Chapter 26
The Ethical and Legal Analysis of Embryo Preimplantation Testing Policies in Europe

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Introduction

In reflecting on regulations for assisted fertility, the law has proven to be a double-edge sword. On one hand, it has repeatedly made attempts to restrict the application of certain contested techniques, and, on the other hand, it has provided a tool to remove existing obstacles to a wider range of other technologies that had been available only to a select few and thus involved some form of discrimination. As a result, new groups of individuals can claim access to assisted reproduction and to the use of preimplantation genetic diagnosis (PGD). So the question emerges: can the law still shape the contours of legitimate uses of this technology? What kind of ethical principles can guide lawmakers and judges to develop grounded responses to the new demands for technology? This chapter will analyze some recent legal debates, the practice of the European Court of Human Rights, and will make an attempt to explore the current legal frontiers of the technology of assisted reproduction.

One of the main questions that have to be raised is what could be the new tool for an ethical and legal assessment of selective reproduction? Should postnatal, prenatal, preimplantation selection be assessed differently? Should the technology—or just the outcome—matter? Can parents simply desire to have children like themselves (even with disabilities) or like a previously born sibling (savior sibling)? Should embryos be screened routinely? And, if yes, should prenatal screening be based on some major serious health conditions, or on all possible testable human traits? In this chapter, I would like to map the contours of this new field by showing what happens if claims referring to the quality of eggs, sperm, and embryos are

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advanced within the preexisting legal framework. My main thesis is that legislators and courts should avoid two traps: First, they should avoid personalizing human body parts and gametes and using simply human rights language uncritically. The other trap would be to accept the property law approach and treating gametes and embryos as commodities.

The advantage of analyzing judicial cases can be found in their limited focus: thus, an otherwise complex theoretical debate is distilled down to one or two questions which specifically concern the parties. These are the questions to which the judge has to apply already agreed-upon legal principles or, in rare cases, to develop new principles to supply the lack of previously available principles. A further element of judicial cases is that judges have to use the apparatus of legal interpretation, including clear and consistent legal categories such as person and body, and to allocate rights, such as the right to privacy or the right to be treated equally. Having said that, we may add that law is one of the most influential contributors to the work of delineating boundaries in the field of biotechnology.

Assisted Reproduction: Disruption of Sexuality and Reproduction

Human reproduction has undergone significant changes since the first successful in vitro fertilization in 1978, and by now it has become a widely spread practice across the world. The other relevant step in biotechnology was the increasingly acknowledged use of genetic testing and screening. These two lines of development in "technoscience" have fundamentally shaped the expectations to human reproduction. Technology blurred the previously clear distinctions between natural and artificial, embryo and fetus, procreation and sexuality, etc. Infertility treatments have been used for two distinct purposes, as a remedy for infertility and also for embryo selection for genetic betterment. A further consequence of these technological advances is that embryos and oocytes can be used for other purposes, such as biomedical research including the production of stem cells. Thus, embryos can be created through fertilization or a process known as somatic cell nuclear transfer (SCNT). In case of assisted reproduction, courts have to face numerous bio-cultural issues and differences which previously they have never faced in the context of unassisted reproduction [1]. In the domain of reproductive rights, the right to privacy (in the United States) and the right to private and family life (in Europe) provide the main pillars of the constitutional framework.

The Oviedo Convention, which has been ratified by 29 European countries already, provides two relevant provisions in the field of preimplantation genetic screening and testing [2]. Article 12 stipulates that "tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counseling." Since preimplantation genetic screening and testing always constitutes a predictive test, this

