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Should the provision of prenatal genetic testing and diagnosis take into account the rights and interests of the future person?

INTRODUCTION

The moral and medical necessity to save lives is a driving force, constantly accelerating technological progress. The different medical procedures, tests and treatments that are now available prior to birth have shown the potential to increase the understanding of chronic genetic conditions. However, considering the possibility of applying some of these techniques in clinical trials requires a different analysis of the persons that may be harmed by these techniques. In this paper, we will be addressing an *illustrative case* in which gene editing techniques in human embryos are accepted and allowed¹ in clinical trials. We will be arguing whether the use of this technique will possibly harm future persons' genetic integrity (who will be born with a genetic modification).

Genetic integrity is the condition of the genome being 'whole' or undivided,² which includes the combination of all the different criteria of personal identity (including traditional features of identity, genetic identity, and the additional *properties* of identity). For our illustrative case, the subjects who are being harmed are future persons, because even if they do not exist at the time of the genetic modification, they *do* exist as genetic persons. Thus, the intrusion of someone over future persons' genetic makeup will inflict harm on their genetic integrity.

In Chapter 1, we will address the development of prenatal genetic tests and diagnosis techniques. In Chapter 2, we will define who we think future persons are, will highlight some of the important debates that have been raised around the concept, and will consider if we owe any duty to them now. In Chapter 3, we will discuss the possible ways future persons may be harmed and will define a baseline for this possible harm. In

¹ By "accepted and allowed", we are assuming that most of the ethical and legal issues has been overtaken, and the technique is safe enough to be applied in human beings.

² Vorstenbosch, Jan. "The concept of integrity. Its significance for the ethical discussion on biotechnology and animals." *Livestock Production Science* 36.1 (1993): 109-112, page 110.



Chapter 4, we will address the possible ways to extend the application of some of the current legal frameworks in order to be applicable for future persons. Finally, we will conclude that the harm to future persons' genetic integrity can only be avoided by banning the technique, thus, the law needs to extend the protection to future persons so the dignity and living vital body of someone who will exist in the future will be safeguarded *in advance*.



CHAPTER 1

Prenatal genetic techniques

During the last decades, the development of new genetic techniques to access the foetus during pregnancy has been enormous and continues to expand. Prenatal diagnostic techniques “are already the most widespread application of genetic technology to humans.”³ There are different assumptions of why these techniques have been developed. Some may argue that it is more of a cultural and social rather than scientific trend,⁴ while others may argue that there is a real *need* for these techniques and the development of new genetic technology.⁵

Nowadays, we tend to define *health* as something normal and good, and *disease* as something bad and abnormal that should be treated.⁶ According to the World Health Organization, “[h]ealth is a state of *complete* physical, mental and social well-being and not merely the absence of disease or infirmity.”⁷ However, the requirement of a *complete* health can be impractical because it “is neither operational nor measurable”⁸ and in some ways it intrinsically incites the medicalisation of society.⁹ We feel we have the need to diagnose what is wrong or incomplete in our body and prescribe drugs to be *completely* healthy again. Moreover, with this definition we also imply, a priori, that

³ Lippman, Abby. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *Am. JL & Med.* 17 (1991): 15, page 15.

⁴ For example, ultrasonographic examination of the foetus is performed routinely in most of pregnant women despite the contrary advice from professional guidelines. Informed consent is not obtained because of the routinely of the procedure during pregnancy, and because, for some, the mother is only a “patient’s fiduciary”, and the patient is the baby. For more information, see: Chervenak, Frank A., Laurence B. McCullough, and Judith L. Chervenak. "Prenatal informed consent for sonogram: an indication for obstetric ultrasonography." *American journal of obstetrics and gynecology* 161.4 (1989): 857-860, page 858; and Lippman, Abby. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *Am. JL & Med.* 17 (1991): 15, page 16.

⁵ As our “special moral duty of providing health care.” (See: Zohar, Noam J. "Prospects for “genetic therapy”-can a person benefit from being altered?." *Bioethics* 5.4 (1991): 275-288, page 275).

⁶ Lippman, Abby. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *Am. JL & Med.* 17 (1991): 15, page 16.

⁷ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

⁸ Jadad, Alejandro R., and Laura O’Grady. "How should health be defined?." *Bmj* 337 (2008).

⁹ *Ibid.*



people with chronic diseases, disabilities or a genetic condition are unquestionably ill, because they are not *completely* healthy. A genetic disorder do not necessarily mean a disability, instead, it could just mean a different condition of life which is not necessarily malignant.¹⁰

The improved accuracy of results obtained by the new prenatal genetic techniques is shaping new abnormalities that we did not know existed before and that do not necessarily need to be considered as a disease that need to be treated. This improvement, perhaps unnecessarily, increases the need for intervention, screening, diagnosis, and even modification of our genes prior to birth. Hence, the new trend of health and disease is oft spoken through the “language of genetics”.¹¹ “Geneticization refers to an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health.”¹² With this perception of *genetics*, scientists and genetic researchers are generally finding, or trying to find, the cure for a huge branch of diseases or disorders, as well as to increase our understanding of genetic conditions in the research sphere and, eventually, to apply this knowledge in clinical trials.¹³

Genetic testing, in general terms, helps us to find out whether a person is carrying a gene that is causing or that may cause in the future a particular medical condition.¹⁴ Nowadays, one of the most common and widespread genetic activity is prenatal

¹⁰ Lippman, Abby. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *Am. JL & Med.* 17 (1991): 15, page 17.

¹¹ *Ibid*, page 18.

¹² *Ibid*, page 19.

¹³ This perception of genetics is leading us to find solutions to health and social problems through a genetic prism (See: Duster, Troy. *Backdoor to eugenics*. Psychology Press, 2003, page 164.) Also determined “how intellectual and financial resources are applied to resolve the health problems... [and influencing] our values and attitudes.” (See: Lippman, Abby. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *Am. JL & Med.* 17 (1991): 15, page 18.) There is a premature labelling of disease as genetic, leading most of the funding to these areas, and decrementing others. (See: Edlin, Gordon J. "Inappropriate use of genetic terminology in medical research: a public health issue." *Perspectives in Biology and Medicine* 31.1 (1987): 47-56). Even though these are important issues related to the term of *geneticising* medicine and society, and how public funding and policies are developing, we are not going to address them in this dissertation.

¹⁴ National Health Service (NHS), available at: <http://www.nhs.uk/Conditions/Genetics/Pages/genetic-testing-and-counselling.aspx>



diagnosis¹⁵ which refers to “all the techniques currently in use or under development to determine the physi(ologi)cal condition of a foetus before birth.”^{16 17}

Prenatal diagnosis techniques are presented as a way of gathering enough information about a woman’s personal health and pregnancy risks in order to expand or to respect a woman’s reproductive choices – allowing her to make an informed, autonomous and non-coerced decision based on that information.¹⁸ Thus, “[a]bridgement of that autonomy – explicitly or implicitly – would diminish the value of [these techniques] and undermine the achievement of their goals.”¹⁹ Nonetheless, beside the respect of autonomy, the *value* of these techniques includes other important matters that should not be diminished either. For example, children who are going to be born after these techniques should not be seen diminishing their value as persons to merely products that we may want to produce or to discontinue,²⁰ or future persons who will be born with

¹⁵ Rapp, Rayna. "12 The Power of " Positive" Diagnosis: Medical and Maternal Discourses on Amniocentesis." *Representations of motherhood* (1996): 204.

¹⁶ Lippman, Abby. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *Am. JL & Med.* 17 (1991): 15, pages 19 – 20.

¹⁷ These techniques are, for example, procedures as maternal serum screening, ultrasonographic examination of the foetus, amniocentesis, or chorionic villus sampling. (See: Diana W. Bianchi. Part V: Genetics. Chapter 18 – Prenatal Genetic Diagnosis, pages 186 – 193. In: Taeusch, H. William, et al. *Avery's Diseases of the Newborn*. Elsevier Health Sciences, 2005, pages 186 to 189).

Moreover, in order to prevent miscarriages during pregnancy in cases of foetuses with a genetic disease, the *preimplantation genetic diagnosis* (PGD) technique has been developed. PGD involves checking the genes and/or chromosomes of embryos created through IVF. (See: Handyside, Alan H., et al. "Birth of a normal girl after in vitro fertilization and preimplantation diagnostic testing for cystic fibrosis." *New England Journal of Medicine* 327.13 (1992): 905-909). Assisted reproductive technologies (ART), like in-vitro fertilisation (IVF), apply the PGD technique in order to remove eggs from women’s ovaries before they are fertilised with sperm in a laboratory. Then, the embryo(s) without the genetic disorder is identified, chosen and re-implanted in the uterus (See: Diana W. Bianchi. Part V: Genetics. Chapter 18 – Prenatal Genetic Diagnosis, pages 186 – 193. In: Taeusch, H. William, et al. *Avery's Diseases of the Newborn*. Elsevier Health Sciences, 2005, page 191. In addition to PGD, *pre-implantation genetic screening* (PGS) is also available. Chromosomal abnormalities are another cause of miscarriages, so the chromosomes of embryos conceived by IVF or intra-cytoplasmic sperm injection (ICSI) are checked for abnormalities (more information in the webpage of the HFEA, available at: <http://www.hfea.gov.uk/PGD.html>)

¹⁸ President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research: *Screening and Counselling for Genetic Conditions: The Ethical, Social, and Legal implications of Genetic Screening, Counselling, and Education Programs*, Report (Washington, D.C.: U.S. Government Printing Office, 1983), 55.

¹⁹ *Ibid.*

²⁰ For instance, treating people, parts of people or future persons as commodities (See: Rothman, Barbara Katz. "Recreating Motherhood Ideology and Technology in a Patriarchal Society." (1989)).



a genetic modification should not have diminishing the value of their *genetic integrity*²¹ by permitting the intrusion of a third person in their genetic makeup.

For several years, questions surrounding research and the possible application of human genome editing techniques in clinical trials have been a common thread in many discussions in medical law.²² The enormous potential of research in genetics of doing “much good for society”²³ cannot be misjudged. Considering the possibility of applying some of these techniques, which are still under research, in clinical trials, requires different analysis of the values and persons that may be harmed by these techniques. Hence, until recently, it was not necessary to address the issue of whether a future person (who is being tested and genetically modified while still a foetus) should be protected or not.

The United Kingdom (UK) has been one of the pioneers in genetic healthcare and research. These activities are regulated by the Human Fertilisation and Embryology Authority (HFEA), which was established through the Human Fertilisation and Embryology Act 1990 (Act). The Act allows some techniques, procedures or activities only with license²⁴ issued by the HFEA, whilst totally prohibiting others.²⁵ The most recent granted license was in February of this year,²⁶ when the HFEA approved the

²¹ The term *genetic integrity* will be addressed in Chapter 3.

²² Chalmers D. Chapter 6: International Medical Research Regulation: From Ethics to Law. In: McLean, S. ed. *Fist Do No Harm. Law, Ethics and Healthcare*. Aldershot: Ashgate, 2006.

²³ Henaghan M. The ‘Do No Harm’ Principle and the Genetic Revolution in New Zealand. In: McLean, S. ed. *Fist Do No Harm. Law, Ethics and Healthcare*. Aldershot: Ashgate, 2006, page 512.

²⁴ The activities which can only be carried out with a license issued include: a) creating human embryos (section 3(1)); b) using or keeping human embryos (section 3(1A)); c) storing gametes(section4(1)(a)); d) using sperm (other than partner donated sperm which has not been processed or stored) to provide treatment services (section 4(1)(b)); e) using the eggs of a woman which have been processed or stored, or the eggs of any other woman, to provide treatment services (section 4(1)(b)); f) procuring, testing, processing or distributing gametes intended for human application (section 4(1A)); g) creating, keeping or using human admixed embryos (section4A(2)); and h) mixing human gametes with animal gametes (section 4A (2)).

²⁵ The activities which are absolutely prohibited: a) placing non permitted gametes or embryos in a woman (including human admixed embryos, non-human embryos or gametes)(sections 3(2) and 4A(1); b) keeping or using a human embryo or human admixed embryo after the appearance of the primitive streak (sections 3(3)(a) and 4A(3)); c) placing a human embryo or human admixed embryo in an animal (sections 3(3)(b) and 4A(4); and d) using female germ cells taken or derived from an embryo or fetus, or using embryos created by using such cells, for the purposes of providing fertility services for a woman (section 3A).

