation genetic diagnosis, genetic enhancement, bioliberalism.

Pre-implantation genetic diagnosis (PGD) is a genetic screening practice associated with *in vitro* fertilization (IVF) of human ova. At the morula stage of embryonic development, the embryo consists of a ball of genetically identical cells, and the removal of one for PGD allows genetic profiling of the embryo without doing it any harm. Negative selection (NS), or the discarding of embryos containing undesirable alleles, is currently being performed in IVF clinics for diseases such as Huntington's, Tay-Sachs and cystic fibrosis (Purdy, 1996; Abraham, 2012). Positive selection (PS), or the selection of embryos that *do* contain a *desirable* allele, is another application of PGD and is most commonly employed today for sex selection (Abraham, 2012).

In a previous work, I presented arguments in favour of all types of PGD (Bleeker, 2013). I first presented a summary of the support for NS, which I will summarize in the following paragraphs. For debilitating, painful or life limiting diseases, NS, or 'gene therapy' (GT) is an attractive technology because it prevents suffering of the unborn child and distress of the parents (Abraham, 2012; Glover, 1984). It is also supported by a variety of bioethicists according to various theories (Tooley, 1972; Purdy, 1996; Thompson, 1971; Singer, 1974), but both NS and PS (called 'genetic enhancement' or GE) of embryos likely resonates best with the bioliberalism philosophymore specifically, a subset of bioliberalism, called transhumanism. Transhumanists argue that genetic selection of embryos could benefit the future individual by improving physical wellbeing, intelligence, emotional stability and resiliency to stressors. To a transhumanist, the failure to use such technologies would be a failure to move humanity forward (Roache & Clarke, 2009). Overall, GT of embryos is favourable to many Canadian families, and there is increasing interest in PS by parents as well (Abraham, 2012). Given the current stance of the Supreme Court of Canada, which prohibits PS of embryos for sex and GE in general, American and Canadian parents have shown willingness to participate in medical tourism in Mexico, where IVF clinics will provide sex selection during PGD (Abraham, 2012). There is not, however, widespread support for PS of GE by Canadians or Americans (Roache & Clarke, 2009; Bostrom & Savulescu, 2008). This presents a dilemma when addressing policy decisions about regulation of PGD applications in Canada – policy should reflect moral rightness as well as provide Canadians with local, safe health care options.

In a previous work, I explored the moral distinction between GT and GE (Bleeker, 2013). In order to find GT morally permissible, but not GE, one must make some moral distinction between the two selection types. My exploration found that such distinctions were weak, and the logical implication of weak distinctive arguments between GT and GE is that we must either accept both or accept neither (because they are morally equivalent). Despite the equivalence logic, I

do believe that a line can be drawn between acceptable and unacceptable PGD practices, and I believe that this line is a practical one that can be determined by the analysis of PGD regulation strategies. Through such analysis, I believe it is possible to draw a conclusion in support of some GE in practice that has satisfactory applicability in medicine today. For example, GE can be used to improve psychological resiliency, resistance to chronic diseases and infectious diseases, and absence of allergic or autoimmune conditions.

An important theme in this discussion will be policy and regulation that can be used to guide the application of PGD technology, and whether such regulatory needs preclude the moral integrity of GE. There is thus one last important assumption to point out: I will assume that, in any given situation, the law would favour the "moral winner." This is obviously not the reality, but it will allow me to assume that certain practices *would* be executed lawfully as long as they were deemed morally sound, and thus provide arguments based on their effect on society.

GT is accepted on the basis of duty to prevent pain and suffering, and due to the moral rightness of practices, even those that are genetic, restore baseline human functioning. GT has subsequently been proven to be indistinguishable from GE. Arguments that claim that GE is either a purely selfish parental wish, a form of eugenics comparable to the Nazi regime, or an evil process that will perpetuate immoral sex selection have proven to be weak. It is also unlikely that we can rely on our intuitive repugnance to GE to guide debate of its morality (Bleeker, 2013).

