

An argument against germline editing on the grounds that morally justified parental consent for such interventions is not possible.

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Date: 03 October 2022

Declaration

I declare that this research is my own unaided work, produced with supervisory assistance. It is being submitted to the Degree of Master of Science in Medicine in the field of Bioethics and Health Law to the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination to any other University.



Signature of Candidate

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List of Abbreviations

GGE: Germline gene editing

TALENs: Transcription activator-like effector nucleases

CRISPR-Cas9: clustered regularly interspaced short palindromic repeats

DNA: Deoxyribose Nucleic Acid

HIV: Human Immunodeficiency Virus

IVF: In Vitro Fertilisation

SA: South Africa

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“The lines are fallen unto me in pleasant places; Yea, I have a goodly heritage.”

-Psalm 16:6 KJV

Dedication

I dedicate this Masters degree to my Lord and saviour Jesus Christ. This life that I live is not my own, for me to live is Christ.

“Whether therefore ye eat, or drink, or whatever ye do, do all to the glory of God.”

- 1 Corinthians 10: 31

Abstract

In 2017, Dr He Jiankui edited the germline of embryos to make them resistant to HIV. The embryos were carried to full term and born. The parents were not held liable but a Chinese court fined Dr. He 3 million Chinese yuan and sentenced him to 3 years in prison for illegal medical practice. It has been established that parents who want to prevent their offspring from inheriting genetic conditions which they carry the genes for can easily find scientists who are keen to edit their future children's germline illegally and not be held liable. In this research I argue that it is not morally justified for parents to consent to editing the germline of their future children and so parents who do so should be held liable because they are abusing their rights to bodily and psychological integrity by disregarding their future autonomy. This research report will be carried out using normative methodology.

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Chapter 1: Introduction

1.1 Background Literature

Germline gene editing is the process in which a person or organism's genetic information is edited such that the new edited genetic material can be inherited by the next generation (WareJoncas *et al*, 2018). This is done by editing genetic material in the reproductive cells of the human body such as the egg and sperm which are called germ cells (Gyngell *et al*, 2017). The word germline means a series of germ (a portion of an organism capable of developing into a new one or part of one) cells that are each successively passed on from generation to generation (Oxford English Dictionary, 2021). Germline gene editing can be performed using different techniques. These techniques have evolved over the years, starting with the use of restriction enzymes in 1970 which have been limited by the fact that they can only recognize a limited number of nucleotide patterns (Randhawa *et al*, 2021). This shortfall led to the discovery of Zinc Finger Nucleases (ZFN) in the 1980s to address this (Randhawa *et al*, 2021). However, the design was more challenging because the 3-base pair requirement and the editing efficiency was compromised (Randhawa *et al*, 2021). In 2011, scientists improved ZFNs and so they came up with Transcription activator-like effector nucleases (TALENs) and then they came up with so-called clustered regularly interspaced short palindromic repeats Cas9 (CRISPR-Cas9) to improve its functioning and lower its cost (Randhawa *et al*, 2021).

CRISPR-Cas9 is more advanced than the other gene-editing techniques and often it is mentioned that the Cas9 enzyme that CRISPR uses to cleave Deoxyribose Nucleic Acid (DNA) at a specific location could also make cuts where it is not intended to, potentially causing more unwanted mutations (Zhang, 2015). This means that the CRISPR-Cas9 technique still needs to be studied, improved and customised so it can be able to accurately correct anywhere from one to all mutations and avoid off-target effects (Zhang, 2015).

The term gene therapy is used to describe a medical approach that treats or prevents genetic diseases by adding the correct gene into the genome to rectify the problematic genes. Gene editing refers to revising, removing or replacing a mutated gene at a DNA level. CRISPR-Cas9 is a gene editing technology that can revise, remove, and replace DNA at highly targeted locations. Germline editing and germline gene editing are synonymous and used interchangeably in this report.

The two types of gene editing therapies that currently exist are germline gene editing and somatic gene editing (Gyngell *et al*, 2017). While somatic gene editing affects only the genes of the patient that is being treated, germline gene editing is the focus in this report because it affects all cells in an organism, including eggs and sperm, and is therefore passed on to future generations, which raises ethical concerns (Gyngell *et al*, 2017).

In 2015, Huang, a stem-cell researcher at Sun Yat-Sen University in Guangzhou and a group of other scientists, become the first to be reported for using the gene-editing tool CRISPR-Cas9 to modify human embryos (Liang *et al*, 2015). Huang used CRISPR-Cas9 to try fixing a blood disease causing gene error in a lab experiment (Liang *et al*, 2015). He used abnormal embryos as test subjects and the embryos were destroyed right after the experiment and there were no attempts to let the embryo grow into a human (Liang *et al*, 2015). This research raised a plethora of concerns amongst the scientific community, particularly regarding the lack of understanding of potential side effects of gene editing (Gyngell *et al*, 2017).