²⁶ As an example of other licensed procedure that has been approved by the HFEA, we can mention the followings: cloning in human embryos was granted its first license in August 2014, and in May of next



proposal from the Francis Crick Institute (FCI) to renew their laboratory licence and to include gene editing of human embryos using the CRISPR/Cas9 technique. This technique has sparked off debates around the world²⁷ because the manipulation and possible modification of human embryos is not a mere act of curiosity anymore.²⁸ Now there is the possibility that this technique *could be* applied in clinical trials in the foreseeable future. Nevertheless, many people with different social and ethical concerns over the technique are intent on banning them.²⁹

However, the promise of genetics “to have the capacity to make the dream of the healthy child a reality”³⁰ is a compelling argument. Nonetheless, without supporting or rejecting this argument, the possibility to allow gene editing techniques in human embryos in clinical trials (like CRISPR/Cas9 technique) demands a new mode of analysis for future scenarios. In this paper, we will be addressing an *illustrative case* in which one of these gene editing techniques in human embryos is accepted and

year, the first cloned embryo from human somatic cells was created (See: Devolder, Katrien, and Julian Savulescu. "The moral imperative to conduct embryonic stem cell and cloning research." *Cambridge Quarterly of Healthcare Ethics* 15.01 (2006): 7-21). Later, in February 2015, the use of mitochondrial donations techniques, as Maternal Spindle Transfer (MST), and Pronuclear Transfer (PNT) to avoid serious mitochondrial disease was approved.

²⁷ Rao Passi G. Gene Editing of Human Embryos. *Indian Pediatrics*, Volume 52, 15 June 2015 [online].

²⁸ McLean, Sheila A. M. "The gene genie: good fairy or wicked witch?." *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 32.4 (2001): 723-739, page 724.

²⁹ There are many legal, social and ethical issues related to these techniques. For example, the **respect of human life**; the **respect of autonomy and privacy** is “related to individuals who cannot give consent to be genetically tested”, or our **responsibility to future generations** (See: International Bioethics Committee. "Report of the IBC on updating its reflection on the human genome and human rights." *United Nations Educational, Scientific, and Cultural Organization, Paris* (2015), para 16 and 106.); the **scope of the technique** and the potential to change so many aspects of the genome and its accuracy; **discrimination** and “the lack of respect for people who have genetic diseases by viewing not only the conditions as ‘undesirable’ but also the existence of such people in society” (Newson, Ainsley J., and Anthony Wrigley. *Identifying key developments, issues and questions relating to techniques of genome editing with engineered nucleases*. Nuffield Council on Bioethics, 2015, para 43 (b).); **human enhancement** and **designer babies concerns**; **safety**, the uncertainty over the effects increases the risk of inaccurate editing (**off-target mutations**) or incomplete editing (**mosaicism**), which can result in significant defects, disabilities and unknown problems to the future person. ; **altering the human germline** as a line in the sand that perhaps should not be crossed, passing down both ‘healthy and safe’ genes and genetic mutations to future generations (National Institute of Health. Statement on NIH funding of research using gene-editing technologies in human embryos, April 29, 2015), just to mention some of them. We will not address all of them in this dissertation, in order to don’t get confused with the different ethical arguments and the possible harm for future persons.

³⁰ McLean, Sheila A. M. "The gene genie: good fairy or wicked witch?." *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 32.4 (2001): 723-739, page 726.



allowed³¹ in clinical trials. We will be arguing whether the use of this technique will possibly harm future persons (who will be born with a genetic modification) and will attempt to discern the possible types of harm that may be inflicted.

³¹ By “accepted and allowed”, we are assuming that most of the ethical and legal issues has been overtaken, and the technique is safe enough to be applied in human beings.



CHAPTER 2

Future persons

The consequences of introducing the aforementioned genetic modification techniques will, definitely, have implications for future persons. In this section, we will define who do we think future persons are, we will highlight some of the important debates that have been raised around the concept, and we will discuss if we owe, now, any duty to them.

2.1. Our ability to *affect* future persons

The impact of our choice to allow gene-editing techniques on future persons, “who at present have no voice in these decisions, are profound beyond comprehension.”³² Our ability to affect future persons, negatively or positively, is immense.³³ We are currently being ‘hooked’³⁴ on science and technology, and both have “given us an unprecedented ability to foresee the long-term consequences of our acts, our innovations, and our policies.”³⁵ The idea of *responsibility* towards future generations has, firstly, been known in International Law concerning environmental damage.³⁶ Environmental duties,³⁷ which later became obligations,³⁸ late back to the year 1893³⁹ and subsequently were included

³² Partridge E. Introduction. In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 1.

³³ Ibid, page 2.

³⁴ Ibid, page 3.

³⁵ Ibid, page 1.

³⁶ Sands, P. “Protecting Future Generations: Precedents and Practicalities.” In Agius Emmanuel, Busuttil Salvino (Ed.), *Future generations and international law*. London: Earthscan Publications Ltda; 1998, page 84.

³⁷ “In the contexts of the dispute between Hungary and Slovakia over the construction of the Gabčíkovo-Nagymaros dam on the Danube, the former has invoke the concept of preserving species for future generations as a ‘moral obligation’ (but not as an international legal obligation).” In reference to the Declaration of Hungary *International Legal Materials*, vol 32 p1247 (1993), Sands, P. “Protecting Future Generations: Precedents and Practicalities.” In Agius Emmanuel, Busuttil Salvino (Ed.), *Future generations and international law*. London: Earthscan Publications Ltda; 1998, page 84.

³⁸ The United Nations Conference on Environment and Development (UNCED) recognized the idea of the protection of future persons needs and interests (as an obligation). See: Sands, P. “Protecting Future



in many treaties⁴⁰ and non-binding international documents. In reference to environmental issues, we can easily foresee the necessities of future persons, like the need of food, clean water or natural resources for their future life and welfare. These *necessities* “can be seems as being in grave jeopardy *now*, and we know this *now*.”⁴¹ Even though this is a valid reason to act or to preserve the environment for future persons, the reasons for acting or protecting future persons that may be harmed by the use of genetic modification techniques are not as straightforward as environmental duties.

2.2. Range of analysis of this paper

For some, “the morally significant aspect of how we conduct ourselves as agents lies in the consequences our conduct has for each and every person who ever lives”⁴² is an outwardly plain⁴³ ‘idea’.⁴⁴ Then, the choices that we make are morally wrong only if it negatively affects *some person*.⁴⁵ Thus, considering this ‘idea’ through the lens of consequentialist⁴⁶ theory, then, the consequences of our conduct should maximise the

Generations: Precedents and Practicalities.” In Agius Emmanuel, Busuttill Salvino (Ed.), *Future generations and international law*. London: Earthscan Publications Ltda; 1998, page 84.

³⁹ Position held by the United States in the *Pacific Fur Seal Arbitration* case. See: Sands, P. “Protecting Future Generations: Precedents and Practicalities.” In Agius Emmanuel, Busuttill Salvino (Ed.), *Future generations and international law*. London: Earthscan Publications Ltda; 1998, page 84.

⁴⁰ For instance, the 1946 International Whaling Convention; the 1968 African Conservation Convention; the 1972 World Heritage Convention; the 1972 Stockholm Declaration; UN General Assembly Resolution 35/8 on ‘Historical Responsibility of States for the Preservation of Nature for Present and Future Generations’ of 30 October 1980.

⁴¹ Partridge E. Introduction. In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 2.

⁴² Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998, page 1.

⁴³ See more: Roberts, Melinda A. “Is the person-affecting intuition paradoxical?.” *Theory and Decision* 55.1 (2003): 1-44.

⁴⁴ This idea is also known as the so-called ‘person-affecting intuition’ argument, which had been suggested first by John Broome (Broome, John. “Counting the cost of global warming.” Cambridge: White Horse, 1992, 124) and then by Larry S. Temkin (Temkin, Larry S. “Intransitivity and the mere addition paradox.” *Philosophy & public affairs* (1987): 138-187).

⁴⁵ Roberts, Melinda A. “Is the person-affecting intuition paradoxical?.” *Theory and Decision* 55.1 (2003): 1-44.

⁴⁶ There are several forms of consequentialist, for instance, “the person-affecting intuition [which] requires that agents bring about the greatest amount of good that they can bring about... [or] to *maximized* the good.” (Ibid, pages 1 and 4) In general terms, it refers that the ultimate moral aim is that outcomes be as



good⁴⁷ – so do not wrong *some person* – and should try to distinguish between the people who may be wronged.⁴⁸

The persons who may be wronged by the consequences of our choices can be identified as: those who exist now ('existing' persons); those who could have but will never exist ('merely possible' persons); and those who do not exist but will in the future ('future' persons).⁴⁹ The main distinctions between these groups of persons are their temporal and moral status⁵⁰ and the relationship between them in the lens of responsibilities and duty to protect each other.⁵¹

Even though all these groups of people can be wronged by the consequences of our choices, it is relevant to make some distinctions in order to clarify the range of analysis of this paper. Firstly, because genetic modification techniques can be applied on human embryos *only* for research purposes,⁵² we will not address the possible harm of 'existing' persons, since there is no living person who has been born after the use of these techniques. Secondly, we will not be discussing whether these techniques are medically effective or not. On the contrary, we will assume a future scenario in which these techniques are safe enough to be applied in clinical trials, hence settling many of the ethical concerns surrounding health risks.⁵³ Thirdly, for this paper, we will focus only on

good as possible. (Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 24). In other words, "consequences that do not make some person's life better do not add to the moral value that a world has." (Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998, page 1)

⁴⁷ *Maximising the good*, encompasses positive acts, taking no action at all, and preventing other actions from happening. However, the aim of this paper is not to make distinctions between acts or omission, or between acts that "promote the good and those that prevent the bad." (Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998, pages 1, 4 and 11)

⁴⁸ *Ibid*, page 2.

⁴⁹ *Ibid*, page 2.

⁵⁰ *Ibid*, page 10.

⁵¹ For example, "[d]o we owe existing people more than we owe future people? Do we ever wrong people by bringing them into existence? It is possible to wrong merely possible people by, say, having failed to bring them to existence? (See: *Ibid*, page 10).

⁵² Only in the United Kingdom, as it was explained in Chapter 1. In fact, it is the first time in history that this type of research is going to be performed with the approval of a governmental authority.

⁵³ As it was mentioned in Chapter 1. Even though the importance of each of these debates, for this paper, we will not address any of them since our illustrative case assumes that all of them have been already solved.



the possible harm towards 'future' persons and not 'merely possible' persons.⁵⁴ For our illustrative case, the consequences of our choices may affect future persons after they are born, thus, 'merely possible' persons cannot be harmed by our choices if they will never exist. In addition, it may also look like the beginning of a debate between a person's existence and non-existence.⁵⁵ However, we will assume that they *will* exist and that our choices may harm future persons, but their factual existence will not be in danger.

In the use of some prenatal testing and diagnosis, for instance *preimplantation genetic diagnosis* (PGD) technique,⁵⁶ the reproductive selection and later choose between one embryo and another to be implanted in a woman's uterus, may create different persons. This assumption raises different questions and debates whether abortion is morally wrong, whether unborn children or embryos that will never exist lack of moral status⁵⁷ or whether "the termination in medical context of human life, without the consent of the human whose life is terminated"⁵⁸ is illegal. For these reason, we need to make an additional distinction between these concepts. Unborn children, embryos and foetus have different moral and legal recognition in different countries. However, our analysis will be focused on a group of persons who has no legal or moral recognition *at all*. We will assume that the technique *per se* is not inflicting any harm, thus, embryos, foetus or unborn children are not being affected. We will not base our analysis on these debates nor religious, metaphysical perspectives, opinions or views about afterlife postulations or wrongful life cases.⁵⁹

⁵⁴ The concerns over 'merely possible' persons are also relevant when we refer, for example, to reproductive rights and the 'choice to reproduce or not'. Even though these are important issues, we do not address them here.

⁵⁵ We will discuss later, in Chapter 3, the importance of the debate between existence and non-existence and the partial applicability of Derek Parfit's 'Non-Identity problem' to our paper.

⁵⁶ Assisted reproductive technologies (ART), like in-vitro fertilisation (IVF), apply the PGD technique in order to remove eggs from women's ovaries before they are fertilised with sperm in a laboratory. Then, the embryo(s) without the genetic disorder is identified, chosen and re-implanted in the uterus.

⁵⁷ Roberts, Melinda A. *Abortion and the moral significance of merely possible persons: finding middle ground in hard cases*. Vol. 107. Springer Science & Business Media, 2010, page 41.