limitation is applicable as well as the requirement of genetic counseling. Indirectly Article 18 is also relevant especially concerning research use of preimplantation genetic screening. Article 18 provides that "where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo. The creation of human embryos for research purposes is prohibited" [2]. The Additional Protocol to the Convention on Human Rights and Biomedicine, concerning genetic testing for health purposes [3], specifically mentions that it does not apply to genetic tests carried out on the human embryo or fetus; therefore, in the lack of specific provisions only the Oviedo Convention abovementioned general provisions may provide some guidance. One of the major legal divisions lies on the distinctions for health, for research, and for nonmedical reasons. In some regulatory frameworks, it is assumed that when embryo testing aims to detect conditions that are not medical, then it becomes eugenic selection. The problem with this approach is that it assumes that medical criteria are infallible in assessing what is eugenic and what is not. One may agree that selection based on detection of a minor pathological condition may be regarded also as eugenic, while selecting a specific, nonmedical trait, such as gender, may not have any eugenic motivation at all. In other words, a classification for eugenic does not necessarily follow a medical vs. nonmedical distinction. It is a widely held view in the disability literature that the same condition may be viewed very differently in the medical and in the social model of disability. So this distinction is not only old fashioned, but it is problematic as well. On the other hand, the term *eugenic* has also seen significant change over time. Now it encompasses more individual choice rather than the expectations by society.

The Embryo and the European Court of Human Rights

In Europe, the advanced reproductive technologies are far more regulated than in the United States. Still, at the pan-European level, there is no consensus on the nature and status of the embryo and/or fetus, although these are beginning to receive some protection in the light of scientific progress and the potential consequences of research into genetic engineering, medically assisted procreation, and embryo experimentation. The European Court of Human Rights is convinced that it is "neither desirable, nor even possible as matters stand, to answer in the abstract the question whether the unborn child is a person for the purposes of the right to life provision of the Convention" (*Vo v. France* [4]; see also [5–9]).

Recent cases have addressed questions of access to in vitro fertilization (IVF), wrongful life and birth, and custodial rights over embryos. In these cases, the potentiality of life has to be assessed, but the applicability of abortion case precedents is disputable. For instance, the very same jurisdictions that allow termination of pregnancy during the first trimester based on the request of the pregnant woman may reach an entirely different conclusion when a woman expresses her wish alone to have an in vitro embryo transferred to her.

The moral caution about the status of the human embryo suddenly has become unbearable in cases of disputes concerning embryos from IVF. The European Court

of Human Rights had already confronted this matter in the *Evans v. the United Kingdom* case [8], where the applicant claimed that her privacy rights were infringed by granting the destruction of her embryos based on the partner's request. While access to many forms of in vitro fertilization is accepted as a rule, the issue here was the *conflict between the rights of the prospective mother and the male producer of the embryo*. It is the in vitro procedure and ex utero storage that creates disruption between the phases of human reproduction. The legal contradiction here is while assisted reproduction was developed with the aim of helping to ensure rights of the infertile and to grant them privacy and health service that would eliminate the pain of being childless, the disruption of the procedure created an opportunity to invade privacy and right to family life which would proceed seamlessly in the course of unassisted (natural) reproduction.

As demonstrated in the *Evans* case, procreative liberty was recognized as a negative liberty (so women should not be prevented to carry on their pregnancy), yet this liberty is not applicable in cases of IVF, because the Court recognized that here the fathers' right not to become a parent should prevail over the woman's interest to become a mother. This case may have many different interpretations. The Court took into account the assessment of the new reproductive technologies when it recognized the uncoupling of procreation and pregnancy with IVF. However, what ethical theory the Court employed it is unclear, as the principles of bioethics are not directly transferred into law which relies on traditional forms of rights and interests. Elsewhere the Court stated that moral considerations are not in themselves sufficient reasons for a complete ban on a specific artificial procreation technique such as oocyte donation [9].

The main ethical dilemma in the *Evans* case therefore was whether biological differences in gamete donation could be taken into account in assessing rights of the male and female donors. Furthermore, the court missed the opportunity to recognize the difference between preventing someone to become a parent and the denial of the right to change opinion on biological parenthood.

Embryo Selection: Is There Any Right to Choose a Child with Specific Traits?