On 10 June 2017, a Chinese couple with Human Immunodeficiency Virus (HIV)-related fertility issues met with Dr. Jiankui, a 33-year-old SUSTech biophysicist for an In Vitro Fertilisation (IVF) procedure (Shaw, 2020). IVF is a process where a women's eggs are fertilised outside of her body (a laboratory) and then placed back inside her body to help her

get pregnant (Kamphius *et al*, 2014). Dr. Jiankui and his postdoctoral fellows obtained consent from the couple to edit the germline of the embryos using the CRISPR-Cas9 technology to make the offspring resistant to HIV by disabling the CCR5 gene (Shaw, 2020). The embryos were carried to full term and born, but the scientific community throughout the world rejected Dr. Jiankui's experiment (Shaw, 2020). Because of this, Dr. Jiankui was fired from his leadership position at a biotech company that was founded by him as well as his university position and writers referred to him with offensive names such as, a "rogue", "China's Frankenstein", and "stupendously immoral" (Dhai, 2020). A Chinese court fined Dr. Jiankui 3 million Chinese yuan and sentenced him to 3 years in prison for illegal medical practice, and the two colleagues who assisted him got shorter sentences (Dhai, 2020).

Upon going through Dr. Jiankui's manuscript on this gene editing project, Kiran Musunuru, noticed a rampant mosaicism (Musunuru, 2019). Mosaicism is when a person has 2 or more set of cells which are genetically different (Musunuru, 2019). This means that different cells showed different changes because the gene edits that Dr. Jiankui made to the embryos did not carry through consistently (Musunuru, 2019). Musunuru said that the twins are most likely to be mosaic because evidence of mosaicism was shown to be present in the embryos of the twins (Musunuru, 2019). This means that there are some parts that may contain edits that Dr. Jiankui did not highlight, while others contain the exact edits that Dr. Jiankui claims to have made and yet other parts may not have any edits at all (Musunuru, 2019).

It has been established that people are experimenting on gene editing by themselves which is very dangerous, but the lack of confirmed and approved laws and regulations concerning gene editing itself makes it difficult to regulate gene-editing (Townsend and Shoji, 2021). In China, it took Dr. Jiankui and his colleagues to perform and announce the germline gene editing project that they had done before China could tighten its laws on gene editing, and the parents of the twins were not punished in any way (Townsend and Shoji, 2021). However, all over the world,

desperate parents and people who have the means to do so may still easily find ways to participate in modifying their genes and their children's genes illegally and they are not held liable (Townsend and Shozi, 2021). Keep in mind that although CRISPR-Cas9 is currently the most affordable and precise gene-editing technique, it is not accurate (Townsend and Shozi, 2021). For this reason, there is always a possibility of off-target mutations and incomplete gene editing which results possibly in more medical conditions that may be incurable and possibly lethal (Townsend and Shozi, 2021).

The word autonomy means self-rule, meaning that it is applicable to people who have the capacity to make informed decisions, free from coercion (Parsapoor *et al*, 2014). In medical practice, autonomy is exercised when a patient consents to treatment or therapy after medical practitioners have obtained informed consent from the patient and they voluntarily make a choice (Parsapoor *et al*, 2014). Informed consent in medical practice includes ethics in the concept of autonomy and also case law in the concepts of medical malpractice and battery in law (Parsapoor *et al*, 2014). It is impossible to apply the principle of autonomy with unborn babies because informed consent includes 3 functions: (1) Patients must be intently and transparently be informed about the proposed treatments, (2) the patient must be able to understand the information that is intently and transparently provided to him or her , and (3) the patient must have capacity to make decisions and obtain informed consent (Parsapoor *et al*, 2014). It is impossible to apply this framework with unborn babies because they are not present to act independently, and they don't have the capacity to make medical decisions (Parsapoor *et al*, 2014). In this case, where the patient is not autonomous, the parent or proxy should make such decisions for the child or unborn baby based on his or her best interest (Parsapoor *et al*, 2014). However, this does not apply to the law when it comes to unborn babies (Smit, 2015). In South Africa, constitutional rights only apply to children who are born and not fetuses and embryos (Strode, 2011). Some ethicists argue that altering germ cells in a way that will affect

future generations raises ethical concerns because consent is not obtained from the future generations who will be affected (Strode, 2011). Other ethicists argue that the central question with germline gene editing on unborn babies, just like all other inventions and medical interventions that are risky for people who are unable to consent, is not about whether the person exposed to the possible risks consents to them or not, but rather whether the benefits outweigh the harms (Gyngell *et al*, 2017).

1.2 The rationale for the study

Several studies have revealed that CRISPR Cas9 can bind to unintended genomic sites for cleavage, this is called off-target effects (Zhang, 2015). Many scientists and bioethicists are concerned that it is highly possible that unapproved gene editing therapies are currently taking place any way in the world (Addison, 2020).