⁵⁸ Elliot, Robert. "Identity and the ethics of gene therapy." *Bioethics* 7.1 (1993): 27-40, page 27.

⁵⁹ These debates *are* related to the used of genetic modify techniques, but for this paper, we will focus only on future persons that will exist in the future.



2.3. Who do we consider a ‘future person’?

Future persons can be conceptualised as those who will be living later but who do not exist now.⁶⁰ Future persons are not distant persons because the consequences of our choices *can* harm them;⁶¹ nor actual persons because their “lifespans will not overlap with ours”⁶² and they will not become a person “at least several decades from now”.⁶³ In the future, as we have seen in Chapter 1, genetic modification techniques prior to birth may be applied in clinical trials. This paper will focus on future persons that clearly are “not someone who *might* exist, but someone who *will* exist”⁶⁴ with their genetic makeup modified by the use of these techniques.

2.3.1. Duties towards future persons

Hippocrates famously extolled two important benchmarks in the treatment of disease: “to help, or at least to do no harm”.⁶⁵ This principle means that we are both morally responsible for the consequences of our actions and for the consequences of our omissions,⁶⁶ at least when we have a duty to act. In any society, people’s interests are constantly interacting. We are “obviously linked together tightly in a cause-and-effect chain.”⁶⁷ Thus, conflicts will eventually arise resulting, sometimes, in actions that may threaten or damage others. “[W]e must ‘answer’ to someone for [these] acts after we

⁶⁰ Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 355.

⁶¹ *Ibid*, page 358.

⁶² Nickel, James W. "Ethical Protections for Future Persons: Is Their Present Non-existence a Serious Problem?." *Journal of Business Ethics* 127.4 (2015): 717.

⁶³ *Ibid*.

⁶⁴ Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998, page 16.

⁶⁵ Hippocrates. *Ancient Medicine. Airs, Waters, Places. Epidemics 1 and 3. The Oath. Precepts. Nutriment*. Translated by W. H. S. Jones. Loeb Classical Library 147. Cambridge, MA: Harvard University Press (1923), page 165.

⁶⁶ Rachels, James. "The end of life: euthanasia and morality." Oxford University Press, 1986.

⁶⁷ Sieger Derr Thomas. "The Obligations to the Future." In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 40.



commit them”,⁶⁸ meaning to have ‘responsibility’ over them. If the consequences of our choices would impact future persons, positively *or* negatively, then we should be responsible for those choices.

Nonetheless, it is complex to feature our obligations towards future persons. According to the ‘lifespan’ view of morality, people “who matter morally at present are exclusively the living ones”⁶⁹ assuring that they, as recipients, have “determinate identities.”⁷⁰ Future persons do not exist yet, so it is not possible to have a moral relationship with them.⁷¹ Reciprocity is, usually, how obligations can be featured.⁷² It means that if future generations will not be able to give anything in exchange or do anything for us, then we are not obey to do anything for them either. Self-interests, on the other hand, can be seen also as a feature of obligations. The duty of protecting the environment, for example, can be justified because we are not only protecting future persons’ interests but also our *present* health.⁷³

As features of obligations, both the application of reciprocity and self-interest⁷⁴ can be challenged.⁷⁵ Firstly, none of these postulates fully deny the moral value of future persons, but argue that “we can[not] have duties *to* them.”⁷⁶ Secondly, we can apply the principles of benevolence and non-maleficence, or the ‘do no harm’ principle for future persons, since we *are* morally responsible for the consequences of our actions. Thirdly, the use of genetic modification techniques prior to birth are not assuring any present benefit nor producing a social welfare for the community as a whole in present time. However, the consequences of our choices will affect future persons, thus, we *are* responsible for the impact these choices have on coming generations.

⁶⁸ Ibid, page 40.

⁶⁹ Nickel, James W. "Ethical Protections for Future Persons: Is Their Present Non-existence a Serious Problem?." *Journal of Business Ethics* 127.4 (2015): 717.

⁷⁰ Ibid.

⁷¹ Ibid.

⁷² Sieger Derr Thomas. "The Obligations to the Future." In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 39.

⁷³ Ibid, page 39.

⁷⁴ See Ibid, pages 37 to 44.

⁷⁵ Nickel, James W. "Ethical Protections for Future Persons: Is Their Present Non-existence a Serious Problem?." *Journal of Business Ethics* 127.4 (2015): 717.

⁷⁶ Ibid.



2.3.2. Different duties to different groups of persons

Many people argue that we have moral duties⁷⁷ towards future persons, and that we should value and care about their welfare.⁷⁸ Even though the existence of these moral responsibilities is not fully denied,⁷⁹ some⁸⁰ argue that they cannot “properly be categorized as *rights* of future persons.”⁸¹ The ‘obligations’ that we have for future persons are not the same as the ones that we have for people who exist now.⁸² “Obligations to future generations are essentially an obligation to produce – or to attempt to produce – a desirable state of affairs *for* the community of the future, to promote conditions of good living for future generations. The many things that we are obliged to do are founded upon this obligation.”⁸³ Thus, obligations to future persons are not immediate or specific legal codes with detailed duties⁸⁴ – we do not have specific acts to do (or to refrain from doing) towards future persons.

Likewise, these duties are ‘special’ because they are *owed* to someone who does not yet exist, so they are owed to an *unspecified* person.⁸⁵ If we say that we owe, at least, moral duties to future persons, then they are not “merely an incidental beneficiary”⁸⁶ of

⁷⁷ A *moral* person should have the ability “to distinguish right from wrong, to act on this distinction, and to experience pride when doing something right and to experience guilt or shame when doing something wrong.” (See: Sigelman, Carol K., and Elizabeth A. Rider. *Life-span human development*. Cengage Learning, 2014, page 596.)

⁷⁸ Nickel, James W. “Ethical Protections for Future Persons: Is Their Present Non-existence a Serious Problem?.” *Journal of Business Ethics* 127.4 (2015): 717, page 717.

⁷⁹ For persons who now exist there is an obligation to look after future generations’ welfare in relation, for example, to environment protection. “Ecologically-minded persons all *assume* this obligation to exist, and in fact their argument and concern are unintelligible without the sense that present practices are mortgaging the future.” (See: Sieger Derr Thomas. “The Obligations to the Future.” In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 37.)

⁸⁰ For a clear debate if future persons have rights or not, Joel Feinberg, Galen K. Pletcher and Annette Baier argue that they *can* have rights. On the contrary, Richard T. De George and Ruth Macklin claimed that they *cannot*. See Partridge (Ed.), *Responsibilities to Future Generations*. Buffalo: Prometheus Books, Part Three: pages 135 to 183.

⁸¹ *Ibid*, page 137.

⁸² Golding, Martin P. “Obligations to Future Generations.” Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 61.

⁸³ *Ibid*, page 62.

⁸⁴ *Ibid*, page 63.

⁸⁵ *Ibid*, pages 63-64.

⁸⁶ *Ibid*, pages 63-64.



them. Instead, we are accepting that future persons have a “presumptive right to it and can assert a claim against [us] for it”.⁸⁷ Therefore, we can affirm that future persons have *conditional* claims for *presumptive* rights, but do not have *full* rights yet.⁸⁸ It is worth highlighting that *making* a claim is different to *having* a claim.⁸⁹ The fact that future persons do not yet exist should not prevent them from being covered by *conditional* claims – conditional to their existence - that cannot be demand *by them* at a point in time, but that will become ‘enforceable’ when they exist. Furthermore, since we are assuming that they *will* exist in the future, their claims are not fictitious but *conditional*.⁹⁰ The same argument can be made for their presumptive rights.

In sum, we are not arguing whether we need to balance between obligations for future generations against our obligations to the present generations.⁹¹ But, we are saying that those obligations are different, and that we owe, at least, a moral duty to respect future persons because they have *presumptive* rights with *conditional* claims. “If future generations do not exist for us, we can, nonetheless, be certain that we *will have existed for them*.”⁹² Our attempts to use techniques that will introduce irreversible changes in their genetic makeup that cannot be undone, means that “we would, in effect, have imposed ourselves upon them, leaving them no option but to accept our legacy.”⁹³ The fact that future persons do not exist *yet* should not be translated to future persons having lesser moral status than ‘existing’ persons nor that we are not constrain to behave properly in order to care about them as we do with ‘existing’ persons.⁹⁴ Certainly, we can claim that we have moral obligations towards future persons, thus, we should abstain from making choices now that may harm them in the future.

⁸⁷ Ibid, pages 63-64.

⁸⁸ Ibid, pages 63-64.

⁸⁹ Ibid, page 64.

⁹⁰ Callahan, Daniel. “What Obligations Do We Have to Future Generations?” In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 82.

⁹¹ Ibid, page 81.

⁹² Ibid, page 73.

⁹³ Ibid, page 82.

⁹⁴ Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998, page 11.



Chapter 3

Harm

Our choices have consequences, both positive and negative, for future persons. Hence, we could claim that we have moral obligations towards them, and should refrain from making current choices that may harm them in the future. For our illustrative case, firstly, we will establish what we consider to be harm; secondly, we will define a baseline or starting point from which we may consider the existence of harm of future persons; and thirdly, we will discuss the possible ways they can be harmed.

At its core,⁹⁵ consequentialist theory concerns the maximization of the good⁹⁶ (which could be interpreted as the absence of wrongdoing to *some person*), hence, we can say that it *also* concerns harm. Thus, harm may be defined as any diminution or decrease in the baseline level⁹⁷ of a person's welfare, where welfare encompasses more than simple physical or psychological aspects.⁹⁸ In our illustrative case, genetic modification techniques may harm future persons, but it "is not a harm that will arise in *every* circumstances"⁹⁹ nor a harm that is ordinary or objectively identifiable. The harm we identify is not the mechanical collection and modification of the genome, but rather it is "finding oneself... or being unconsentedly placed in (whether one discovers it or not)"¹⁰⁰

⁹⁵ Traditional forms of consequentialism care about the "diminution of the total aggregate well-being across the entire population", and not the diminution of some *person* or the well-being of each person who ever exists (Roberts, Melinda A. "Cloning and Harming: Children, Future Persons, and the Best Interest Test." *Notre Dame JL Ethics & Pub. Pol'y* 13 (1999): 37, page 39-40). We have mentioned that the consequences of our choices may affect, in particular, the *specific person* who may be genetically modified. Thus, we use this theory in its simplest way of expression: maximised the good; rather than referring to theories or considerations as overall well-being, level of aggregate well-being, totalism, or averaging. For more information on these topics see: Sen, Amartya. "Inequality re-examined. Clarendon." (1992); Parfit Derek, *Reasons and Persons* 351-375 (1984); Feldman, Fred. "Justice, desert, and the repugnant conclusion." *Utilitas* 7.02 (1995): 189-206.

⁹⁶ Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998, pages 1 and 4.

⁹⁷ Roberts, Melinda A. "Cloning and Harming: Children, Future Persons, and the Best Interest Test." *Notre Dame JL Ethics & Pub. Pol'y* 13 (1999): 37, page 39.

⁹⁸ *Ibid*, page 39.

⁹⁹ *Ibid*, page 42.

¹⁰⁰ *Ibid*, page 55.



a situation where our genetic makeup has been modified prior to our existence. For this reason, it is essential to facilitate a broader and more open discussion about possible non-ordinary harm towards future persons and an appropriate baseline level for these types of harm.

3.1. Baseline

John Stuart Mill's 'Principle of Harm' (stated in his essay *On Liberty*¹⁰¹) asserts that the only justifiable way that a state can interfere with the liberty of individuals is by preventing harm to others.¹⁰² Mill's intentions were to construct a general and very simple principle that can be capable of governing individuals among society.¹⁰³ The intervention¹⁰⁴ in people's right to liberty over their actions or omission against their will intends must intend to prevent the harm of the interests of others.¹⁰⁵ Mill "never clearly indicates where to draw the line on "harm"."¹⁰⁶ Many scholars have proposed different restrictions on what can be qualified as 'harm',¹⁰⁷ most referring to the violation of

¹⁰¹ Mill, John Stuart. "On liberty." *A Selection of his Works*. Macmillan Education UK, 1966. 1-147.

¹⁰² Ogunkoya, A. D. "John Stuart Mill's 'Harm Principle' as the Foundation for Healthy Social Relations." *The Journal of International Social Research* 4.17 (2011): 516-532, page 520.