There are many examples of selective breeding in humans which reach back to the very origins of civilization. The concept was not alien to Plato's Republic; it manifests in the ancient Spartan practice of terathanasia (i.e., the death of an abnormal infant) as well as in policies of forced sterilization (of the "mentally ill") in the first half of the twentieth century. Now, selecting and screening have taken different forms such as the selection of "super" sperm and egg donors in modern-assisted reproduction. The unspecified desire "to have children" was associated with the woman's wish or—in traditional societies—with the one and only aim of women's lives. Selecting specified characteristics of the child (gender and other desirable features of the offspring) was regarded as a method for establishing public control

over the individual's (mainly the woman's) desire to have children. This distinction between an individual's desire to have children and public expectations to have a child with certain specified characteristics (such as being an only child, a male child, an intelligent child, a physically strong child, a "perfect" child, etc.) has become much less clear. Borrowing the term from Habermas, "liberal eugenics" is based on free and individual choices and not on coercive social expectations. Nevertheless, a preference still exists for the selection of a healthy, strong, and intelligent child, and this preference obviously reflects a commitment to unspoken eugenic purposes.

The first step to screen embryos and fetuses was a derivative effect of ultrasound, which had been developed during World War I to detect submarines. Later, medical doctors used this technology to examine fetuses while still in utero. Although ultrasound can identify some fetal anomalies, IVF clinics now offer genetic testing of embryos before transfer or implantation. Preimplantation genetic testing (i.e., PGD) can be seen as an alternate screening approach for embryos produced by parents with certain genetic predispositions. But now as a result of the development of PGD, soon-to-be parents who long for a "perfect healthy baby, have turned to science, through prenatal testing, to assuage any fears about pending pregnancies" [10]. Carrier testing is one of the more common methods, which involves testing both parents for genetic conditions before they begin trying to conceive to determine the chance they have of passing on any disorders to their children [11].

The genetic tests on the in vitro embryo prior to implantation in the uterus have become the subject of heated debates not only among professionals but also in various social groups. The theoretical possibility of "perfecting humankind" has moved people's imagination, and it often overridden the dispute about the real possibilities offered by PGD. This method has been primarily used worldwide as a screening method for β-thalassemia, sickle cell anemia, cystic fibrosis, spinal muscular atrophy, Huntington's chorea, Duchenne and Becker muscular dystrophy, and fragile X syndrome and hemophilia. So, in these respects, PDG is employed to screen against severe illnesses and not to "create" blue-eyed, athletic-looking children with high IQ scores. The use of embryo selection and the selection criteria themselves have caused significant ethical discussion worldwide. Some of the arguments against PGD include that it relativizes the value of human life, it further marginalizes and discriminates against people with disabilities, and it fashions the mother's body into an even more "clinical object" due to these new interventions. Indeed, the medical literature has now refined the more complex PGD process itself, which involves testing some cells removed from the embryo, and, based on the test results, selecting one embryo for transfer.

Moral Justification

The need for preimplantation genetic tests originates from the desire to avoid abortion following prenatal genetic tests and the resulting physical and emotional suffering by using this technique. It provides help primarily to families where hereditary diseases may be screened before the embryo is implanted in the uterus.

Technology has undergone a number of changes since 1989 when Handyside's team successfully screened an embryo for a genetic disorder related to the X chromosome and subsequently resulted in a successful pregnancy in England [12]. As far as the legal regulatory environment, very little consensus exists in this field. Two of the articles of the 1997 Oviedo Convention contain some reference to the topic [2]: Article 14 prohibits the embryo sex selection and states "the use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-linked disease is to be avoided." In other words, selection of the sex is permitted to screen for serious, sex-linked disorders. But this applies only to a part of preimplantation genetic tests. The other basis is Article 18 of the Convention, which specifies that "where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo. The creation of human embryos for research purposes is prohibited."