Parents who are desperate to prevent their offspring from inheriting genetic conditions which they carry the genes for, may find themselves approaching scientists for assistance. But what happens when an embryo that has been genetically edited is carried full term and born with conditions that are worse than intended or expected, thereby affecting the child negatively with a genetic disease as a result of an off-target mutation or mistakes? Is it ethical for parents to consent to genetic editing that will affect their future babies and generations? And in an event that there are negative off-target mutations, should the parents be held liable, and should their actions be punishable?

In her article titled “informed consent for human embryo genome editing”, Erica Jonlin uses Dr Jiankui’s’ informed consent form and process to discuss how researchers can obtain proper informed consent from recipients of edited embryos in the event that human embryo genome editing is safe enough for therapeutic use (Jonlin, 2020). Although Jonlin admits that the individuals being genetically edited are most susceptible to harm, they have no

prospective opportunity to give informed consent and require protection the most. The ethical implications of the parents consenting to editing the germline of their future children was not the scope of her study. Whether or not the act of a parent consenting to germline gene editing that will affect their unborn baby and future generations is ethical, needs to be analysed. I will do so in this research report, making use of utilitarianism to weigh the possible harms and benefits. I will also use the principle of respect for persons derived from the ethical theory of Deontology to analyse the autonomous rights of the future children and generations. I will then use the nasciturus fiction to argue that parents who consent to editing the germline of their future children are abusing their rights to bodily and psychological integrity by disregarding their future autonomy, and should therefore be held liable and I will be doing so in this normative novel.

1.3 Research Question

Is it morally justified for parents to consent to the germline gene editing of their future children, and should the parents be held liable?

1.4 Thesis

I argue that morally justified parental consent to germline gene editing on behalf of future children is not possible and parents should be held equally liable like the scientists involved.

1.5 Research Aim

To defend the thesis that morally justified parental consent to germline gene editing on behalf of future children is not possible and parents who do so should be held liable.

1.6 Research Objectives

1. To argue that the possible harms of parental consent to germline gene editing their babies are not morally defensible, even with possible benefits.
2. To argue that parental autonomy is not justified when it comes to germline gene editing because of the potential autonomy of future generations.
3. To argue that there should be shared liability for consenting to germline gene editing between parents who consent to germline gene editing of their unborn babies and the scientists involved.

1.7 Argumentative Strategy

To defend my thesis statement, I claim that:

1. The possible harms of parental consent to germline gene editing far outweigh the possible benefits.
2. Parental autonomy is not justified when it comes to germline gene editing because it affects future generations
3. There should be shared liability for consenting to germline gene editing between parents who consent to germline gene editing of their unborn babies and the scientists involved

The claims listed above are supported by using scientific articles and ethical theories that support my thesis.

The harms of parental consent to germline gene editing far outweigh the possible benefits. This speaks to the basics of non-maleficence which says that it is more important to avoid the possibility of harm which may outweigh the intended good (Sanders, 2015). The utilitarianism states that we should act always so as to produce the greatest good for the greatest number (Sanders, 2015).

In South Africa, legible persons according to the National Health Act Section 55(a) and 62 can legally donate their embryo to be genetically edited for research purposes (National Health Act Section 63, 2003). However, if parents are intending on carrying the embryo full term until the baby is born, then the future autonomy of the child and future generations should be considered. This means that there should be a restriction to their freedom when it comes to them consenting to germline gene editing their embryos which they intend to keep and give birth to. I will argue that parental autonomy is not justified when it comes to germline gene editing because it affects future generations (Gyngell *et al.*, 2017).

I will use the nasciturus fiction to argue that a genetically modified embryo that is eventually born should acquire all the rights of any child, therefore there should be shared liability between scientists involved and the parents for potentially negatively affecting the rights to bodily and psychological integrity and potential autonomy of future generations

Using all the arguments listed above, I will conclude with an argument against germline gene editing because morally justified parental consent on behalf of future children for such editing is not possible and I will support my objective of shared liability between the parents and the scientists involved.

1.8 Overview of Chapters

Chapter 1: Introduction

In this chapter, I give background literature on what gene editing is, the different types and techniques of gene editing, and discuss the current laws, dilemmas and ethical issues of germline gene editing. The rationale of the study, research question, thesis, research aim, research objectives and argumentative strategy are included.

Chapter 2: The possible harms resulting from parental consent to germline editing their babies are not morally defensible, even with possible benefits.

I will first give some background on utilitarianism according to Jeremy Bentham and John Stuart Mill, then I will apply utilitarianism to analyse the morality of parents consenting to germline gene editing and show that the harms far outweighs the benefits. This I will do by applying the principle of non-maleficence to identify the harms and the principle of beneficence to identify the benefits and then briefly discuss what actions maximises utility. From this I will show that even with possible benefits, the harms far outweigh the benefits. I will then discuss counter arguments from Savulescu and respond to the counter arguments from Elizabeth Gedge. Finally, I will then discuss my opinion and argue that the possible harms caused by parents who consent to germline gene editing their babies are not morally defensible, even with possible benefits.

