BIOETHICS AND HUMAN RIGHTS IN INTERNATIONAL LAW: GENETIC ENGINEERING, EUTHANSIA AND/OR PHYSICIAN-ASSISTED SUICIDE

By

Carina Teresa de Oliveira

Submitted to the Public Law Department
University of Cape Town
2021

A minor research dissertation presented for the approval of Senate in partial fulfilment of the requirements for the Degree LLM in International Law in approved courses and a minor dissertation. The other part of the requirement for this qualification was the completion of a programme of courses.

I hereby declare that I have read and understood the regulations governing the submission of the LLM in International Law minor dissertations, including those relating to length and plagiarism, as contained in the rules of this University, and that this dissertation conforms to those regulations.

Signature: Signed by candidate
Date: 13 February 2022 (Revised: 28 June 2022)
Word Count: 27 495

ACKNOWLEDGEMENTS

There are many people whom I would like to acknowledge and thank for their contributions, both directly and indirectly, to my thesis.

I would like to first thank my supervisor, Amanda Barratt, for her invaluable supervision, support, and motivation during the course of my Masters degree. This thesis could not have been completed without her knowledge, advice, and encouragement.

I would also like to extend my gratitude to my parents, Joao de Oliveira and Fatima de Oliveira, two immigrants from the island of Madeira, Portugal, who sacrificed everything in their livelihood to ensure my siblings and I would have the opportunity to pursue tertiary educations. It was based on their encouragement and sacrifices that I decided to leave a firm after completion of my articles of clerkship in order to return to my tertiary studies to complete this Masters degree. It cannot go without saying that without their undying support, prayers, encouragement, and sacrifices, I would not be in the position I am today. This appreciation also extends to my two siblings, the rest of my family, as well as all my close friends who have supported me throughout this journey.

Finally, I would like to dedicate this thesis to my late maternal grandparents, Deonilde de Oliveira and Jose Nunes de Oliveira, who never failed to depict their pride and support for their family even while being on the other side of the world. Their continuous outpouring of love, prayers and support for all their grandkids – especially for those who were across the globe – during their lives was a central factor in my own motivation to complete this Masters degree.

ABSTRACT

Medical advancements and improved scientific knowledge has introduced various benefits to society, while also creating contentious debates and issues concerning the impacts these medical advancements and/or procedures have had on human rights. In particular, the impact on human rights that medical and scientific advancements have arisen in regards to specific forms of genetic engineering, euthanasia and physician-assisted suicide. This dissertation is aimed at specifically focusing on the dichotomy of ideologies and legislation concerning the rights to human dignity and privacy in relation to the medical advancements involving genetic engineering, euthanasia and physician-assisted suicide. Genetic engineering is broadly considered to be an umbrella term that comprises various medical technologies, including preimplantation and prenatal genetic testing and selection, as well as genetic editing. Preimplantation and prenatal genetic testing enables the detection of a disease or defective condition of an embryo or foetus, while genetic editing enables the alteration of an embryo or foetuses genes to remove mutations or defective conditions to improve the overall living condition of the embryo when it is born. These different practices within the broad realm of genetic engineering use medical technologies to essentially "pick and choose" what physical and medical traits an individual should bear, in an attempt to avoid offspring with serious illnesses or unwanted conditions that could potentially cause the individual a lifetime of suffering. Although it is important to note that genetic engineering has also confronted a plethora of ethical and legal objections, a specific form of medical technology within the broad framework of genetic engineering, specifically preimplantation and prenatal genetic testing, is still generally more accepted on a global scale, both by society and by legislatures, than the practices of genetic editing or euthanasia and/or physician-assisted suicide, which aims to restore an individual's human dignity, privacy and autonomy by assisting these individuals suffering from severe illnesses or defective conditions to peacefully conclude their undignified lives. Euthanasia and/or physician-assisted suicide, essentially involves an individual or medical practitioner administering a lethal agent to a patient in order to relieve them of their severe and chronic suffering. This dissertation intends to analyse the bioethics and international law concerning the dichotomy present between the application of preimplantation and prenatal genetic testing utilized in the selection process of a life to attempt to ensure an individual without illnesses, with the more dominant prohibition on

euthanasia and/or physician assisted suicide to terminate the life of a human being suffering with those very same traits, conditions and/or illnesses that preimplantation and prenatal genetic testing intends to detect and then allow an individual to either terminate the embryo or foetus, or not. This bioethical debate seems to be increasingly contradictory, whereby preimplantation and prenatal genetic testing, although still facing criticism by some states, is being introduced and accepted far more commonly across the globe, while the option of an individual having the freedom of autonomy to make an informed decision to bring an end to their suffering through euthanasia and/or physician assisted suicide, is largely rejected. This dissertation essentially explores the irony present in bioethics in the manner in which there exists far greater societal and legislative support for preimplantation and prenatal genetic testing and selection to effectively allow the avoidance of chronic suffering, than there is for the protection of the human dignity and autonomy of individuals by terminating the severe chronic suffering caused by these very same conditions that the former medical interventions intend to eradicate.

TABLE OF CONTENTS

I. INTRODUCTION

Two individuals meet, fall in love, get married, create a baby together, grow old, and eventually die peacefully. This is the general utopian "ideal life" that society has imprinted on us. However, this reality differs immensely for many. The ability to even create another life in the "traditional sense" is either impossible for some or simply unwanted out of fear that the offspring might inherit a debilitating life threatening disease. The fear of bringing another life into this world, that might have to suffer as a result of one's genetic makeup is a contentious issue that many individuals have to confront. In fact, it is so common that it has led to medical and scientific advancements that assist one in detecting potential unwanted conditions in an embryo or foetus, without the dread of passing on these defective genes, through the medical technology utilized in the practice of preimplantation and prenatal genetic testing and selection. However, the international support for the legalisation of this practice is far more than the support for the termination of suffering through euthanasia and/or physician-assisted suicide. Although euthanasia and/or physician-assisted suicide are practiced to terminate suffering of an individual with a fatal and debilitating disease or disorder, it is often treated with a more somber outlook than other medical interventions, and in most countries, even criminalized.

As science and technology have improved rapidly over the years, so has the vast horizon of freedom of choices granted upon individuals. This freedom of choice or autonomy of individuals enables them to make choices regarding their very existence, how they choose to live or endure it, and if they choose to terminate it. The increase in awareness of human rights and autonomy has had many advantages, but it has also brought many challenges to the very area it originates from, the law. Freedom of choice and autonomy has had increasing debates confronting legal, ethical and moral issues within the legal sphere, particularly regarding medical related topics. This has brought upon the concept of bioethics. Although the concept of bioethics is not strictly confined into a single uniform term, it has been referred to in many legal and philosophical literature as a sub-category of ethics that investigates all ethical concerns and dilemmas that arise from medical, biological and healthcare fields.[1] The manner in which the application of law and bioethics has

---

[1] Mirjam Sophia Clados *Bioethics in International Law: An analysis of the intertwining of bioethical and legal discourse* (unpublished philosophy doctorate dissertation, Ludwig-Maximillians University, 2012) at 3.

been applied internationally, has either hindered or supported the autonomy of an individual to make an informed decision to either alter the beginning process of a life to avoid suffering, or to end a life that is experiencing suffering.

This paper will analyze the impact that bioethics has had on human rights from an international law perspective. Bioethics here refers to the moral and ethical considerations related to two specific yet contrary areas of medical interventions, the selection of life through preimplantation and prenatal genetic testing, as well as the termination of life through euthanasia and/or physician-assisted suicide. The analysis of the impact of bioethics on human rights will particularly be focused on the possible dichotomy of laws and societal support offered for medical interventions related to preimplantation and prenatal genetic testing, and selection, while euthanasia and/or physician-assisted suicide are still largely criminalized by most countries and still deemed taboo by society. This dissertation will pay attention to the manner in which human rights are affected as a result of these contradictions of international laws and societal support regarding the different forms of preimplantation and prenatal genetic testing and selection, and euthanasia and physician-assisted suicide, particularly the rights of human dignity and privacy which essentially form the basis of an individual’s overall autonomy in order to avoid or terminate suffering.

The discussion on this dichotomy of ideologies concerning the human rights impacted by bioethics will be approached in the following manner, Chapter I will discuss the concept of bioethics and how the science of eugenics has essentially shaped the development of medical interventions in limited ways, such as genetic engineering and the different types that exist today. Chapter II will discuss the dichotomy of societal support between preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician assisted suicide. Chapter III will then discuss the impact that these aforementioned medical technologies have had on the right to human dignity and privacy of an individual, and whether it restricts the potential autonomy of that individual which they ought to be entitled to.

II. LITERATURE REVIEW

In reviewing the literature on the impact of bioethics on human rights on an international scale, between preimplantation and prenatal genetic testing, and euthanasia, one notes that a dichotomy exists between the international legislative and societal support for preimplantation and prenatal genetic testing selection, and euthanasia and/or physician-assisted suicide. Although much literature and research has been published on euthanasia and the legal implications as a result of it, in a largely negative light, only a few researchers have actually considered the possible contradiction of laws and the impact on human rights of the significantly larger approval of medical advancements that promote preimplantation and prenatal genetic testing, and the general disapproval of medical interventions aimed at practices of euthanasia. Hence, there exists a gap in the literature concerning why a clear dichotomy exists between the support of human rights concerning preimplantation and prenatal genetic testing and selection to avoid suffering, and the lack of support of human rights concerning euthanasia in the termination of life to end suffering.[2]

i. Bioethics as a field not a discipline

In terms of the reviewed literature, it is also vital to understand the context in which bioethics is being applied and/or understood within the research utilized, as well as the context to be understood when referring to bioethics within this dissertation. Bioethics in itself is often defined as a branch of practical ethics related to the medical field, which is ultimately rooted in the notion of philosophy.[3] Bioethics is generally either considered in a broad or narrow notion, the broad notion of bioethics encompasses the study of ethics in medicine, medical law and medical politics,[4] while the narrow notion of bioethics refers to a mere inquiry into medical ethics on a philosophical basis.[5] There has been various research published in support of both the broad and the narrow notion of bioethics, however it seems that some scholars prefer the narrow notions of bioethics to be applied, as this notion and/or approach believes that aspects such as medical law and medical

---

[2] Cinzia Picciocchi 'Bioethics and Law: Between Values and Rules' (2005) 12 *Indiana Journal of Global Legal Studies* 2(6) at 471.
[3] Sarah Chan 'A bioethics for all seasons' (2015) 41 *J Med Ethics* at 18.
[4] David Benatar 'Clinical Ethics: Bioethics and health and human rights: a critical view' (2006) 37 *J Med Ethics* at 17.
[5] Ibid at 17.

politics do not fall within the concept of bioethics and thus should be excluded from its definition.[6] These scholars believe that referring to bioethics as a concept that encompasses all fields merely related to medicine, often leads to the creation of erroneous assumptions that medical law and medical ethics are one and the same.[7] However, the problem with giving too much prominence to the narrow notion of bioethics, can also lead to the complete isolation of bioethics, under the pretence that it does not greatly impact and/or rely on areas such as law, politics and the economy.[8] In fact, this idea that bioethics does not greatly rely on other areas such as law or politics could not be further from the truth, as despite much debate on what exactly bioethics constitutes and whether it relies on other fields, what cannot be disputed is that bioethics has ultimately relied on the legal arena in order to place its research into effect through policies.[9] The field of bioethics has been vital not only in preventing future medical related disasters, but it has also greatly assisted in the information and research available on the advancements that have taken place in the medical and scientific fields, such as preimplantation and prenatal genetic testing, euthanasia, or even reproductive cloning, which is one very clear way that bioethics has effectively depicted its reliance on law through domestic legislatures and international agreements, which have either resulted in the enactment of laws and policies for or against certain medical practices that have become available through these medical advancements.[10] Thus, it is important for bioethics to be interpreted in a manner that neither restricts nor extends the bounds of its concept. Merely relying on a definition that is too narrow or broad seems insufficient in capturing the entirety of the concept of bioethics and the impact and reliance it has had on various areas and fields in society, even outside of the medical field. Bioethics should be interpreted in a manner whereby it is not equated to and/or made synonymous with law or politics, but rather remains cognizant of the relationship it has with external actors of the medical arena, such as lawyers, economists and politicians.[11] This cognizance of bioethics' overlapping relationship with external actors sourcing from various other fields, is not only necessary to the overall definitional concept of bioethics, but it is also necessary to have awareness of the particular external area of bioethics that the specific information was

---

[6] Supra note 4 at 17.
[7] Ibid at 17.
[8] Duncan Wilson 'What can History do for Bioethics?' (2013) 27 *Bioethics* 4 at 215.
[9] Susan M Wolf 'Law and Bioethics: From Values to Violence' (2004) *Journal of Law, Medicine and Ethics* 32 at 294.
[10] Ibid at 293.
[11] Supra note 4 at 17.

sourced from during the application of bioethics in either research and/or practice in order to discern the context attached to it.[12]

Some researchers have suggested that an increasing problem that has emerged not only within the concept of bioethics on paper, but also within research published on bioethics, is in fact the issue of the contribution of external actors, such as lawyers, economists and politicians who have an interest in the topic, as these researchers argue that they tend to dangerously overstep their knowledge within the field of bioethics, by making uneducated conclusions regarding their opinions of bioethics in relation to medical interventions, and presenting it as factual evidence.[13] These researchers rely on this argument by asserting that various research which has been published on bioethics and often times included in academic or medical journals, containing information concerning bioethics while the source is neither a medically or scientifically trained individual.[14] Hence, in light of this perspective, when bioethics is viewed as a discipline, whereby any individual that is not formally trained within the medical field can mould the concept as it sees fit, then it potentially leads to the creation of a problematic slip into assumptions of a field that is very much related to the medical field, and which according to this perspective, strictly requires such expertise only.[15] This perspective is essentially centred around the idea that while bioethics ought to be considered as a field on its own, it also requires formal standards and understanding to be met, and without these standards, this particular view determines that the concept of bioethics will remain a subject where external actors will “erroneously” feel justified to dictate its concept, applicability and morality, while lacking any special knowledge or expertise required in order to make the necessary informed statements on it.[16] However, this particular perspective of bioethics posed is vulnerable on an argumentative basis as it fails to consider that bioethics encompasses more elements that require a contributory approach of a variety of different expert knowledge and skillsets to inform the relevant context of bioethics which is being applied, as opposed to the field of bioethics only strictly being dependent on medical personnel and scientists to inform society of

---

[12] Supra note 3 at 17.

[13] Supra note 4 at 17.

[14] Ibid at 18.

[15] Cascais AF ‘Bioethics: History, Scope, Object’ (1997) 10 *Global Bioethics* at 19.

[16] Supra note 4 at 18.

all the relevant components that encompass the entirety of what constitutes bioethics.[17]

While bioethics ought to be considered a field of its own, other researchers correctly suggest that this doesn't require that this field be isolated from the external actors that are necessary to adequately inform the concept of bioethics, nor that there has to be a single strict definition of what bioethics constitutes or what actors can contribute to it.[18] While the overall aim of bioethics is to effectively inform policies in a justifiable and applicable manner, it also importantly aims to provide an appropriate structural approach to moral disagreements,[19] especially those which arise in response to the increase in medical advancements and technology over the recent years.[20] Thus it is important that bioethics is considered in a view that is neither isolated from the external actors and the areas it impacts, nor is it entirely reliant on the context created by these external actors. Rather bioethics should be understood as a term whereby experts in the medical and science fields are able to contribute to the "bio" aspect, while external actors, being from the legal, philosophical and sociological fields, contribute to the relevant aspect within their expertise that encompasses the "ethics" aspect.[21] In a nutshell, further research and understanding of bioethics as a field of study, should be conducted by the contributory efforts of a team of scholars consisting of different experts, each with knowledge in a different aspect of bioethics, namely being medicine, ethics and law.[22]

ii. The impact of bioethics on human rights

Bioethics in its current understanding is generally regarded as a field that provides critical views not only on medical advancements, but also on international human rights frameworks.[23] In fact, the most prominent characteristic that underlies the relationship between law and bioethics, is the

---

[17] Supra note 15 at 19.

[18] Supra note 3 at 18.

[19] Ibid at 18.

[20] Paul R Ehrlich 'Bioethics: Are Our Priorities Right?' (2002) 53 *BioScience* 12 at 1207.

[21] Supra note 4 at 18.

[22] Supra note 8 at 220.

[23] Judit Sandor 'Bioethics and Basic Rights: Persons, Humans, and Boundaries of Life' in Michel Rosenfelds et al (eds) *The Oxford Handbook of Comparative Constitutional Law* (2012) at 1144.

manner in which bioethical principles were reflected and recognized to an extent through the terminology of human rights in legal instruments.[24] Bioethics is associated with four main principles that have since been incorporated and enshrined in the international human rights frameworks,[25] notably, autonomy, the power to make informed decisions; beneficence, the positive duties that physicians owe patients; nonmaleficence, the physician's duty not to harm patients, and justice, that all patients are treated fairly and equally.[26] These bioethics principles, while not human rights themselves have merged human rights norms with bioethical concerns, and this essentially laid the foundation of the development of some of the first international instruments that portrayed bioethical concerns, both the Nuremburg Code[27] and Declaration of Helsinki,[28] although not legally binding, these instruments further promoted the importance of protecting the interests of patients and the autonomy and informed consent of individuals when it comes to medical interventions.[29] Although there is no single definition of bioethics utilized across the globe, one is able to discern its meaning from the different definitions it holds in various instruments,[30] in fact the most dominant definition within the international legal framework seems to be derived from one of the first organisations that expressly addressed the relevance of bioethical issues, the United Nations Social, Educational and Cultural Organization (hereinafter referred to as "UNESCO"), which developed the Universal Declaration on Bioethics and Human Rights (hereinafter referred to as the "UDBHR"),[31] which defines bioethics as "ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions".[32] The UDBHR represented one of the first international legal documents to set out bioethical standards with human rights, and is a core feature of the manner in which bioethics and law have influenced each other, in that the international legal community recognized the need for an updated text that specified human rights within the context of the

---

[24] Daniel Sperling 'Law and Bioethics: A rights-based relationship and its troubling implications' (2008) 11 *Current Legal Issues* at 39.

[25] Supra note 1 at 118.

[26] Basil Varkey 'Principles of Clinical Ethics and their application to practice' (2021) 30 *Medical Principles and Practice* at 17.

[27] Nuremburg Code, 1947.

[28] Declaration of Helsinki, 1964.

[29] Supra note 15 at 11.

[30] Ibid at 12.

[31] UNESCO's Universal Declaration on Bioethics and Human Rights, 2005.

[32] Ibid at article 1.

principles of bioethics.[33] Hence, the UDBHR was necessary as the existing human rights framework did not effectively cater to the new concerns that bioethics revealed. Human rights are largely considered to be obligatory in an international context, while bioethics principles are rather considered as exploratory notions of what ought to be permissible within the fields of healthcare and science.[34] While the UDBHR remains quite broad, it represented a significant step in advancing bioethics from a mere philosophical debate to the expression of specific human rights that exist within a particular principle of bioethics, in order to guide the regulations and practices of advancements in the medical arena.[35] Bioethics raises various questions including those posed around life and death, human embryo research, and reproductive cloning, which have all had a significant impact on the development of international legal frameworks with bioethical concerns, comprising both international legally binding and non-legally binding treaties.[36] While its impact in the domestic framework has largely resulted in the incorporation of some bioethical principles into national legislation, the constitutions of these domestic regions remain largely untouched.[37] The developments in case law of bioethical questions both internationally and domestically have effectively created a framework within which new bioethical issues can be disputed and addressed in order to keep up with the continuous changes due to medical advancements. Hence, the relationship between law and bioethics, while rooted in the human rights discourse, continues to be a complementary one of mutual influence and consideration for the dichotomy between legal frameworks and the values of bioethics.[38]

As mentioned before, bioethics should be viewed as a field of its own, unfortunately the reality is that it is often erroneously viewed in a sense that it is synonymous with human rights, specifically in relation to rights in healthcare, which can lead to problematic assumptions that erroneously equate morality with law.[39] While the jurisprudence of law is explicitly not under debate in this dissertation, it is still important to note the differentiation between the two types of jurisprudential

---

[33] Howard Wolinsky 'Bioethics for the world' (2006) 7 *European Molecular Biology Organisation* 4 at 354.
[34] Ibid at 355.
[35] Ibid at 355.
[36] Supra note 23 at 1145.
[37] Ibid at 1146.
[38] Supra note 1 at 124.
[39] Arthur Scheller Jr 'Law and Morality' (1953) 36 *Marquette Law Review* 3 at 319.

theories of law in order to understand why law is not necessarily synonymous with morality. The jurisprudence of law is based on the notion that two theories of law exist that essentially critically analyse the philosophy and theory of legal systems in order to comprehend the nature and purpose of law, as well as what makes it valid and why society follows it.[40] The two main theories that are debated in legal jurisprudence are namely natural law and legal positivism.[41] Natural law is generally understood to assert that all law must be able to be justified on a moral basis in order for it to be deemed a legitimate and valid law.[42] In terms of the natural law theory, a legal system has to fully incorporate the elements of natural law in order for it to be regarded as a valid system of law, which includes promoting the common good for all, encouraging good acts, and avoiding those deemed as evil acts.[43] It is also known that many natural law theorists believe certain misconceptions of legal positivism as they tend to consider that positivism is completely separate from ethics, in that anything that an authority dictates as law, whether moral or immoral, is law by virtue of it being sourced from a recognized source of authority.[44] However, legal positivists dispute this perspective of positivism as a misconception of the theory of positivism, as most of these theorists argue that positivism is in fact rooted in the notion that there is no guaranteed link between law and morality, and rather the validity of a legal system is based on whether it conforms to the standards of that particular society.[45] Legal positivism itself is complex and can be further categorized into inclusive positivism and exclusive positivism, with exclusive positivists believing that it is practically impossible for law to incorporate morality, while inclusive positivists believe that law can in fact incorporate moral principles, and as such law and morality while somewhat related, are not synonymous.[46]

As such, it is no new phenomenon that the law is neither synonymous with morality, nor is it an extension of it.[47] This is evident in various legal systems and societies where law operates, as legal

---

[40] Denise Meyerson *Understanding Jurisprudence* 1 ed (2006) at 1.