As an international trend, PGD is slowly but steadily gaining ground even in countries traditionally taking a more conservative approach. A good example would be Germany where a 2010 ruling of the federal court acquitted a physician who performed preimplantation tests despite regulatory prohibitions. As a result of the legal debate that erupted, the strictness of the law was finally eased. It was in 2012 when the human rights aspects of PGD were brought before the European Court of Human Rights in a request submitted against Italy [13]. Under a 2004 Italian law, no preimplantation tests are permitted, but abortion may be requested in a later stage of pregnancy even based on the same health condition which could have been screened by PGD. Awareness of the inconsistency of that legal regulatory environment and the resulting controversial human rights situation was raised by an Italian couple who had already had a child suffering from cystic fibrosis, and the mother was forced to request abortion of a later pregnancy for the same reason. As they did not want to go through the ordeal of abortion again yet they longed for another child, they requested PGD although this was not permitted under Italian law. I believe that the court correctly concluded that the right to respect for private and family life (stipulated under Article 8 of the European Convention on Human Rights) was violated when the Italian law subjected a woman to repeated failed pregnancy when this could have been avoided with PGD.

While Austria, Switzerland, and Italy maintain a strict, prohibition-based legal position, Belgium, the Czech Republic, France, Greece, the Netherlands, Sweden, and Slovenia are more permissive in the field of preimplantation genetics. French regulations are more cautious and made changes in a piecemeal way: the bioethics law (amended in 2004) permits preimplantation genetic tests in highly restricted cases when one of the genetic parents carries a genetic mutation that provides a reason for the test. The Norwegian debate in bioethics is characterized by the fear of selection and social isolation, which explains their cautious attitude towards PGD. In 2011, the European Council prepared a comprehensive study on preimplantation and prenatal genetic tests that covered not only the polymerase chain reaction (PCR), fluorescent in situ hybridization (FISH), and comparative genomic hybridization (CGH) but also the whole genome amplification (WGA) method that involves the analysis of the entire genome. If the clinic has knowledge about the

embryo to be implanted carrying a severe disease, it is obligated by law to inform the person(s) requesting the IVF and PGD. However, reproduction is still primarily an element of natural family planning, so the concept of "product liability" is still alien to this field. Hopefully IVF and pre-IVF PID, PGD, or even PGS (WGA) will remain as exceptions and available only in justified cases. Otherwise, we would find ourselves in the world of *Gattaca*, where natural selection is only secondary to carefully planned genetic selection. Due to the lower birth rate in many postindustrial societies, there is a significant incentive towards selective reproduction. And this, of course, puts a greater burden on women as they are the ones who must undergo the physical and emotional consequences of gonadotropin therapy for ovulation induction, embryo transfer, possible spontaneous abortion, embryo selection, reduction, prenatal testing, etc. Therefore, their privacy rights, physical integrity, and reproduction rights must be respected.

In the philosophical debate, a counterargument along the lines of Habermas was presented according to which the prenatal or preimplantation selection of the embryo that meets the parents' wishes may actually affect the personal autonomy of the future child. This element of the debate, however, relates more to the eugenic-type embryo selection rather than the genetic test aimed at preliminary screening of certain disease types.

Preimplantation screening raises more ethical and legal issues than targeted preimplantation genetic testing. The key ethical counterargument is that a full-scale genetic screening would result in eugenic embryo selection instead of the previous approach aimed at avoiding certain diseases. It is also hard to determine whether the danger of a disease that would develop later or with a higher possibility in the future child's life could also justify this procedure or it should be limited to serious diseases to appear early—for example, during childhood. One may live happily for 40–50 years before the disease develops, and during that period of time, there is still a chance for treatment to be found. In such cases, therefore, it is hard to justify embryo selection. A powerful argument for broader genetic screening is that if a specific genetic disorder can be identified, then why should we not make sure that the embryo has no tendency for other serious diseases in addition to the disease the embryo is originally tested for? From the patients' point of view, it is understandable that if they opt for IVF and PGD, they would be deeply disappointed to find out that their baby suffers from another severe genetic disorder that could have been screened. As genetic screening is rapidly evolving, there may be a case for diagnosis when the use of genetic screening would emerge. For this reason, the Human Fertilization and Embryology Authority of England is required to make a separate decision based on a special request before screening for each new genetic disease. The request must specify the so-called OMIM (Online Mendelian Inheritance in Man) number of the specific disease.