Chapter 3: Parental autonomy ought to be limited when it comes to germline gene editing

In this chapter, I will start off by discussing the history of the concept of autonomy, followed by Immanuel Kant's concept of deontology. I will then apply Kant's categorical imperative of humanity as an end to parents consenting to editing the germline of their future children and show that parental autonomy ought to be limited when it comes to germline gene editing because it affects future generations. I will then discuss counter arguments to this by deMiguel Beriain and Savulescu and then give my response to counter arguments.

Chapter 4: Shared liability between parents and scientists involved in consenting to germline gene editing

In this chapter, I will discuss how Dr. Jiankui was held liable for medical malpractice by the courts in China, then I will discuss liability and medical malpractice. This will then be followed by the status of the law regarding proxy autonomy and then I will use the case of the Road Accident Fund (RAF) v Mxolisi; where a child who was born with brain damage as a result of an accident that his mother was involved in while he was still a foetus;; to show that the nasciturus fiction can be used to hold parents liable for consenting to editing the germline of their future children and thereby abusing their rights to bodily and psychological integrity by disregarding their future autonomy..

Chapter 5: Conclusion

In this chapter, I will summarise all my findings from chapter 2, 3 and 4 which align with all my objectives. I will demonstrate that I defended my thesis against germline gene editing because morally justified parental consent on behalf of future children for such editing is not possible and there should be shared liability between scientists involved and parents.

Chapter 2: The possible harms resulting from parents who consent to germline gene editing outweighs the benefits

2.1 Introduction

This chapter argues that the possible harms caused by parents who consent to editing the germline of their future babies are not morally defensible, even with possible benefits. This is done by using the ethical theory of utilitarianism which states that the right thing to do is that which brings the greatest good for the greatest number of people. The greatest good for the greatest number is discovered by weighing the good and the bad against each other and selecting that which benefits the greatest number. In this chapter, the harms and benefits of germline gene editing are identified and weighed using the principles of non-maleficence and beneficence and the outcome is used to show that the harms of germline gene editing outweigh the benefits. Therefore, parental consent on behalf of future generations cannot be justified.

2.2.1 History and concept of Utilitarianism

Utilitarianism is a moral ethical theory which is the paradigm case of consequentialism, and it was originally championed by Jeremy Bentham and later John Stuart Mill, who was the student of Jeremy Bentham (Welch, 2006). According to utilitarianism, a moral action is the one which is more favourable to a larger number of people (Welch, 2006). Jeremy Bentham, who is now dubbed the founder of modern philosophy states that the standard of right action, which is applicable to both governments and individuals is pleasure because humans are controlled by pleasure and pain, but they strive for pleasure and avoidance of pain (Welch, 2006). According to Bentham, actions that produce unhappiness or pain are rejected and actions that produce happiness, the good life or pleasure are accepted. (Welch, 2006). Bentham believed that all pleasure is the same; for example, the pleasure of getting drunk is the same as the pleasure of reading an interesting book that stimulates your intellect. However, critics say that this can't be

right because some pleasures are easier to get than others, and if all pleasures are the same, one should not spend more effort or resources obtaining a pleasure that is the same as any other pleasure (Welch, 2006). This is known as the philosophy of pigs because Bentham's theory implies that all pleasures are the same and that one should just go for the easiest pleasure instead of one that will require a lot of effort or resources, therefore encouraging people to live like pigs (Welch, 2006).

John Stuart Mill argued that the rules of action must be labelled by the results that they comply with because all action is for a purpose, and it seems natural to suppose that the rules of action must take their whole character from the end to which they are subservient (Janada, 2011). To understand and do what is morally right, our actions should be judged rightly. Mill says that actions are right in proportion as they tend towards promoting happiness and pleasure and they are wrong as they tend towards promoting pain and deprivation of pleasure (Janada, 2011). Mill disagreed with Bentham regarding pleasure; he says that some pleasures are essentially more valuable than others (Janada, 2011). However, in response to this, critics say that for some people, voluntarily choosing lower pleasures over higher pleasures or give up certain pleasures all together can be more valuable and satisfying to them (Relay, 2014). An example of this can be an individual who gives up his or her income to charity, instead of spending it on the things that he or she likes. To this Mill says even though some people do give up pleasure willingly, but they do this for a greater end, which is the happiness of others or God and this in turn is more valuable to them because it brings them pleasure (Relay, 2014). Mill disagrees with the pig philosophy by saying that there are different kinds of pleasures, and some are lower than others. To tell which pleasure is the higher, you take a look at what people who have tried all the kinds of pleasures prefer (Relay, 2014). And from this, the greatest good for the greatest number can be obtained, in this way, there is a higher chance of the good being maximized

(Relay, 2014). This means that any life; even if it was accompanied by discomfort; is good if it produces happiness or pleasure that cannot be traded by a higher pleasure.

A wrong action such as taking government money from schools to give to poor students, can be justified if only actions that produce the greatest good mattered (Nathanson, 2014). For this reason, utilitarianism was divided into two types- act utilitarianism and rule utilitarianism.