[41] William C Starr 'Law and Morality in H.L.A Hart's Legal Philosophy' (1984) 67 *Marquette Law Review* 4 at 673.

[42] Supra note 39 at 322.

[43] Supra note 41 at 674.

[44] Ibid at 675.

[45] Supra note 40 at 4.

[46] Danny Priel 'Farewell to the Exclusive–Inclusive Debate' (2005) 25 *Oxford Journal of Legal Studies* 4 at 675.

[47] Supra note 4 at 19.

systems and laws can always be defective on a moral basis.[48] An example of such immorality experienced in legal systems that have enforced laws despite being immoral and/or unethical, would be the Apartheid legal regime in South Africa prior to 1994, where the minority white population ruled and created an unjust legal system aimed at discriminating and oppressing the majority black, coloured and Indian populations.[49] Although morality is not synonymous with law, it is most definitely still somewhat related to it, as throughout history it has been depicted that a law or a legal system can legally operate and be enforced without necessarily being moral or ethical, but in addition to this law can also incorporate moral principles, as is also evident throughout history that many democratic legal systems and human rights frameworks have in fact developed and emerged in response to immoral and unethical legal systems, such as was the manner in which the United Nations was established in a global response to the atrocities witnessed in World War II.[50] It is against this backdrop of the existence of the distinction yet still interrelated relationship between law and morality, that one must also understand the existing distinction between legal rights and moral dilemmas.

Despite literature being divided over the natural and positivism legal theory debate, a large portion of literature seems to support the notion that law and morality are not synonymous but that they are in fact relative, which raises queries regarding whether this view is still applied in practice today, considering legal rights and morality, especially when considering legal rights in healthcare.[51] A vast amount of literature has also reflected the natural law ideology that laws and/or legal rights must be moral in order for them to be enforceable.[52] Although this seems somewhat "just" in order to prevent a fundamentalist society that blindly enforces laws, regardless of the discrimination or negative consequences it may have on individuals, it also presents an issue concerning the level of morality that ought to be applied as well as the factors that ought to be considered in order to deem a law or legal right as just. Many issues arise from aspects of both

---

[48] Supra note 4 at 19.

[49] Mavis B Mahlauli, End Salani and Rosinah Mokotedi 'Understanding Apartheid in South Africa through the Racial Contract' (2015) 5 *International Journal of Asian Social Science* 4 at 205.

[50] George P Smith 'Human Rights and Bioethics: Formulating a Universal Right to Health, Health Care, or Health Protection?' (2005) 38 *Vanderbilt Journal of Transnational Law* at 4.

[51] Supra note 4 at 19.

[52] Supra note 41 at 674.

these theories of law, particularly concerning the question of when a law in a society would simply exist based on an individual's rights, as opposed to trying to resolve society's moral or ethical dilemmas with the particular law itself. For example, the pertinent issue concerning medical interventions, such as preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician assisted suicide, is the centre of great debates concerning moral and ethical dilemmas, however whether a particular state has determined these practices legal or not is based on the enforced laws within a particular society, which is usually subject to that particular society's recognized legal standards or constitution which generally embodies principles of human rights. As many societies require their laws to abide with principles of human rights, then one would generally think that the practices of preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician assisted suicide, would be more socially and legally accepted, given that they are directly related to the promotion of an individual's human rights to dignity and privacy.

The notion of human rights is neither grounded in natural law, nor legal positivism.[53] Legal positivists believe that human rights are sourced from an authority making rule power that governs a particular society, while natural law theorists believe that natural rights derive from a divine origin that are universal and inalienable, and thus human rights are inherent to all individuals.[54] Human rights in the contemporary sense, constitute a set of standards and norms that govern how individuals ought to be treated by both state and non-state actors alike, as they are rooted in the foundation of principles that are thought to be necessary for individuals to live a satisfying life.[55] Human rights are referred to as rights that are inalienable and universal, which essentially entails that all individuals across the globe, regardless of one's nationality, race, religion, gender or social class, are inherently entitled to these rights in virtue of them simply being human beings.[56] However, it was not until after the gross atrocities that took place in World War II, where millions of individuals were abused, tortured and murdered under the Nazi regime, that forced the

---

[53] Louis Henkin 'Introduction: The Human Rights Idea' in David Weissbrodt, Fionnuala D Ni Aolain & Mary Rumsey (ed) *Development of International Human Rights Law* vol 1 (2014) at 24.

[54] Stephen P Marks 'Human Rights: A Brief Introduction' (2016) *Harvard University* at 3.

[55] Heirweigh Tess *Euthanasia, one's final human right?: The case of euthanasia for* children (unpublished Masters Degree in Human Rights and Democratization thesis, Uppsala University, 2016) at 21.

[56] Jack Donnelly 'The relative universality of human rights' (2007) 29 *Human Rights Quarterly* 2 at 282.

international community to cooperate in prioritizing the proper recognition and protection of human rights through the establishment of the United Nations in 1945 in an effort to ensure international peace and security.[57] Soon after its establishment, the United Nations then proceeded to adopt what has become known as the core foundation of international human rights, the Universal Declaration of Human Rights (hereinafter referred to as the "UDHR").[58] The UDHR represented the international community's first shift to the adoption of an international agreement that set out the rights and freedoms that all individuals across the globe ought to be entitled to. The UDHR codified the basic human rights of individuals into a document,[59] which outlined the international standard of how states ought to treat their citizens in order to ensure that all individuals' basic human rights are upheld and protected.[60]

Human rights in international law are adopted through various international treaties and declarations, the most significant being the UDHR, adopted by the General Assembly of the United Nations.[61] While the UDHR was not intended to be legally binding itself,[62] it is a declaration that has significantly influenced the development of other human rights instruments and treaties that effectively provide legal binding force to similar rights listed in the UDHR, namely the International Covenant on Civil and Political Rights (hereinafter referred to as the "ICCPR"),[63] and the International Covenant on Economic, Social and Cultural Rights (hereinafter referred to as the "ICESCR").[64] The UDHR, ICCPR and ICESCR together are collectively referred to as the international bill of rights,[65] as they enshrine numerous human rights, including the rights related to dignity and privacy, which are of particular significance to this dissertation as these rights are central to medical interventions involving either the potential beginning and/or the termination of an individual's life. Some research has attempted to oversimplify this contentious issue by

---

[57] Supra note 53 at 23.

[58] Universal Declaration of Human Rights, 1948.

[59] Marci Hoffman 'International Human Rights Law' (2013) *American Society of International Law.*

[60] Ibid.

[61] Jack Donnelly and Daniel J Whelan *International Human Rights* 6 ed (2020) at 6.

[62] Karin Mo *The Practical Implementation of Human Rights – Universal or Contextual?* (unpublished Faculty of Theology thesis, Uppsala University, 2015) at 29.

[63] International Covenant on Civil and Political Rights, 1976.

[64] International Covenant on Economic, Social and Cultural Rights, 1976.

[65] Danwood Mzikenge Chirwa 'The Right to Health in International Law: Its implications for the obligations of state and non-state actors in ensuring access to essential medicine' (2003) 19 *SAHJR* at 546.

presenting it as a mere debate between the right to life versus the right to choose to die.[66] However, this over simplification is not the most suitable when considering medical interventions and the various rights it impacts. Many scholars have also argued that the right to life is also intrinsically linked to the quality of the life it purports to protect as most international frameworks encompass the notion that an individual ought to have a right to life and liberty, hence arguments in literature attempting to separate the quality of life from the right to life seem rather illogical.[67] Although the right is infamously recited and listed in human rights instruments, the notion of a right to choose to die, although not recognized in most regional and international human rights instruments, is increasingly gaining prominence given the emergence of medical and scientific advancements.[68] The contentious debate concerning whether the existing framework of human rights supports the right to choose to die in cases of suffering, through the existing human rights of human dignity and privacy, is one that will be analysed further in this dissertation, in order to further comprehend the dichotomy of a predominately larger societal and legislative support for the avoidance of suffering, as opposed to the termination of suffering. The issues that bioethics presents to human rights are not only contentious but have been increasingly divisive across the world in various states and legal systems, particularly with the advancement of medical technology and science.[69]

iii. Medical advancements utilized in the beginning and the end of life - eugenics, genetic engineering, preimplantation and prenatal genetic testing and selection, and euthanasia

Technological and scientific advancements in the medical and science fields in relation to various medical interventions such as eugenics, genetic engineering and euthanasia, have rapidly increased in recent decades.[70] Eugenics is mentioned in this dissertation as it is necessary to understand the origins and development of medical and scientific interventions in human life in order to comprehend many of the fears and challenges confronted with enabling the utilization of a more

---

[66] Rebecca Reingold ‘An International Human Right to Die with Dignity’ (2019) *O’Neil Institute for National & Global Health Law – Georgetown Law* available on https://oneill.law.georgetown.edu/an-international-human-right-to-die-with-dignity/, accessed on 8 July 2021.

[67] Dr John I Fleming ‘Euthanasia: Human Rights and Inalienability’ (1996) 63 *The Linacre Quarterly* 1(5) at 45.

[68] Tom L Beauchamp ‘The Right to Die as the Triumph of Autonomy’ (2006) 31 *Journal of Medicine and Philosophy* at 643.

[69] Alexander Morgan Capron ‘Law and Bioethics’ in *Bioethics* 4 ed (2014) at 1793.

[70] Atina Krajewska ‘Bioethics and Human Rights in the Constitutional Formation of Global Health’ (2015) 4 *Laws* at 782.

modern medical intervention such as genetic engineering, which has essentially branched off the science of eugenics in a way with regard to its shared element of "improvement".[71] In this way, eugenics could be said to have somewhat informed the "basis" in the science arena, of which certain elements of the science has led to the development of other medical advancements in recent decades, particularly that of genetic engineering. Eugenics in itself essentially encompasses the ideology of improving the human gene pool, which has largely been deemed a negative medical intervention in that it was historically utilized by state powers and authorities in its negative form to limit the reproduction of individuals with certain disabilities and traits that were deemed to constitute an individual that was considered to be less than perfect.[72] Eugenics, like genetic editing and preimplantation and prenatal genetic testing and selection, is related to an improvement of life through medical technology and science, however they differ greatly in their purpose and overall impact on society.

Genetic engineering, also often referred to as genetic enhancement and/or genetic modification, is essentially a branch sourced from the framework of eugenics in that, broadly speaking, it utilizes medical technology to effectively enhance the natural condition of a human being or foetus.[73] Genetic engineering is essentially a framework or umbrella term that encompasses a broad array of medical interventions, of which some are more legally and socially accepted than others, such as genetic editing and preimplantation and prenatal genetic testing and selection, which both assist in the possible avoidance of suffering of a potential life, by utilizing certain testing and screening methods on an embryo or foetus to identify defects or disorders that could possibly result in suffering and ultimately affect the dignity and privacy of a future individual.[74] Genetic engineering in regard to its practice of genetic editing, is currently illegal in most states across the world given its fears of the potential abuse and unnecessary enhancement of potential individuals, while preimplantation and prenatal genetic testing and selection, is a much more accepted and well-established medical intervention that can still achieve the ultimate goal of avoiding the suffering

---

[71] Rupert Suckling, Susan Root and Pablo Millares-Martin 'Eugenics Debate' (2000) 320 *British Medical Journal* 7328 at 1.

[72] Stephen Wilkinson ' 'Eugenics Talk' and the language of bioethics' (2008) 34 *J Med Ethics* at 467.

[73] J Harris and S Chan 'Understanding the ethics of genetic enhancement' (2008) 15 *Gene Therapy* 24 at 338.

[74] Margaret Somerville 'Birth, Death and Technoscience – Searching for Values at the Margins of Life' *Recognizing Religion in a Secular Society* at 83.

of a potential individual.[75] Preimplantation and prenatal genetic testing and selection enables the avoidance of suffering by granting potential parents with the unique opportunity to discover whether their child, while still an embryo or foetus, carries a "defective" gene, disability or disease, and then offers these parents the ability to decide for themselves whether they are willing to proceed with the implantation of an embryo or pregnancy of a foetus if a particular gene is present, or if they would prefer to rather discard the embryo or abort the foetus due to the presence of the defective gene.[76] Hence, preimplantation genetic testing and selection is relied on during the stage prior to the implantation of the embryo through in vitro fertilisation (hereinafter referred to as "IVF"), which is a reproductive technique involving various steps including the retrieval of eggs, embryo culture and the embryo implantation.[77] According to various medical research and studies, the transfer of embryos containing defective genes or "aneuploidies" is directly related to higher rates of IVF failure, which highlights the significance of preimplantation genetic testing and selection for viable pregnancies.[78] Similarly, prenatal genetic testing, which occurs prior to the birth of the foetus, involves the testing of the foetus to identify certain genetic disorders or conditions that could result in potential suffering.[79] The overall purpose of preimplantation and prenatal genetic testing and selection is aimed at granting individuals the ability to undergo testing to identify particular genes that they would prefer their embryo or foetus to not have in the hope it would ultimately avoid the development of a particular disease or disability which could result in suffering.[80] Most medical professionals in the genetics field believe that preimplantation and prenatal genetic testing and selection is beneficial as it allows people to have healthy babies free of any disability or disorder and therefore free of any suffering, however this can also essentially place a negative societal value on individuals living with certain conditions, illnesses or

---

[75] Alix Lenia v. Hammerstein, Matthias Eggel and Nikola Biller-Andorno 'Is selecting better than modifying? An investigation of arguments against germline gene editing as compared to preimplantation genetic diagnosis' (2019) 20 *BMC Medical Ethics* 83 at 1.

[76] Supra note 2 at 471.

[77] A Pedro and K Mwaba 'An exploratory study of South African women's experiences of In Vitro fertilizations and embryo transfer (IVE-ET) at fertility clinics' (2013) 3 *Open Journal of Preventive Medicine* 8 at 5-6.

[78] Ann Strode and Sheetal Soni 'Preimplantation diagnosis to create 'saviour siblings': A critical discussion of the current and future legal frameworks in South Africa' (2012) 102 *SAMJ* 1 at 21.

[79] Sheetal Soni 'The legal framework for preimplantation genetic testing in South Africa' *Next Biosciences Articles* available at https://nextbio.co.za/the-legal-framework-for-preimplantation-genetic-testing-in-south-africa/, accessed on 25 June 2022.

[80] Jason Christopher Roberts 'Customizing Conception: A survey of preimplantation genetic diagnosis and the resulting social, ethical and legal dilemmas' (2002) 1 *Duke Law & Technology Review* at 3.

disabilities.[81] As a result, most research has depicted that there is a general acceptance in the genetics field that it is desirable to prevent the birth of certain foetuses that exhibit particular traits, conditions or disabilities that could be linked with possible suffering in a living individual.[82] Ultimately, the selection of an embryo or foetus undertaken under the auspices of preimplantation and prenatal genetic testing and selection, should lead to somewhat of a better life for that particular potential human being, as the practice is rooted in the notion that the selection ought not to result in perfect and/or superior to normal outcomes, but it should just result in a better outcome overall, such as the reduction of the possibility or severity of a potential individual's suffering.

The medical advancements for purposes of selection in the beginning of life, has largely emphasized the importance of an authorized individuals' autonomy in selecting whether to proceed with the implantation of an embryo or the development of a pregnancy based on the discovery of defective or undesirable genes. Most literature regarding preimplantation and prenatal genetic testing and selection seems to largely support the role of the law in ensuring the promotion of increased personal autonomy granted to individuals in these processes.[83] However, in complete contrast to the promotion of increased autonomy of individuals, an evident pattern in literature and legislation in various countries, calls for a decrease of autonomy granted to individuals when it relates to the termination of an ill and/or suffering individual's life. Most research often portrays euthanasia as a negative medical intervention aimed at removing a life from this earth, and focusses on how contrary it sits on the spectrum of rights in relation to the right to life, instead of it being portrayed for what controlled practices of euthanasia offers, a peaceful termination of an ill, suffering and undignified life.[84] Most literature lacks a proper discussion and debate in the evident unequal standards in how it is more common for societies and legal systems to have encouraged and promoted human dignity and privacy for the potential suffering of lives with defective genes, or foetuses, while predominantly discouraging the same human dignity and privacy for ill and/or disabled and suffering individuals.[85] Individuals across the world, are now faced with the difficulty

---

[81] Tom Shakespeare 'Choices and Rights: Eugenics, genetics and disability equality' (1998) 13 *Disability &* Society 5 at 668.
[82] Ibid at 668.
[83] Supra note 2 at 471.
[84] Supra note 74 at 83.
[85] Ibid.

of having knowledge of the existence and benefits that advanced medical interventions such as preimplantation and prenatal genetic testing and selection, euthanasia and/or physician-assisted suicide offers, with the additional layer that their whereabouts or residence in a particular country, may either prevent or enable their access of such necessary medical interventions for some individuals, as certain countries have in fact criminalized these interventions, making it inaccessible to individuals by law.

It is clear from the aforementioned information prominent throughout the available literature, that the concept of bioethics needs to be interpreted in a manner that ensures that the necessary experts are relied on to research and gain further knowledge on the working of bioethics. A contributory and cumulative approach to understanding bioethics will assist in dealing with the impact it has on society, as bioethics does not only affect the medical field, but legal systems, and social systems too. It is also vital that although bioethics greatly impacts both the law and morality, it should not be made out to be synonymous with either. Bioethics is necessary in guiding the vital and co-dependent relationship that exists between the medical field and the law. It is through bioethics, that medical and scientific advancements, such as assistance in reproduction in the beginning of an undefective life, as well as assisting terminally ill and suffering patients in the termination of an undignified life, have challenged and developed existing social norms and even laws in some states and sectors of society.[86] Some states have managed to cope with the rapid increase of medical interventions, by simultaneously and timeously adapting these changes to reflect in their rights and laws. However, an overwhelming number of states and their legal systems have still failed to adequately adapt and keep up with the increased autonomy and freedom of choice of individuals within the rapid increase of medical and scientific advancements, which has led to the present dichotomy of which this paper seeks to discuss. There is also still a lack of literature on the dichotomy presented by the contradiction of how these medical interventions have been received and applied socially and legally both in the domestic and international spheres.

---

[86] Supra note 69 at 1793.

III. METHODOLOGY

The main purpose of this minor dissertation is to utilize research conducted by scholars as well as legislation in order to dissect the contentious issues behind the dichotomy presented whereby human rights are affected by preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician-assisted suicide. The research consists of two categories through which human rights are affected, namely the selection process in the beginning of life through preimplantation and prenatal genetic testing, and the termination of life through euthanasia and/or physician assisted suicide. This purpose of this paper aims to contribute in the exploratory manner in relation to the lack of proper research undertaken in the dichotomy of societal norms and laws regarding medical interventions and their impacts on human rights. The gap in relevant literature has exposed the issues that have arisen as a result of this under-researched problem which concerns the dichotomy of societal support for medical interventions aimed at avoiding suffering, as opposed to those aimed at ending suffering. I will largely rely on secondary data, such as medical articles, news articles, legislation and journal articles pertaining to the protection and/or violation of human rights through the enforcement of laws established to either promote or criminalize the abovementioned medical advancements. I believe it to be the best method upon which to approach this paper, as although there has been much literature published pertaining to euthanasia, there has been very little literature regarding the contradiction of laws that protect human rights of privacy and dignity through preimplantation and prenatal genetic testing and selection to avoid suffering in the beginning of life, while violating those very rights when it is confronted with euthanasia and/or physician assisted suicide to end suffering in the termination of life.

In the collection of data, the method of qualitive research was best suited for this paper, as the interpretations of the concepts of bioethics, preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician-assisted suicide, and how these interpretations have been applied, are vital in the discussion of the overall impact it has on human rights. I think it is important to make a comparative analysis on how different scholars and legislators have elected to either support or reject the two different medical advancements, particularly in the sense that they both are so intrinsically connected to the rights of privacy and human dignity. Many articles and societal norms have resulted in many misunderstandings of the purpose and benefits provided by both medical advancements, which has resulted in it being utilized by different legislators and governments in power to enforce certain laws that hinder these medical interventions and violate these very human rights that the illegality claims to be purporting to protect.

IV. ANALYSIS AND DISCUSSION

1. CHAPTER I – UNDERSTANDING THE HISTORY AND DEVELOPMENT OF THE CONCEPTS OF BIOETHICS AND MEDICAL INTERVENTIONS

1.1 The history and development of bioethics

The concept of bioethics was developed in the early 1970s by philosophers and theorists looking to establish a field of study that could assist in applying moral standards to a variety of fields and subjects, such as law, economics, philosophy and healthcare.[87] In tracing back the development of bioethics as a concept, it seems that research published by a professor of anaesthesiology, Henry Beecher, was instrumental in the developing stages of bioethics.[88] Beecher published research in the late 1960s on issues arising out of advancements in medical and scientific technologies, such as the extent of the involvement in medicine when a life of an individual could barely be deemed conscious, as well as when medical treatment being supplied to an individual ought to be terminated.[89] This early development of bioethics, importantly highlighted how the rapid increase in medical advancements were simultaneously leading to rapid increases in ethical issues relating to the autonomy and care of individuals in healthcare.[90] This research into medical ethics and the consequences it brought along with it, was initially aimed solely to inform medical experts, who were regarded as the "most reliable safeguard" to form an appropriate solution against the unethical issues that challenged patient interests.[91]

One of the most significant factors that was vital to the development of the field of bioethics, was the change experienced in the doctor-patient relationship.[92] Prior to the late 1960s, the medical

---

[87] Jennifer Flynn 'Theory and Bioethics' in Edward N. Zalta (ed.) *The Stanford Encyclopedia of Philosophy* (2021), accessed on https://plato.stanford.edu/archives/spr2021/entries/theory-bioethics/.