With the expansion of the techniques and the range of diseases that can be identified by screening, we come to learn more about the limitations of PGD. For example, it should be noted that there will be embryos whose constituent cells are not all identical (mosaics). As a result, the cell removed for diagnosis may not necessarily provide an accurate picture of the genetic risks of the complete embryo.

In a special type of preimplantation tests, the purpose of embryo selection is to ensure compatibility with an existing person. Usually, parents can use this method to find a suitable donor for an older sibling already born. This application type of preimplantation and HLA tests raises a number of ethical and legal issues. The procedure selects embryos based on some principle of "usefulness," which means that an otherwise healthy embryo is not implanted if it is incompatible—that is, if it does not possess the qualities that could enable the future child to help the ill sibling.

From the perspective of the mother, if IVF and its associated gonadotropin therapy and invasive follicle aspirations occur only to help select one from any number embryos, and if this were an entirely voluntary decision by the mother free of any coercion, it obviously can constitute a violation of her dignity and right to self-determination if this were prohibited. But the so-called "slippery slope" argument in ethics implies that if today we permit embryo selection based on HLA compatibility, tomorrow we may allow selection for other qualities. Obviously, a therapeutic objective is an ethically reasonable and a serious aspect. If the procedure is compared with genetic tests already applied, saving one's life is more acceptable ethically than mere selection based on other criteria. It is a more serious question whether the human dignity of the child produced in this way is violated by the fact that a crucial aspect in his or her creation was to have certain biological properties that can help others at a later point in time. From a different viewpoint, prenatal selection may lead to instrumentalization, which is a decisive danger in terms of human dignity. We need to make several distinctions in terms of ethics. When a mother agrees to a new pregnancy to thereby help her existing sick child, this is different from a scenario where properties relevant in terms of donorship are taken into account in an already planned IVF program.

In addition to developing and enforcing legislation, appropriate information and genetic counseling will also play a key role. Special care must be exercised with regard to the personal rights of the patients and couples as they turn to their physician in this very important private matter. As with all new techniques, a relationship based on honest partnership must be sought with women, men, and couples requesting IVF treatment. Since this is a dynamically changing field, information supply must be adjusted accordingly. For instance, women of reproductive age now can expect to receive information regarding additional options for reproduction. The information provided must be accurate, objective, and personalized and may not be based on prejudices or any nonscientific views on women, disabilities, or age.

Medical and Nonmedical Indications

PGD is usually permitted in special cases to avoid specific and severe genetic diseases. In 2002, the United Kingdom Department of Health issued guidelines for the use of PGD. Nonmedical reasons refer to cases when embryos are selected for gender or specific desired trait. A liberal attitude to PGD can be seen in Belgium, Czech Republic, Portugal, and Spain [14]. In the United Kingdom, PGD has been applied since 1994. More reluctance can be seen in the German-speaking countries.

But even in countries that are labeled as "liberal" in their biomedical law, there are some restrictions on the use of preimplantation genetic screening. In Belgium, the law on assisted reproduction adopted in 2007 prohibits the use of PGD for eugenic choices which is understood as choosing embryos for selection or enhancement of non-pathological genetic characteristics [15]. The other possible approach is to differentiate between various causes of the medical conditions to be tested. Following this line of thought, the Portuguese law [16] does not allow preimplantation genetic screening for multifactorial conditions in which the predictive value of the test is very low.