Where does that leave us? Is bioconservatism a worthless moral attitude when applied to GE by PGD? Are we to adopt the opposite view, transhumanism, and enforce all forms of GE using PGD? Before defending my own conclusions to this impasse, I would like to present one final argument made by bioconservatives. I believe this argument to be the most important in influencing my conclusion because it shifts the perspective of the debate. Instead of assessing the objective morality of GE using PGD, it addresses the more subjective consideration that must be made of the moral agents who will be applying it. It also addresses the pervasive theme of regulation, and demonstrates how the need for regulation reflects the questionable morality of the agents, and not of the technology itself.

Much of the bioconservative philosophy, in addition to its concern with intuitive repugnance, attacks GE on the basis that it threatens a certain "humanness," or human dignity (Bustrum & Savulescu, 2008; Vallor, 2009). Although the debate about human dignity is an interesting one, I have chosen not to include it in this essay. I have found that debates

about human enhancement often look beyond PGD as germ line genetic alterations and human cloning become ever more tangible, and are therefore largely outside the scope of this debate. The idea proposed by the bioconservatives that does influence PGD specifically, and which I think is relevant to the current debate, concerns not the process of GE itself, but the virtue of the moral agents who will be responsible for executing the enhancement. As Shannon Vallor describes, the bioconservative position rests in large part on a “deep uncertainty about the intellectual ability and moral will of today’s humans to transform themselves wisely and well... do we today possess the extraordinary ambition, moral imagination and prudential insight needed to wisely and effectively implement such a radical program?” (Vallor, 2009, p. 41). The pessimistic answer, she says, is that our actions have proven that we are lacking the virtue – the ability to dependably think and act morally – to use technologies such as PGD in a moral way, regardless of whether it is moral or not (Vallor, 2009). We need look no further than the genocide, rape, sex slavery or terrorism that go on today to feel compelled to deeply distrust at least some people with the power of selecting embryos for enhancement reasons (Roache & Clarke, 2009). What bodes worse for human virtue is our apparent inability to learn from our mistakes. A major resistance to GE using PGD lies, as we have seen, in our deep desire to avoid anything related to Nazi Germany. Transhumanist philosopher Nick Bostrom describes it as a defence mechanism set against repeating the history of genocide (Bostrom, 2005). To me, however, this argument is weak. It is difficult to feel convinced that we have assimilated anything at all from our past experiences if we stood by and allowed history to repeat itself less than fifty years later in Rwanda (Bostrom, 2005). Where was our defense mechanism then?

Such doubt in the quality of human virtue leads to apprehensive thoughts about the employment of PGD for GE. As Vallor recognizes, however, an anti-GE resolution is not appropriate either, for current doubt can neither be “rejected on the grounds of cynicism alone, as transhumanists have done” nor “confirmed by mere intuition” as many bioconservatives would prefer (Vallor, 2009, p. 41). This, says Vallor, leaves the debate at an impasse until either hypothesis can be proven – thus also resulting in an impasse on application of PGD for GE.

With respect to the morality of the procedure itself, the debate has been progressing steadily in the defense of the moral soundness of GE using PGD. When considering its application, Vallor’s arguments lead us to an unsatisfactory deadlock. Although unrelated to the morality of GE itself, the human virtue debate is intimately tied to this discussion due to the fact that PGD relies on moral agents for its execution. An impasse like this is of no use to applied ethics, which seek to guide practices that are already happening. Wise decisions

about policy need to be made now, and we cannot afford to risk the consequences of waiting until the impasse is resolved. The last question I must ask is this: is there some way to resolve the impasse without concluding that GE is a lost cause, that its morality has been undone by its moral agents? In other words, is it possible to apply a morally sound procedure in such a way as to constrain its misuse, or should we reject the entire idea?

Bioliberalist Jonathan Glover proposed an attractive formula for implementation of GE that preceded articulations of uncertainties about humans as moral agents such as those of Vallor. Firstly, it acknowledged the distinction between the morality of GE itself and of its moral agents. Secondly, it gave some merit to our intuitions about PGD while also accommodating their transient nature. Thirdly and most importantly, it provides a practical solution to the virtue impasse and GE application.