[88] S Scher and K Kozlowska 'The Rise of Bioethics: A Historical Overview' (2018) *Rethinking Health Care Ethics* 2018 at 32.

[89] Ibid at 32.

[90] Supra note 69 at 1795.

[91] Supra note 88 at 32.

[92] Supra note 15 at 13.

field was dominated by medical paternalism, where the doctor with medical expertise was essentially the only authority responsible for determining the interests of the patient and deciding on the best suited medical interventions and/or treatments, regardless of the will of the patient.[93] Medical paternalism was most dominant in western societies, particularly during the emergence of politics and debates of healthcare and medical technologies, where the healthcare and medical treatment of individuals were put at the behest of the State.[94] Enabling State policy to dictate the healthcare and medical treatments available to patients led to an immense number of state endorsed medical atrocities, such as those perpetrated by the Nazi's in Germany during World War II.[95] State policies enabled both Nazi officials and doctors under the regime to commit crimes such as committing medical experiments, without any consent obtained, on the human beings detained in the concentration camps.[96] These non-consensual medical interventions and experiments included forms of euthanasia and eugenics, which ultimately resulted in the fatality and/or disfigurement of almost all the human beings that were forcefully subjected to these experiments.[97] In fact, these atrocities were of such monstrous proportions that it led to the publishment of the Nuremberg Code in 1947, which reiterated the need for medical experimentation on human beings to not only be legitimate, but based on strict conditions, particularly in relation to obtaining the informed consent of the individual.[98] The Nuremberg Code also influenced the UDHR which further emphasizes the importance of regulating medical experimentation on human beings as subjects.[99] This regulation is emphasized through article 25 of the UDHR which essentially recognized an adequate standard of living for one's health and well-being,[100] which led to the recognition of the right to health in the ICESCR,[101] which the right to health within itself contains various underlying freedoms and entitlements both for access to treatment for diseases, and against non-consensual medical experimentation.[102] In addition to this, in 1964 the World Medical Association issued the Declaration of Helsinki, which contributed to the efforts made by both the Nuremburg Code and the UDHR, in order to further promote the importance of protecting the interests of patients and

---

[93] Supra note 15 at 13.
[94] Ibid at 13.
[95] Supra note 54 at 7.
[96] Supra note 15 at 11.
[97] Ibid at 10.
[98] Supra note 54 at 7.
[99] Supra note 15 at 11.
[100] Supra note 58 at article 25.
[101] Supra note 64 at article 12.
[102] Supra note 65 at 547.

the autonomy and informed consent of individuals when it comes to them undergoing medical interventions and/or treatments.[103] As can be seen from the legislation enacted over the decades, bioethics has also resulted from the continuous evolution from a period of medical paternalism to a period where an ever increasing significance is placed on the autonomy of patients and/or individuals.[104]

Medical and scientific advancements were increasing at a much more unprecedented pace than the medical profession and medical ethics in the late 1960s could cope with.[105] The ethics issues brought up were far beyond what constituted medical ethics prior to the 1960s, in fact the issues that arose in the late 1960s were as a result of medical and scientific advances such as genetic innovations and further knowledge, expanded forms of contraception, medically safe abortions, organ transplantation, termination of life, as well as interventions to maintain life over its normal limits of self-sustainment.[106] These issues led to bioethics formally being recognized in the 1970s, as it encompassed debates concerning not only healthcare related rights such as autonomy and dignity of patients, but also the need for amended policies and regulations in respect of various medical interventions.[107] Bioethics identified the complexity of balancing medical expertise and advanced medical interventions and/or treatments, with the need for policy to regulate and determine the conditions and/or rules concerning medical interventions such as preimplantation and prenatal genetic testing and selection, and euthanasia, in order to ensure that a balance is struck between the rights and obligations of individuals and society as a whole.[108] This resulted in a gap both in research and within society with the medical profession's practices and treatments, and the general public's increasing need to address issues relating to their rights and autonomy that came along with medical and scientific advancements.[109]

---

[103] Supra note 15 at 11.
[104] Ibid at 13.
[105] Supra note 88 at 32.
[106] Daniel Callahan 'Bioethics and Policy – A History' (2015) *The Hastings Center* available at https://www.thehastingscenter.org/briefingbook/bioethics-and-policy-a-history/, accessed on 26 July 2021.
[107] Ibid.
[108] Ibid.
[109] Supra note 88 at 32.

Bioethics is now commonly known as a study committed to understanding the implementation of ethics and moral standards in the ever emerging medical and biological advances in health care.[110] Bioethics has essentially been the foundation through which most ethical dilemmas arising from these medical advancements have been propelled to the forefront of society through the prohibition and/or enforcement of them through the legal system, where courts have made decisions on their understanding of the significant implications of the ethical issues that have resulted as a consequence of the success experienced of the advancements in the medical and biological field.[111] It has brought up medical and ethical debates to the legal forefront, concerning an abundance of issues, particularly the modification of embryos and creation of a mutation free life, as well the illegality of assisting in terminating a fatally ill life.[112] It is a fact that medical and scientific advancements are changing the way individuals live and function in society, as an individual's life expectancy is not only increased but also improved.[113] The challenge with this is that an increased life expectancy now opens individuals to more risks of developing "elderly" related disabilities or diseases in their old age, such as Dementia or Alzheimers.[114] In an attempt to reduce the risks of developing chronic diseases or life threatening illnesses, individuals are also turning to advancements in genetic innovations to possibly prevent their own offspring from having to endure similar struggles and suffering in their elderly years.[115] It is evident that these medical advancements and the accessibility of more medical interventions bring about benefits, but these advantages are also coupled with the unfortunate exclusivity of high costs and policy dilemmas, making it inaccessible to the individuals in society who require it the most.[116] These ethical debates concerning medical advancements have been exacerbated by the limelight that has been shone, particularly over the past few years, on the desperate need to protect individual rights, promote human dignity and ensure justice prevails for the individual regardless of the opinions of those in society who oppose the same view.[117] This essentially encompasses the issue that this paper will

---

[110] Supra note 69 at 1789.
[111] Ibid at 1790.
[112] Supra note 74 at 83.
[113] Supra note 106.
[114] Ibid.
[115] Tania Ascencio-Carbajal, Garbine Saruwatari-Zavala & Fernando Navarro-Garcia, et al 'Genetic/genomic testing: defining the parameters for ethical, legal and social implications' (2021) *PubMed.*
[116] Supra note 106.
[117] Supra note 69 at 1790.

analyse, the dichotomy of laws, human rights and societal perceptions in terms of the avoidance of suffering through preimplantation and prenatal genetic testing and selection in the beginning of life, as well as the ending of suffering through euthanasia in the termination of life.

1.2 How the establishment of the system of eugenics has led to certain eugenic elements shaping the development of the advanced medical interventions

The development of eugenics and how it has evolved throughout history is not only necessary to comprehend in terms of the scientific development of medical interventions on human beings, but it is most significant in order to fully comprehend the severe apprehension of societies and opponent groups to medical interventions that either prevent or end suffering, such as preimplantation and prenatal genetic testing and selection, and euthanasia. In the early 1800s, the concept of eugenics was introduced and developed by Sir Francis Galton, who defined it as the "science which deals with all the influences that improve and develop the inborn qualities of a race".[118] Eugenics had a significant impact in Western societies in the 1800s, as it became increasingly accepted that eugenics could be utilized in order to categorize and divide the "inferior" human beings apart from the fit human beings.[119] During this period, individuals were deemed inferior and thus unfit, if they had physical and/or mental disabilities.[120] The aim to utilize eugenics to limit the genetically inferior groups of populations developed into such a popular ideology in Western societies that by the early 1900s, most Nordic and Western states had actually enforced sterilization laws aimed at carrying out social experiments on human beings.[121] These eugenics social experiments targeted any individual deemed inferior based on mental and/or physical defects or disabilities and forced them to undergo permanent sterilization.[122] These social experiments developed from a point of forceful sterilization, to a belief encouraging further elimination of inferior human beings, which resulted in eugenic policies being directed to further levels of eradicating the inferior groups through terminating the life of individuals completely,

---

[118] Merryn Ekberg 'Eugenics: Past, Present and Future' in Marius Turda *Crafting Humans: From Genesis to Eugenics and Beyond* Vol 5 (2013) at 89.

[119] Lars Grue 'Eugenics and Euthanasia: Then and Now' (2009) *Scandinavian Journal of Disability Research* at 2.

[120] Felipe E Vizcarrondo 'Human Enhancement: The new eugenics' (2014) 81 *The Linacre Quarterly* 3 at 239.

[121] Supra note 119 at 2.

[122] Allen Buchanan 'Institutions, Beliefs and Ethics: Eugenics as a Case Study' (2017) 15 *The Journal of Political Philosophy 1* at 22.

often through medical interventions such as euthanasia.[123] This was evident in Germany, where in 1933,[124] eugenics policies were first passed through voluntary sterilizations laws, where over 400 000 individuals were sterilized based on possessing certain defects that included but were not limited to physical disabilities, deformities, mental illnesses and even addictions such as alcoholism.[125] These sterilization policies in Germany, quickly developed into the systematic eradication of individuals deemed inferior, based on nothing more than their race, ethnicity, sexual orientation or religion, in order to create what was deemed a perfect human race of superior beings.[126] Despite most western societies utilizing eugenics policies in one form or another, the Nazi regime in Germany during World War II was known for implementing the most violent and cruel forms of eugenics on individuals, mostly Jewish individuals, simply deemed inferior based on their race, ethnicity, sexual orientation and even religious association.[127] Due to this, eugenics has justly become known as a radical, evil and lethal science aimed at eliminating any disabled or inferior individual,[128] with a complete abandonment of any consideration of morality or rights in favour of a skewed perception of what was deemed to be in the interests of the welfare of society by those implicated with the application policies.[129]

It is evident that the early utilization of eugenics by many Western states in Europe and America tainted its reputation to one of a system of pure scientific racism whereby the practice of eugenics was relied on to eradicate entire communities and populations.[130] Some researchers justly believe that the system of eugenics was far too sinister and racist to ever be applied in modern day science, others still believe that a weaker form of eugenics could be relied on and applied today. In terms of this view, weak eugenics, which is also commonly referred to as liberal eugenics,[131] is said to

---

[123] Susan Bachruch 'In the Name of Public Health – Nazi Racial Hygiene' (2004) 351 *New England Journal of Medicine* at 419.

[124] Thorsten Noack and Heiner Fangerau 'Eugenics, Euthanasia and Aftermath' (2007) 36 *International Journal of Mental Health* 1 at 113.

[125] Supra note 120 at 240.

[126] Ibid.

[127] Supra note 119 at 3.

[128] Ibid at 3.

[129] Supra note 122 at 22.

[130] Vincenzo Pavone 'Science, Eugenics and Utopia: Comparing Scientific humanism and liberal eugenics on human genetic enhancement' (2006) *Spanish National Research Council* at 11.

[131] Nicolae Sfetcu 'The new (liberal) eugenics' in Multimedia Publishing (ed) *Evolution and Ethics of Eugenics* (2018) at 3.

refer to efforts towards the promotion of certain medical advancements and/or technologies in reproduction selection methods through an individual's freedom of choice.[132] In this view, the concept of eugenics has evolved and is able to be separated from the historical violent application of eugenics which was rooted in an authoritarian basis, to a more liberal sense of eugenics,[133] which is considered morally acceptable in that it considers the choice of an individual.[134] However, this idea that the entirety of eugenics could be applied and utilized today, simply rebranded as liberal eugenics, is not only dangerous considering its sinister past, but also the actual notion that a single individual could have any autonomy or freedom of choice within the system of eugenics, seems contrary to the formal definition of eugenics itself, which is a system aimed at the improvement of qualities considered superior imposed on a whole population.[135] Thus the consent, or lack thereof, of a single individual within that population would seem to be insignificant to the overall system of eugenics given that eugenics policies were largely all rooted in practices that trumped an individual's autonomy as these policies concerned compulsory medical interventions such as sterilization or abortion, or the prohibition of procreation with communities deemed undesirable based on their physical traits, race, ethnicity or religious association.[136]

In light of this understanding that the entirety of eugenics can never be removed from the atrocities of its past acts and the potential of repeating these acts again, it can still be fairly deduced that specific elements or similarities that are rooted in the science of eugenics has in fact become somewhat more acceptable in modern day science through medical advancements such as preimplantation and prenatal genetic testing and selection. Whereby the system of eugenics was historically aimed at relying on science in order to improve the human race, preimplantation and prenatal genetic testing and selection has relied on a different aim and purpose for society, one aimed at individuals who freely opt to utilize its practice, as opposed to one forcibly imposed on

---

[132] Supra note 81 at 669.

[133] Supra note 72 at 467.

[134] Dov Fox 'The Illiberality of 'Liberal Eugenics' ' (2007) *Ratio* at 2.

[135] Fred D Ledley 'Distinguishing genetics and eugenics on the basis of fairness' (1994) 20 *Journal of Medical Ethics* at 164.

[136] Chad E Brack 'Hume's Law and Genetic Engineering: Considering the Possible Implications of Positive Eugenics in Light of our Horrific Past' (2020) 12 *Inquiries Journal* 10, available on http://www.inquiriesjournal.com/articles/1828/humes-law-and-genetic-engineering-considering-the-possible-implications-of-positive-eugenics-in-light-of-our-horrific-past, accessed on 2 May 2021.

an entire population. While preimplantation and prenatal genetic testing and selection are entirely different practices with a different purpose, it is still largely based on the similar notion of improvement, while the purpose and application differs to eugenics, preimplantation and prenatal genetic testing and selection aims at improving a potential individual through the direct identification of certain defective or undesirable genes in an embryo or foetus to prevent it from possibly resulting in a disability or disease that would result in suffering.[137] While the medical interventions involved in preimplantation and prenatal genetic testing and selection such as genetic screening and diagnosis, are somewhat similar to what has been labelled as positive, weak and/or liberal eugenics, it is not eugenics based on its formal definition, and should thus only be referred to as preimplantation and prenatal genetic testing and selection, particularly given the stark difference in the moral distinctions and the practices that are allowed between the terms of eugenics and preimplantation and prenatal genetic testing and selection.[138]

---

[137] Daniel Wikler 'Can we learn from eugenics?' (1999) 25 *Journal of Medical Ethics* at 183.

[138] Walter Viet, Jonathan Anomaly, & Nicholas Agar, et al 'Can 'Eugenics' be defended?' (2021) 39 *Monash Bioethics Review* at 62.

2. CHAPTER II – THE DICHTOMOY OF SUPPORT BETWEEN PREIMPLANATION AND PRENATAL GENETIC TESTING AND SELECTION, AND EUTHANASIA AND/OR PHYSICIAN-ASSISTED SUICIDE

2.1 Understanding the differentiation between eugenics, genetic engineering and the different forms of preimplantation and prenatal genetic testing and selection

Although genetic engineering has developed through the evolvement of certain elements of eugenics, it still differs in various aspects, particularly given that it essentially provides individuals with the freedom to make choices based on obtained genetic information and technologies in order to assist with preventing chronic illnesses, diseases and defective traits from passing on to offspring during reproduction which could potentially cause a lifetime of suffering.[139] Genetic engineering highly favours the autonomy of individuals, or potential parents, concerning their health and reproduction,[140] while the past notion of eugenics and related experiments was largely understood to be applied under duress, enforced by state policy or involuntary mechanisms.[141] Most groups who oppose the medical intervention of genetic engineering, do so under the auspice of its links and/or similarities to what some researchers have coined as liberal eugenics.[142] As previously noted, liberal eugenics has essentially been established as an attempt to reframe the sinister term in a new light to show the alleged evolvement of eugenics from an immoral and racist system, based on defining features such as coercion, state mandated policies and collectivism, to what is considered a more moral system which is said to be based on defining features such as voluntariness, individualism, and state-neutrality.[143] Genetic engineering, while similar in both its nature of existing as a medical intervention, as well as its aim to improve an individual, is differentiated on the basis that it is voluntary, private, optional and for the purpose of individuals, as opposed to eugenic state mandated policies aiming to genetically engineer entire populations and eradicate diversity.[144] While eugenics was motivated by an underlying notion to improve the human race, genetic engineering is motivated by individuals who freely elect to make informed

---

[139] Supra note 130 at 3.

[140] Supra note 119 at 8.

[141] Ibid at 8.

[142] Supra note 131 at 3.

[143] Supra note 134 at 3.

[144] Supra note 131 at 3.

choices concerning their own health, and/or the health of their potential children.

Genetic engineering can be understood as a framework within which various medical interventions broadly exist, including the similar yet different practices of genetic editing and preimplantation and prenatal genetic testing and selection. However, it is vital to note that although these practices are similar in relation to their overall purpose of ensuring a potential individual who is free of suffering, they are also vastly different in regards to their legality, societal support and application.[145] Hence, as advancements in medical interventions are generally clustered within the same framework of genetic engineering and eugenics, it is necessary to comprehend the differentiation between the two similar yet different practices in order to understand why preimplantation and prenatal genetic testing and selection is the preferred medical intervention to ensure that individuals are born without debilitating diseases and conditions that would result in severe suffering. Genetic editing essentially involves the alteration of defective genes of foetuses or embryos, in order to create the life of a potential individual without any inherited conditions or mutations.[146] In short, this correction of the abnormal functioning of the defective gene which aims to improve the functioning of the gene thereby eliminating the disease and potential suffering, is achieved through various practices including by effectively inserting a functioning and/or correct copy of the defective gene into the genome of the cells present in a tissue or organ, or altering and/or modifying the genetic sequence of the human genome in order to correct the defective gene.[147] In fact, the gene that is targeted during the genetic editing also contributes to the bioethical debate, given that it can be conducted on both somatic cells and reproductive cells,[148] which has dire consequences for future generations, given that alterations to the somatic cell gene are solely restricted to the individual affected, while alterations to the reproduction cell genes can be passed on to subsequent generations which could result in a much wider impact on the lives of future individuals, which is seen as both a positive in terms of disease prevention, as well as a negative

---

[145] Supra note 75 at 2.

[146] Donrich Thaldar, Marietjie Botes, & Bonginkosi Shozi, et al 'Human germline editing: Legal-ethical guidelines for South Africa' (2020) 116 *S Afr J Sci* 9/10 at 1.

[147] Juliette Delhove, Ivana Osenk, Ivanka Prichard and Martin Donnelley 'Public Acceptability of Gene Therapy and Gene Editing for Human Use: A Systematic Review' (2020) 31 *Human Gene Therapy* 1 at 20.

[148] Susannah Baruch, Audrey Huang, & Daryl Pritchard, et al 'Human Germline Genetic Modification: Issues and Options for Policymakers' (2005) *Genetics and Public Policy Center* at 13.

in terms of the passing on of possible associated risks.[149] It is largely for this reason, that genetic editing remains controversial as a dominant proportion of the global community remains critical of the practice given the reality of the potential dangerous effects on future generations as well as the serious ethical concerns of the practice.[150]

Recent developments in the advancements of the field of genetic editing, CRISPR-Cas 9 (clustered regularly interspaced short palindromic repeats), has recently become the forefront of increased ethical and legal concern, where now even therapeutic forms of genetic editing are under much criticism concerning whether it ever ought to be adopted and if it could be regulated.[151] Although the practice of genetic editing applied to reproductive cell genes which can be inherited by subsequent generations is currently prohibited in most jurisdictions' research and clinical trials,[152] CRISPR-Cas9 has still proceeded in some regions despite these regulations. CRISPR-Cas9 essentially allows scientists to edit the human genome in order to remove, replace or insert new genes to the DNA sequence which can be used to eradicate diseases and disorders at a much lower cost and much more scientifically accurate than ever before.[153] In fact, a scientist in China became the first to utilize CRISPR-Cas9 in order to edit twin human embryos to disable a gene that was responsible for enabling HIV to enter healthy cells, which these embryos then subsequently went on to be born with in late 2018, and represented the first genetically edited twin babies to be born in history with altered genes to make them immune to HIV.[154] Although CRISPR-Cas9 offers a range of benefits to society in eradicating diseases and disorders that ultimately result in suffering, its current form still poses too many risks to society given the unpredictable dangers of the potential future lives of those it modifies, and its ability to create "designer babies" with preferred cognitive

---

[149] Ryota Tamura and Masahiro Toda 'Historic Overview of Genetic Engineering Technologies for Human Gene Therapy' (2020) 60 *Neurol Med Chir* at 484.

[150] Supra note 75 at 2.

[151] Giulliana Augusta Rangel Goncalves and Raquel de Melo Alves Paiva 'Gene Therapy: Advances, Challenges and Perspectives' (2017) 15 *Einstein* 3.

[152] Christine Critchley, Dianne Nicol and Gordana Bruce, et al 'Predicting Public Attitudes Towards Germ Editing of Germlines: The Impact of Moral and Hereditary Concern in Human and Animal Applications' (2019) 9 *Frontiers in Genetics* 704 at 2.

[153] Adam Conti 'Drawing the Line: Disability, Genetic Intervention and Bioethics' (2017) 6 *Laws* 9 at 1.