¹⁰³ Ibid, page 520.

¹⁰⁴ Criticisms and debates have risen after Mill's essay, in reference to liberty and self-interest, but we are not going to discuss them in this paper. We are using his arguments to understand more the principle of harm in reference to future persons and the need to draw a different base line. However, we are not arguing in detail about moral obligations, imperfect or perfect duties, rights-violation view or justice and justifiable social interference. See Turner, Piers Norris. "'Harm' and Mill's Harm Principle." *Ethics* 124.2 (2014): 299-326.

¹⁰⁵ Ogunkoya, A. D. "John Stuart Mill's 'Harm Principle' as the Foundation for Healthy Social Relations." *The Journal of International Social Research* 4.17 (2011): 516-532, page 520.

¹⁰⁶ Turner, Piers Norris. "'Harm' and Mill's Harm Principle." *Ethics* 124.2 (2014): 299-326, page 300.

¹⁰⁷ For instance, "injury to the vital interests of others," where these comprise the interests in autonomy and in security" (Gray, John. *Mill on liberty: a defence*. Routledge, 2013, page 57); actions that "violate or threaten imminent violation of those important interests of others in which they have a right" (Brink, David O. "Mill's liberal principles and freedom of expression." *Mill's On Liberty. A Critical Guide* (2008): 46-49, page 42); "violation of vital interests of others, and not . . . less weighty matters" (Donner, Wendy. "Autonomy, tradition, and the enforcement of morality." *Mill's On Liberty: A Critical Guide* (2008): 138-164, page 161); "prejudice to fundamental interests" (Dyzenhaus, David. "John Stuart Mill and the harm of pornography." *Ethics* 102.3 (1992): 534-551, page 546); "perceptible damage experienced against one's wishes" (Riley, Jonathan. "JS Mill: On Liberty." Routledge, 1998, page 99). All mentioned in Turner, Piers Norris. "'Harm' and Mill's Harm Principle." *Ethics* 124.2 (2014): 299-326, page 300.



existing rights or interests.¹⁰⁸ For future persons (with presumptive rights only), then, we should propose a different baseline for the possible harm inflicted.

In reference to Mill's notion of harm,¹⁰⁹ we can say that a conduct is 'harmful' if and only if a person is 'worse off' as a consequence of that conduct. Being 'worse off' means a detrimental variation in state relative to a previous state in which the person is 'better off'.^{110 111} Thus, the genetic modification prior to birth is harmful to the future person who will be born with a 'new' genetic makeup *if and only if* the future person is 'worse off' after this genetic modification, *and* the harm to its genetic integrity *is caused by* the genetic modification.¹¹² This *comparative account of harm*¹¹³ implies a comparison of a previous state when the person was 'better off'.¹¹⁴ However, given the fact that existing is always preferred to not existing,¹¹⁵ and given the fact that future persons do not exist at the time of the genetic modification, this comparative account fails to identify any harm inflicted upon the genetically modified person prior to birth.

By using a *non-comparative account of harm*, on the other hand, we can say "an action harms a person if it causes that person to be in a bad state."¹¹⁶ A 'bad state' is bad *in itself*, and not because it has been compared with a 'good state' or with a previously

¹⁰⁸ Turner, Piers Norris. "'Harm' and Mill's Harm Principle." *Ethics* 124.2 (2014): 299-326, page 300.

¹⁰⁹ Feinberg, Joel. "Wrongful life and the counterfactual element in harming." *Social Philosophy and Policy* 4.01 (1986): 145-178, page 146.

¹¹⁰ Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214, page 201.

¹¹¹ Also, "'worse off' could be taken to refer, either to someone's level of happiness, or more narrowly to his standard of living, or, more broadly, to the quality of his life." (See: Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, pages 357 and 358)

¹¹² Using the following equation as a base: "[a] person P is harmed by an act (or an event) *a* iff, as a result of *a*, P is made worse off in terms of well-being." (Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214, page 200).

¹¹³ For a better understanding between comparative and non-comparatives accounts of harm see: Ibid. For supporters of non-comparative account of harm see: Harman, Elizabeth. "Harming as causing harm." *Harming future persons*. Springer Netherlands, 2009. 137-154. For criticism to this type of account see: Bradley, Ben. "Doing away with Harm." *Philosophy and Phenomenological Research* 85.2 (2012): 390-412.

¹¹⁴ Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214.

¹¹⁵ We will address Derek Parfit's 'Non-Identity' problem and the debate between existence and non-existence later in this Chapter.

¹¹⁶ Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214, page 203.



established baseline.¹¹⁷ Hence, future persons may possibly be harmed under this framework. Here, harm does not necessarily depend on a comparison of a previous state, but instead on an act (or choice) that harms them.

In addition to the complexity of creating a baseline under these circumstances, future persons may be harmed but they may also be 'better off'. By 'better off' we are referring to the fact that the genetic modification prior to birth will change a specific gene, which will prevent future persons from suffering a deadly genetic disease during their lifetime. Future persons, then, may be harmed by someone's action even though they will actually be 'better off' with their 'new' genetic makeup relative to the one that they were supposed to be born with *but for* the genetic modification.¹¹⁸ Hence, this paper proposes that a *counterfactual baseline*¹¹⁹ is appropriate for our illustrative case. Future persons are harmed by someone's act, when they are thus made 'worse off' in comparison to a situation where someone doesn't perform the act.¹²⁰

The application of this baseline needs to take into account some specific considerations. Firstly, we are not arguing that this baseline should be generally applied for all cases of possible harm towards future persons, but for our illustrative case only. There is no exact formula for this baseline, so it will depend on the different interpretations and forms of harm. Secondly, we are not addressing the harms associated *omissions*.¹²¹ For our illustrative case, if this *act* doesn't occur, future persons would certainly suffer a deadly genetic disease during their lifetime. Thus, if the genetic modification is not causing ordinary harm to future persons and if is the use of the genetic modification

¹¹⁷ Harman, Elizabeth. "Harming as causing harm." *Harming future persons*. Springer Netherlands, 2009. 137-154.

¹¹⁸ Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214, page 208.

¹¹⁹ Which means: "Individual P1 is harmed by P2 iff: by doing (or allowing) act a, P2 brings it about that P1 is worse off in terms of well-being than P1 would have been in the absence of a." (Ibid, page 208).

¹²⁰ We can also refer to other alternative baselines, which in our opinion, are not appropriate for our illustrative case. For example, temporal baseline: "Individual P1 is harmed by P2 iff: by doing (or allowing) act a, P2 brings it about that P1's well-being after a is lower than it was *prior to a*" (See more in: Pogge, Thomas. 2010. *World poverty and human rights*. Cambridge: Polity, 2010, page 19); the baseline from mankind: "Individual P1 is harmed by P2 iff: by doing (or allowing) act a, P2 brings it about that P1's level of well-being is *lower than the well-being for mankind*" (See more in: Harrosh, Shlomit. "Identifying harms." *Bioethics* 26.9 (2012): 493-498). As mentioned in Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214, pages 203 – 208.

¹²¹ Kagan, Shelly. 1998. *Normative ethics*. Boulder, CO: Westview Press, page 84-85.



technique is also not causing harm *per se* (because we suppose that the techniques are safe and risk-free), then what *is* being harmed?

3.2. What is being harmed?

As consequences of different types of wrongdoings, people may suffer different types of harms, for example, physical harm, in reference to the body; emotional harm, in reference to the ability to express emotions; or psychological harm, in reference to the mind and cognitive processes.¹²² For our illustrative case, we will discuss the possibility of future persons being harmed, physically and psychologically (i.e. *ordinary harm*), as well as a more extended view of those harms: *harm to their genetic identity and genetic integrity*.¹²³

Physical harm includes a wrongdoing upon someone's else body, goods, land, economic interests, liberty or reputation.¹²⁴ In our illustrative case, at the time of the putative harm, future persons have no legal recognition, no existing rights or physical body that can be damaged, thus, there is no *ordinary* physical harm. Psychological harm, on the other hand, is more complicated. People vary in the way they assimilate and manage information that may cause psychological harm.¹²⁵ On the one hand, knowing about (and modifying) our genetic information "can be helpful for preventing and treating diseases."¹²⁶ On the other hand, "upon learning that he or she has unconsentedly been placed in a situation in which he or she"¹²⁷ has been genetically modified may possibly cause extensive psychological injury, including "anxiety,

¹²² Which we will refer as 'ordinary harms'.

¹²³ In reference to gene editing techniques prior to birth, as with reproductive techniques, future persons may have possible physical harms from the manipulation of embryos, and possible psychological harms from the diminishing of individuality and personal autonomy. However, in reference to the distinctions that have been made, this paper will not be addressing any of *these* possible harms. (See: National Bioethics Advisory Commission. "Cloning human beings: Report and recommendations of the National Bioethics Advisory Commission." (1997), pages 63-65, and 79-82).

¹²⁴ Oliphant, Ken. *The law of tort*. LexisNexis Butterworths, 2007.

¹²⁵ Weir, Tony. *An introduction to tort law*. Oxford University Press, 2006, page 51.

¹²⁶ International Bioethics Committee. "Report of the IBC on updating its reflection on the human genome and human rights." *United Nations Educational, Scientific, and Cultural Organization, Paris* (2015), para 12.

¹²⁷ Roberts, Melinda A. "Cloning and Harming: Children, Future Persons, and the Best Interest Test." *Notre Dame JL Ethics & Pub. Pol'y* 13 (1999): 37, page 48.



uncertainty [becoming] a significant moral burden.”¹²⁸ The possible psychological distress will depend on the person. For our illustrative case, if this unconsented genetic modification does not occur, future persons would certainly suffer a deadly genetic disease during their lifetime. *If* the single intention was to prevent such a genetic condition in the future, the psychological harm associated with discovering that we were genetically modified prior to birth seems far less compelling.

We want, and expect, *to have control* over our body, and this includes control over our genetic information. However, the “unconsented placement of ourselves by others”¹²⁹ in a situation where our genetic information has been modified, certainly, detracts from our *control over* our body. This lack of the control comprises of our genetic identity and genetic integrity.¹³⁰ Thus, we may argue that the loss of control over future persons’ genetic makeup constitutes harm.¹³¹ In order to discuss the possible harm to future persons’ genetic identity, it is important to understand the construction of *personal* identity.

3.2.1. Harm to personal identity

Noam Zohar believed that genetic procedures should not be permitted as a treatment under “the special moral duty of providing health care.”¹³² These procedures would not *directly* benefit and may even harm future persons, thus, they do not qualify as *therapies*. This argument, made by Zohar, clearly states the importance of “the basic philosophical problem of personal identity persisting through significant alterations - especially the alteration of genotype.”¹³³

“The question of what constitutes personal identity is not a new one, but it has been

¹²⁸ International Bioethics Committee. "Report of the IBC on updating its reflection on the human genome and human rights." *United Nations Educational, Scientific, and Cultural Organization, Paris* (2015), para 12.

¹²⁹ Roberts, Melinda A. "Cloning and Harming: Children, Future Persons, and the Best Interest Test." *Notre Dame JL Ethics & Pub. Pol'y* 13 (1999): 37, page 46.

¹³⁰ *Ibid*, page 48.

¹³¹ *Ibid*, pages 49 and 50.

¹³² Zohar, Noam J. "Prospects for “genetic therapy”-can a person benefit from being altered?." *Bioethics* 5.4 (1991): 275-288, page 275.

¹³³ *Ibid*, page 275.



given a new twist in the light of developments in human genome analysis.”¹³⁴ For many years, psychological and physical features were the main criterions of the concept of personal identity.¹³⁵ Based on this features, many philosophers have also discussed the importance of the criterion of identity *over-time*,¹³⁶ as well as the *continuity* of the body and the mind.¹³⁷ All these theories of identity are predominantly focused on how personal identity is constructed *after* the person is born, and how identity can change during a lifetime – the *continuity over time* requirement. The putative harm on future persons’ identity may occur in a previous state when they are not persons yet. Thus, there is not clear interruption to psychological or physical *continuity*.

In addition, the change in the genetic makeup, which aims to alleviate genetic conditions, will have a *delayed* effect on future persons.¹³⁸ The impact or change will be felt only after they become ‘existing’ persons. Thus, the modification “is not itself massively disruptive of psychological continuity.”¹³⁹ The genetic modification will determine a future person’s health condition, but will still remain “a psychological continuity between all stages of the persons”¹⁴⁰ after they are born. Hence, there is no ordinary harm inflicted to future person’s personal identity under these circumstances

¹³⁴ Chadwick, Ruth. "Personal Identity: Genetics and Determinism." *eLS* (2003), page 1.