Act utilitarianism focuses on the actions of an individual. This means that the action that will create the greatest net good is the one that is morally right (Nathanson, 2014). In other words, the principle of utility requires that actions or behaviours be regarded as right if they produce happiness or pleasure, thereby yielding more utility, and wrong if they promote unhappiness or pain (Nathanson, 2014).

Rule utilitarianism focuses more on the moral rules (Nathanson, 2014). This means that an action is morally right only if it abides by a justified moral rule, and the moral rule is justified if it will yield the most utility when it is included into our moral code (Nathanson, 2014).

The key difference between act and rule utilitarianism is that act utilitarianism applies the utilitarian principles to the actions and rule utilitarianism considers the rules that result in the greatest good (Nathanson, 2014). Both types of utilitarianism should produce the most utility (Nathanson, 2014). In this chapter, I will use act utilitarianism to determine the morality of parents consenting to editing the germline of their future children.

2.2.2 Applying utilitarianism to the morality of parents consenting to germline gene editing their future children

In this section, I will identify the morality of parents consenting to germline editing their future children by weighing the possible harms and benefits of their actions by applying the following

steps that have been used by many ethicists over the years in their articles, including Shanks (Shanks *et al*, 2012):

1. “Identify the individuals involved”
2. “Identify the various courses of action”
3. “Determine all the foreseeable benefits and harms that would result from each course of action”
4. “Choose the option that provides the greatest benefits”

1. “Identify the individuals involved”

When parents consent to editing the germline of their future children, the following parties are affected by their decision: the consenting parents, the children that the parents will give birth to, the future generations of the parents and the scientists involved in carrying out the procedure. The children and future generation will be affected by this action either positively or negatively, depending on both the results of the gene editing and what the children would have desired. The scientists involved may also be negatively affected by the scientific community and the law, like the way Dr. Jiankui was affected. The parents will also be affected positively or negatively depending on how the procedure turns out. It is important to remember that even though the parents may be negatively or positively affected, they are the ones who made the choice to consent to editing the germline of their future children.

2. Identify the various courses of action

The available courses of action for the parents who would make the decision to consent to editing the germline of their future children depends on the reasons for parents wanting to

consent to editing the germline of their future children. If it's due to genetic medical conditions that they carry the genes for, parents can opt for allopathic medical treatments which have been used and monitored under professional surveillance for years. For example, a genetic medical condition like sickle cell diseases, can sometimes be treated with a bone marrow transplant to allow the formation of normal blood cells and some cancerous diseases caused by mutated genes can be managed by screening or preventative surgery (Zitter, 2005).

3. Determine all the foreseeable benefits and harms that would result from the course of actions

The principle of utility is a moral principle that recognises benefits and harms and it considers the consequences of an action, rather than the action itself. The principle of utility says that the action that produces the most amount of benefit after harm has been taken away is good. Therefore, to use the principle of utility is to maximise the net utility. In this section, there will be a focus on utility through the analyses of the benefits and the harms. The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research validated principlism in the Belmont Report as one of the techniques to make moral decisions (Taylor, 2013). Beauchamp and Childress officially developed the principlism ethical framework that focuses on the four ethical principles namely: autonomy, beneficence, non-maleficence, and justice (Taylor, 2013). The possible consequences for germline gene editing can either be harmful or beneficial. In this section, I will use the ethical principle of non-maleficence and beneficence for guidance in identifying the possible harms and benefits that can be caused by germline gene editing, to assist in applying the principle of utility as I identify actions that will promote the greatest benefits. This will be done by first defining the principle of non-maleficence, defining harm and the kinds of harm that may occur from germline gene editing, stating the severity and then the probability of the harms. Next, I will define beneficence, list the possible benefits that may come from germline gene editing and the probability of the benefits of germline gene editing.

Non-maleficence is the obligation to not cause harm (Clarkeburn, 2000). This principle supports moral rules such as do not kill, do not cause pain or deprive others of a good life (Clarkeburn, 2000). The principle of non-maleficence provides that we should not intentionally inflict harm on others or that we should prevent inflicting harm on others. This is linked to the expression that says “Above all, do no harm” (Clarkeburn, 2000). In healthcare, non-maleficence also means not causing harm through recklessness, negligence, or inexcusable ignorance (Clarkeburn, 2000). Harms such as pain, suffering or injury can sometimes be unavoidable and therefore in these situations, one can practice non-maleficence by weighing the harms and producing the least amount of pain possible. An example of this would be when the available treatments for a patient will also cause the patient some pain and the medical doctor opts for the treatment that will cause the least pain out of all the treatments. By this, the doctor has practiced non-maleficence.

Harm is defined as loss, disadvantage or injury done to someone or others that would injure their rights or set back important interests that benefit them (Woolard *et al*, 2021). The difference between harm and offense is that an offense, according to Mill, is something which we would say 'hurt our feelings' and it is less serious than harm because what may hurt one person's feelings may not hurt another, therefore offences are not universal and should not be prevented (Woolard *et al*, 2021). A study showed that there are various types of harm that can occur such as: psychological harm, legal harm, economic harm, social harm, and physical harm, amongst others (Woolard *et al*, 2021).