[154] Vera Lucia Raposo 'The First Chinese Edited Babies: A leap of faith in science' (2019) 23 *JBRA Assisted Reproduction* 3 at 197.

and physical traits that could essentially raise concerns of inequality and discrimination.[155] According to expert evidence tendered in a South African case, in *AB v Minister of Social Development*,[156] "designer babies" refers to a baby whose physical traits were elected on a cosmetic non-therapeutic basis by its parents prior to the implantation of an embryo or foetus.[157] While a broad scientific and ethical debate exists on the exact distinction between what actually constitutes therapeutic versus non-therapeutic forms of medical intervention, it seems that one evident distinction separating the two applications is that therapeutic forms of medical interventions are rooted in the notion that it must have therapeutic and/or disease treating ends, while non-therapeutic forms are rooted in the notion of achieving non-therapeutic aims, such as enhancing intelligence, sex selection or physical features.[158]

It is with the understanding of the potential dangers and fears associated with genetic editing, that one can comprehend the need to highlight the ethical and legal differences concerning the practices of preimplantation and prenatal genetic testing and screening. Preimplantation genetic testing, which was first developed in the 1980's, has developed into one of the most used and popular interventions in reproductive medical procedures across the globe.[159] Preimplantation genetic testing essentially involves a diagnostic procedure that is conducted on various embryos created through IVF, that then each undergo specific genetic testing in order to identify genetic diseases or conditions that would effectively result in a suffering life.[160] During this process, the affected embryos are then discarded, while the unaffected embryos are implanted into the female's uterus in the hope of a viable pregnancy that will result in a life that is not suffering from an inherited disease or condition.[161] Preimplantation genetic testing comprises two applications, namely preimplantation genetic screening and preimplantation genetic diagnosis, with the former referring

---

[155] Shawna Benston 'CRISPR, A crossroads in genetic intervention: Pitting the right to health against the right to disability' (2016) 5 *Laws* 1 at 13.

[156] *AB v Minister of Social Development* 2017 3 BCLR 267 (CC).

[157] Ibid at para 149.

[158] Daniel R Peterson 'Policing Future Nontherapeutic Applications of Genetic Enhancement through International Agreement' (2008) 30 *Houston Journal of International Law* 3 at 745.

[159] Joyce C Harper 'Preimplantation genetic screening' (2018) 25 *Journal of Medical Screening* 1 at 1.

[160] Ibid at 1.

[161] Rebecca Knox 'Preimplantation genetic diagnosis: Disease control or child objectification?' (2003) 22 *Saint Louis University Public Law Review* 2 at 436.

to the process whereby embryos are analysed in a laboratory to determine whether an embryo contains the normal number of chromosomes required in what is regarded as a healthy embryo and then selected for implantation, while the latter refers to the technique that provides information on the genetic make-up of the embryo's cells through an embryo biopsy which involves the removal of cells that are then tested in a laboratory to identify whether it possesses any single gene disorders or "aneuploid" and if not it is then frozen in preparation for implantation into a uterus.[162] Although preimplantation genetic testing is largely utilized for therapeutic purposes to detect genetic diseases in order to avoid offspring that could potentially suffer, the technology can also be utilized for non-therapeutic purposes, which are largely regulated or prohibited in most jurisdictions, such as sex selection and the enhancement of physical traits including behavioural traits, intelligence and physical features. Preimplantation genetic testing is largely legal in most states and supported internationally, in fact legislative regulations or frameworks permitting preimplantation genetic testing exist in various countries including Austria, Belgium, Canada, France, Germany, India, Netherlands, South Africa and the United Kingdom amongst others, while other countries permit the practice under professional guidelines such as Australia, Brazil, Japan and the United States.[163] The increase of societal and legislative support for preimplantation genetic testing is evident with countries that have previously banned the practice but have since introduced legislation to allow for the practice of it, such as Germany, Switzerland and Austria.[164] However, it is worth noting that the majority of these countries permit preimplantation genetic testing for therapeutic purposes relating to high risk or severe genetic disorders,[165] and all of the aforementioned countries, including South Africa,[166] actually prohibit preimplantation genetic testing for non-therapeutic purposes such as sex selection, aside from the United States of America, where the practice is neither regulated nor prohibited.[167]

---

[162] Bianca Carzis, Tasha Wainstein, Lawrence Gobetz, and Amanda Krause 'Review of 1- years of preimplantation genetic diagnosis in South Africa: implications for a low-to-middle income country' (2019) 36 *Journal of Assisted Reproduction and Genetics* at 1909.

[163] Margaret EC Ginoza and Rosario Isasi 'Regulating preimplantation genetic testing across the world: A comparison of international policy and ethical perspectives.' (2022) *Cold Spring Harbour Laboratory Press* at 3.

[164] Ibid.

[165] Wybo Dondorp and Guido de Wert 'Refining the ethics of preimplantation genetic diagnosis: A plea for contextualized proportionality' (2019) 33 *Bioethics* at 296.

[166] Sheetal Soni '*Prêt-à-Porter* Procreation: Contemplating the Ban on Preimplantation Sex Selection' (2019) 22 *PER/PELJ* at 16.

[167] Supra note 163 at 6.

Prenatal genetic testing, while similar, is different concerning the phase which the testing of the genes occur, as the testing is conducted on the foetus during the pregnancy to detect defective genes or conditions.[168] Prenatal genetic testing also comprises of two applications, notably prenatal genetic screening and prenatal genetic diagnosis, with the former referring to screening involving blood tests or ultrasounds to identify whether the foetus possesses any possibility of genetic disorders, which if identified, the physician will then likely advise for the latter application, where a diagnostic test is conducted to confirm the diagnosis, such as chorion villi sampling and amniocentesis, which is slightly more invasive and does pose a risk of miscarriage.[169] Although genetic testing is also largely permitted and practiced across the globe, differences in legality exist concerning the type of prenatal genetic test, with non-invasive applications being permitted by the majority of countries in Europe, Australia and the United States of America,[170] while invasive applications are still permitted but not to the same global extent to that of non-invasive applications.[171] Additional ethical dilemmas also exist with prenatal genetic testing, as some groups argue that preimplantation genetic testing is preferable given that the testing is conducted on embryos that have not yet been implanted, while prenatal genetic testing is conducted on a foetus while in the womb which could carry an additional dilemma for those who perceive a foetus to have a moral status, as opposed to an embryo in a lab.[172] If the potential parents agree, the detection of a defective gene in an embryo will likely result in the discarding of that embryo, while the detection of a defective gene in a foetus will likely result in the termination of that pregnancy. According to a study conducted in South Africa, the main reason provided by individuals who pursued preimplantation genetic testing between 2006 and 2016, concerned the possibility to avoid having a child affected with some severe disorder, as well as a desire to avoid the possible termination of pregnancy.[173] Preimplantation and prenatal genetic testing and selection is largely

---

[168] Paola Frati, Vittorio Fineschi, & Mariantonia Di Sanzo, et al 'Preimplantation and prenatal diagnosis, wrongful birth and wrongful life: a global view of bioethical and legal controversies' (2017) 23 *Human Reproduction Update* 3 at 339.

[169] Supra note 80 at 3.

[170] Kasper Gadsboll, Olav B Petersen, & Vincent Gatinois, et al 'Current use of noninvasive prenatal testing in Europe, Australia and USA: A graphical presentation' (2020) 99 *Acta Obstet Gynecol Scand* at 729.

[171] Dr Ismail Bhorat, Dr Lawrence Chauke, & Prof Edward Coetzee 'Challenges and Controversies in prenatal genetic screening in the South African context' (2018) 28 *Obstetrics and Gynecology Forum* at 34-35.

[172] Supra note 168 at 341.

[173] Supra note 162 at 1913.

available worldwide due to the significant benefits it offers to potential parents as it is considerably much safer than other reproductive procedures, it is associated with minimal errors, it enables individuals to have offspring free from severe genetic diseases and conditions, and preimplantation genetic testing offers the additional benefit that could possibly avoid abortions through the early detection of genetic diseases in an embryo before it is implanted which could assist potential parents from having to endure the strenuous effects, both mentally and physically, that undergoing an abortion could create for some individuals.[174] Both genetic editing and preimplantation and prenatal genetic testing and selection offer many benefits to prevent diseases and/or disabilities that result in severe suffering, the potential risks involved with genetic editing seem to far outweigh those of preimplantation and prenatal genetic testing and selection,[175] and stand as evidence as to why preimplantation and prenatal genetic testing and selection is the preferred option both morally and legally in most jurisdictions in order to prevent a future potential life of suffering.

Preimplantation and prenatal genetic testing and selection practices have also greatly impacted individuals with genetic diseases and disorders that do not have cures, like cystic fibrosis, Tay-Sachs disease, Huntington's disease, and Down-Syndrome, which can also be inherited by a child from an affected gene from each parent.[176] Through preimplantation and prenatal genetic testing and selection, the possibility to pursue medical interventions to screen embryos with preimplantation genetic testing and foetuses with prenatal screening, in order to detect affected genes were made possible, and as a result such screening programmes have prevented a significant number of fatalities related to genetic disorders such as, Huntington disease, Tay-Sachs disease or cystic fibrosis from possibly occurring.[177] Today, preimplantation and prenatal genetic testing and selection has enabled society with the technological advancements and scientific research to conduct over 1000 different types of genetic testing in order to allow individuals and families to hold accurate information to make informed choices and the freedom to decide whether they want to detect defective genes in their potential children, while embryos and foetuses, and ultimately

---

[174] Supra note 161 at 438.

[175] Robert Ranisch 'Genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?' (2020) 34 *Bioethics* at 68.

[176] Harvey J Steyn 'Preimplantation genetic diagnosis: prenatal testing for embryos finally achieving its potential' (2014) 3 *Journal of Clinical Medicine* at 283.

[177] Ibid at 283.

prevent having future children who might suffer from debilitating hereditary diseases or disorders.[178]

Many prospective parents do in fact elect to have preimplantation and prenatal genetic testing and selection done in order to identify possible defective or mutated traits in embryos, which further allow individuals and prospective parents with the opportunity to seek such a method which is broadly rooted in the realm of genetic engineering, in order to opt to possibly discard the embryo or abort a foetus in order to ensure a pregnancy free of diseases or conditions that would cause severe suffering. While this form of preimplantation and prenatal genetic testing and selection seems rather beneficial in that it is aimed at the avoidance of an individual's suffering, many who oppose it claim that potential parents who seek to pursue this method to identify certain defective genes, might be doing so more for themselves to prevent the risk of a child having a disability which would potentially create a financial and practical burden on the family.[179] Advocates for disability rights are generally known to be firm opposers of preimplantation and prenatal genetic testing and selection, usually claiming that these medical interventions are unnecessary as their argument is based on the notion that the practice, broadly considered a part of genetic engineering, is rooted in the ideology of eugenic practices as it allegedly intends to eradicate people with disabilities from future generations,[180] and they allege that scientists will then consider individuals with disabilities to be inferior if they have defective genes.[181] The disability rights advocates against preimplantation and prenatal genetic testing and selection argue that when these methods are utilized to eradicate all genes considered "defective", then even genes that result in disabilities will be considered fair play to eradicate, thus further devaluing disabled individuals and how they are viewed by society.[182] In terms of this perspective, individuals with undesirable traits that cause disabilities will essentially be viewed as an unnecessary cost to society purely based on their genetic makeup and/or presence of defective genes,[183] as this argument is based on the notion that

---

[178] Supra note 119 at 8.

[179] Supra note 81 at 679.

[180] Supra note 161 at 439.

[181] Sandy Sufian 'The Threat that CRISPR Poses to Disabled People' 15 March 2021 *BrinkNews*, available at https://www.brinknews.com/the-threat-that-crispr-poses-to-the-disabled/, accessed on 5 January 2022.

[182] Supra note 81 at 679.

[183] Supra note 153 at 2.

individuals with such disabilities are viewed as a negative societal burden who cannot contribute effectively to society or to an economy, and as such the rationale of cost-effective benefits are typically relied on to advocate for the eradication of such disabilities through rigid reproductive selection methods.[184] These advocates rather argue that society ought to separate the idea of disabilities from the notion of suffering and poor quality of life altogether, however, while this argument is true for some individuals living with disabilities, it cannot be declared that all disabilities caused by genetic conditions do not cause severe suffering, because a large proportion of these genetically caused disabilities do cause severe suffering.[185] In fact, it is necessary to consider that there is a significant difference between preferring a potential future child to not have a specific disease or disability, to that of considering a living human being with the same disease or disability as less valuable or worthy of life.[186]

The advancements of medical interventions such as preimplantation and prenatal genetic testing and selection are not aimed at genetically engineering populations, it is rather aimed at granting potential parents the autonomy to decide whether they personally would want to proceed with the growth of an embryo or foetus if defective genes are identified. In fact, the arguments in favour of adopting preimplantation and prenatal genetic testing and selection, at least for therapeutic purposes, are largely rooted in the notion of preventing severe suffering, thus it should only be limited to identifying certain debilitating diseases and even some disabilities that are considered to significantly impair the quality of life of the potential child, as well as their ability to have an open future, without restrictions based on suffering caused by debilitating diseases or disabilities. Thus, in order to balance both the respect for the rights of disabled individuals, with the increasing benefits that preimplantation and prenatal genetic testing and selection offers to society, it is necessary to distinguish between individuals with disabilities that constitute impairments that do not cause severe suffering such as deafness for some individuals, with individuals with disabilities or diseases that result in severe pain and/or suffering such as Ty-Sachs disease.[187] This is not to

---

[184] Supra note 81 at 679.

[185] Felicity Boardman ‘Letter to the editor. Gene Editing and disabled people: a response to Inigo de Miguel Beriain’ (2020) 11 *Journal of Community Genetics* at 246.

[186] Supra note 75 at 7.

[187] Supra note 81 at 670.

say that all embryos and foetuses that present with such traits should automatically be considered candidates that ought to have undergone preimplantation and prenatal genetic testing and selection, but rather only those potential parents who voluntarily choose to opt for the practice and who happen to have embryos or foetuses who exhibit such defective traits, should then be legally allowed to undertake medical interventions such as preimplantation and prenatal genetic testing and selection in order to ensure that based on their own private and personal view, preventing the growth of an embryo or terminating a foetus, after identifying a certain disease and/or disability, will ultimately be in the best interest of their potential child. It is with the involvement of public opinion that a just system of legal regulation can be put in place to oversee the adoption of advancements in preimplantation and prenatal genetic testing and selection in order to ensure that the rights of individuals are respected and that effective regulation will ensure that a balance is struck between those seeking preimplantation and prenatal genetic testing and selection for therapeutic purposes and those who choose to decline it, thereby preventing fears of a slippery slope towards eugenic practices.

Given the advancements in the field of genetic engineering, it seems logical that while preimplantation and prenatal genetic testing and selection, offers great benefits to society, it can also pose risks which often lead to the notion of a slippery slope back to eugenic practices.[188] However, preimplantation and prenatal genetic testing and selection for therapeutic purposes that are aimed at ensuring the most open future for a potential child by identifying genes that will ultimately result in suffering for a particular individual, and/or their subsequent generations should and is largely allowed, if and only if the potential parent of the embryo which exhibits such defective traits, freely and voluntarily agrees to do so in an effort to avoid their child's potential suffering. If preimplantation and prenatal genetic testing and selection is adopted through thorough and strict regulations, with the requirement of certain criteria to be fulfilled in order for the practice be undertaken, then it will assist in avoiding the practice being abused by those with eugenic-related intentions.[189] In order to ensure that this abuse is avoided, the adoption of preimplantation and prenatal genetic testing and selection should be adopted subject to strict criteria that include a

---

[188] Supra note 153 at 1.

[189] Supra note 135 at 164.

clear identification of an individual (whether it is a potential parent of an embryo or foetus), that freely and voluntarily gives fully informed consent to agree to either undergo preimplantation and prenatal genetic testing and selection for therapeutic purposes to avoid suffering, to be undertaken on the embryo or foetus of their potential child.[190] Therefore, since preimplantation and prenatal genetic testing and selection for therapeutic purposes ought to be adopted within the limitations of the purpose being to spare present and future generations a life of suffering caused by debilitating diseases or disabilities that have no cures,[191] the same consideration ought to be given to individuals already living with these same diseases and/or disabilities that can no longer endure the pain and suffering, and wish to terminate their own lives which they personally consider to be undignified and of little to no quality, through medical interventions such as euthanasia and/or physician-assisted suicide.[192]

2.2 Understanding the development and forms of euthanasia and physician-assisted suicide

Prior to the 1800s, very little public mention was made of euthanasia, if it was ever mentioned at all in medical writings, it was predominantly rejected outright and portrayed in an extremely negative light.[193] In fact, any form of euthanasia was equated to a severe violation of the Hippocratic oath taken by physicians, or even considered sinful in terms of what society deemed the religious law of God.[194]Although there was not much public justification and/or support for euthanasia in the early 1800s, this did not mean that it was not performed in secrecy by physicians or by suffering individuals themselves. Between the mid and late 1800s, an increasing number of physicians were relying on various forms of medication and lethal substances to aid their patients suffering, particularly those suffering of cancer and debilitating diseases, by assisting them to terminate their lives in a more dignified manner than spending additional months in chronic and severe pain, without any realistic possibility of a cure or recovery.[195] However, it was not until the late 1880s, that the American Medical Association took a firm and public stance against

---

[190] Supra note 135 at 164.
[191] Supra note 154 at 198.
[192] Supra note 81 at 670.
[193] Michael Stolberg 'Two Pioneers of Euthanasia around 1800' (2008) *Hastings Center Report* 1 at 19.
[194] Ibid at 20.
[195] Anna Hiatt 'The History of the Euthanasia Movement' *JSTOR Daily* 16 January 2016, available at https://daily.jstor.org/history-euthanasia-movement/, accessed on 10 August 2021.

euthanasia, by announcing their official opposition of voluntary euthanasia.[196] This firm stance against euthanasia, and ultimately against the termination of an individual's suffering, essentially sparked the global debate regarding the ethical and legal consequences of euthanasia and physician-assisted suicide, with the majority of states and societal groups casting the practice as a taboo medical intervention that should remain illegal. Despite the largely negative receipt globally of assisted dying practices, such as euthanasia and physician-assisted suicide, an unprecedented case in the Netherlands sparked the reignition of support for the movement towards legalising euthanasia.[197] In fact, this case was not only significant for what it reignited in society, but it also made history as upon the conclusion of the matter, which involved reconsidering the sentencing of a physician who assisted in the early and empathetic termination of her own suffering mother's life by administering a legal substance,[198] the Netherlands became the first country in history to legalise euthanasia in 2002.[199] This case turned on the wheels for the judiciary in various countries across the globe, however it only resulted in the legal debate of euthanasia to have been approved and effectively legalised in seven jurisdictions, including Netherlands, Belgium, Luxemburg, Colombia, Canada, Victoria, as well as Western Australia.[200]

The development of euthanasia and/or or physician-assisted suicide was not positively received in most states across the globe, nor has its current global status drastically changed since its early development. In fact, euthanasia still remains to be perceived by most states as a completely negative intervention that is solely aimed at harshly removing an individual from this earth, this view offers no consideration of the benefits it grants to relieving suffering individuals from these undignified lives. In fact, this view of euthanasia and/or physician-assisted suicide is largely influenced by the fears of returning to a eugenic system such as the system utilized under the Nazi regime whereby medical interventions involving euthanasia were relied on to murder innocent individuals deemed inferior and thus considered unworthy of life.[201] Since the language and terms

---

[196] Supra note 195.

[197] Sarah Mroz, Sigrid Dierickx, & Luc Deliens, et al 'Assisted dying around the world: a status quaestionis' (2021) 10 *Annals of Palliative Medicine* 3 at 3541.

[198] Ibid.

[199] Ibid.

[200] Ibid at 3542.

[201] Josef Kure 'Everything Under Control: How and When to Die – A Critical Analysis of the Arguments for Euthanasia' in Joseph Kure (ed) *Euthanasia – The "Good Death" Controversy in Humans and Animals* (2011) at 141.

concerning practices of assisted dying invoke memories of negativity related to eugenic practices or murder, it is vital to understand the actual definition of the terms in order to distinguish eugenic practices of killing from assisted dying practices such as euthanasia and/or physician-assisted suicide. Across the globe, euthanasia and/or physician-assisted suicide are defined as two distinct practices, while the definition and/or interpretation of these practices are not consistent across various regions.[202] The definition of euthanasia itself can be defined as the purposeful and intentional death of a suffering individual performed by another individual, in the best interests of the recipient individual, in order to ease any pain and/or suffering of the recipient individual.[203] Euthanasia itself can be categorized as either active euthanasia or passive euthanasia.[204] Although these two categories of euthanasia are not inherently different in their purpose, they are deemed to rather differ on the basis where a substance and/or procedure is either administered or withheld.[205] Active euthanasia refers to the process of euthanasia which involves the intentional termination of a terminally ill or suffering individual's life by another individual, performed through the deliberate administration of a fatal substance and/or procedure, in the best interests of the suffering individual.[206] While passive euthanasia refers to the process of euthanasia which involves the intentional termination of a terminally ill or suffering individual's life by another individual, performed through the deliberate withdrawal and/or withholding of actions to administer a life-saving substance and/or procedure, also with the overall purpose being to achieve the best interests of the suffering individual.[207] Although both forms of euthanasia are ultimately motivated to ease the suffering of a terminally ill and/or pain stricken individual, the largest difference lies in that during the processes of both forms of euthanasia, active euthanasia involves a direct act as the cause of an individual's death, while passive euthanasia involves an omission of any act as the cause of an individual's death. Those who advocate for euthanasia, particularly active euthanasia, rely on the argument that it is in fact morally permissible to relieve an individual who is severely suffering from a disease or disorder, as the individual is most likely going to die regardless of any

---

[202] RK Jacobs 'Legalising physician-assisted suicide in South Africa: Should it even be considered?' (2018) 11 *SAJBL* 2 at 66.