Glover supports the GE procedure on the basis that it is morally indistinguishable from GT and on the basis that it will benefit humanity (Glover, 1984). Although bioconservatives have argued that human intuition against GE proves its immorality, these intuitions prove to be poor in logic and usefulness (Bleeker, 2013). Glover and other philosophers since him do, however, echo Vallor’s concern about moral agents and their threat to the applicability of an otherwise moral enhancement procedure (Glover, 1984). As Thomas Baldwin describes in his review of Glover’s work, for example, “the trouble lies not with techniques for enhancement...but with a society’s commitment to equality” (Baldwin, 2006, p. 673). As much as our intuitions can be problematic, the human relationship to a procedure like GE should not be completely discarded when it comes to our virtue as moral agents. Where does that leave us with regards to implementation of GE?

Perhaps the dogma “optimism in principle, caution in practice” (Baldwin, 2006, p. 673), is the best way to summarize the two mutually crucial components of GE implementations; in other words, the dogma of acceptance not only of the morality of the GE procedure, but also that constraints may be necessary to protect against the poor virtue of its human agents. As with other new or powerful technologies such as virus engineering, geo-mapping or social media, I believe that regulation of GE applications is not only appropriate, but it is necessary if we are to benefit from such powerful (and otherwise morally sound) technologies while restricting their exploitation by those of poor virtue.

I recognize the disadvantage of implementing regulations: one has replaced the problem of power given to a morally suspect humanity with power given to a morally suspect few. Who will enforce the regulations? More importantly, who will decide which to enforce? These questions could be

answered in the cynical perspective of the virtue debate. We could say that it is doubtful if *any* body of power will prove to have moral virtue, and that the powerful few will exploit GE in immoral ways, and that all potential for GE to benefit humanity will be lost.

One of Glover's central points in his analysis of GE implementation is that the demand for caution does not necessitate an outright ban on enhancement (Fost, 2004). Acknowledging regulation as a necessary concession does not preclude the possibility that PGD is both moral and beneficial to humanity (discussed in detail in another work) (Bleeker, 2013). Should we destroy all the viral vectors we are developing for the delivery of drugs because centralized bodies restrict its use for biowarfare? Should we destroy all communication satellites because regulation of their application is necessary to protect privacy? Should we destroy all forms of social media because a powerful few can restrict its use for pornography, pedophilia or hate crimes?

If the risk of undesirable outcomes were enough to stop a technology from going forward, we would see little innovation, as most new technologies come with risks (Fost, 2004). Recall that even libertarians such as Nozick are willing to cede some autonomy in exchange for a rights-based regulation system (Glover, 1984). As there are appropriate, rights-based regulations in place for satellite or internet use, there must be some appropriate version of regulation available for PGD. I propose that regulations should be considered, but only in 2 ways: 1) as an equalizing force, and 2) to prevent rights abuse. In the first case, regulation would not favour one outcome or another but may flip flop in its trajectory depending on the ratio between two outcomes, the perfect example being the sex ratio equalizing regulation proposed by Nozick (Glover, 1984). In the second case, our decisions could mimic existing rights-based legislature for other technologies. In addition, it could include Glover's suggestion that centralized bodies exist only to enforce regulations, and to act as veto in otherwise public decisions about the legislature (Glover, 1984). This democratic implementation of PGD regulations would both reflect the public's current pessimistic intuitions about human virtue and provide flexibility for gradual changes in our intuitions (Glover, 1984).

Luckily, in the case of PGD, there are several biological laws that will regulate the progression of PGD in a cautious and gradual way. To start, allowing parents to select embryos with the intent of enhancing their children will not produce unbridled enhancement of children born through PGD, nor will it produce an extreme phenotypical enhancement in one generation. There are two forces behind this. First, PGD does not create genetic material *de novo*, and is thus limited by the available genetic material. A woman has a limited number of eggs. As genes are added to the list of desired phenotypes, the

probability that any one embryo will contain them all decreases exponentially. Second, an embryo that was selected because it has a gene linked to increased height will not produce a 7-foot person. Mendelian traits, or phenotypes that are linked to only one gene, are rare (Abraham, 2012). The majority of our traits are the products of several genes interacting with each other and with the environment in complex ways, and so the effect that GE using PGD will have on progeny will be limited to Mendelian genotypes (Abraham, 2012).