According to the current Czech law [17], genetic examination of a human embryo or a fetus may be performed with the proviso that a doctor with specialization in the area of medical genetics provides genetic consultation. Laboratory genetic examinations of a human embryo or a fetus shall only be performed after the submission of information and with written consent of the mother. In the Netherlands, a detailed website provides assistance to couples who seek PGD [18]. The website specifies the conditions in which PGD is available, such as Huntington's disease, hereditary breast and ovarian cancer, myotonic dystrophy type I (Steinert's disease), familial adenomatous polyposis coli (FAP), Marfan syndrome, neurofibromatosis type I, cystic fibrosis, spinal muscular atrophy, fragile X syndrome, hemophilia A&B, and Duchenne muscular dystrophy. The British HFEA website also lists conditions in which preimplantation genetic testing can be performed and also on those conditions in which PGD is still contested [19]. The Swiss law [20] seems to be one of the most conservative with regard to preimplantation genetic testing, partly due to the fact that the Swiss Constitution addresses this issue [21].

Cases of Savior Siblings: Is There a Right to Select a Single "Matching" Embryo?

As a result of advances in medical genetics and embryology, it is now possible to examine a set of embryos produced through IVF to choose a healthy embryo that fits to some relevant medical criteria. Thus, preimplantation genetic testing may be used to ensure that the child to be born does not carry a certain genetic disease that has occurred in the family. Similarly, donor compatibility with an already born sibling might also be a reason for selecting a healthy embryo out of a pool of embryos for single transfer. In a rather journalistic and sensationalist way, such a child, once born, is sometimes termed a "savior sibling." The ethical dilemma of whether it is right and acceptable to create a savior sibling has been discussed in relation to a number of well-known cases. The first such case was the birth of Adam Nash in 2000 in the United States [22]. Adam was the first newborn baby who was deliberately selected as an embryo from several IVF embryos to help in curing his ill sibling. Adam was born in Chicago after four unsuccessful attempts at embryo implantation, and the stem cells extracted from his umbilical cord blood was used to cure his sister suffering from Fanconi anemia.

In England, two similar cases raised further ethical questions: shall we limit the use of embryo selection to saving family members suffering from genetic diseases or may we extend the application of this technique to other illnesses as well? In the *Hashmi* case, the family requested the selection of an embryo that does not carry the gene responsible for the development of β-thalassemia, a blood disorder. In 2002, the British Human Fertilization and Embryology Authority (HFEA) accepted this request and approved the embryo selection. In the *Whitaker* case, however, the family asked the authorities for approving embryo selection in the IVF process in order to bring a baby to life who could help in curing their child suffering from Diamond-Blackfan anemia, a rare form of anemia where the bone marrow produces few, or no, red blood cells. The origin and causes of this disease are not completely known, and only a matching bone-marrow donor could help the patient. Such donor could not be found, however. Shortly after approving embryo selection in the *Hashmi* case, the HFEA rejected the Whitakers' request. The panel's decision was based on the consideration of whether the child to be born benefits from the intervention. While in the previous case the couple used preimplantation genetic diagnosis (PGD) in order to prevent the passing of a hereditary disease on the embryo, in the latter case, the embryo itself would not benefit from PGD because the *sole purpose* of conducting PGD was to determine if the embryo is a suitable donor. Since the Whitakers' request was not granted in England, the family traveled to Chicago where IVF and embryo testing was successfully done. A healthy "savior sibling" was born in 2004, which allowed the older brother, Charlie, to undergo stem cell therapy.

In 2004 another British family, the Fletchers, asked the HFEA to approve a similar procedure, and the authority granted the request in this case. The Human Fertilisation and Embryology Act of 1990 (as amended in 2008; see [23]) provides the legal condition for savior siblings: the intended recipient of any donated tissue from a child born following tissue typing must (a) be a sibling of any child born as a result of treatment and (b) suffer from a serious medical condition that could be treated by umbilical cord blood stem cells, bone marrow, or other tissue (excluding whole organs) of any resulting child. The law also permits tissue typing if the embryo will not, in addition to the histocompatibility test, be tested for a particular genetic or mitochondrial abnormality.