Physical harm is bodily pain, injury, impairment, or disease suffered by an individual as a result of someone's actions (May *et al*, 2014). An example of physical harm is when a parent or care giver inflicts pain on a child (May *et al*, 2014).

Social harm is defined as the combination of all the negative impacts associated with disorderly acts that may be legal or illegal or social control intervention (May *et al*, 2014). Examples of social harms include inequality, crime, pollution, or lack of adequate food or shelter amongst people (May *et al*, 2014). Social harms can result in negativity within individuals and thus in societies which can lead an increase in the social ills (May *et al*, 2014). Social harms comprise the lack fulfilment of human needs such as shelter, healthcare, education etc., and in so doing result in identifiable harms such as physical, mental autonomy related or relational harms (May *et al*, 2014).

Psychological harm is damage caused to a person's mind due to an event or events that causes an individual a lot of stress which exceeds his/her ability to cope or function normally psychologically, and may lead to serious, long-term negative consequences (Cusack *et al*, 2018). Examples of psychological harm include intimidation, harassment or blackmailing among others. Psychological harm can make a person feel trapped, humiliated or threatened, making a serious impact on a person's mental health (Cusack *et al*, 2018). Most of the signs that show that someone is suffering from psychological harm relate to their mental state and changes in behaviour (Cusack *et al*, 2018).

I will start by discussing the physical harms that may result from germline gene editing, the first being caused by off-target mutations. Off-target mutations of gene editing takes place when complexes of genetic engineering nuclease technologies do not bind at the target site and

therefore cause non-specific genetic modifications which may consist of unintended point mutations, deletions, insertions and translations (de Miguel Beriain *et al*, 2020). In the case where CRISPR-Cas9 is used, it would be the Cas9 protein complex that cleave on some off-target sites (de Miguel Beriain *et al*, 2020). The results of these off-target mutations, whether good or bad, can be misleading because they are not reproducible since they happen randomly and unintentionally (de Miguel Beriain *et al*, 2020). These off-target mutations can cause mutations that can result in loss of gene function which will result in more genetic diseases. Off-target mutations can also aggravate the creation of cancer cells and cause an individual to be more sensitive to infections that they would have normally not be sensitive to. (de Miguel Beriain *et al*, 2020). This may result in people easily succumbing to diseases that they would have normally overcome, thereby increasing the burden on the medical system and ultimately causing deaths (de Miguel Beriain *et al*, 2020).

Another problem that can arise is an issue of identity, because when an off-target mutation has taken place, it will be difficult to indicate the connection between the damage and the event (Krekora-Zajac, 2020). This is because a germline gene editing that can prevent one from expressing a certain disease, may on the other hand make the child highly vulnerable to another disease. This can make it difficult to identify whether the child was naturally vulnerable to the disease or whether it was caused by the gene editing (Krekora-Zajac, 2020).

Another physical harm can be caused when edited genes which are not expressive and therefore do not affect the carrier, turn out to be pathogenic with time or when the carrier pro-creates (Krekora-Zajac, 2020). This may result in an individual or a whole population being affected by possible pathogenic effects of the edited genes and aggravate safety concerns regarding germline gene editing (Krekora-Zajac, 2020).

Social harms include the possibility of eugenics. The word “eugenics” comes from the Greek roots for “good” and “origin,” or “good birth” and involves applying genetic editing that affect heredity to enhance the human genome (Oxford English Dictionary, 2021). Eugenics can take place intentionally or unintentionally with germline gene editing when the target gene does not get edited to cure a genetic condition but rather, an off-target mutation takes place to obtain a certain immunity, an unnatural ability or an unnatural appearance (Krekora-Zajac, 2020). If this gets practiced by more people, it may ultimately cause a loss of genetic diversity which may ultimately increase the risk of extinction of the natural human genetic pool and interrupts natural human evolution as some heritable genes get wiped off the gene pool while we get new kind of babies with edited genes that make them healthier, more intelligent and better looking than they would have been (Krekora-Zajac, 2020).

Eugenics may also increase unjust discrimination, with natural babies being seen as inferior to those who have been engineered to have the “ideal genes” (Baltimore *et al*, 2015) (Hildt, 2016). Inequality and injustice are already some of the crucial social issues that we are dealing with today and the creation of enhanced human race can worsen the issues (Baltimore *et al*, 2015).

Psychological harm can result from a germline editing that went wrong and caused physical harms instead of benefit. The emotional impact of the harms caused by the gene editing can lead to depression, withdrawal, isolation, feelings of hopelessness and suicidal thoughts (Cusack *et al*, 2018). There are also some psychological genetic disorders such as bipolar disorder and autism amongst others that one can suffer from if the responsible genes are mutated by off-target mutations (Craddock and Sklar, 2013).