[203] Iain Brassington 'What passive euthanasia is' (2020) 21 *BMC Med Ethics* 41 at 2.

[204] Mojalefa LJ Koenane 'Euthanasia in South Africa: Philosophical and theological considerations' (2017) 38 *Verbum Et Ecclesia* 1 at 3.

[205] B Gert and C M Culver 'Distinguishing between active and passive euthanasia' (1986) 2 *Clinics in geriatric medicine* 1 at 29.

[206] Supra note 203 at 3.

[207] Ibid at 3.

intervention, hence prolonging their suffering seems far less merciful than allowing the termination of suffering in limited situations.[208]

Within the context of classifying euthanasia, an additional layer of differentiation exists, this includes voluntary and involuntary euthanasia. While both these forms of euthanasia are said to be aimed at achieving the overall benefit of the suffering individual, it differs based on the person who requests the life ending practice.[209] Voluntary euthanasia refers to the process of euthanasia whereby a suffering or terminally ill competent individual voluntarily requests another individual to proceed with the process to terminate his/her life.[210] While involuntary euthanasia refers to process of euthanasia whereby a suffering or terminally ill individual is neither competent or conscious to make a valid choice to request euthanasia to terminate his/her life, therefore an individual with the relevant authority to make such a decision on the incompetent and/or unconscious suffering individual's behalf will do so.[211] However, involuntary euthanasia seems far more problematic that any other form of assisted dying practice, as euthanasia is generally only supported given that the suffering individual themselves elected to voluntarily request to end their own suffering.[212] When the suffering individual themselves makes the decision to terminate their life based on an inability to endure unbearable suffering and pain, it effectively counters the common slippery slope argument that most opponents to euthanasia usually hold, which is that legalising euthanasia will surely lead to an abuse of power when individuals are euthanised without having any choice, let alone consenting to it themselves.[213] The slippery slope argument against euthanasia is essentially rooted in the fear that an individual's autonomy will essentially be violated and thus revoked if others have access to make the decision of whether individuals ought to live or die, hence voluntary euthanasia seems to guard against this possible abuse, as it is the form of euthanasia that is most ethical and aligned with upholding the human rights of human dignity and privacy, in that a single individual ought to have the autonomy to self-determination

---

[208] Supra note 204 at 4.

[209] Ibid at 4.

[210] Ogunbanjo GA and Knapp Van Bogaert 'Voluntary active euthanasia: Is there a place for it in modern day medicine' (2008) 50 *SA Fam Pract* 3 at 38.

[211] Radhika Kannan and Deepu Thottath 'Death on Demand: A comparison between Euthanasia Laws in the Netherlands and India, 2001 to 2020' (2021) 10 *Research on History of Medicine* 3 at 186.

[212] Supra note 204 at 4.

[213] Ibid at 4.

concerning whether they believe that continuing to endure a suffering life is far worse than the possibility of a painless death.[214]

Furthermore, in discussing the individual who bears the responsibility to decide on euthanasia, it is also imperative to consider the individual who possibly assists or aids in the euthanasia process, which is vital for determining the type of euthanasia applicable in a particular matter. This information is significant when defining physician-assisted suicide, which is often referred to as a synonymous term for euthanasia, however the difference between the two lies in the individual who administers the lethal substance that ultimately caused the death of the other individual.[215] Physician-assisted suicide involves a physician intentionally and directly assisting a suffering individual to terminate their own life, at the voluntary request of the competent suffering individual, by either writing a prescription for a lethal dose of a substance for the individual or even providing the lethal substance itself to the suffering individual.[216] Many opponents of assisted dying practices don't only rely on the slippery slope argument of potential abuse, but they also contend that physician-assisted suicide violates the moral obligation of physicians in that they claim that the Hippocratic Oath that physicians and medical professionals have to take entails that they ought to do everything possible to preserve the life of patients.[217] However, this notion that physicians ought to do anything and everything seems to contradict the duty to do no harm to patients, as choosing to rather let individuals endure continued suffering is effectively ensuring that harm is done to these already suffering patients, especially when there is the alternative of prescribing them with a lethal dose of medication to draw an end to their suffering and pain, if these individuals voluntarily chose to do so.[218] Therefore, if physicians are no longer able to achieve their overall duty to provide care to suffering patients, then it seems morally justifiable that it is more humane for them to then adhere to the wishes of the patient and assist in bringing

---

[214] David Benatar 'A legal right to die: responding to slippery slope and abuse arguments' (2011) 18 *Current Oncology* 5 at 207.

[215] Supra note 210 at 38.

[216] Adriaan Koetze and Shaun de Freitas 'The Protection of Conscientious Objection against Euthanasia in Health Care' (2019) 22 *PER / PELJ* at 5.

[217] Supra note 204 at 4.

[218] Jitender Jakhar, Saaniya Ambreen and Shiv Prasad 'Right to Life or Right to Die in Advanced Dementia: Physician-Assisted Dying' (2021) 11 *Frontiers in Psychiatry* at 4.

an early end to their unbearable suffering, rather than prolonging their misery.[219]

Since the first emergence of any form of dignified death and/or assisted dying practices, it has been the target of numerous ethical and legal dilemmas across various regions. Although these dilemmas have continued until the present day, there is still a large proportion of the population worldwide that are seemingly in favour of assisted dying practices, which in this context will include physician-assisted suicide and active voluntary euthanasia. In fact, euthanasia (voluntary active) is currently legal in Colombia, Canada, New Zealand, Victoria and Western Australia – part of Australia, where surveys illustrated that while the majority of the population were in favour of euthanasia, those most resistant to it were actually the politicians in parliament until only very recently.[220] Furthermore, a survey conducted in 2013 in over 47 countries across Europe, reported that the majority of the population in Western European countries – including Denmark, Belgium, France, Netherlands, Sweden and Luxembourg – were in favour of assisted dying practices, while the majority of the population in Eastern European countries – including Kosovo, Cyprus, Turkey, Georgia and Armenia were against assisted dying practices.[221] In comparison to a similar study conducted in 2008, the largest increase in the percentage of the population in favour of assisted dying practices in the 2013 survey were identified in Spain, Portugal, Great Britain, Germany and Italy, while the largest decrease percentage-wise against assisted dying practices were identified in the Russian Federation, Ukraine, Greece, Belarus and the Slovak Republic.[222] This increase in the public support towards assisted dying practices of certain Western European countries between 2008 and 2013 is significant, given that Germany, and Spain are a few of the more recent European countries to have joined the group of European countries who have legalised some form of assisted dying practices, namely Netherlands, Belgium, Luxembourg and Switzerland.[223] Since a recent German Federal Constitutional Court ruling in 2020, where it was confirmed that while no person

---

[219] Supra note 204 at 4.

[220] Tracee Kresin, Jacinta Hawgood, Diego De Leo, and Frank Varghese ‘Attitudes and Arguments in the Voluntary Assisted Dying Debate in Australia: What are they and how have they evolved over time’ (2021) 18 *International Journal of Environmental Research and Public Health* at 4.

[221] Joachim Cohen, Paul van Landeghem, & Nico Carpentier, et al ‘Public Acceptance of Euthanasia in Europe: A survey study in 47 countries’ (2014) 59 *International Journal of Public Health* at 145.

[222] Ibid at 145.

[223] Marija V Mendzhul, Adrianna Yu Badyda, & Yuliia I Fetko, et al ‘Euthanasia: Legal Regulation in European Countries and Prospects for Legalization in Ukraine’ (2021) 7 *Laplage em Revista (International)* 3 at 481.

should be forced to do it, every person should have a right to self-determine their own death if the situation necessitates it.[224] Germany is now on par with Switzerland with the legalisation of both physician-assisted suicide and passive euthanasia, while Belgium, Luxembourg, Netherlands and Spain have legalised euthanasia and physician-assisted suicide, and Norway, Finland, Sweden and Austria have legalised passive euthanasia.[225] Despite an increase in a few European countries moving towards legalising some form of assisted dying practice, it still seems that the public acceptance for the entirety of Europe remains largely low to moderate.[226] It is also important to note here that the terminology utilized to define each different term related to assisted dying practices differs across each country, hence this has also contributed to the lack of understanding which has attributed to a lack of support for the practices aimed at a dignified death.[227] The irony in this lies in the fact that while France is among the European states that prohibit any form of euthanasia, it also passed legislation in 2016 that empowers terminally ill patients to undergo continuous deep sedation to relieve suffering prior to their death,[228] which some might argue is in fact closely intertwined with assisted dying practices. Another matter of irony is Germany, the country that had the most traumatic and negative historical experience of "euthanasia", as the exact same term was used by the Nazis when conducting their systematic murdering of thousands of individuals deemed inferior, which has had a significant impact in the way people across the globe view euthanasia, is also the country where the Federal Constitutional Court in *BVerfG, Judgement of the Second State* of 26 February 2020,[229] recently held that an individual's express wish to end their own life must be respected by the state and/or society as an act of autonomous self-determination which is rooted in human dignity.[230] In fact, a predominant trend that was identified across the globe in the attitudes that favoured the legalisation of assisted dying practices, was a compassionate argument underlying the autonomy of an individual in deciding to choose a dignified death in order to provide some form of relief of suffering for those individuals with

---

[224] Rob Hyde 'Germany overturns ban on assisted suicide' (2020) 395 *The Lancet* at 774.

[225] Supra note 223 at 481.

[226] Supra note 221 at 148.

[227] Isabelle Marcoux, Brian L Mishara and Claire Durand 'Confusion between euthanasia and other end-of-life decisions' (2007) *Canadian Journal of Public Health* at 235.

[228] Supra note 223 at 482.

[229] *BVerfG, Judgement of the Second State of 26 February 2020* – 2 BvR 2347/15 (BVerfG, Urteil des Zweiten Senats vom 26. Februar 2020, 2 BvR 2347/15), available at https://www-bundesverfassungsgericht-de.translate.goog/SharedDocs/Entscheidungen/DE/2020/02/rs20200226_2bvr234715.html?_x_tr_sl=de&_x_tr_tl=en&_x_tr_hl=en&_x_tr_pto=sc.

[230] Ibid at para 207-209.

debilitating diseases or disorders.[231]

As previously mentioned, euthanasia can be classified as either active or passive, as well as voluntary or involuntary, and it can even involve a physician which will deem the act physician-assisted suicide. These aforementioned forms of euthanasia, as well as physician-assisted suicide are not only different in their meaning, process and ethical attributes, but also carry differences in terms of their legality in various countries across the globe. Some countries have equated all the aforementioned terminology and encompassed it under the single term of euthanasia, while other countries separate the terminology and only refer to the particular form of the assisted dying practice that is intended.[232] As a result, the legal definitions of assisted dying practices varies across the globe and is not consistent, nor is there universally agreed upon terminology, which has further contributed to the controversy and confusion surrounding these practices and their legality.[233] In fact, a report conducted in Canada in 2002 highlighted that an average of 72% of the participating population believed that euthanasia and physician-assisted suicide was the same, 66% assumed that withdrawal of treatment also amounted to euthanasia, while 49% thought that providing pain medication to accelerate death constituted euthanasia.[234] The international lack of uniformity and the failure to conclude a universally agreed concept in the terminology relating to assisted dying practices has largely contributed to the lack of societal and global support for these dignified processes of death. These concepts and the significant differentiation between them are vital in order to effectively comprehend their actual meanings and their beneficial roles within different jurisdictions. This inconsistency with universal terminology has greatly impacted the understanding and differentiation of these practices across the globe, as they have largely all been erroneously painted with the same brush that was historically linked to eugenic practices of euthanasia which were conducted abusively without the consent of the individuals, nor was it committed to relieve them of suffering. Thus, the term euthanasia is often emotionally charged with thoughts and feelings that surge from the past evil uses of similar practices.[235] Although

---

[231] Supra note 220 at 8.
[232] Supra note 197 at 3541.
[233] Ibid.
[234] Supra note 227 at 237.
[235] Supra note 227 at 235.

unregulated legalisation of euthanasia can no doubt lead to fears of the possibility of reverting back to past eugenic practices of involuntary euthanasia, a regulated specific form of euthanasia, that is not only properly differentiated in its terminology, but is also subject to strict criteria, can greatly benefit society by ensuring the adherence of the human rights of individuals who are enduring severe suffering. Thus, the significant difference between unethical forms of euthanasia and/or involuntary euthanasia, is that the practice should always be applied at the wishes of the suffering individual in line with their best interests. In this way, it seems evident that the two forms of acceptable euthanasia to be regulated is voluntary active euthanasia, which involves another individual or proxy administering a lethal substance and/or procedure according to the will and request of the suffering individual to terminate his/her life, as well as physician-assisted suicide which involves the physician merely assisting the process by providing the cause of death, while the suffering individual themselves commits the final lethal act to terminate his/her own life.[236] Incorporating the regulated practices of voluntary active euthanasia and physician-assisted suicide, will ensure that the human rights doctrine is upheld, as well as maintain a guard against possible fears of a slippery slope towards an uncontrollable abuse of power attached to assisted dying practices.[237] In fact, just preceding the legalisation of assisted dying practices in Victoria, Australia, an advocacy organisation, Dying with Dignity Victoria, argued that the fears produced by the slippery slope perspective is more likely to come about in a society where voluntary euthanasia is prohibited as it will take place "under the radar" without any proper accord for an individual's rights or safety, hence the most comprehensive manner to ensure that the slippery slope argument leading to abuse of the practice is prevented is to ensure that voluntary euthanasia is allowed in society through the regulation of a transparent and legislative framework.[238] Enacting the legislation to allow for these assisted dying practices will merely create a choice for suffering and terminally ill individuals to make on their own terms.[239] The proper regulation of these assisted dying practices are central to their proper functioning and prevention of abuse in society, the practices of voluntary active euthanasia and physician-assisted suicide ought to be subject to the

---

[236] Supra note 210 at 38.
[237] Annemarie Strohwald *Dignity in Death: A critical analysis of whether the right to human dignity serves as appropriate justification for the legalisation of assisted death* (unpublished LLM Research Project; University of Stellenbosch, 2014) at 36.
[238] Australian Human Rights Commission 'Euthanasia, Human Rights and the Law' (2016) *Issues Paper* at 12.
[239] Keymanthri Moodley 'The Fabricius decision on the Stransham-Ford case – and enlightened step in the right direction' (2015) 105 *SAMJ* 6 at 435.

fulfilment of a set of strict criteria; including that individuals seeking the practice must be mentally competent,[240] a request for the practice must be voluntary and sustained or repeated by the competent individual themselves, the individual must have a debilitating disease, disorder, condition or illness that is incurable, the individual must be in unbearable severe suffering and/or pain either physically or psychologically which cannot be alleviated.[241] In addition to the criteria that the individual seeking the life terminating practice must meet, there should also be additional procedural criteria to ensure that the process is adhered to properly and that fears of abusing the practices are avoided, such as compulsory consultation with a second physician before the practice is conducted, as well as a reasonable but still short mandatory waiting period between the request made and the provision of the selected practice.[242] Hence, these aforementioned regulations ought to be the foundational requirements in order to provide sufficient substantive and procedural safeguards when adopting the practices of voluntary active euthanasia and physician-assisted suicide across all regions, in order to ensure that the option of a dignified death is made available to individuals who are in dire need of respect for their human rights of human dignity and privacy.

---

[240] Supra note 204 at 4.

[241] Kirsty Lee Frances *Implementing a permissive regime for assisted dying in South Africa: a rights-based analysis* (unpublished LLM thesis, University of Kwa-Zulu Natal, 2015) at 143.

[242] Ibid at 140.

3. CHAPTER III – THE INTERNATIONAL HUMAN RIGHTS IMPACTED BY BIOETHICS

3.1 The human right to dignity in international law

The concept of human dignity is relevant to the international human rights discourse and is prevalent in both international and domestic jurisdictions.[243] Dignity is one of the core rights of human beings as it is a fundamental feature in expressing an individual's human value.[244] Despite the dignity and integrity of an individual human being representing such a significant feature of one's existence, it is still often violated and as a result it has been stipulated in various international treaties and conventions in an effort to ensure the protection of this vital right.[245] The Preamble of the UDHR highlights the significance of the value of human dignity as a core foundation upon which most human rights rely, as its opening line states the following:

> *"Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,…".*[246]

The Preamble of the UDHR essentially sets the stage for the understanding that the human right of dignity is in fact inherent in all members of the human family.[247] The use of the term "inherent" reiterates the fact of a quality of value attached to every human being,[248] hence dignity is one that is pre-existing to all human beings, while simultaneously being permanent, unconditional and cannot be removed by any form of authority.[249] Dignity is a non-negotiable value that is shared by all individuals simply by virtue of existing as a human being.[250] Although human dignity is regarded as one of the core human rights and is referred to in most international treaties, the actual exact definition of dignity itself is not offered in the overall framework of international and/or regional human rights.[251] However, many researchers have concurred that the central core of the

---

[243] Rinie Steinmann 'The core meaning of human dignity' (2016) 19 *PERLJ* at 1.

[244] Loredana Vlad 'The Person and the Right to Life – Philosophical, Bioethical and Law Approach' (2020) 7 *European Journal of Law and Public Administration* 2 at 153.

[245] Ibid at 153.

[246] Supra note 58 at Preamble.

[247] Supra note 244 at 153.

[248] Lucy Michael 'Defining Dignity and Its Place in Human Rights' (2014) 20 *The New Bioethics* 1 at 13.

[249] Supra note 55 at 20.

[250] Inigo de Miguel Beriain 'Human Dignity and Gene Editing: Using human dignity as an argument against modifying the human genome and germline is a logical fallacy' (2018) *EMBO Reports* at 1.

[251] Ginerva Le Moli 'The Principle of Human Dignity in International Law' (2019) *Koninklijke Brill NV* 352.

concept refers to the recognition that each human being possesses intrinsic worth that ought to be respected and protected by the state.[252] Despite the lack of a concise universal definition, the language used in most provisions relating to human dignity does provide one with a general understanding of the values that the right of human dignity intends to represent. Article 1 of the UDHR states that,

> *"All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood".*[253]

The language in article 1 of the UDHR reflects the notion that dignity applies equally to all people, which also includes the notion of its applicability regardless of one's health, condition, genetic abnormality, illnesses, or disabilities, which may no doubt impact them and their livelihood negatively.[254] This sentiment that all human beings are entitled to dignity and to have this right protected in the UDHR has influenced various other international conventions to follow suit in highlighting the significance of the right of dignity. These include but are not limited to, article 13(1) of the ICESCR through the attainment of education that assists in the full development of a human personality and the sense of its dignity,[255] as well as article 10(1) of the ICCPR which states that,[256]

> *"All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person".*[257]

Article 10(1) of the ICCPR essentially places an obligation on states to ensure that the human dignity of individuals is protected against the deprivation of their liberty and humanity.[258] The right to dignity in regard to preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician-assisted suicide then not only directly encompasses liberty, but also

---

[252] Christopher McCrudden 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19 *The European Journal of International Law* 4 at 723.

[253] Supra note 58 at article 1.

[254] Supra note 55 at 21.

[255] Supra note 64 at article 13.

[256] Supra note 63 at article 10.

[257] Ibid.

[258] Jane Kotzmann 'Dignity in International Human Rights Law: Potential Applicability in relation to International Recognition of Animal Rights' (2017) 26 *Michigan State International Law Review* 1 at 21.

the right to be free from suffering in the form of inhumane torture or treatment.[259] Article 5 of the UHDR states that,

> *"No one shall be subject to torture or to cruel, inhuman or degrading treatment or punishment".[260]*

The notion of an individual being deprived of humanity is essentially intertwined with being treated inhumanely, which highlights an important interrelated relationship between the protection of human dignity which is listed both in article 1 and article 10 of the UDHR and ICCPR respectively, with article 5 of the UDHR influencing the binding protection provided in article 7 of the ICCPR which states that,

> *"No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation".[261]*

Article 7 of the ICCPR is increasingly significant to the realm of bioethics and the advancements of technologies as it effectively creates a barrier against the possible misuse of practices that could violate the wishes of an individual, thereby overriding their autonomy in order to achieve medical and/or scientific advances. This barrier against the abuse of medical and scientific advancements is ensured by the fact that the provision incorporates that an individual need not to be subjected to experimentation without their "free consent".[262] Therefore, the medical and scientific practices being referred to in article 7, are not of a eugenic nature seeing that it concerns obtaining the voluntarily given consent of single individual to undergo such practices, hence article 7 seems to protect practices such as preimplantation and prenatal genetic testing and selection, and voluntarily euthanasia and/or physician-assisted suicide where either an individual gives consent for themselves, their embryo or their foetus to undergo medical intervention with the aim to avoid or end suffering. In addition to this protection against the abuse of involuntary practices, article 7 also prohibits the subjection of individuals to torture, inhuman or degrading treatment, which

---

[259] Jordan J Paust 'The Human Right to Die with Dignity: A Policy-Oriented Essay' (1995) *Human Rights Quarterly* at 477.

[260] Supra note 58 at article 5.

[261] Supra note 63 at article 7.