¹³⁵ According to the *physical* criterion, in order to determine personal identity, the *physical continuity* of the whole body of a person is not necessary, but instead, only of a sufficient part of the brain to be considered the brain of a living person. The *psychological* criterion concerns the continuity of “a purely mental *entity*, or thing - a soul, or spiritual substance.” Also known as the Cartesian theory. (See: Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, pages 204 and 205) John Locke, on the other hand, suggested that experience-memory provides the criterion of personal identity, and is founded on our consciousness (as *psychological continuity*) rather than in our soul. He argues that we cannot refer to the continuity of the body, the brain or the soul, but instead on the continuity of our *memory*. Memory, as he suggested, is what “makes most of us aware of our own continued existence over time” (See: Locke, John. *An essay concerning human understanding*. 1841, section 16). As a criticism to this assumption, Joseph Butler argues that Locke’s argument is a ‘wonderful mistake’ but identity cannot be founded on consciousness because the consciousness *presupposes* identity (See: Personal Identity in Butler, Joseph. *The analogy of religion, natural and revealed, to the constitution and course of nature: to which are added, two brief dissertations: on personal identity, and on the nature of virtue; and fifteen sermons*. HG Bohn, 1856, p. 100). As well, Thomas Reid, argued that personal identity cannot be found on memory, but on a *chain of memories* or continuity of memories (See: Reid, Thomas, James Walker, and William Hamilton. *Essays on the intellectual powers of man*. J. Bartlett, 1850, pp. 317–318). Butler and Reid, in sum, disagree with Locke on what identity consist of, but agree on other parts of its argument. (See: Nimbalkar, Namita. "John Locke on personal identity." *Mens sana monographs* 9.1 (2011): 268).

¹³⁶ Locke, John. *An essay concerning human understanding*. 1841, section 16.

¹³⁷ Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 203.

¹³⁸ Elliot, Robert. "Identity and the ethics of gene therapy." *Bioethics* 7.1 (1993): 27-40, page 39.

¹³⁹ *Ibid*, page 39.

¹⁴⁰ *Ibid*, page 39.



either.

The development of personal identity includes internal and socio-contextual dimensions.¹⁴¹ “Because identity is a transitive relation, the criterion of identity *must* be a transitive relation.”¹⁴² In fact, according to Erikson (1968), identity has bipolar dimensions representing, first, the transition between childhood and adult identification resulting in self-identified ideas, and second, the inability to work out all these transitions and different ideas to have an adult identity.¹⁴³ Indeed, identity can be constructed through the person’s life cycle, from childhood to adolescence to adulthood.¹⁴⁴ Memory theory, for instance, appears to work only from childhood whence people remember themselves, and not before.¹⁴⁵ Most recently, postmodern theorists have argued that identity is not based on biological matters, but rather that it is a social or individual construction.¹⁴⁶ If identity is transitive and a continuous construction during our lifetime *starting* from childhood, then, the genetic modification prior to birth cannot harm this development path either.

3.2.1.1. Derek Parfit’s Non-Identity Problem

At first might seem that we are entering in Derek Parfit’s ‘Non-Identity Problem’, but there is an important distinction between the definition of identity that we have mentioned (about continuity and construction over-time) and the debate about existence or non-existence of future persons. According to Parfit, the consequences of our choices will affect the number of people who will exist in the future as well as their

¹⁴¹ Erikson, Erik H. *Identity: Youth and crisis*. No. 7. WW Norton & Company, 1994.

¹⁴² Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 206.

¹⁴³ The former is identity *synthesis* and the latter is identity *confusion*. “The individual still possesses enough self-knowledge to survive in the late modern era and to make consistent and useful choices (i.e., personal and social aspects of identity). On the other hand, the individual should be clear that there are aspects of himself or herself of which he or she is not consciously aware (i.e., the most fundamental aspects of his or her identity).” (See: Schwartz, Seth J. “The evolution of Eriksonian and, neo-Eriksonian identity theory and research: A review and integration.” *Identity: an international journal of theory and research* 1.1 (2001): 7-58)

¹⁴⁴ Erikson, Erik H. *Identity: Youth and crisis*. No. 7. WW Norton & Company, 1994.

¹⁴⁵ Zohar, Noam J. “Prospects for “genetic therapy”-can a person benefit from being altered?.” *Bioethics* 5.4 (1991): 275-288, page 280.

¹⁴⁶ Foucault, Michel. *The birth of the clinic*. Routledge, 2012.



identity or whom they are when they exist.¹⁴⁷ For Parfit, “an action, state of affairs, or world, cannot be wrong, or bad, unless it would wrong, or be bad for, someone.”¹⁴⁸ Something *bad*, even though it does not have an impact now may be bad for someone in the future.¹⁴⁹ Our choices will not be *bad* for anyone now but may have negative effects on future persons, so we have a moral reason not to make these choices.¹⁵⁰ For instance, if we choose to delay conception by a month, the future person who will exist would not be the same person that would have existed if we had have chosen to conceive immediately. Hence, according to the Non-Identity Problem, we have affected the latter by not letting him/her to exist,¹⁵¹ which reflects how “easily [we can] affect the identities of future people.”¹⁵² Parfit’s argument take us into debates about how “life cannot be judged to be either better or worse than nonexistence,”¹⁵³ or how a life worth living or worth not living will be better than nothing or than non-existence.¹⁵⁴ Parfit’s philosophical paradigms¹⁵⁵ can be applied in our illustrative case as follows: firstly, some persons have lives so tragic that life itself is harmful; secondly, despite the harm that may be caused, they exist and have, at least, a decent life to live.¹⁵⁶ In reference to the aforementioned *counterfactual baseline*, future persons would certainly suffer a deadly genetic disease during their lifetime without the genetic modification; thus, their lives may be so tragic that life itself will be harmful. Hence, the intrusion of

¹⁴⁷ Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 355.

¹⁴⁸ Roberts, Melinda A. *Child versus childmaker: future persons and present duties in ethics and the law*. Rowman & Littlefield, 1998.

¹⁴⁹ Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 363.

¹⁵⁰ The ‘Three Kind of Choices’ of Derek Parfit arise because of our great ability to affect future persons, thus, we should know the consequences and the effects of those choices, and then morally decide which one is better – moral Theory X. The first kind of choice is called ‘Different Number Choices’ that will affect the number and identities of future persons; the second is ‘Same Number Choices’ that will affect the identities of future persons but no their number, because different future persons will exist depending in the action or decision that we make, but their number will be the same; and the third, ‘Same People Choices’ that affect neither, because the same future persons (in number and identity) will still exist regardless which action or decision we make. (See: *Ibid*, pages 355-357)

¹⁵¹ *Ibid*, page 377.

¹⁵² *Ibid*, page 377.

¹⁵³ *Ibid*, 1984, page 487.

¹⁵⁴ *Ibid*, page 487.

¹⁵⁵ These philosophical paradigms, usually, are focused on the magnitude of the injury, on debates about existence and non-existence, on unnecessary and necessary future suffering, and between quality of life and quantity of persons that may exist in the future (See: *Ibid*, pages 356 - 357).

¹⁵⁶ Peters Jr, Philip G. "Harming future persons: obligations to the children of reproductive technology." *S. Cal. Interdisc. LJ* 8 (1998): 375, page 375.



their genetic makeup may be justified and headed by necessity. The *necessity*, in our case, exists because if this *act* doesn't occur, future persons would certainly suffer a deadly genetic condition. Despite the intrusion, they will exist and have, at least, a decent life to live.

The non-identity problem, and especially the argument between existence and non-existence, is problematic. We may try to compare concepts out of our range of knowledge, like non-existence with life itself.¹⁵⁷ Some argue that the intrusion to future persons' genetic integrity is only justified if without it they would not have been conceived.¹⁵⁸ This argument may be too strict, but it cannot be totally disregarded, especially in circumstances where the future persons' genetic modification would always be better than not being born. However, our illustrative case refers to the notions of possible harm inflicted to future persons as a consequence of being genetically modified, but not to the *possibility* of existence of future persons. We are assuming that they *will* exist.

Parfit's argument can be applied in the analysis of how our choices can affect future persons and how their life will be 'better off' even though a possible harm may be inflicted – *justified* harm. "We should revise the ordinary use of the word 'harm.' If what we are doing will not be worse for some other person, or will even be better for this person, we are not, in a morally relevant sense, harming this person."¹⁵⁹ The genetic modification *per se* will not necessarily *harm* future persons according to physical or psychological identity criterions. Thus, future persons may be harmed in some other ways, for instance, with respect to their genetic identity and genetic integrity.

3.2.2. Harm to genetic Identity

Extensions to the aforementioned philosophical postures are being developed. Now there is "a new type of physical account, [which] has been the interpretation of personal

¹⁵⁷ National Bioethics Advisory Commission. "Cloning human beings: Report and recommendations of the National Bioethics Advisory Commission." (1997), page 66.

¹⁵⁸ Peters Jr, Philip G. "Harming future persons: obligations to the children of reproductive technology." *S. Cal. Interdisc. LJ* 8 (1998): 375, page 383.

¹⁵⁹ Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 374.



identity as consisting in the genes.”¹⁶⁰ In addition, identity can be *also* seen “*as certain properties of the person* [including] certain [features such as] sex, ethnicity or personality”.¹⁶¹ Hence, the possible harm to future persons’ identity should be analysed considering all these different features. In a similar vein to Kristin Zeiler,¹⁶² we are shifting from the classic considerations of what constitutes a person,¹⁶³ to a focus on future persons as *genetic* persons and the possible harm to their *genetic* integrity.

Genes are claimed to be physical features of personal identity, so they “are subject to the problems of how to account for division.”¹⁶⁴ A human genome, for instance, “is the sum of the estimated three billion pairs of bases that form the approximately twenty-eight thousand to thirty-five thousand genes in humans.”¹⁶⁵ Each person (and each future person) has (and will have) their own and unique genome, which is part of the physical account of their genetic identity.¹⁶⁶ The idea that genes are part of psychological features, on the other hand, is not as simple as that of physical features. There is still no exact answer to the question of “what degree our genes determine the kind of character and psychological characteristics that we develop.”¹⁶⁷ However, our genetic makeup contains ‘information’ that is going to be passed onto the genes of our descendants and will thus determine our genetic heritage. Hence, this information will form part of our psychological characteristics but *in itself* cannot clearly determine our personal identity.

Some may argue that in order to do no harm to someone’s genetic identity, not *all* but *most* of the genome must remain the same.¹⁶⁸ Thus, what sort of changes may be considered as an ordinary harm to future persons’ genetic identity and in what

¹⁶⁰ Chadwick, Ruth. "Personal Identity: Genetics and Determinism." *eLS* (2003), page 1.

¹⁶¹ Zeiler, Kristin. "Who am I? When do “I” become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 26.

¹⁶² *Ibid.*

¹⁶³ Zeiler, shifted from considerations of identity as a set of properties or identity-over-possible worlds to identity-over-time. (See: *Ibid.*, page 26.)

¹⁶⁴ Chadwick, Ruth. "Personal Identity: Genetics and Determinism." *eLS* (2003), page 2.

¹⁶⁵ Taussig, Karen-Sue. *Ordinary genomes: science, citizenship, and genetic identities*. Duke University Press, 2009, page 58.

¹⁶⁶ *Ibid.*, page 58.

¹⁶⁷ Chadwick, Ruth. "Personal Identity: Genetics and Determinism." *eLS* (2003), page 2.

¹⁶⁸ Zeiler, Kristin. "Who am I? When do “I” become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 28.



extension would this change “count as losing the properties that define someone as a person”?¹⁶⁹ The foundation of the idea of genetic information, from a functional perspective, is that the “essential identity of the whole is in the organization and interrelationship of its parts - and it is this which is encoded in the genetic ‘blueprint’.”¹⁷⁰ Thus, a minimal change will not affect future person’s phenotype.¹⁷¹ In our case, there will be a genetic alteration but not necessarily enough to change future persons’ genetic identity¹⁷² or their phenotype; thus, future persons will remain *approximately genetically identical over-time*.¹⁷³ Being *genetically identical over-time* means that the person “is the same as regards a certain gene or certain genes” (and not necessarily the whole genome).¹⁷⁴ Identity is the construction of many different features that change over time. Hence, the genetic modification will partially modify a specific part of one of these features, but does not necessarily imply harm in the way we construct our identity as persons.¹⁷⁵

Genetics do not determine the *whole* identity of future persons,¹⁷⁶ thus, a small and specific genetic modification in their genetic makeup does not clearly harm their identity. However, we cannot imply that “[o]ur genes may [not] play a very important role in our

¹⁶⁹ Olson, Eric T., "Personal Identity", The Stanford Encyclopedia of Philosophy (Spring 2016 Edition), Edward N. Zalta (ed.), URL = <<http://plato.stanford.edu/archives/spr2016/entries/identity-personal/>>

¹⁷⁰ Zohar, Noam J. "Prospects for “genetic therapy”-can a person benefit from being altered?." *Bioethics* 5.4 (1991): 275-288, page 285.