Creating a savior sibling from IVF is based on the results of PGD. In France, the National Consultative Ethics Committee for Health and Life Sciences (CCNE) published its Opinion No. 107 on ethical issues related to prenatal and preimplantation diagnosis in 2009 [24]. In this opinion, the Committee pointed out that the creation of a *bébé-médicament* (or "therapeutic baby") should be considered only as a last resort solution, when no other type of treatment would prove to be effective. Instead, the committee encouraged development of the system of community-based umbilical cord blood banks to provide stem cells for as many children suffering from genetic illnesses as possible. If a child is already born with a genetic disease and the selection of a donor embryo is the only viable solution, then the CCNE proposes that the couple making the decision is provided with medical and psychological assistance.

The most common argument against selecting a savior sibling is that the birth of the child is not an end itself but rather is designed with the definite purpose of saving the life of another person—and this contradicts the principle of human dignity. This is indeed a significant argument that needs to be taken into consideration, and any legal regulation should be based on the foundation of protecting this principle. But we also have to bear in mind that the birth of a savior sibling is preceded by the same nine months of childbearing and laborious childbirth as in the case of any other fetus, and thus the whole process rests a much heavier burden on the mother than a simple act of embryo selection. No woman could undergo such an arduous procedure without a strong emotional bond with the future offspring and feeling of responsibility.

If we compare PGD and single embryo transfer for a savior sibling to other genetic examinations, then saving the life of another person is certainly a more ethically acceptable reason for selecting an embryo for any other consideration. It is a more complicated issue to consider if the right to human dignity of a child is violated, if it was a crucial aspect in deciding over his/her birth to life that he/she has the biological traits making him/her suitable to help others. In other words, can we claim that prenatal selection in itself leads to the danger of instrumentalization so decisive in relation to human dignity?

If we continue the analogy of a living donor, then it might be argued that for the "savior sibling," it remains a life-long moral and psychological gain that he or she has already saved someone else's life. Follow-up studies on cases of transplantation involving living donors has shown an interesting outcome: among living donors, they are likely to live longer than age-matched individuals who did not donate organs.

The first savior sibling in France was born on January 26, 2011, to parents of Turkish origin, and he was named Umut Talha ("our hope" in Turkish) [25]. As an embryo, he was selected through IVF and PGD to cure his siblings of β-thalassemia, a genetic disease that causes severe anemia. Based on the results of the initial tests, the stem cells extracted from the umbilical cord of the newborn baby can be used first to treat Umut Talha's sister. The family plans to use the same technique to help his brother as well. Of note, the public comments on ethical scruples were largely focused on how Umut was "objectified," how he had been used as a mere means. In contrast, the ethical issues related to the mother who sacrificed the most in the IVF process—with the numerous injections required to produce eggs and the surgical harvesting of oocytes—was regarded as less important. It was the mother who herself underwent the savior embryo transfer (selected out of 27 embryos) and stands ready to bear another savior sibling to help Umut's ill brother, if necessary. From the mother's perspective, her right to dignity and self-determination may well have been violated if it was not her fully autonomous, unenforced decision to undergo the IVF sequence.

In the bioethics literature by applying a slippery slope argument, it is often stated that if today we select according to HLA compatibility, then there will be other characteristics tomorrow to base our selections on. It is evident, though, that therapy remains an ethically respectable and serious goal of any such intervention.

Also from a bioethical perspective, it must be made clear that the single embryo selected in the IVF process is not simply a therapeutic tool, not just a method to

perform a surgery, not merely a type of medication, but an intervention which will likely culminate in the birth of an autonomous human being—a new individual. It is doubtful that any parent would endeavor to undergo such processes, especially since they are exhausting and psychologically draining for the mother, only to produce a child compatible with an already living sibling. While such a calculative decision is possible, it seems more likely for a couple to genuinely want a new baby anyway; if it should be an added benefit that the umbilical cord blood of the newborn baby (produced from IVF) can help cure an older sibling suffering from some debilitating disease, then this would simply be a double positive outcome.