[262] Ibid.

essentially goes hand in hand with the notion of enduring severe and prolonged suffering. The overall purpose of article 7 is aimed to protect the dignity of individuals, as well as their physical and mental integrity,[263] and thus it imposes a duty on state parties to protect individuals from such harm within their jurisdiction.[264] Aside from the state imposed duty to prevent suffering, one would consider that there is also a general moral duty on all individuals, especially medical professionals, to ensure the relief or prevention of the possibility of one having to endure such unbearable suffering.[265] In this context, pain and suffering refers to both physical and psychological pain that an individual endures as a direct result of a debilitating disease, disorder, or condition that they possess or have the potential to possess.

While pain and suffering are often used interchangeably, it is important to distinguish between the two within the realm of bioethics. Pain may be fleeting or chronic, but it does not always involve suffering, as some individuals such as mothers who give birth to their children might describe labour as being painful, but will not necessarily regard it as suffering,[266] while the concept of suffering has rather been defined as severe distress that is directly associated with events that threaten the intactness of the individual.[267] Hence, the manner in which pain and suffering is experienced by the individual is vital in determining one's severity of suffering. If an individual feels that their dignity is undermined and that it cannot be restored as a result of severe suffering, given that happiness or contentment is believed to be the overall aim in life, then the endurance of unbearable pain and suffering directly contradicts the purpose of the existence of life as human beings, as it invades one's personal world by violating their very integrity, autonomy, dignity and even their physical and mental capabilities.[268] Therefore, suffering plays a central role in the arguments posed by those in favour of both preimplantation and prenatal genetic testing and selection for therapeutic purposes and voluntarily active euthanasia and/or physician-assisted

---

[263] Paul M Taylor 'Article 7: Torture, Cruel, Inhuman or Degrading Treatment or Punishment' (2020) *Cambridge University Press* at 172.

[264] Supra note 258 at 21.

[265] Daryl Pullman 'Human Dignity and the Ethics and Aesthetics of Pain and Suffering' (2002) 23 *Theoretical Medicine and Bioethics* at 75.

[266] Ibid at 77.

[267] Roberto Andorno and Cristiana Baffone 'Human Rights and the Moral Obligation to Alleviate Suffering' in Ronald Green and Nathan Palpant (eds) *Suffering and Bioethics* (2014) at 182.

[268] Ibid at 182.

suicide, as suffering directly impacts the potential quality of life of an individual, which is linked to an individual's overall well-being and happiness.[269] In fact, the action of relieving the suffering of an individual, possibly through preimplantation and prenatal genetic testing and selection or voluntary active euthanasia, is attributed to improving the overall quality of life of that individual.[270] The improved quality of life is linked with the underlying notion that unbearable pain and suffering deprive individuals of dignity, and therefore it is often believed that either the selection of a disease free life (preimplantation and prenatal genetic testing and selection) or death (euthanasia and/or physician-assisted suicide) is preferable to prolonging an undignified life.

In a sense this prohibition on subjecting individuals to degrading and inhumane treatment is in fact very similar to what opponents against the legalisation of euthanasia and/or physician-assisted suicide advocate for. In fact, the opponent groups who are against these practices aimed at the peaceful termination of an individual's suffering, essentially advocate for individuals who are enduring pain and suffering as a result of diseases or conditions that either threaten the overall health or quality of life of that individual, to continue enduring the inhumane and degrading treatment which no doubt violates their right to dignity, as well as their right to be free of subjection to such cruelty. Therefore, it seems that opponent groups who argue against the practices that aid in the termination of suffering, contradict the very notion they argue for, by rejecting competent and suffering individuals from accessing life terminating practices for themselves. The rejection of practices such as euthanasia and/or physician-assisted suicide seems to also contradict article 2 of the UDHR, which states that,

> *"Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status...".*[271]

---

[269] Ronald E Anderson *Human Suffering and Quality of Life: Conceptualizing Stories and Statistics* (2013) at 23.
[270] Ibid at 22.
[271] Supra note 58 at article 2.

According to article 2 of the UDHR, which influenced a similarly phrased provision, article 26 of the ICCPR,[272] states that no individual regardless of any possible distinction of any kind should be deprived of their rights contained in this international human rights framework. Hence, this assurance of all the rights contained in the UDHR and the ICCPR, specifically human dignity, privacy, and health, cannot be deprived based on the status of individuals who are terminally ill, dying or even suffering from a severely debilitating disease or condition.[273] Society across the globe has largely enabled the views of opponent groups by maintaining laws and rules that prohibit and prevent bringing permanent relief to competent individuals who are severely suffering through an undignified life while having to be forced to endure the inhumane torture of "living" with serious and life-affecting conditions while their personal freedom to act in a manner to terminate such a disastrous quality of life is restrained and limited.[274] Supporters of the legalisation of preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician-assisted suicide argue that the availability of seeking out these practices to either select implantation or pregnancy or not, or to terminate a life of suffering does in fact preserve potential parents and/or individual's freedom of choice and self-determination and as a direct result euthanasia and/or physician-assisted suicide enables individuals to choose a dignified death by electing to terminate their suffering in a peaceful and quick manner. In fact, most individuals who would seek out such practices are often individuals who are suffering from conditions that cause chronic pain, as well as life threatening and deteriorating diseases such as cancer, and would either like to prevent their future children from facing similar suffering or to end their own unbearable suffering.[275] Therefore, it seems that the effects of the unbearable suffering that an individual with a terminal illness or debilitating disease or disorder endures, negatively affects both their physical and mental integrity, and thereby infringes their human right to dignity as listed in the aforementioned international instruments, as well as in article 1 and 10 of the UDHR and ICCPR respectively.[276]

---

[272] Supra note 63 at article 26.

[273] Supra note 259 at 478.

[274] Ibid at 467.

[275] Kalaivani Annaduari, Raja Danasekaran and Geetha Mani 'Euthanasia: Right to Die with Dignity' (2014) 3 *Journal of Family Medicine and Primary Care* 4 at 478.

[276] Supra note 243 at 17.

In terms of regional human rights law, various instruments adopted in the regions of Africa, America and Europe have also echoed the significance of the dignity of human beings. Article 5 of the African Charter on Human and People's Rights (hereinafter referred to as the "African Charter"),[277] reiterates the importance of every individual's right to have their inherent dignity respected and recognized.[278] Dignity as previously noted, is also intrinsically linked to the integrity of an individual, as it refers to the manner in which an individual pursues to live a dignified life through the adherence of particular morals and/or principles. While article 5 of the American Convention on Human Rights (hereinafter referred to as "American Convention"),[279] states that every individual is entitled to have their physical, mental, and moral integrity respected based on the inherent dignity of the human being.[280] Article 1 of the Charter of the Fundamental Rights of the European Union (hereinafter referred to as the "European Charter"),[281] states that the human dignity of an individual must be respected and protected and cannot be infringed upon by any form of authority, which reiterates the human rights ideology of this right being inalienable.[282] The interrelated aspect between dignity and integrity is important to note as article 3(1) of the European Charter states that,

> *"Everyone has the right to respect for his or her physical and mental integrity".*[283]

Article 3(1) clearly denotes the idea that the integrity of an individual encompasses both physical and mental freedom in the adherence of pursuing a life based on certain morals and/or principles. This can be interpreted in a sense that an individual who pursues a dignified life based on the general notion of what constitutes decent morals and/or principles, should be able to have the freedom to determine their own manner of living their respective dignified life while enjoying full respect for their physical and mental integrity. Article 3(1) is essentially limited by article 3(2) which prohibits eugenic practices.[284] The existence of article 3(2) listed in the same instrument as

---

[277] African Charter of Human and People's Rights, 1981.
[278] Ibid at article 5.
[279] American Convention on Human Rights, 1969.
[280] Ibid at article 5.
[281] Charter of the Fundamental Rights of the European Union, 2009.
[282] Ibid at article 1.
[283] Ibid at article 3(1).
[284] Ibid at article 3(2).

article 3(1), further assists in preventing the risks of the slippery slope argument which fear that certain procedures could result in abuse and unethical use, especially when relying on the notion that is somehow respecting one's integrity. Therefore, article 3(2)'s prohibition on eugenic practices is justified given the historical sinister past of those practices aimed at engineering entire populations in hopes to achieve a population existing only of "superior" beings in the interest of the welfare of the state, however it does not and should not extend to a prohibition on other medical advancements such as preimplantation and prenatal genetic testing and selection for therapeutic purposes and euthanasia and/or physician-assisted suicide, given that the purpose of these practices is to prevent and/or alleviate suffering and effectively ensure that individuals are free of humiliation from the unfair and undignified prolonging of one's severe suffering from a debilitating disease and/or disorder. Thus, human dignity plays a central role in international human rights, in that it aims to protect against violations of an individual's privacy and self-determination, as well as against inhumane, humiliating and degrading treatment.[285]

3.2 The human right to privacy in international law

The UDHR does not only recognize that every human being is entitled to live with dignity and have their human dignity respected, but article 12 of the UDHR also reaffirms the respect and value that ought to be bestowed on an individual through the recognition of the right to privacy.[286] Article 12 of the UHDR states that

> "*No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks on his honour and reputation".*[287]

Article 12 of the UDHR is somewhat given binding effect through article 17 of the ICCPR, as article 17 reiterates the same protection against the violation of one's privacy, almost verbatim, subject to article 17's addition that nobody should be subjected to "unlawful interference" as well

---

[285] Ivana Radacic 'Does International Human Rights Law Adequately Protect the Dignity of Women' in Paulus Kaufmann, Hannes Kuch, Christian Neuhauser, and Elaine Webster (ed) *Humiliation, Degradation, Dehumanization: Human Dignity Violated* (2011) at 121.

[286] Supra note 259 at 477.

[287] Supra note 58 at article 12.

as arbitrary interference.[288] This means that article 17 of the ICCPR does not merely require the state to adopt legislative and/or other measures necessary to protect the right to privacy, but it also imposes a duty on the state to prohibit any interference with the right, whether sourcing from state authorities or natural persons.[289] The incorporation of the term "arbitrary interference" highlights that should the interference of the right to privacy occur, it needs to be reasonably permissible, lawful and non-arbitrary, and thus proportional to the ends sought by such interference with the right.[290] This similarly phrased right to privacy and a private life is further reiterated in regional instruments such as article 11 of the American Convention,[291] as well as article 8 of the European Charter.[292]

Similar to that of human dignity, the term privacy has no uniformly agreed upon definition across international and regional jurisdictions.[293] Generally, privacy is understood to concern issues related to protecting one's personal details, information, and even identity.[294] However, the notion of the right to privacy of an individual encompasses much more than merely protecting private information and details, it also extends to the right of a personal and private choice regarding the termination of an undignified and suffering life that individuals ought to have the right to decide on.[295] The right to privacy is directly interconnected with the right to human dignity, as the right to privacy in human rights instruments aims to protect against violations of an individual's dignity, reputation and esteem.[296] The right to privacy is also rooted in the freedom of an individual to take personal decisions and choices that are free from unjustified interference from state authorities or society, provided that the decision and/or choice itself are of an inherently personal and private nature,[297] as is the decision for an individual to undergo medical interventions such as preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician-

---

[288] Supra note 63 at article 17.
[289] Nihal Jayawickrama *The Judicial Application of Human Rights Law: National, Regional and International Jurisprudence* 2 ed (2017) at 600.
[290] Ibid at 603.
[291] Supra note 279 at article 11.
[292] Supra note 281 at article 8.
[293] Ali Alibeigi, Abu Bakar Munir, MD Ershadul Karim 'Right to Privacy, a Complicated Concept to Review' (2019) *Library Philosophy and Practice* at 29.
[294] Ellen Wright Clayton, Barbara J Evans and James W Hazel 'The law of genetic privacy: applications, implications and limitations' (2019) *Journal of Law and Biosciences* at 5.
[295] Supra note 259 at 477.
[296] Supra note 293 at 30.
[297] Supra note 289 at 605.

assisted suicide. Supporters of the legalisation of these medical interventions tend to rely on this protection of one's right to privacy to make their own choices particularly when it comes to the preimplantation genetic testing of an embryo, prenatal genetic testing of a foetus, and euthanasia and/or physician-assisted suicide, as it essentially entails an option to either avoid or terminate one's suffering life in order to protect against the possible imminent threats of inhumane torture that come along with certain conditions and diseases that could ultimately threaten a living or future individuals' right to dignity. Hence, the right to privacy should ideally encompass the right of a competent individual to make personal and private choices regarding their own lives, when it is being threatened by factors that would deteriorate all and any dignity that an "ordinary" life of a somewhat healthy individual not suffering from chronic pain would likely entail.

3.3 The link between the rights to human dignity, privacy and one's autonomy

The right to privacy encompasses an individual's right to make personal choices, and thus privacy is also directly interconnected with the autonomy of an individual, which is essentially the same as the notion of privacy being based in one's autonomous identity which was reiterated by the Constitutional Court in South Africa in *Bernstein and Others, v Bester NO and Others*.[298] The autonomy of an individual is not explicitly listed as a recognized right in any human rights instrument, the reason for this is that while autonomy itself is not a human right, the framework of human rights are considered to be interconnected, interdependent and interrelated with autonomy, in that one cannot exist and function without the other.[299] Autonomy could also be interpreted as the manifestation of an individual's legal and mental capacity in order to make an informed decision, once the individual is able to properly comprehend a situation and all the relevant consequences pertaining to it.[300] The human dignity of an individual is directly linked to the autonomy and self-determination that an individual is entitled to concerning their life and the right to pursue their own actions freely.[301] This was further echoed by the Supreme Court of Appeal in South Africa in *British American Tobacco South Africa (Pty) Ltd v Minister of Health,*[302] where the court supported the notion of the close link between human dignity,

---

[298] *Bernstein and Others, v Bester NO and Others* 1996 (2) SA 751 (CC) at para 89.

[299] Jaunius Gumbis, Vytaute Bacianskaite & Jurgita Ranakeviciute 'Do Human Rights Guarantee Autonomy' (2008) 62/63 *Cuadernos Constitutcionales de la Catedra Fadrique Furio Ceriol* at 79.

[300] Sidney F Engelbrecht 'Can Autonomy be limited? An ethical and legal perspective in South Africa' (2014) 32 *Journal of Forensic Odontostomatology* 1 at 35.

[301] Donrich W Jordaan 'Human Dignity and the future of voluntary active euthanasia in South Africa' (2017) 107 *SAMJ* 12 at 1050. (1050).

[302] *British American Tobacco South Africa (Pty) Ltd v Minister of Health* [2012] ZASCA 107.

privacy and freedom, as well as the ability to form opinions and make decisions regarding these rights.[303] Autonomy itself consists of two ancient Greek terms, "autos" meaning his or her own, as well as "nomos" meaning rule, which essentially encompasses the notion that the autonomy of an individual is linked to them ruling over their own choices and actions.[304] Hence, every individual is entitled to personal autonomy by virtue of them being a human being with human dignity,[305] who is also considered to be an independent entity.[306]

Autonomy is essentially an individual's freedom to self-determine any and all aspects that directly impact their personal lives. In *Barkhuizen v Napier*,[307] the Constitutional Court in South Africa held that self-autonomy, which is a central component to human dignity, also concerns the ability to regulate one's own affairs even if it is to their own detriment.[308] This South African position concerning the interpretation of autonomy was further depicted in *MEC for Education: Kwazulu-Natal v Pillay*,[309] where the Constitutional Court held that an individual is entitled to have their own individual and personal set of ends respected – essentially understood as referring to autonomy – and that this autonomy effectively comprises of a central element of the dignity and freedom of an individual.[310] In fact, advocates in favour of medical interventions such as preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician assisted suicide argue that the value of one's personal self-determination underlies the right to undergo these aforementioned medical interventions as individuals have a fundamental right to direct the course of their own lives, and thus this right to self-determination should essentially encompass the right to choose the timing of one's termination of their own suffering, given they are terminally ill and satisfy the relevant safeguards. However this "right" to autonomy and/or self-determination that essentially underlies the internationally recognized human rights of human dignity and privacy, is not resistant to influence by external factors of society and/or state control.[311] In fact, state control is one of the main external factors that limits an individual's autonomy in the sense that in order for an individual to reside

---

[303] Supra note 302 at para 13.
[304] PD Motloba 'Understanding of the Principle of Autonomy (Part 1)' (2018) 73 *SADJ* 6 at 418.
[305] D W Jordaan 'Human dignity and the future of the voluntary active euthanasia debate in South Africa' (2017) 107 *SAMJ* 5 at 384.
[306] Supra note 299 at 77.
[307] *Barkhuizen v Napier* [2007] ZACC 5.
[308] Ibid at para 57.
[309] *MEC for Education: Kwazulu-Natal v Pillay* [2007] ZACC 21.
[310] Ibid at para 64.
[311] Supra note 304 at 419.

freely in a specific state, they are required to abide by the laws and regulations imposed by that particular state.[312] Such a limitation on an individual's autonomy is considered rational for the greater good of society, however the same cannot be said about the limitations imposed on an individual's autonomy by society or the state when it relates to more private and personal matters, such as the rules and regulations concerning preimplantation and prenatal genetic testing and selection, and euthanasia and physician-assisted suicide. An act undertaken by an individual can only be considered to be autonomous, if the individual freely makes the decision to undertake the specific act.[313] Hence, when an individual's choice regarding their private medical practices is drastically limited by rules and regulations imposed by society and/or state, it cannot then be said they have full autonomy with regards to their own medical choices.

The entitlement of an individual to have the freedom to choose to undertake any actions they wish and the freedom to choose how to live their own lives, subject to these choices not being harmful to any other person, is directly linked to the human right of privacy. As mentioned before, the right to privacy is contained in various international treaties, and it encompasses not only the right to privacy itself, but also the right to be treated equally and fairly without discrimination based on one's status or personal choices.[314] The right to privacy also provides individuals with protection from external unwarranted interferences in their private lives and choices.[315] However, as previously noted these rights are not absolute, and as such the right to privacy within the realm of autonomy is also capped by limitations imposed by state authorities, if the violation of the individual's privacy is justifiably reasonable in terms of the law in an effort to uphold the common interest for the good of society.[316] The issue that arises here is that society has essentially accepted limitations on various rights of human beings, even when it is deemed excessive to an extent. These types of excessive limitations on certain rights, are arguably neither reasonable or justifiably rational, in the sense that they have not been put in place to prevent harm from occurring to other persons as a result of a choice undertaken by a specific individual. But rather, these limitations on the autonomy of individuals, and thus the right to privacy, seem to have been

---

[312] Supra note 299 at 78.
[313] Ibid at 78.
[314] United Nations 'Article 12: Right to Privacy' available at https://www.ohchr.org/en/press-releases/2018/11/universal-declaration-human-rights-70-30-articles-30-articles-article-12?LangID=E&NewsID=23907, accessed on 10 December 2021.
[315] Ibid.
[316] Ibid.

put in place in order to maintain an arguably outdated societal perspective of medical interventions, particularly concerning the excessive limitations in the form of the prohibitions on euthanasia and/or physician-assisted suicide, while preimplantation and prenatal genetic testing and selection experiences a much less severe blanket prohibition as it is considered more morally accepted within conditions imposed by the various regions.

3.4 The relationship between preimplantation and prenatal genetic testing and selection, and the rights of human dignity and privacy

Although preimplantation and prenatal genetic testing and selection is more “ethically popular” on an international scale, there are still various opponents to these medical advancements, particularly when undertaken for non-therapeutic purposes, that argue that human dignity is intrinsically linked to the human genome, also known as a human being’s set of genetics or their DNA, and as a result the selection of an embryo or foetus directly based on the presence or lack of certain traits could constitute a violation of human dignity.[317] However this argument is highly problematic in this context in that preimplantation and prenatal genetic testing and selection does not involve the alteration or modification of one’s genes in the way that genetic editing does, in fact it simply reaffirms the dignity of the potential parent to have the autonomy to decide whether to undergo a procedure to detect possible defective genes in their embryo or foetus and then to determine whether they would prefer to discard an embryo or terminate a foetus given the informed knowledge of the potential suffering of their future child from these genetic diseases or conditions. In fact, it is actually rational to rather opt for medical interventions involving preimplantation and prenatal genetic testing and selection for therapeutic purposes in order to test and select the embryo for IVF or the foetus of an impregnated woman to prevent disabilities or conditions that could result in chronic suffering, which would ultimately pose a more severe risk to the future life and dignity of a human being, than would omitting to do so in favour of promoting the so-called intrinsic dignity of the human genome.[318]

---

[317] Supra note 250 at 2.

[318] Ibid.