¹⁷¹ Phenotype, as a set of observable traits that result from the interaction between genes and environment. (See: *Ibid*, page 285).

¹⁷² *Ibid*, page 279.

¹⁷³ For our illustrative case, we will not be addressing *genomic identity over time*, but only *genetic identity over time*. The former means the total genetic information in someone’s cells, and to be *genomic identical over time* or do not have any harm to our genomic identity, all the cells *needs* to remain the same. However, we are considering the existence of a genetic modification in future person’s genetic makeup, so it is not appropriate to include this distinction in this paper work. (See: Zeiler, Kristin. "Who am I? When do “I” become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32)

¹⁷⁴ Zeiler, Kristin. "Who am I? When do “I” become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 25.

¹⁷⁵ Applying Derek Parfit’s argument, in fact, future persons wouldn’t be different or another person, because they would have not existed. (Parfit, Derek. *Reasons and persons*. OUP Oxford, 1984, page 351)

¹⁷⁶ Zeiler, Kristin. "Who am I? When do “I” become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 29.



sense of who we are"¹⁷⁷ nor that there *is not* a relationship between future persons' genetic information and their identity.¹⁷⁸

Additionally, because of constant *natural* mutations in our genome during our lifetime, *exact genomic identity* is not possible.¹⁷⁹ If the genome is going to change over time, we cannot argue that the genetic modification prior to birth is clearly harming future persons' genetic identity. However, if we distinguish between natural mutations¹⁸⁰ and mutations resulting from human intervention, then a possible harm *may* be identified.

3.3. Genetic integrity

In accordance with Kristin Zeiler, we also believe that genetics have an impact on identity. The philosophical postures of identity can be brought together, creating a 'multi-layered' concept of identity, in order to expand the possible harm that may be inflicted on future persons.¹⁸¹

The concept of 'genetic integrity' is not new, but it has been predominantly used in reference to animals and plants rather than human beings. Jan Vorstenbosch, in 1993, questions whether genetic modification on animals can be also stated in terms of integrity.¹⁸² For him, integrity meant "wholeness', 'intactness', [and] an 'unharmful or

¹⁷⁷ Chadwick, Ruth. "Personal Identity: Genetics and Determinism." *eLS* (2003), page 2.

¹⁷⁸ Nordgren, Anders, and Eric T. Juengst. "Can genomics tell me who I am? Essentialistic rhetoric in direct-to-consumer DNA testing." *New Genetics and Society* 28.2 (2009): 157-172.

¹⁷⁹ This view is also known as the *exact genetic identity over-time*, which for our illustrative case means that after the genetic modification, a future person will be born different but not necessarily *another* person. (See: Zeiler, Kristin. "Who am I? When do "I" become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, pages 28 and 30).

¹⁸⁰ Our paper is not about the details of the possible mutations in future person's genetic makeup, however, it is important to mention the types of mutations and some of its effects. For example, "functional genomic identity-over-time is present also when the exact genomic identity is changed over time by point mutations (which may have severe effects) *as long as* these mutations do *not* result in changed functions of the genome as a whole. Sequential genomic identity-over-time is present when the order of the constituents of the whole genome remains the same over time." (See: Zeiler, Kristin. "Who am I? When do "I" become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 29).

¹⁸¹ Zeiler, Kristin. "Who am I? When do "I" become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 25.

¹⁸² Vorstenbosch, Jan. "The concept of integrity. Its significance for the ethical discussion on biotechnology and animals." *Livestock Production Science* 36.1 (1993): 109-112, page 109.



undamaged' state of something, presumably a living being."¹⁸³ Genetic integrity, then, is the condition of the genome being 'whole' or undivided,¹⁸⁴ which includes not only the "the sum of the estimated three billion pairs of bases that form the approximately twenty-eight thousand to thirty-five thousand genes in humans",¹⁸⁵ but also the combination of all the different criteria of personal identity (including traditional features of identity, genetic identity, and the additional *properties* of identity).

Genetic integrity may have different subjects such as animals, plants or human beings. For our illustrative case, the subjects who are being harmed are future persons, because even if they do not exist at the time of the genetic modification, they *do* exist as genetic persons. This special *categorisation* of future persons as *genetic persons* may allow us to extend the protection of some legal frameworks towards future persons.

The definition of genetic integrity is linked to genetic modifications through human actions and the moral responsibilities of these actions.¹⁸⁶ The condition of the genome being undivided implies that any intrusion will jeopardise future persons' genetic integrity. Hence, this definition could address concerns about the moral responsibility of the consequences of the intrusion in the wholeness of the genome.

The next question to answer is the extent to which future person's genetic integrity is the same before and after this *intrusion*.¹⁸⁷ Kristin Zeiler has tried to answer this question in similar circumstances. She uses a *multi-layered concept of identity-over-time*, where *personal identity-over-time* is understood to be one layer and *genomic identity-over-time* as another layer.¹⁸⁸ This differentiation between layers allows Zeiler to have grades of difference, where a person can be identical to someone else with respect to one layer, but different with respect to another layer.¹⁸⁹

¹⁸³ Ibid, page 110.

¹⁸⁴ Ibid, page 110.

¹⁸⁵ Taussig, Karen-Sue. *Ordinary genomes: science, citizenship, and genetic identities*. Duke University Press, 2009, page 58.

¹⁸⁶ Vorstenbosch, Jan. "The concept of integrity. Its significance for the ethical discussion on biotechnology and animals." *Livestock Production Science* 36.1 (1993): 109-112, page 111.

¹⁸⁷ Zeiler, Kristin. "Who am I? When do "I" become another? An analytic exploration of identities, sameness and difference, genes and genomes." *Health Care Analysis* 15.1 (2007): 25-32, page 26.

¹⁸⁸ Ibid, pages 26 and 27.

¹⁸⁹ This perspective, for instance, can be applied to embryos in the PGD technique. The selected or chosen embryo, before fertilisation, is numerical, qualitative and *genetically identical* as the rest of the embryos that were not chosen. But, after fertilisation, the chosen embryo may be genetically *different* in



However, our argument may go further than this. We consider all the different features of identity-over-time not as different layers, but as a single construction that includes all layers as a 'whole': *genetic integrity*. Genetic integrity cannot be decomposed into different layers because they are mutually integrated, and part of a whole *genetic person*. Hence, individually, any of these features cannot clearly determine a person's identity *by itself*.¹⁹⁰ Thus, the magnitude of the genetic modification does not matter in determining the harm to future persons' genetic integrity, just that an intrusion *occurred*.

comparison to the others. (See: Ibid, page 30).

¹⁹⁰ Elliot, Robert. "Identity and the ethics of gene therapy." *Bioethics* 7.1 (1993): 27-40, page 37.



CHAPTER 4

Conventional legal analysis of harm

The intrusion on future person's genetic makeup may *unconventionally harm* their *genetic integrity*. In this Chapter, we will address the possible ways to extend the application of some of the current legal frameworks in order to be applicable for future persons. We will address the conventional legal analysis of harm, using the law of tort as a reference, and the reasons why this conventional analysis is not appropriate for our illustrative case. Moreover, we will analyse the protection of personal identity and personal integrity under the international law of human rights, and see if this protection can be extended to future person's genetic integrity.

4.1. Legal Wrongs

For legal wrongs, the law will usually have a form of redress for the victim or claimant.¹⁹¹ The law of tort is applied by courts in civil procedures sustained by someone who claims to have suffered injury or damage as a result of the wrongful act of another,¹⁹² and its main role is to compensate the victim and to vindicate essential rights that were inflicted.¹⁹³ So, the law of tort "is about when 'liability' exists, and 'a tort' is conduct which renders the defendant liable unless he has some defence."¹⁹⁴ Hence, not all acts or omissions that contradict a moral code or that are socially unacceptable can be considered as tort. Liability "arises from the breach of a duty primarily fixed by law"¹⁹⁵ and varies in accordance to the type of tort that is being claimed. The court will use a 'conventional analysis' of elements like liability, intentional injury, justifiable conduct,

¹⁹¹ Winfield, Percy Henry, John Anthony Jolowicz, and William Vaughan Horton Rogers. *Winfield and Jolowicz on tort*. Sweet & Maxwell, 1971, 12th ed., pages 1-2.

¹⁹² *S.C.M. (United Kingdom) Ltd. v. Whittall and Son Ltd.* [1971] 1 Q.B. 337, 247-348, per Winn L.J.

¹⁹³ Oliphant, Ken. *The law of tort*. LexisNexis Butterworths, 2007, page 1.

¹⁹⁴ Weir, Tony. *An introduction to tort law*. Oxford University Press, 2006, page 1.

¹⁹⁵ Winfield, Percy Henry, John Anthony Jolowicz, and William Vaughan Horton Rogers. *Winfield and Jolowicz on tort*. Sweet & Maxwell, 1971, 12th ed., page 3.



magnitude of harm, and the proximity between the claimant and the defendant. Such conventional legal analysis is readily applicable to ordinary and straightforward harm,¹⁹⁶ such as a wrongdoing over someone else's body, goods, land, economic interests, liberty or reputation.¹⁹⁷

In addition, some tort cases require the analysis of the intention of the defendant, which can only be deduced by its conduct.¹⁹⁸ Intention can be inferred by the claimant's knowledge of the consequences of his actions and the desire to bring about those consequences.¹⁹⁹ In our illustrative case, whereby the defendant acts intentionally with full knowledge of the result of the technique, and whereby the harm seems to be justified by the improvement of the quality of life of the person in the future. Hence, the intention is clear - *to avoid future persons from suffering a genetic condition*; the harm is known – *the intrusion to future person's genetic integrity*; thus, the desire to act may be justifiable.

The conventional legal analysis focuses on loss, such as injuries, loss of earning capacity and loss of property. Nonetheless, our illustrative scenario does not concern something being 'lost'. On the contrary, future persons are genetically modified in order to avoid a future loss, like being a victim of a genetic condition that may cause them a premature death.

4.1.1. The law of tort as a reference

In a tort case, in which 'A hurt B', the conventional analysis is required to answer three main questions. Firstly, what did A do (conduct)? Secondly, what did B suffer as a consequence (effect of the conduct - harm)? And thirdly, is the suffering the result of A's conduct (causation)?²⁰⁰

¹⁹⁶ Peters Jr, Philip G. "Harming future persons: obligations to the children of reproductive technology." *S. Cal. Interdisc. LJ* 8 (1998): 375, page 381.

¹⁹⁷ Oliphant, Ken. *The law of tort*. LexisNexis Butterworths, 2007.

¹⁹⁸ Winfield, Percy Henry, John Anthony Jolowicz, and William Vaughan Horton Rogers. *Winfield and Jolowicz on tort*. Sweet & Maxwell, 1971, 12th ed., page 44.

¹⁹⁹ *Ibid*, page 44.

²⁰⁰ Weir, Tony. *An introduction to tort law*. Oxford University Press, 2006, pages 12 - 13.



Conduct: A's conduct can include actions and omissions.²⁰¹ Was A's conduct inappropriate? Is A to blame? Was A acting without caution? These conducts are evaluated on what the court thinks was the appropriate, reasonable and reputable way to act.²⁰² Nonetheless, A's intention is also a special matter for evaluation. The 'harm' that may be inflicted on a future person is done with the intention of avoiding future genetic conditions. A's intention is to bring about an outcome that improves B's welfare, thus, the court may hold that a real harm is justifiable, thus, there is no tort.²⁰³

Harm: In reference to B's harm, tort law recognise different forms and is constantly acknowledging new types of harm.²⁰⁴ In some tort cases, the victim has suffered ordinary physical or psychological harm, and in others, the victim has suffered no physical harm, but his rights may have been violated.²⁰⁵ When the law of tort vindicates rights there is no need to prove the damage, only that the right was violated.²⁰⁶ However, genetic identity and genetic integrity are neither included in the interests that are now protected by the law of tort, nor recognised as rights or raised in any other specific statute.