Since its early applications in treating infertility, IVF has been used in a growing range of other cases including those for various therapeutic purposes. It seems that preimplantation instrumentalization as such may not lead to commodification, because after the selection of an embryo, an independent human being will exist. The unlikely circumstances which prompted Habermas' concerns in his work on *The Future of Human Nature* [26] seem unlikely to infringe upon the relation between generations, as the savior sibling is an autonomous being whose umbilical cord could save life.

IVF and Wrongful Life Cases: Is There a Right to Have a Healthy Child?

While IVF was developed to "cure" infertility, very soon after its first clinical application concerns towards the quality of gametes used in the procedure were addressed. If infertile couples (or persons) pay for reproduction services, could they claim higher standards of therapy or at least the prescreening of certain serious medical conditions of the gamete donors? Would it change the transaction from a type of personal donation to something akin to product liability?

Naturally born children do not have a fundamental right to be born free of genetic defects. Egg donation does not make a difference in this regard. Similarly, plaintiffs cannot recover damages for the emotional distress they experienced as a result of having a child with a genetic disease. The emotional distress suffered by parents as a result of the birth of a genetically diseased child after IVF cannot be treated any differently from that sustained by any other parents who conceived without medical assistance. However, plaintiffs may state a cause of action for the pecuniary expense arising from the heightened care and treatment of their sick child, including claims for compensation related to the mother's decision to leave her job so that she could care for her child on a full-time basis. Furthermore, plaintiffs can state a cause of action for punitive damages based on allegations of defendants' grossly negligent or reckless conduct.

In 2011, the case of *R.R. v. Poland* [27], the European Court of Human Rights dealt with the complaint of a young Polish mother of several children who, for a month, had to travel from one medical institution to another between Łódź and Kraków to confirm a severe fetal disorder (suspected during ultrasound exam). That information was critical in helping her decide to request an abortion. Her request was denied because genetic exams required a specialist doctor's referral. After long

delays, genetic tests in April 2002 confirmed that her unborn baby did have Turner syndrome. In accordance with a 1993 Polish law, her request for abortion on this basis could be granted. However, fulfillment of her request to terminate the pregnancy was denied on the grounds that the gestational age was too advanced.

Thus, on July 11, 2002, the plaintiff gave birth to a girl with Turner syndrome, as predicted by the prenatal tests. The young woman went to several Polish courts, and in her claim she wanted recognition that her doctors prevented her from the timely completion of the genetic test and an application for abortion based on Polish laws. One peculiarity of the case is that the Strasbourg Court not only found the violation of privacy rights based on information restraint, involuntary pregnancy, and living in fear but also ruled that the inhuman and degrading treatment shown towards the complainant was in violation of Article 3 of the European Convention on Human Rights (ECHR) [28].

Conclusions

As we have seen in the examination of legal cases, contemporary legal discourse in the field of biomedicine with respect to human dignity and the right to privacy may be used to interpret decisions on human reproduction, in general, and PGD, in particular. In this domain, the conceptual problem is how to distinguish between the core scientific and related socials norms. The delineation between science and its application in reproductive biotechnology is often hard to make. Furthermore, interpretation of scientific results in a broader social scope is often problematic. If law simply codifies or acknowledges the science of today, it often contributes to inevitable errors in ad hoc interpretations of current scientific paradigms.

Contemporary judicial interpretation must face scientific questions and terms in a complex way. The mission of the law is to separate scientific advances from commercial interests, to peel off the legacy of an older, paternalistic professional tradition, and to deflect eugenic and reductionist thinking. In the future, it seems that the mere reference to the term “eugenic” will become insufficient for deciding about the legitimacy of PGD. It seems that there is a huge gap between the historical and philosophical expressions in the sporadic regulations on PG, and the highly technical and changing abbreviation used by the clinicians.

Conflict of Interest The author declares no conflict of interest.

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