This type of argument posed by many opponents of preimplantation and prenatal genetic testing and selection, is often rooted in the notion that the practice would allegedly violate the human dignity of the human genome of an embryo or foetus. However, it is vital to note that an embryo or foetus is not identical to the potential future existence of that individual, hence many jurisdictions including South Africa recognize that the embryo or foetus cannot bear rights,[319] and thus it's human dignity cannot then be violated by preimplantation and prenatal genetic testing and selection as that right is not held by it.[320] Despite the argument of linking human dignity to the human genome being rather vulnerable, an idea that should rather be considered by those both for and against preimplantation and prenatal genetic testing and selection in order to reach somewhat of a mutual agreement, is that although a future individual in the form of an embryo or foetus does not have rights, the individual or potential parent who has the authority to decide whether an embryo or foetus with certain genes that could develop into debilitating diseases or conditions should undergo preimplantation and prenatal genetic testing and selection, should bear this responsibility while taking into account the plausible best interests of that future individual.[321] In light of this viewpoint, the embryo or foetus, while not having rights itself, represents somewhat of a placeholder of potential rights that might develop in a future individual, therefore preimplantation and prenatal genetic testing and selection should be undertaken for justified purposes where it is practiced to avoid or prevent suffering and in that sense it can promote the future individual's potential future autonomy.[322] The plausible best interests of a future individual is rooted in the notion of a child's right to have their best interests respected, and as a result the individual with the authority to decide on whether an embryo or foetus should be genetically tested and selected or not if they possess certain defective traits, is based on how that authorized individual perceives what the best interests of that future individual would entail at the time of the decision, hence it need not be an identical conclusion to that which the future individual perceives as what might have been in their best interests, as long as it is clearly justifiable that the decision

---

[319] D J McQuid Mason 'Overturning refusal of a hospital to terminate life support for a brain-dead mother until the fetus was born: What is the law in South Africa' (2014) 104 *SAMJ* 8 at 554.
[320] Benjamin Gregg 'Regulating genetic engineering guided by human dignity, not genetic essentialism' (2021) *Politics and the Life Sciences* at 12.
[321] Ibid at 2.
[322] Ibid at 3.

to undertake or forgo preimplantation and prenatal genetic testing and selection was done in the best interests of that future potential individual considering the impact the defective traits might have on the future quality of their life and potential suffering.[323]

The notion of the future plausible best interest of a future potential individual can also be linked to the wrongful birth and wrongful life debates. Wrongful birth is referred to as an action that can be undertaken by the parents of a disabled and/or suffering child as a result of a medical professional failing to inform those parents of the disability before the child was born, while wrongful life is an action that can be undertaken by the child itself against the fact that they were essentially born into life with a disability or a disease causing suffering.[324] While wrongful birth cases are frequently instituted successfully, wrongful life cases are not, given that the term wrongful life is difficult to institute as it implies that a life is inherently wrong based on its existence of possessing a certain disability or disease,[325] which is essentially the argument that many disability groups advocate against, as an individual's worth is not decreased based on the presence of a disability or condition. In South Africa, in *H v Fetal Assessment Centre*,[326] the child's action for wrongful life was initially dismissed by the High Court on exception on the failure to disclose a cause of action, which was then appealed to the Constitutional Court.[327] The Constitutional Court upheld the appeal and granted leave to amend the cause of action under the determination of the High Court to decide on whether the cause of actions exists, as well as to consider the best interests of the child.[328] Wrongful life cases like these are rather contentious based on the notion that the court is essentially expected to answer whether a child's life is worthy of living given their disability or disease,[329] and this ideology of determining another individual's worth based on their capabilities or lack thereof directly violates the notion of human dignity, which is intrinsically linked to the fact that an individual ought to be able to choose for themselves,

---

[323] Supra note 320 at 12.

[324] Johann Neethling 'The Constitutional Court affirms the potential existence of an action for wrongful suffering as a result of disability in South African law' (2016) 79 *THRHR* at 533.

[325] Ibid at 537.

[326] *H v Fetal Assessment Centre* 2015 2 SA 193 (CC).

[327] Ibid at para 5.

[328] Ibid at para 81.

[329] Joel R Cornwell 'Wrongful Life and the Problem of Euthanasia' (1987) 23 *Gonz L Rev* 573 at 586.

or for their potential offspring, whether they consider their life dignified or not, given their suffering. Upholding wrongful life cases seems like it could possibly lead to a blanket application that considers that all lives with disabilities or diseases are inherently unworthy of life, and this would directly violate the rights of individuals living with disabilities and diseases who personally consider their life to be dignified and worth living. In light of this, it is possibly worth considering the pursual of a wrongful suffering action, whereby individuals who are suffering from a disability or disease, could voluntarily decide for themselves that the endurance of such suffering is wrongful given that there was a possibility for the medical professional to advise that the embryo or foetus undergoing preimplantation and prenatal genetic testing of a potential individual would likely carry defective genes, in order to eradicate the defective embryo or foetus.[330] In this way, no blanket application of one's worth or lack thereof will be applied to whether the individual possesses a disability and/or disease or not, and in this way the human dignity, privacy of choices and autonomy of all individuals are respected, given that an individual and/or potential parent will decide for themselves, without state interference, whether they should pursue preimplantation and prenatal genetic testing and selection to identify certain defective genes and decide whether to continue with an implantation or pregnancy in the best interests of their future child.

3.5 The relationship between euthanasia and physician-assisted suicide and the rights of human dignity and privacy

The rights of human dignity and integrity are also integral to the debates concerning the legalisation of euthanasia and/or physician assisted suicide. At present, there is no recognized human right to die with dignity recorded in any international human rights instruments, however there are various principles and articles contained in various international human rights instruments that infer that individuals are in fact entitled to live and thus to die with dignity.[331] These principles can be inferred from rights concerning dignity, integrity, and privacy amongst many others. The international and regional human rights framework consists of various

---

[330] Supra note 324 at 535.

[331] Supra note 259 at 476.

significant rights that are central to the general notion of a human right to die with dignity.[332] Although the international human rights concerning human dignity, privacy, liberty, and the prohibition against inhumane treatment essentially lay the foundation for a right to a dignified death, these international human rights are still in conflict with most domestic legislation which still in fact largely prohibit the practices that are aimed at alleviating the discomfort and suffering of competent individuals by terminating their undignified lives.[333] This evident conflict between the international human rights that conform and effectively support the notion of a human right to die with dignity and the dominant domestic legislation against that very same right effectively prevents competent individuals from having the right to choose the time of their own death when it is essentially the last resort to prevent the continuation of severely debilitating pain, suffering or a life without dignity.[334] Death is an evident part of life, of which the timing and whereabouts of remain unknown to most individuals, however as individuals are entitled to the freedom to privately choose how to live their life, this freedom of self-determination should also extend to choosing the manner and time of the conclusion of their life, if suffering and pain necessitates it.[335]

Severe pain and suffering endured by an individual in most cases is largely responsible for preventing individuals from the adequate physical capabilities to pursue meaningful endeavours that they might have yearned for, but instead their unbearable suffering often results in unfulfillment, frustration and financial hardships, not only for themselves but also for their family and friends as the notion of suffering may extend beyond just the single patient suffering, especially if the debilitating disease or disorder has left their body confined to a vegetative state.[336] In fact, such unbearable suffering endured by individuals with debilitating diseases or disorders often violates one’s claim to self-respect which is intrinsically linked to the rights to human dignity and privacy, in that self-respect here refers to the understanding that an individual ought to be capable of self-determination particularly in respect to how they wish to live their own life.[337] The link between self-respect and human dignity was set out in *Law*

---

[332] Supra note 259 at 486.
[333] Ibid at 486.
[334] Ibid.
[335] Sipho Tumelo Mdhluli ‘Your life, your decision? The Constitution and euthanasia’ (2017) 25 *De Rebus*.
[336] Supra note 265 at 84.
[337] Peter Schaber ‘Absolute Poverty’ in Paulus Kaufmann, Hannes Kuch, Christian Neuhauser, and Elaine Webster (ed) *Humiliation, Degradation, Dehumanization: Human Dignity Violated* (2011) at 153.

v Canada (Minister of Employment and Immigration),[338] where the court defined that human dignity is when an individual or group feels self-respect and self-worth, concerning both their physical and psychological integrity.[339] In this sense, an individual's human dignity and ability to live a life with self-respect, adhering to his/her own wishes, is often violated through the infliction of torture, which in this context is not referring to someone inflicting pain on another, but rather to the mental torture of humiliation that is endured when one's physical and even mental capabilities are impaired to the extent that they become a physical and financial burden on those around them, which extends their circle of suffering as they become completely incapable of living their life as they once desired.[340]

The unbearable suffering endured by the individual themselves as well as their support system, that has violently robbed them of their human dignity and liberty, has played a central role in many cases across the globe, including in South Africa where in *Stransham-Ford v Minister of Justice and Correctional Services*,[341] the court held that "… the right to life is more than existence, it is a right to be treated as a human being with dignity: without dignity, human life is substantially diminished. …".[342] The court further held here that an individual's decision on when they wish to end their life is a manifestation of their own personal human dignity and integrity, and should thus be upheld given it satisfies certain requirements that ameliorate one's dignity, such as the endurance of severe pain, possible confusion and dissociation, inability to care for own's hygiene, and the high likelihood of dying away from home and loved-ones without the ability or consciousness to properly say goodbye.[343] However, it is worth nothing that this case was successfully taken on appeal and set aside by the Supreme Court of South Africa in *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford*,[344] where the court did not engage on any further discourse regarding the legalisation of euthanasia, as they considered it to be without purpose given that the Applicant in the High Court matter had passed away shortly before the appeal was held.[345] Withholding any decisive judgement on the legalisation of euthanasia and/or physician-assisted suicide, meant that the Court essentially left

---

[338] *Law v Canada (Minister of Employment and Immigration)* 1 SCR 497 (1999).

[339] Ibid at para 53.

[340] Supra note 337 at 153.

[341] *Stransham-Ford v Minister of Justice and Correctional Services* [2015] ZAGPPHC 230, 2015 (4) SA 50 (GP).

[342] Ibid at para 12.

[343] Supra note 243 at 17.

[344] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2016] ZASCA 197, [2017] (3) SA 152 (SCA).

[345] Ibid at para 26.

the door open for similar matters to be heard and disputed relating to the euthanasia and/or physician-assisted suicide of suffering individuals,[346] however this opportunity to make a decision on a similar case has not yet occurred in South Africa.[347] The court also held that similar applications for physician-assisted suicide that are made by terminally ill and suffering individuals who wish to terminate their undignified lives, should be considered on the merits of each individual case brought forward.[348] Whether an individual considers a life to be dignified, worth living, and thus free of humiliation and unbearable suffering is personal, private and should be up to each individual while they are still competent to decide or to direct an instruction for a physician to assist them when the appropriate time comes.

While international frameworks have not yet recognized a right to die, many legal jurisdictions have highlighted the interconnected relationship between the right to life and the choice to die. The right to life is a very well-known human right enshrined in most, if not all, international and regional human rights instruments, and is central to the arguments posed by both supporters and opponents of euthanasia and/or physician assisted suicide. Supporters of euthanasia utilize the right to life when arguing for the legalisation of euthanasia by relying on the notion that we have a duty to prevent the suffering of individuals,[349] while opponents argue that permitting a choice to die contradicts the existence of one's life and thus violates the right to life.[350] However, the opponent's arguments is vulnerable considering that the terminology of the right to life does not necessarily encompass a duty to continue living and as such suffering individuals ought to be able to waive their right of living an undignified life depending on the circumstances.[351] In fact, the Indian Supreme Court held that the right to life enshrined in the Indian Constitution should be read as a "right to live life with dignity…",[352] while in South Africa in *S v Makwanyane*,[353] the court held that the right to life incorporates the right to dignity, not just the right

---

[346] Carla Kotze and Johannes L Roos 'End-of-life care in South Africa: Important legal developments' (2022) 28 *South African Journal of Psychiatry* at 1.

[347] D J McQuid-Mason 'Assisted suicide and assisted voluntary euthanasia: Stransham-Ford High Court case overruled by the Appeal Court – but the door is left open' (2017) 107 *SAMJ* 5 at 382.

[348] D J McQuid-Mason 'Doctor-assisted suicide: What is the present legal position in South Africa' (2015) 105 *SAMJ* 7 at 527.

[349] Suresh Bada Math and Santosh K Chaturvedi 'Euthanasia: Right to life vs right to die' (2012) 136 *Indian J Med Res* at 900.

[350] Ibid at 899.

[351] Supra note 346.

[352] Supra note 252 at 693.

[353] *S v Makwanyane* 1995 3 SA 391 (CC).

to live as “mere organic matter”.[354] This connection between the right to life and human dignity was further illustrated in *Dawood and another v Minister of Home Affairs and others*,[355] where it was held that the right to dignity informs the interpretation of various other rights, including the right to life.[356] Thus, this right to live a life with dignity could be said to be indicative of a right to choose to die given that a dignified life could be deemed to not exist by a particular individual when he/she is subjected to a debilitating disease or disorder causing them to endure unbearable suffering, both mentally and physically, restricting their capabilities and overall quality of life. [357] While a large portion of the limited case law in favour of assisted dying practices relies predominately on human dignity, the European Court of Human Rights in *Pretty v United Kingdom,*[358] recognized the right to privacy as a justifiable means to assisted dying.[359] The court also recognized that the applicant, who was competent but severely suffering from a motor neuron disease that left her paralysed, and incapable of talking or feeding herself, was essentially being forced to endure the rest of her life, against her private choice, in an undignified manner which directly impacted her quality of life.[360] In fact, the court held that the right to a private life, as listed in article 8 of the European Charter, not only encompasses both the physical and mental integrity of an individual, but also the notion of autonomy which underlies the right to privacy, and thus a competent individual suffering from a debilitating fatal disease should have her right to a private choice respected if she wishes to bring an end to her suffering.[361] Thus, the right to human dignity and privacy is infringed when a competent terminally ill patient suffering from a debilitating disease or disorder is prevented from voluntarily choosing to access practices that will bring an end to their suffering.[362] The legalisation of voluntary active euthanasia and physician-assisted suicide with the appropriate safeguards in place, will not only uphold the right to human dignity, but also the right to privacy, along with the promotion of an individual’s autonomy.[363]

---

[354] Supra note 353 at para 326.

[355] *Dawood and another v Minister of Home Affairs and others* 2000 (8) BCLR 837 (CC).

[356] Ibid at para 35.

[357] Suhayfa Bhamjee ‘Is the right to die with dignity constitutionally guaranteed? Baxter v Montana and Other Developments in Patient Autonomy and Physician Assisted Suicide’ (2010) *Obiter* at 352.

[358] *Pretty v United Kingdom* (European Court of Human Rights, Chamber, Application No2346/02, 29 April 2002).

[359] Ibid at para 67.

[360] Ibid at para 67.

[361] Ibid at para 61.

[362] Rinie Steinmann ‘Law and human dignity at odds over assisted suicide’ (2015) 24 *Die Rebus*.

[363] Supra note 238 at 5.

V. CONCLUSION

The dichotomy present in the two halves of one coin, the avoidance of suffering and the termination of suffering, is a contentious debate in modern bioethics, particularly due to medical advancements, such as preimplantation and prenatal genetic testing and selection, and euthanasia and/or physician-assisted suicide. The evident divide is noted not only in the international legality of these medical interventions, but also in the societal support both for and against these different medical practices. Preimplantation and prenatal genetic testing and selection, while encompassing different forms, is significantly more accepted legally and socially, at least for therapeutic purposes, than the practices of euthanasia and/or physician-assisted suicide. This dichotomy could be linked to the fact that the terminology of euthanasia is historically often linked to eugenic notions of murder under the guise of social experiments that disregard autonomy, while preimplantation and prenatal genetic testing and selection has been linked to a more modern "liberal" form which is closely connected to upholding the autonomy of individuals.

Preimplantation and prenatal genetic testing and selection within itself encompasses its own dichotomy of legislative and societal support, between the utilization for therapeutic purposes, involving the detection of serious defective genes or conditions, is generally legal and regarded as beneficial, while utilization for non-therapeutic purposes such as sex selection or physical enhancement is not. The embryo or foetus is still under the authority of its potential parents, and those are the authorised individuals that ought to be considered when considering the rights affected by bioethics, as these authorised individuals ought to have the right to privacy to make their own choice in the best interests of the potential future individual, whether the embryo or foetus ought to undergo preimplantation and prenatal genetic testing to detect defective genes that will potentially result in suffering, which would then affect the open future and choices of the future individual, which could possibly affect the human dignity of the future individual. The benefits of preimplantation and prenatal genetic testing and selection far outweigh the objections to it, and as a result preimplantation and prenatal genetic testing and selection, although already accepted and allowed in many states, ought to be allowed across the globe too, subject to specific safeguards and rules on how they ought to be utilized, such as restricting it for therapeutic purposes of detecting and identifying traits of severely debilitating diseases or traits that would negatively impact the life and functioning of the future individual in society. While euthanasia and/or physician assisted suicide are applicable solely to living individuals with rights, it is still considered inherently taboo both socially and legislatively, as it seems that the interventions aimed at terminating one's suffering are considered far more dire and unacceptable by the global majority than simply discarding an embryo or foetus to avoid potential suffering. Ironically, it seems far more inhumane to force a living competent individual to endure continuous suffering for an incurable disease or condition, than to allow them to determine their own time and circumstances of death. Every competent individual who is terminally ill should be entitled to the right to evade and thus bring an end to unbearable suffering through a private and person choice to die a dignified death through voluntary active euthanasia and/or physician-assisted suicide subject to the relevant safeguards being in place to prevent possible abuses of the practice.

While the medical interventions and subjects of the practices differ which may contribute to the international divide between the two practices, the continuous link is that of suffering, and its undeniable impact on the potential quality of life of an individual or future individual. Opting for a society that completely eradicates all and any hereditary diseases, traits, conditions or disabilities will neither improve the overall standard of society, nor will it ensure an elimination of all suffering of mankind.[364] However, ensuring that individuals, in making decisions for their themselves or their embryos or foetuses, are entitled to the autonomy to decide on either avoiding or terminating suffering through medical interventions, will no doubt protect their human rights to dignity and privacy, and thus provide adequate justification on whether they would want to undergo a medical intervention or not.

---

[364] Supra note 81 at 678.

BIBLIOGRAPHY

Primary Sources

International Statutes:

African Charter of Human and People's Rights (1981).

American Convention on Human Rights (1969).

Charter of the Fundamental Rights of the European Union (2009).

Declaration of Helsinki (1964).

International Covenant on Civil and Political Rights (1976).

International Covenant on Economic, Social and Cultural Rights (1976).

Nuremburg Code (1947).

Universal Declaration of Human Rights (1948).

Universal Declaration on Bioethics and Human Rights (2005).

Cases:

AB v Minister of Social Development 2017 3 BCLR 267 (CC).

Barkhuizen v Napier [2007] ZACC 5.

Bernstein and Others, v Bester NO and Others 1996 (2) SA 751 (CC).

British American Tobacco South Africa (Pty) Ltd v Minister of Health [2012] ZASCA 107.

BVerfG, Judgement of the Second State of 26 February 2020 – 2 BvR 2347/15 (BVerfG, Urteil des Zweiten Senats vom 26. Februar 2020, 2 BvR 2347/15), translation available at https://www-bundesverfassungsgericht-de.translate.goog/SharedDocs/Entscheidungen/DE/2020/02/rs20200226_2bvr234715.html?_x_tr_sl=de&_x_tr_tl=en&_x_tr_hl=en&_x_tr_pto=sc.

Dawood and another v Minister of Home Affairs and others 2000 (8) BCLR 837 (CC).

H v Fetal Assessment Centre 2015 2 SA 193 (CC).

Law v Canada (Minister of Employment and Immigration) 1 SCR 497 (1999).

MEC for Education: Kwazulu-Natal v Pillay [2007] ZACC 21.

Minister of Justice and Correctional Services v Estate Late James Stransham-Ford [2016] ZASCA 197, [2017] (3) SA 152 (SCA).

Pretty v United Kingdom (European Court of Human Rights, Chamber, Application No2346/02, 29 April 2002).

Robert James Stransham-Ford v Minister of Justice and Correctional Services (GNP) (unreported) case number 27401/15 of 4 May 2015.

S v Makwanyane 1995 3 SA 391 (CC).

Secondary Sources

AF, Cascais "Bioethics: History, Scope, Object" (1997) 10 *Global Bioethics* at 9-24.

Alibeigi, Ali; Abu Bakar Munir, & MD Ershadul Karim 'Right to Privacy, a Complicated Concept to Review' (2019) *Library Philosophy and Practice* at 1-35.

Australian Human Rights Commission 'Euthanasia, Human Rights and the Law' (2016) *Issues Paper* at 1-47.

Anderson, Ronald E *Human Suffering and Quality of Life: Conceptualizing Stories and Statistics* (2013) at 1-129.

Andorno, Roberto; & Cristiana Baffone 'Human Rights and the Moral Obligation to Alleviate Suffering' in Ronald Green and Nathan Palpant (eds) *Suffering and Bioethics* (2014) at 182-200.

Annaduari, Kalaivani; Raja Danasekaran & Geetha Mani 'Euthanasia: Right to Die with Dignity' (2014) 3 *Journal of Family Medicine and Primary Care* 4 at 477-478.

Ascencio-Carbajal, Tania; Garbine Saruwatari-Zavala & Fernando Navarro-Garcia, et al 'Genetic/genomic testing: defining the parameters for ethical, legal and social implications' (2021) *PubMed.*

Bachruch, Susan 'In the Name of Public Health – Nazi Racial Hygiene (2004) 351 *New England Journal of Medicine* at 417-420.

Baruch, Susannah; Audrey Huang, & Daryl Pritchard, et al 'Human Germline Genetic Modification: Issues and Options for Policymakers' (2005) *Genetics and Public Policy Center* at 1-63.

Beauchamp, Tom L 'The Right to Die as the Triumph of Autonomy' (2006) 31 *Journal of Medicine and Philosophy* at 643-654.

Benatar, David 'A legal right to die: responding to slippery slope and abuse arguments' (2011) 18 *Current Oncology* 5 at 206-207.

Benatar, David 'Clinical Ethics: Bioethics and health and human rights: a critical view' (2006) 37 *J Med Ethics* at 17-20.

Benston, Shawna 'CRISPR, A crossroads in genetic intervention: Pitting the right to health against the right to disability' (2016) 5 *Laws* 1 at 1-18.

Beriain, Inigo de Miguel 'Human Dignity and Gene Editing: Using human dignity as an argument against modifying the human genome and germline is a logical fallacy' (2018) *EMBO Reports* at 1-4.

Bhamjee, Suhayfa 'Is the right to die with dignity constitutionally guaranteed? Baxter v Montana and Other Developments in Patient Autonomy and Physician Assisted Suicide' (2010) *Obiter* at 333-352.

Boardman, Felicity 'Letter to the editor. Gene Editing and disabled people: a response to Inigo de Miguel Beriain' (2020) 11 *Journal of Community Genetics* at 245-247.