Causation: The harm or violation must be linked or directly related to A's conduct.²⁰⁷ The rules of causation are usually understood as a temporal sequence,²⁰⁸ representing different moments in time, where the claimant was 'better off', but through A's conduct becomes 'worse off'. In fact, "[e]ven the thinnest notions of causality place sequence as a necessary condition: [A] has to precede [B] to be able to cause [B]."²⁰⁹ For our illustrative case (as we explained in Chapter 3 regarding baselines of harm), this *temporal* view cannot be clearly applied for future persons. Firstly, because future persons do not exist at the moment of the act nor do they have 'existing' rights, but they

²⁰¹ Ibid, page 13.

²⁰² Ibid, pages 13 - 14.

²⁰³ Wright, Cecil A. "Introduction to the Law of Torts." *The Cambridge Law Journal* 8.03 (1944): 238-246.

²⁰⁴ For example, in 2000, the House of Lords held that a jeopardizing a child's level of achievement is an actionable harm (See: *Phelps v Hillingdon LBC* [2000] 4 A11 ER 504)

²⁰⁵ Weir, Tony. *An introduction to tort law*. Oxford University Press, 2006, page 16.

²⁰⁶ Ibid, page 16.

²⁰⁷ Weir, Tony. *An introduction to tort law*. Oxford University Press, 2006, page 17.

²⁰⁸ Grzymala-Busse, Anna. "Time will tell? Temporality and the analysis of causal mechanisms and processes." *Comparative Political Studies* (2010): 0010414010390653, page 1268.

²⁰⁹ Ibid, page 1271.



may be harmed at this previous moment *before* their legal existence. Secondly, given the fact that existing is always preferred to not existing, there is no previous state before their existence when the person was 'better off'.²¹⁰

4.1.1.1. Genetic data as *personal data*

Considering someone's genetic data as *personal data*, the unauthorized access or misuse of that information can be considered as a type of harm that the law recognizes.²¹¹ In principle, only the person who is being genetically tested has the right to decide to be part of a test and what to do with the information obtained. For future persons, as a group of "individuals who cannot give consent to be genetically tested"²¹² the respect of their autonomy and privacy is still widely disputed.²¹³ Future persons will be born with a change in their genetic makeup without their *consent*.²¹⁴ Under this circumstance, it is problematic to construct a comprehensive framework of protection and, legally speaking, we cannot demand the respect of autonomy of someone who does not exist and who does not have any legal status yet. So, if effective consent cannot be given, the genetic modification prior to birth should be in their 'best interest'.²¹⁵ As future persons are 'better off' with the genetic modification, we may imply that it *is* in their best interests.

The length of the application of the 'best interests' test for future persons may raise questions as to whether they have rights that should be protected. Nevertheless, this

²¹⁰ Petersen, Thomas Søbirk. "Being worse off: but in comparison with what? On the baseline problem of harm and the harm principle." *Res Publica* 20.2 (2014): 199-214.

²¹¹ International Bioethics Committee. "Report of the IBC on updating its reflection on the human genome and human rights." *United Nations Educational, Scientific, and Cultural Organization, Paris* (2015), para 11.

²¹² *Ibid*, para 16.

²¹³ This debate is usually framed on germline modification and its ethical concerns (Cyranoski, David. "Scientists sound alarm over DNA editing of human embryos." *Nature* 12 (2015)). For some, germline editing is not only seen as genetically altering future generations, but also human evolution itself (The International Summit on Human Gene Editing. On Human Gene Editing: International Summit Statement. December 3rd, 2015 [online]. Available at: <http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a>)

²¹⁴ Cyranoski, David. "Scientists sound alarm over DNA editing of human embryos." *Nature* 12 (2015).

²¹⁵ Roberts, Melinda A. "Cloning and Harming: Children, Future Persons, and the Best Interest Test." *Notre Dame JL Ethics & Pub. Pol'y* 13 (1999): 37, page 46.



can be analysed in a more extended view regarding parents' justifiable decision to undergo this procedure. The main argument of our illustrative case is that the genetic modification *will* help future persons, *will* be beneficial for their health, and *will* be in their 'best interest'. On the contrary, we may also argue that it is not in their 'best interest' because we are not truly making our choices to benefit future persons but rather to avoid the responsibility of taking care of someone who will suffer from a genetic condition.²¹⁶ This is in line with our previous criticism of the definitions of health and disease.

If we say that the harm is not caused by the technique *per se*, it may be caused by the *unjustifiable* reasons of our choices to genetically modify them. Hence, the *reasons* to undergo this procedure should be put to the 'best interest' test for future persons. This test "seems [to be] a plausible test for courts to use in determining the permissibility of the application"²¹⁷ of these techniques. Thus, we suggest that a "judicial approval on grounds of best interest should be made a statutory prerequisite of any application of [genetic modification] techniques" as a way to protect future persons.^{218 219}

4.2. Human rights protection

The international law of human rights regulates the relationship between the state and the people within its territory.²²⁰ Hence, this law concerns the *interference* of the state in

²¹⁶ This can be another ethical argument that will not necessarily be addressed on this paper. However, it is worth it to be mentioned since our argument is being constructed from the good or bad consequences of our choices.

²¹⁷ Roberts, Melinda A. "Cloning and Harming: Children, Future Persons, and the Best Interest Test." *Notre Dame JL Ethics & Pub. Pol'y* 13 (1999): 37, page 53.

²¹⁸ *Ibid*, page 53.

²¹⁹ This argument can raise debates about eugenics, designer babies or genetic determinism. Researchers may overestimate the influence of genetics on the phenotype of a person, leading to an underestimation of other important factors. "This would result in a failure of the research to identify the real causes of the disease and would be a loss of opportunity for the individual". (See: International Bioethics Committee. "Report of the IBC on updating its reflection on the human genome and human rights." *United Nations Educational, Scientific, and Cultural Organization, Paris* (2015), para 25.) These debates are relevant for the topic, however, because of the length of this paper they are not going to be discussing here.

²²⁰ Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 15.



people's lives and over their individuals' rights.²²¹ The foundation of human rights is that we all are *born* free and equal by the virtue of being *human beings*.²²² Thus, human rights law entails the protection of 'existing' persons who are *already* born.²²³

The law perceives future persons as persons who lack any recognition of rights because they do not exist yet. Nevertheless, this legal categorization which disregards future persons, at least, from presumptive rights, may leave open doors to possible harm. Future persons *will* hold the same human rights as we do now; hence, the possibility of exploiting this gap in legal protection raises concerns. "[H]uman rights law can be seen as the 'on-going and always failing struggle to close the gap between the abstract man and the concrete citizen'."²²⁴ Thus, it might be time to evolve and to expand the current boundaries of human rights protection in order to include a new group of *pre-existing* human beings who may be harmed prior to birth.

4.2.1. Human right to personal identity

Article 8²²⁵ of the European Convention on Human Rights (ECHR)²²⁶ is considered by the European Court of Human Rights to be a broad term "not susceptible to exhaustive

²²¹ Ibid, page 17.

²²² UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III). Article 1.

²²³ Also, "the human rights movement has revived a belief in human sanctity". In other words, we are human beings with *souls*, and therefore, we are beneficiaries of law. In a more secular but still religious view, in comparison to other species, we have a certain type of biologically development of the brain, certain capacities of reasoning and compassion for others; thus, we have the "memberships as subjects of law." (See: Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 27)

²²⁴ Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 9, quoting Costas Douzinas. 'Seven Theses on Human Rights: (2) Power, Morality and Structural Exclusion', available at: <http://criticallegalthinking.com/2013/05/21/seven-theses-on-human-rights-2-power-morality-structural-exclusion/>.

²²⁵ European Convention on Human Rights. Article 8: Right to respect for private and family life 1. Everyone has the right to respect for his private and family life, his home and his correspondence. 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

²²⁶ Council of Europe, *European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14*, 4 November 1950, ETS 5, available at: <http://www.refworld.org/docid/3ae6b3b04.html> [accessed 20 July 2016]



definition”,²²⁷ which includes “rights protecting the integrity, *identity* and autonomy of the person.”²²⁸ Hence, the human right to personal identity should be interpreted under the provision of Article 8 as part of the right to respect for one’s private life.²²⁹ ‘Private life’ encompasses elements of social and physical identity such as gender identification, sexual orientation and personal development.²³⁰

Article 8 protects people from arbitrary intrusions of public authorities.²³¹ Thus, this right concerns persons’ private sphere, freedom and control over their own affairs and faculties.²³² “This protection of our inner privacy relates to our identity formation”²³³ because it preserves the essential conditions “for proper individuation and realization of the self over time.”²³⁴

To extend the range of protection of the human right to personal identity may be possible by making claims against arbitraries’ intrusions to the *physical* features of future persons’ genome. Considering someone’s genetic data as *personal data*, as we mentioned at the beginning of this chapter, the unauthorized access or misuse of that genetic information can be considered as a type of intrusion. Even though future persons do not exist at the moment of the arbitrary intrusion, their genetic identifiable information *does* exist. Hence, this ‘personal data’ (an important part of their *future* personal identity) should be protected from intrusions in order to preserve a condition necessary for proper realization of the self over time.

²²⁷ *X and Y v. the Netherlands*, judgment of 26 March 1985, Series A no. 91, para 11 and 22.

²²⁸ Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 14.

²²⁹ *Goodwin v the UK* (2002) 35 EHRR 18, para 90; *I v the United Kingdom* Application 25680/94, Judgement 11 July 2002, para 70.

²³⁰ *Pretty v the UK* (2002) 35 EHRR 1, para 61, which also mentions other important cases like: *Mikulić v. Croatia*, no. 53176/99, § 53, ECHR 2002-I, *B. v. France*, judgment of 25 March 1992, Series A no. 232-C, pp. 53, 54, 63; *Burghartz v. Switzerland*, judgment of 22 February 1994, Series A no. 280-B, p. 28 - 24; *Dudgeon v. the United Kingdom*, judgment of 22 October 1981, Series A no. 45, pp. 18, 19, 41; *Laskey, Jaggard and Brown*, cited above, p. 131; and *Friedl v. Austria*, judgment of 31 January 1995, Series A no. 305- B, opinion of the Commission, p. 20, 45.

²³¹ *Tysiac v Poland* [2003] Application no. 5410/03.

²³² United Kingdom, Calcutt Committee, 1990.

²³³ Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 37.

²³⁴ *Ibid*, page 37.



4.2.2. Human right to personal integrity

Article 3²³⁵ of the Charter of Fundamental Rights of the European Union²³⁶ anchors the right to personal integrity. In the Inter-American System of Human Rights, the right to personal integrity has also been recognised in article 5²³⁷ of the American Convention on Human Rights.²³⁸ In the ECHR, however, there is no specific article that refers to *personal integrity* as such. Nonetheless, articles 8 and 13²³⁹ may satisfy the standard of protection that the right to personal integrity requires. The Court has established that the right to private life also includes physical, moral and psychological integrity of a person.²⁴⁰

The history of the application of this right²⁴¹ suggests that all persons deprived of liberty must be treated with respect for their personal integrity.²⁴² The infringement of the right

²³⁵ Charter of Fundamental Rights of the European Union. Article 3. Right to the integrity of the person: Everyone has the right to respect for his or her physical and mental integrity. In the fields of medicine and biology, the following must be respected in particular: the free and informed consent of the person concerned, according to the procedures laid down by law; the prohibition of eugenic practices, in particular those aiming at the selection of persons; the prohibition on making the human body and its parts as such a source of financial gain; the prohibition of the reproductive cloning of human beings.

²³⁶ European Union, *Charter of Fundamental Rights of the European Union*, 26 October 2012, 2012/C 326/02, available at: <http://www.refworld.org/docid/3ae6b3b70.html> [accessed 20 July 2016]

²³⁷ American Convention on Human Rights. Article 5. Right to Humane Treatment: 1. Every person has the right to have his physical, mental, and moral integrity respected. 2. No one shall be subjected to torture or to cruel, inhuman, or degrading punishment or treatment. All persons deprived of their liberty shall be treated with respect for the inherent dignity of the human person. 3. Punishment shall not be extended to any person other than the criminal. 4. Accused persons shall, save in exceptional circumstances, be segregated from convicted persons, and shall be subject to separate treatment appropriate to their status as unconvicted persons. 5. Minors while subject to criminal proceedings shall be separated from adults and brought before specialized tribunals, as speedily as possible, so that they may be treated in accordance with their status as minors. 6. Punishments consisting of deprivation of liberty shall have as an essential aim the reform and social readaptation of the prisoners.