Severity of the possible harms that can be caused by germline gene editing.

The physical, social and psychological harms that can be caused by germline gene editing differ in severity, but all of them are harms that cannot be taken lightly. The physical harms that result in causing more genetic conditions, aggravating the creation of cancer cells or make an individual to be more sensitive to diseases that they would normally not be sensitive to can be very serious and lead to deaths. Social harms such as those that may result in eugenics are also moderately serious because societies in different countries all over the world are already dealing with issues of discrimination and inequality which are also propagators of crime. Eugenics due to germline gene editing will only aggravate these issues. Other relatively less serious harms include psychological harms such as psychological conditions which can be managed by medical interventions.

Probability of the harms

The probability of individual harms listed above cannot be determined because they are caused by off-target mutations which are not reproducible since they happen randomly and unintentionally. However, the frequency of off-target mutations has been studied by scientists all over the world. In their article titled “High frequency off-target mutagenesis induced by CRISPR-Cas9 nucleases in human cells”, Fu observed that CRISPR RNA-guided endonucleases (RGENs) caused about 66,7 % of off-target mutations targeted to endogenous loci in human cells and in addition to this, there were some partially mismatched sites as well (Fu *et al*, 2013). These off-target sites contained up to five mismatches with frequencies higher than those that occur at the intended sites. (Lin *et al*, 2014) The article also states that multiple studies found that off-target genetic modifications occur at a frequency of more than 50 % and change the normal function of genes that are intact and on-site. (Lin *et al*, 2014). In the years, numerous types of approaches have been developed to reduce off-target effects. Various techniques used to decrease off-target mutations have been reported, including different bioinformatics approaches and choosing an appropriate off-target detection tool to detect and

correct off-target mutations. Various techniques can be used to reduce off-target mutations but the frequency at which they would be reduced was not discussed in detail (Neem *et al*, 2020). Currently, researchers are in the race to improve the Cas9 variant and develop new gene editing techniques that have insignificant off-target effects in human and other mammalian cells to improve genome medical intervention (Naeem *et al*, 2020). But until then, the frequency at which off-target mutations take place is too high for use in humans even if it was reduced by 90% because the mutations will be inherited by future generations (Naeem *et al*, 2020).

Beneficence is the principle of acting with the best interest of the other in mind (Beauchamp, and Childress, 2001). In biomedical research involving human participants, the principle of beneficence requires that the researchers act in such a way that will benefit the participants. This aligns with any moral rule of non-maleficence (Veit, 2018). It is important to note that beneficence is different to non-maleficence in that beneficence does not just avoid harm, but also prioritizes benefiting people and promoting their welfare (Veit, 2018).

The possible benefits of children whose germline has been edited as a result of parents who consent to editing the germline of their embryos which they intend to give birth to includes that the children and future generations will not have to suffer from the genetic conditions that the parents carry. So far, couples with genetic risks depend on gamete donation, embryo selection or adoption to avoid having children with genetic conditions that they carry the genes for. Gamete donation helps people to have a child by using eggs or sperm that have been donated by someone else (Sullivan-Pyke and Dokras, 2018).

In addition to disease prevention, germline gene editing can potentially also be used to treat infertility. The only current option for absolutely infertile patients to create offspring is through gamete donation (Chen *et al*, 2018). Gamete donation comes with legal restraints as it is illegal

in most countries around the world (Chen *et al*, 2018). Gamete donation also come with ethical concerns that question the privacy of donors regarding the nature of their relationship with the children born (Chen *et al*, 2018). The disadvantages of gamete donation is that the resulting child is not genetically related to the parents as the genetic material of the donor is used and therefore defeats the purpose of having a genetically related offspring, secondly, gamete donation treatment is not easily available because it is prohibited in many countries around the world (Chen *et al*, 2018). Another alternative to gamete donation is adoption, which also does not meet the requirements of genetically related offspring (Chen *et al*, 2018).

For a couple suffering from retractable infertility, germline mitochondrial modification technique is used. When germline mitochondrial modification is used, the cytoplasm from the donor's oocyte, which contains the germline mitochondria is transferred into the patient's eggs. The cytoplasm is important because it contains factors that are important for embryonic development and poor quality of such factors can result in infertility. The germline mitochondrial modification technique provides good quality cytoplasmic factors such as DNA, RNA, proteins and other factors from the donor helps to rejuvenate the eggs of the infertile woman and thereby contributes to the development of a pregnancy in the infertile woman (Gómez-Tatay, 2017). The genetic material created during this technique will also be inherited by future generations because it is done to the germ cells (Gómez-Tatay, 2017). Mitochondrial germline gene editing could be a viable alternative to PGD (Pre-implantation genetic diagnosis), gamete donation, and adoption (Chen *et al*, 2018). It makes a significantly genetically related child a possibility for potential parents, however, off-target mutations can also take place (Chen *et al*, 2018).