Brack, Chad E 'Hume's Law and Genetic Engineering: Considering the Possible Implications of Positive Eugenics in Light of our Horrific Past' (2020) 12 *Inquiries Journal* 10, available on http://www.inquiriesjournal.com/articles/1828/humes-law-and-genetic-engineering-considering-the-possible-implications-of-positive-eugenics-in-light-of-our-horrific-past, accessed on 2 May 2021.

Brassington, Iain 'What passive euthanasia is' (2020) 21 *BMC Med Ethics* 41 at 1-13.

Buchanan, Allen 'Institutions, Beliefs and Ethics: Eugenics as a Case Study' (2017) 15 *The Journal of Political Philosophy 1* at 22-45.

Callahan, Daniel 'Bioethics and Policy – A History' (2015) *The Hastings Center* available at https://www.thehastingscenter.org/briefingbook/bioethics-and-policy-a-history/, accessed on 26 July 2021.

Capron, Alexander Morgan 'Law and Bioethics' in *Bioethics* 4 ed (2014) at 1789-1797.

Carzis, Bianca Carzis; Tasha Wainstein, Lawrence Gobetz, and Amanda Krause 'Review of 1-years of preimplantation genetic diagnosis in South Africa: implications for a low-to-middle income country' (2019) 36 *Journal of Assisted Reproduction and Genetics* at 1909-1916.

Chan, Sarah 'A bioethics for all seasons' (2015) 41 *J Med Ethics* at 17-21.

Chirwa, Danwood Mzikenge 'The Right to Health in International Law: Its implications for the obligations of state and non-state actors in ensuring access to essential medicine'r (2003) 19 *SAHJR* at 541-566.

Clados, Mirjam Sophia *Bioethics in International Law: An analysis of the intertwining of bioethical and legal discourse* (unpublished philosophy doctorate dissertation, Ludwig-Maximillians University, 2012) 1-277.

Cohen, Joachim; Paul van Landeghem, & Nico Carpentier, et al 'Public Acceptance of Euthanasia in Europe: A survey study in 47 countries' (2014) 59 *International Journal of Public Health* at 143-156.

Conti, Adam ‘Drawing the Line: Disability, Genetic Intervention and Bioethics’ (2017) 6 *Laws* 9 at 1-23.

Cornwell, Joel R ‘Wrongful Life and the Problem of Euthanasia’ (1987) 23 *Gonz L Rev* 573 at 573-592.

Critchley, Christine; Dianne Nicole & Gordana Bruce, et al ‘Predicting Public Attitudes Towards Germ Editing of Germlines: The Impact of Moral and Hereditary Concern in Human and Animal Applications’ (2019) 9 *Frontiers in Genetics* 704.

Delhove, Juliette; Ivana Osenk, Ivanka Prichard & Martin Donnelley ‘Public Acceptability of Gene Therapy and Gene Editing for Human Use: A Systematic Review’ (2020) 31 *Human Gene Therapy* 1 at 20-46.

Dondorp, Wybo and Guido de Wert ‘Refining the ethics of preimplantation genetic diagnosis: A plea for contextualized proportionality’ (2019) 33 *Bioethics* at 294-301.

Donnelly, Jack ‘The relative universality of human rights’ (2007) 29 *Human Rights Quarterly* 2 at 281-306.

Donnelly, Jack & Daniel J Whelan *International Human Rights* 6 ed (2020) at 1-350.
b
Dr Bhorat, Ismail; Dr Lawrence Chauke, & Prof Edward Coetzee ‘Challenges and Controversies in prenatal genetic screening in the South African context’ (2018) 28 *Obstetrics and Gynecology Forum* at 33-36.

Dr Fleming, John I ‘Euthanasia: Human Rights and Inalienability’ (1996) 63 *The Linacre Quarterly* 1(5) at 44-56.

Ehrlich, Paul R ‘Bioethics: Are Our Priorities Right?’ (2002) 53 *BioScience* 12 at 1207-1216.

Ekberg, Merryn ‘Eugenics: Past, Present and Future’ in Marius Turda *Crafting Humans: From Genesis to Eugenics and Beyond* Vol 5 (2013).

Engelbrecht, Sidney F ‘Can Autonomy be limited? An ethical and legal perspective in South Africa’ (2014) 32 *Journal of Forensic Odontostomatology* 1 at 34-39.

Flynn, Jennifer ‘Theory and Bioethics’ in Edward N. Zalta (ed.) *The Stanford Encyclopedia of Philosophy* (2021), accessed on https://plato.stanford.edu/archives/spr2021/entries/theory-bioethics/.

Fox, Dov ‘The Illiberality of ‘Liberal Eugenics’’ (2007) *Ratio* at 1-25.

Frati, Paola; Vittorio Fineschi, & Mariantonia Di Sanzo, et al ‘Preimplantation and prenatal diagnosis, wrongful birth and wrongful life: a global view of bioethical and legal controversies’ (2017) 23 *Human Reproduction Update* 3 at 338-357.

Frances, Kirsty Lee *Implementing a permissive regime for assisted dying in South Africa: a rights-based analysis* (unpublished LLM thesis, University of Kwa-Zulu Natal, 2015) at 1-170.

Gadsboll, Kasper ; Olav B Petersen, & Vincent Gatinois, et al ‘Current use of noninvasive prenatal testing in Europe, Australia and USA: A graphical presentation’ (2020) 99 *Acta Obstet Gynecol Scand* at 722-730.

Gert, B & Culver, ‘Distinguishing between active and passive euthanasia.’ (1986) 2 *Clinics in geriatric medicine* 1 at 29-36.

Ginoza, Margaret EC and Rosario Isasi “Regulating preimplantation genetic testing across the world: A comparison of international policy and ethical perspectives.” (2022) *Cold Spring Harbour Laboratory Press* at 1-13.

Goncalves, Giulliana Augusta Rangel & Raquel de Melo Alves Paiva ‘Gene Therapy: Advances, Challenges and Perspectives’ (2017) 15 *Einstein* 3.

Gregg, Benjamin ‘Regulating genetic engineering guided by human dignity, not genetic essentialism’ (2021) *Politics and the Life Sciences* at 1-16.

Grue, Lars ‘Eugenics and Euthanasia: Then and Now’ (2009) *Scandinavian Journal of Disability Research*.

Gumbis, Jaunius; Vytaute Bacianskaite & Jurgita Ranakeviciute ‘Do Human Rights Guarantee Autonomy’e (2008) 62/63 *Cuadernos Constitutcionales de la Catedra Fadrique Furio Ceriol* at 77-93.

Hammerstein, Alix Lenia v; Matthias Eggel and Nikola Biller-Andorno ‘Is selecting better than modifying? An investigation of arguments against germline gene editing as compared to preimplantation genetic diagnosis’ (2019) 20 *BMC Medical Ethics* 83 at 1-13.

Harper, Joyce C ‘Preimplantation genetic screening’ (2018) 25 *Journal of Medical Screening* 1 at 1-5.

Hyde, Rob ‘Germany overturns ban on assisted suicide’ (2020) 395 *The Lancet* at 774.

Harris, J & S Chan ‘Understanding the ethics of genetic enhancement’ (2008) 15 *Gene Therapy* 24 at 338.

Henkin, Louis ‘Introduction: The Human Rights Idea’ in David Weissbrodt, Fionnuala D Ni Aolain & Mary Rumsey (ed) *Development of International Human Rights Law* vol 1 (2014) at 23-32.

Hiatt, Anna ‘The History of the Euthanasia Movement’ *JSTOR Daily* 16 January 2016, available at https://daily.jstor.org/history-euthanasia-movement/, accessed on 10 August 2021.

Hoffman, Marci 'International Human Rights Law' (2013) *American Society of International Law*.

Jacobs, RK 'Legalising physician-assisted suicide in South Africa: Should it even be considered?' (2018) 11 *SAJBL* 2 at 66-69.

Jakhar, Jitender; Saaniya Ambreen & Shiv Prasad 'Right to Life or Right to Die in Advanced Dementia: Physician-Assisted Dying' (2021) 11 *Frontiers in Psychiatry* at 1-8.

Jayawickrama, Nihal *The Judicial Application of Human Rights Law: National, Regional and International Jurisprudence* 2 ed (2017) at 1-1089.

Jordaan, D W 'Human dignity and the future of the voluntary active euthanasia debate in South Africa' (2017) 107 *SAMJ* 5 at 383-385.

Jordaan, Donrich W 'Human Dignity and the future of voluntary active euthanasia in South Africa' (2017) 107 *SAMJ* 12 at 1050.

Kannan, Radhika; & Deepu Thottath 'Death on Demand: A comparison between Euthanasia Laws in the Netherlands and India, 2001 to 2020' (2021) 10 *Research on History of Medicine* 3 at 185-195.

Knox, Rebecca 'Preimplantation genetic diagnosis: Disease control or child objectification?' (2003) 22 *Saint Louis University Public Law Review* 2 at 435-455.

Koenane, Mojalefa LJ 'Euthanasia in South Africa: Philosophical and theological considerations' (2017) 38 *Verbum Et Ecclesia* 1 at 1-9.

Koetze, Adriaan and Shaun de Freitas 'The Protection of Conscientious Objection against Euthanasia in Health Care' (2019) 22 *PER / PELJ* at 1-32.

Kotze, Carla and Johannes L Roos 'End-of-life care in South Africa: Important legal developments' (2022) 28 *South African Journal of Psychiatry* at 1-3.

Kotzmann, Jane 'Dignity in International Human Rights Law: Potential Applicability in relation to International Recognition of Animal Rights' (2017) 26 *Michigan State International Law Review* 1 at 1-41.

Krajewska, Atina 'Bioethics and Human Rights in the Constitutional Formation of Global Health' (2015) 4 *Laws* at 771-802.

Kresin, Tracee; Jacinta Hawgood, Diego De Leo, & Frank Varghese 'Attitudes and Arguments in the Voluntary Assisted Dying Debate in Australia: What are they and how have they evolved over time' (2021) 18 *International Journal of Environmental Research and Public Health* at 1-11.

Kure, Josef 'Everything Under Control: How and When to Die – A Critical Analysis of the Arguments for Euthanasia' in Joseph Kure (ed) *Euthanasia – The "Good Death" Controversy in Humans and Animals* (2011) at 127-164.

Ledley, Fred D 'Distinguishing genetics and eugenics on the basis of fairness' (1994) 20 *Journal of Medical Ethics* at 157-164.

Mahlauli, Mavis B; End Salani & Rosinah Mokotedi 'Understanding Apartheid in South Africa through the Racial Contract' (2015) 5 *International Journal of Asian Social Science* 4 at 203 – 219.

Marcouz, Isabelle; Brian L Mishara & Claire Durand 'Confusion between euthanasia and other end-of-life decisions' (2007) *Canadian Journal of Public Health* at 235-239.

Marks, Stephen P 'Human Rights: A Brief Introduction' (2016) *Harvard University* at 1-21.

Math, Suresh Bada & Santosh K Chaturvedi 'Euthanasia: Right to life vs right to die' (2012) 136 *Indian J Med Res* at 899-902.

McCrudden, Christopher 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19 *The European Journal of International Law* 4 at 655-724.

McQuid Mason, D J 'Overturning refusal of a hospital to terminate life support for a brain-dead mother until the fetus was born: What is the law in South Africa' (2014) 104 *SAMJ* 8 at 553-554.

McQuid-Mason, D J 'Assisted suicide and assisted voluntary euthanasia: Stransham-Ford High Court case overruled by the Appeal Court – but the door is left open' (2017) 107 *SAMJ* 5 at 381-382.

McQuid-Mason, D J 'Doctor-assisted suicide: What is the present legal position in South Africa' (2015) 105 *SAMJ* 7 at 526-527.

Mdhluli, Sipho Tumelo 'Your life, your decision? The Constitution and euthanasia' (2017) 25 *De Rebus*.

Mendzhul, Marija V; Adrianna Yu Badyda, & Yuliia I Fetko, et al 'Euthanasia: Legal Regulation in European Countries and Prospects for Legalization in Ukraine' (2021) 7 *Laplage em Revista (International)* 3 at 479-486.

Meyerson, Denise *Understanding Jurisprudence* 1 ed (2006).

Michael, Lucy 'Defining Dignity and Its Place in Human Rights' (2014) 20 *The New Bioethics* 1 at 12-34.

Mo, Karin *The Practical Implementation of Human Rights – Universal or Contextual?* (unpublished Faculty of Theology thesis, Uppsala University, 2015).

Moodley, Keymanthri ‘The Fabricius decision on the Stransham-Ford case – and enlightened step in the right direction’ (2015) 105 *SAMJ* 6 at 434-435.

Moli, Ginerva Le ‘The Principle of Human Dignity in International Law’ (2019) *Koninklijke Brill NV* at 352-368.

Motloba, PD ‘Understanding of the Principle of Autonomy (Part 1)’ (2018) 73 *SADJ* 6 at 418-420.

Mroz, Sarah; Sigrid Dierickx, & Luc Deliens, et al ‘Assisted dying around the world: a status quaestionis’ (2021) 10 *Annals of Palliative Medicine* 3 at 3540 – 3553.

Neethling, Johann ‘The Constitutional Court affirms the potential existence of an action for wrongful suffering as a result of disability in South African law’ (2016) 79 *THRHR* at 533-550.

Noack, Thorsten & Heiner Fangerau ‘Eugenics, Euthanasia and Aftermath’ (2007) 36 *International Journal of Mental Health* 1 at 112-124.

Ogunbanjo, GA; & Knapp Van Bogaert ‘Voluntary active euthanasia: Is there a place for it in modern day medicine’ (2008) 50 *SA Fam Pract* 3 at 38-39.

Paust, Jordan J ‘The Human Right to Die with Dignity: A Policy-Oriented Essay’ (1995) *Human Rights Quarterly* at 463-487.

Pavone, Vincenzo ‘Science, Eugenics and Utopia: Comparing Scientific humanism and liberal eugenics on human genetic enhancement’ (2006) *Spanish National Research Council.*

Pedro, A and K Mwaba ‘An exploratory study of South African women’s experiences of In Vitro fertilizations and embryo transfer (IVE-ET) at fertility clinics’ (2013) 3 *Open Journal of Preventive Medicine* 8 at 1-9.

Peterson, Daniel R ‘Policing Future Nontherapeutic Applications of Genetic Enhancement through International Agreement’ (2008) 30 *Houston Journal of International Law* 3 at 743-777.

Picciocchi, Cinzia ‘Bioethics and Law: Between Values and Rules’ (2005) 12 *Indiana Journal of Global Legal Studies* 2(6) at 471-482.

Priel, Danny ‘Farewell to the Exclusive–Inclusive Debate’ (2005) 25 *Oxford Journal of Legal Studies* 4 at 675-696.

Pullman, Daryl ‘Human Dignity and the Ethics and Aesthetics of Pain and Suffering’ (2002) 23 *Theoretical Medicine and Bioethics* at 75-94.

Radacic, Ivana ‘Does International Human Rights Law Adequately Protect the Dignity of Women’ in Paulus Kaufmann, Hannes Kuch, Christian Neuhauser, and Elaine Webster (ed) *Humiliation, Degradation, Dehumanization: Human Dignity Violated* (2011) at 119-132.

Ranisch, Robert ‘Genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?’ (2020) 34 *Bioethics* at 60-69.

Raposo, Vera Lucia ‘The First Chinese Edited Babies: A leap of faith in science’ (2019) 23 *JBRA Assisted Reproduction* 3 at 197-199.

Reingold, Rebecca ‘An International Human Right to Die with Dignity’ (2019) *O’Neil Institute for National & Global Health Law – Georgetown Law* available on https://oneill.law.georgetown.edu/an-international-human-right-to-die-with-dignity/, accessed on 8 July 2021.

Roberts, Jason Christopher ‘Customizing Conception: A survey of preimplantation genetic diagnosis and the resulting social, ethical and legal dilemmas’ (2002) 1 *Duke Law & Technology Review* at 1-21.

Sandor, Judit 'Bioethics and Basic Rights: Persons, Humans, and Boundaries of Life' in Michel Rosenfelds et al (eds) *The Oxford Handbook of Comparative Constitutional Law* (2012) at 1143-1161.

Schaber, Peter 'Absolute Poverty' in Paulus Kaufmann, Hannes Kuch, Christian Neuhauser, and Elaine Webster (ed) *Humiliation, Degradation, Dehumanization: Human Dignity Violated* (2011) at 151-158.

Scheller Jr, Arthur 'Law and Morality' (1953) 36 *Marquette Law Review* 3 at 319-327.

Scher, S; & K Kozlowska 'The Rise of Bioethics: A Historical Overview' (2018) *Rethinking Health Care Ethics* 2018 at 32.

Sfetcu, Nicolae 'The new (liberal) eugenics' in Multimedia Publishing (ed) *Evolution and Ethics of Eugenics* (2018) at 1-6.

Shakespeare, Tom 'Choices and Rights: Eugenics, genetics and disability equality' (1998) 13 *Disability &* Society 5 at 665-681.

Starr, William C 'Law and Morality in H.L.A Hart's Legal Philosophy' (1984) 67 *Marquette Law Review* 4 at 673-689.

Steyn, Harvey J 'Preimplantation genetic diagnosis: prenatal testing for embryos finally achieving its potential' (2014) 3 *Journal of Clinical Medicine* at 280-309.

Strohwald, Annemarie *Dignity in Death: A critical analysis of whether the right to human dignity serves as appropriate justification for the legalisation of assisted death* (unpublished LLM Research Project; University of Stellenbosch, 2014) at 1-61.

Stolberg, Michael 'Two Pioneers of Euthanasia around 1800' (2008) *Hastings Center Report* 1 at 19-22.

Smith, George P ‘Human Rights and Bioethics: Formulating a Universal Right to Health, Health Care, or Health Protection?’ (2005) 38 *Vanderbilt Journal of Transnational Law*.

Somerville, Margaret ‘Birth, Death and Technoscience – Searching for Values at the Margins of Life’ *Recognizing Religion in a Secular Society* at 80-94.

Soni, Sheetal ‘The legal framework for preimplantation genetic testing in South Africa’ *Next Biosciences Articles* available at https://nextbio.co.za/the-legal-framework-for-preimplantation-genetic-testing-in-south-africa/, accessed on 25 June 2022.

Soni, Sheetal ‘*Prêt-à-Porter* Procreation: Contemplating the Ban on Preimplantation Sex Selection’ (2019) 22 *PER/PELJ* at 1-36.

Sperling, Daniel ‘Law and Bioethics: A rights-based relationship and its troubling implications’ (2008) 11 *Current Legal Issues* at 1-40.

Steinmann, Rinie ‘Law and human dignity at odds over assisted suicide’ (2015) 24 *Die Rebus*.

Steinmann, Rinie ‘The core meaning of human dignity’ (2016) 19 *PERLJ* at 1-32.

Strode, Ann; Sheetal Soni ‘Preimplantation diagnosis to create ‘saviour siblings’: A critical discussion of the current and future legal frameworks in South Africa’ (2012) 102 *SAMJ* 1 at 21-24.

Suckling, Rupert; Susan Root & Pablo Millares-Martin ‘Eugenics Debate’ (2000) 320 *British Medical Journal* 7328 at 1-2.

Sufian, Sandy ‘The Threat that CRISPR Poses to Disabled People’ 15 March 2021 *BrinkNews*, available at https://www.brinknews.com/the-threat-that-crispr-poses-to-the-disabled/, accessed on 5 January 2022.

Tamura, Ryota; & Masahiro Toda 'Historic Overview of Genetic Engineering Technologies for Human Gene Therapy' (2020) 60 *Neurol Med Chir* at 483-491.

Taylor, Paul M 'Article 7: Torture, Cruel, Inhuman or Degrading Treatment or Punishment' (2020) *Cambridge University Press* at 171-217.

Tess, Heirweigh *Euthanasia, one's final human right?: The case of euthanasia for* children (unpublished Masters Degree in Human Rights and Democratization thesis, Uppsala University, 2016).

Thaldar, Donrich; Marietjie Botes, & Bonginkosi Shozi, et al 'Human germline editing: Legal-ethical guidelines for South Africa' (2020) 116 *S Afr J Sci* 9/10 at 1-7.

United Nations 'Article 12: Right to Privacy' available at https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=23907&LangID=E , accessed on 10 December 2021.

Varkey, Basil 'Principles of Clinical Ethics and their application to practice' (2021) 30 *Medical Principles and Practice* at 17-28.

Viet, Walter; Jonathan Anomaly, & Nicholas Agar, et al 'Can 'Eugenics' be defended?' (2021) 39 *Monash Bioethics Review* at 60-67.

Vizcarrondo, Felipe E 'Human Enhancement: The new eugenics' (2014) 81 *The Linacre Quarterly* 3 at 239-243.

Vlad, Loredana 'The Person and the Right to Life – Philosophical, Bioethical and Law Approach' (2020) 7 *European Journal of Law and Public Administration* 2 at 151-157.

Wikler, Daniel 'Can we learn from eugenics?' (1999) 25 *Journal of Medical Ethics* at 183-194.

Wilson, Duncan ‘What can History do for Bioethics?’ (2013) 27 *Bioethics* 4 at 215-223.

Wilkinson, Stephen ‘ ‘Eugenics Talk’ and the language of bioethics’ (2008) 34 *J Med Ethics* at 467-471.

Wolf, Susan M ‘Law and Bioethics: From Values to Violence’ (2004) *Journal of Law, Medicine and Ethics* 32 at 293-306.

Wolinsky, Howard ‘Bioethics for the world’ (2006) 7 *European Molecular Biology Organisation* 4 at 354-358.