²³⁸ Adopted at the Inter-American Specialized Conference on Human Rights, San José, Costa Rica, 22 November 1969.

²³⁹ European Convention on Human Rights. Article 13: Prohibition of torture: No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

²⁴⁰ *Botta v. Italy* (Application No. 21439/93, Judgement of 24 February 1998.

²⁴¹ This historical definition has been usually uses as 'state terror', and does not clearly state other coercive actions that may also violate this right (See: Poe, Steven C., and C. Neal Tate. "Repression of human rights to personal integrity in the 1980s: a global analysis." *American Political Science Review* 88.04 (1994): 853-872.) For arbitrary intrusions, this right refers to physical coercion without the process of law (Stohl, Michael, et al. "State violation of human rights: Issues and problems of measurement." *Hum. Rts. Q.* 8 (1986): 592) and without reasons that warrant its use, like illegal imprisonment (Cingranelli,



to physical and mental integrity, then, is a kind of violation that has several gradations and ranging from torture to other types of humiliation or cruel, inhuman or degrading treatment.²⁴³

To extend the range of protection of this human right may be possible by making claims against arbitrary intrusions in the genetic person as a 'whole'. For our illustrative case, there is no torture, cruel or degrading treatment. Nonetheless, with respect to our argument that genetic modification may not be in future persons' 'best interest',²⁴⁴ then, we can imply that the intrusion is based upon *unjustifiable reasons*. Hence, the *act* may be considered as a cruel or inhuman treatment, which diminishes future persons' value as persons to merely products that we may want to produce or to discontinue.²⁴⁵

On the other hand, we argue in Chapter 4 that future persons' genetic integrity cannot be subdivided into different layers because all of them are mutually integrated and attached and part of a whole *genetic person*. Hence, we consider that it is not necessary to prove the existence of inhuman treatment; instead, the *occurrence* of an intrusion that interferes with the wholeness of future persons' genetic integrity.

4.2.3. General comments

"Genetic 'identity' as a notion in and of itself is controversial."²⁴⁶ Technological advances in medicine, like prenatal genetic techniques and diagnosis prior to birth, "have led to arguments that human rights now have a biological dimension."²⁴⁷ Personal identity

David L., and David L. Richards. "Measuring the level, pattern, and sequence of government respect for physical integrity rights." *International studies quarterly* 43.2 (1999): 407-417).

²⁴² I/A Court H.R., Case of Neira Alegría et al. v. Peru. Merits. Judgment of January 19, 1995. Series C No. 20, para 86; and I/A Court H.R., Case of Durand and Ugarte v. Peru. Merits. Judgment of August 16, 2000. Series C No. 68, para 78.

²⁴³ I/A Court H.R., Case of Loayza Tamayo v. Peru. Merits. Judgment of September 17, 1997. Series C No. 33, para 57. See also: I/A Court H.R., Case of Caesar v. Trinidad and Tobago. Merits, Reparations and Costs. Judgment of March 11, 2005. Series C No. 123, para 69; I/A Court H.R., Case of Ximenes Lopes v. Brazil. Merits, Reparations and Costs. Judgment of July 4, 2006. Series C No. 149, para 127.

²⁴⁴ Because we are not truly making our choices to benefit future persons but rather to avoid the responsibility of taking care of someone who will suffer from a genetic condition.

²⁴⁵ More explicitly, treating people, parts of people, or future persons as commodities (See: Rothman, Barbara Katz. "Recreating Motherhood Ideology and Technology in a Patriarchal Society." (1989)).

²⁴⁶ Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 118

²⁴⁷ *Ibid*, 118.



seems not to be 'complete' anymore, since we do not have our 'exact' genetic information at hand.²⁴⁸ The 'language of genetics', thus, has implications for human rights law.²⁴⁹

The importance of our genetic information as part of our identity is prevelant. In the UK, for instance, in cases of Assisted Reproductive Techniques (ART) like gametes donations, the anonymity of the donor was abolished in 2004.²⁵⁰ The HFEA enabled donor-conceived children to access the identity of their sperm, egg or embryo donor upon reaching the age of 18.²⁵¹ The change aimed to prevent the 'genealogical bewilderment'²⁵² of children who are born by ART, because the right to identity includes the "right not to be deceived about one's true origins."²⁵³ Thus, if for gamete donations, the law already considers the protection of children's genetic identity, by revealing information about an act that happened before they exist (when children were only *future persons*), then the intrusion to future persons' genetic integrity may be also protected using this analogy.

4.3. Unconventional legal analysis

In this paper, we propose an unconventional legal analysis. We acknowledge the need for further discussion on the issue, thus, we will recommend some important points as starting point.

²⁴⁸ Ibid, page 119.

²⁴⁹ Nonetheless, for some, human rights law should not be extended to the point of creating a problematic view of identity, which may make people "feel inadequate and incomplete when they do not know who their sperm or egg donors are, and indeed, even their birth givers." Also, the fact that the right to freedom to access and obtain information about our existence (See: *Gaskin v the UK* (1990) 12 EHRR 36) is part of the human right of identity, Jill Marshalls be on the opinion that is "very different to linking identity with one's biological parentage in the sense that it is more 'natural' and 'true'." She argued that until recent times, the lack of knowledge of our past *before we were born* does not mean that we do not have a real and true identity, hence, there is no need to make our realities more complicated of what they already are. (See: Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, pages 119 and 120).

²⁵⁰ The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004, No. 1511.

²⁵¹ Ibid.

²⁵² Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 125.

²⁵³ Ibid, page 125.



Prenatal genetic modification techniques should not necessarily become a new type of tort,²⁵⁴ but the law should recognise the existence of a moral duty to protect future persons, considering them as a new type of victim that can be harmed. The law should also allow a new type of ‘analysis’ of wrongful acts that will change the conventional way to address tort actions. For instance, it could extend the analysis of causation beyond that of linear temporality.²⁵⁵

The law, in general, is capable of developing and adjusting to new scenarios. Thus, “new heads of liability can come into existence”.²⁵⁶ The harm of future persons may be addressed in court, “not because of a general theory of liability but because the court feels that here is a case in which existing principles of liability may properly be extended.”²⁵⁷

The analysis should neither focus on individual victims nor on ordinary harm, but on the way public health decisions may affect future persons, and how the recognition of possible harm can be included in the law in order to safeguard these new victims. For example, a public health decision, which approves the use of prenatal genetic modification techniques in clinical trials, will permit an arbitrary intrusion over future persons’ genetic integrity. Hence, previously, it should establish, firstly, the unique and justifiable reasons to permit its application; secondly, which modification are going to be permitted, and lastly, the possible ways to redress the modified person in the future.

Moreover, the special *categorisation* of future persons as genetic persons may allow public officers to apply a legal framework towards future persons’ harm. Even though they do not exist at the time of the genetic modification, their genetic makeup does. Thus, we may say that future persons *already* exist as genetic persons, which can be

²⁵⁴ “But when a new tort has come into being, it might fairly seem to have done so, if the whole history of its development is taken into account, in virtue of the principle that unjustifiable harm is tortious.” (Junior Books Ltd. v. Veitchi Co. Ltda. [1982] 3 W.L.R. 477; post, p. 78. Quoted by: Winfield, Percy Henry, John Anthony Jolowicz, and William Vaughan Horton Rogers. *Winfield and Jolowicz on tort*. Sweet & Maxwell, 1971, 12th ed., page 14).

²⁵⁵ Temporality as a concept by which humans confront the experience of duration— as a linear progression past, present, or future. (See: Disch, Lisa et al. *Temporality*. Oxford University Press, 2016).

²⁵⁶ Winfield, Percy Henry, John Anthony Jolowicz, and William Vaughan Horton Rogers. *Winfield and Jolowicz on tort*. Sweet & Maxwell, 1971, 12th ed., page 15.

²⁵⁷ “The Foundation of Tortious Liability” (1939) 7 C.L.J. 131; Salmond and Heutson, *Torts*, 18th ed., pp. 13-16



categorised as a new group of victims. We have, at least, a moral duty to respect future persons. “Thus, to the degree that our policy-makers and legislators respond to valid moral arguments, the interests of future generations will be far better served if we can succeed in defending the notion that succeeding generations have rights-claims against the living who, in turn, have the moral duty to respect and respond to these rights.”²⁵⁸

The UK has been one of the pioneers in genetic healthcare and research. The HFE Act implies a code of what can or cannot be done with the use of gametes and embryos in fertility treatments and research procedures. However, this paper highlights the need for additional legal documents that clearly identify the key moral issues of the application of these techniques. It should not only concern the safety of these techniques, but also what they could imply for future generations. We may introduce irreversible changes in future person’s genetic makeup that cannot be *undone*, which means that we would have “imposed ourselves upon them, leaving them no option but to accept our legacy.”²⁵⁹

²⁵⁸ Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 136.

²⁵⁹ Callahan, Daniel. “What Obligations Do We Have to Future Generations?” In Partridge, Ernest. ed. *Responsibilities to future generations: environmental ethics*. Prometheus Books, 1980, page 82.



CONCLUSION

The decision to allow prenatal genetic techniques in clinical trials would have consequences, both positive and negative, on future persons. In this paper, we have addressed an *illustrative case* in which a prenatal genetic technique is accepted and allowed in clinical trials. We have explored the possible ways these techniques may harm future persons (who will be born with a genetic modification) and we have proposed some possible extensions to the current legal frameworks in order to protect them. As a conclusion, we consider that because of the possible harm to future persons' genetic integrity, the provision of prenatal genetic testing and diagnosis *should* take into account the rights and interests of future persons before they carry out genetic modification.

On the one hand, if these techniques are allowed in clinical trials, a *counterfactual baseline* could be applicable. Through this lens, we are *not* harming future persons, in a morally relevant sense. On the contrary, we are considering their interests to have a healthy life in the future.

On the other hand, we develop therapies and treatments because we feel we have the need or the moral duty to help others. Noam Zohar²⁶⁰ argues, however, this *need* or *moral duty* cannot justify gene therapy. Firstly, because gene therapies disrupt a person's identity; secondly, because existing will always be preferred to not existing;²⁶¹ and thirdly, because an individual "cannot be harmed by its original genetic constitution, no matter what unfortunate conditions it produces."²⁶² Despite the criticism of Zohar's arguments,²⁶³ we have formed a similar conclusion in this paper.

²⁶⁰ See: Zohar, Noam J. "Prospects for "genetic therapy"-can a person benefit from being altered?." *Bioethics* 5.4 (1991): 275-288.

²⁶¹ Ibid.

²⁶² Ibid, pages 277 to 278, and 285 to 287.

²⁶³ Kahn, Jeffrey P. "Genetic harm: bitten by the body that keeps you?." *Bioethics* 5.4 (1991): 289-308, pages 300-302.



The possible application of this technique could imply further medicalization of society. We already feel we have the need to diagnose what is wrong or incomplete in our body and prescribe drugs to be complete again; with this technique, we may do so before we are born.

The development of these prenatal genetic techniques is still ambiguous, but we claim in this paper that they will negatively affect future persons. We find that the intrusion of a future person's genetic integrity (regardless of the magnitude of the genetic modification) qualifies as unconventional harm. Thus, we argue that prenatal genetic testing and diagnosis should not be allowed in clinical trials.

Neither the conventional legal analysis of the law of tort nor the international law of human rights can clearly and objectively protect future persons' genetic integrity. This protection needs to be extended to future persons so that the dignity and living vital body of someone who will exist in the future will be safeguarded *in advance*.²⁶⁴ Future debates should not only acknowledge the risks of harming the child, but also the possibility of harming their *genetic integrity* before they exist. If this harm can "be avoided only through a ban or restriction,"²⁶⁵ then, even the most compelling arguments in favour of these techniques would not undermine the moral obligation to consider future persons' interests and rights.

²⁶⁴ Marshall, Jill. *Human rights law and personal identity*. Routledge, 2014, page 199.

²⁶⁵ Roberts, M.A. Cloning and harming: children, future persons, and the "best interest" test. (Emerging Issues in Technology). *Notre Dame Journal of Law, Ethics & Public Policy*, Spring, 1999, Vol.13(1), p.37-61 [Peer Reviewed Journal], page 38.



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