In summary, a combination of Glover's principles and biological limitations provides a very practical way forward from the transhumanist-bioconservative impasse. GE using PGD is morally indistinguishable from GT using PGD. Limiting its use is illogical, especially while we simultaneously use GT for the benefit of humanity. GE implementation need not produce inequality, whether socioeconomic, gender-based or rights-based. Despite the absence of rights-abuse, change in human intuitions may come slowly, but I believe that taking a libertarian but cautious approach in the application of GE using PGD would facilitate that adjustment process and provide us with concrete experiences on which to critically evaluate our intuitions. Based on historical examples of novel ideas about technology and human social structures, a shift in our moral compass and an acceptance of its benefits seems entirely possible if we employ appropriate regulation and implement GE gradually.

References

- Abraham, C. (2012, January 7). Unnatural selection: Is evolving reproductive technology ushering in a new age of eugenics? *The Globe and Mail*. Retrieved from <http://www.theglobeandmail.com/life/parenting/unnatural-selection-is-evolving-reproductive-technology-usher-in-a-new-age-of-eugenics/article1357885>
- Baldwin, T. (2006). Book review: The chosen child. *European Molecular Biology Organization Reports* 7(7), 673.
- Bleeker, H. (2013). The ethics of pre-implantation genetic diagnosis. *Revue interdisciplinaire des sciences de la santé - Interdisciplinary Journal of Health Sciences*, 3(1), 31-45.
- Bostrom, N. (2005). A history of transhumanist thought. *Journal of Evolution and Technology* 14(1), 1-30.
- Bostrom, N., & Savulescu, J. (2008). *Introduction chapter* (1-22) from *Human Enhancement*. Oxford, United Kingdom: Oxford University Press.
- Fost, N. C. (2004). Conception for donation. *The Journal of the American Medical Association* 291(17), 2125-2126.

Glover, J. (1984). Questions about some uses of genetic engineering. In Kuhse, H. and Singer, P. (Eds.), *Bioethics: An Anthology* (pp. 187-198). Malden, MA, USA: Blackwell Publishing.

Nussbaum, M. (2004). *Hiding from humanity: Disgust, shame, and the law*. New Jersey, USA: Princeton University Press.

Purdy, L. M. (1996). Genetics and reproductive risk: Can having children be immoral? In Kuhse, H. and Singer, P. (Eds.), *Bioethics: An Anthology* (pp. 115-122). Malden, MA, USA: Blackwell Publishing.

Roache, R., & Clark, S. (2009). Bioconservatism, bioliberalism, and the wisdom of reflecting on repugnance. *Monash Bioethics Review*, 28(1), 1-21.

Savulescu, J. (1999). Sex selection: The case for. In Kuhse, H. and Singer, P. (Eds.), *Bioethics: An Anthology* (pp. 145-150). Malden, MA, USA: Blackwell Publishing.

Singer, P. (1974). All animals are equal. In Kuhse, H. and Singer, P. (Eds.), *Bioethics: An Anthology* (pp. 568-578). Malden, MA, USA: Blackwell Publishing.

Thompson, J. J. (1971). A Defence of abortion. In Kuhse, H. and Singer, P. (Eds.), *Bioethics: An Anthology* (pp. 40-51). Malden, MA, USA: Blackwell Publishing.

Tooley, M. (1972). Abortion and infanticide. In Kuhse, H. and Singer, P. (Eds.), *Bioethics: An Anthology* (pp. 25-40). Malden, MA, USA: Blackwell Publishing.

Vallor, S. (2009). Enhancement technologies and human dignity: On the virtue of transformation [Abstract].

Proceedings of The Society for Philosophy and Technology: Converging Technologies, Changing Societies, p. 40-41. Retrieved from <http://www.utwente.nl/gw/wijsb/archive/Archive%20activities/spt2009/programme/proceedings.pdf>