4. Choose the option that provides the greatest benefits

According to utilitarianism the best option would be that which provides the best benefits for the greatest number of people. To recap the possible harms discussed above, germline gene editing can cause the following harms: loss of gene function, can cause more genetic conditions due to off-target mutations, aggravate creation of cancer cells and making an individual to be more sensitive to diseases that they normally would not have been sensitive to, the mutated gene may become pathogenic over time, mental conditions caused as a result of the physical harms and socially, the possibility of eugenics. The benefits include that children and future generations will not have to suffer from the genetic conditions that their parents carry the genes for, and also retractable infertility can be overcome with germline gene editing.

From a quick glance, there is a longer list of harms than the benefits. However, to this Mill would say that there are different kinds of benefits, and some are higher than others. The severity and prevalence of the harms would help us to rank the harms and compare the harms with the benefits. The harms of germline gene editing range from mild illness or loss of function to death, distraction of future generations which we can assume that they are more in number because reproduction is continuous, also considering chronic illnesses such as mental diseases that need to be managed. These are all serious and morally indefensible harms. However, there is also a possibility of the off-target mutations to results in mutations that are not life threatening such as change in appearance, higher or lower IQ, and some additional or lesser abilities. These mutations that are not life threatening could also become a disadvantage to many upcoming people in the next generations who would rather prefer their natural selves as “nature” would have intended for them to be and or reserve their own autonomy to decide whether they want to be genetically modified or not. Act Utilitarianism is when the actions taken would result to the greatest good. This also depends on the results of the off-target mutations if they take place, if parents decide to consent, their action can either benefit their children and next generations or disadvantage them.

Upon application of utilitarianism, it is clear that the possible harms of germline gene editing outweigh the benefits and even if the physical and social harms can be avoided should there be no off-target mutations. The children and future generations may suffer from psychological harms if they would want to reserve their own right to decide if they want to be genetically modified or not. The action that can maximise utility would be to allow the child to be born and afford the child the right to choose if they prefer somatic gene editing instead of editing the germline. This way, the child and future generations are not genetically modified without their consent and any harms that may occur will be incurred by the consenting child alone and not inherited by their generations. After all, if one can decide to abandon their profession and possessions to become a monk under obedience; this shows that a person's choices are not always obvious, and we therefore cannot assume that a child would want to change their genetic susceptibility or disease even with the option to choose germline gene editing. Therefore, based on utilitarianism, it is not morally defensible for parents to consent to editing the germline of their future babies even with possible benefits.

2.2.3 Procreative Beneficence

Procreative beneficence is a term that was coined by Julian Savulescu and it is against my analyses above. Procreative beneficence states that parents who are in a position to select their children (by adoption or embryo selection) should select a child who is expected to have the best life out of all the possible children that they might have (Veit, 2018). This means that in a situation where the parents carry genes for a certain disease and carry out a pre-implantation genetic diagnosis where the embryos are screened for genetic traits before they are implanted into the womb, during this stage, according to procreative beneficence, the parents are obliged to select the embryo that is without the diseased genes and have the best traits including both diseased and non-diseased genetic traits (Veit, 2018). Regardless of the consequences and discrimination that may follow as a result (Veit, 2018). Savulescu's points that are in support

of procreative beneficence are that some non-diseased genes affect the likelihood of us leading the best life (Savulescu *et al*, 2012). This means that some non-diseased genes such as low IQ affect the likelihood of us leading the best life in that a person with a low IQ is most likely to get a low paying hard labour-intensive job that is not appealing, while a person with a higher IQ is more likely to get a “good job” and be trusted with leadership positions and big responsibilities.

Second, potential parents have a reason to use information and technology which is available about desirable and non-desirable genes in our reproductive decision-making (Savulescu *et al*, 2012). The same way a pregnant woman’s reason for wanting to terminate a pregnancy or give up the child for adoption can be valid, like instances where the mother does not have the ability or means to care for the baby, potential parents have a reason to use the available information and technology to ensure that their child lives the best life possible.

Third, embryos or foetuses which are most likely to have the best life based on the available genetic information are the ones that should be selected by aspiring parents to avoid suffering and increase comfort (Savulescu *et al*, 2012). This means that, parents who consent to edit the germline of their future children are justified because they are doing what they possibly can to ensure that their children live a “better life” than they would without the gene editing.

Elizabeth Gedge believes that procreative beneficence enables expressivism, which sends the message that persons with less desirable genes are unhealthy and therefore inferior (Gedge, 2010). Expressivism is a family of views in the philosophy of moral language that claim that:

1. There are no moral facts
2. We should not convict people of falling into big error in their moralizing because moral language does not describe moral reality but rather expresses feelings, attitudes, prescriptions as to how one should behave (Dreier, 2009).

This means that

an expressivist would ask: Does it mean that parents who consent to editing the germline of their future children send out a negative message to parents who don't, or do they send out a message that it would be better if parents who don't consent to editing the germline of their future children don't bear children at all. The answers to these questions would obviously vary because there is no proof of the intention of these potential parents. Using these inconclusive answers, an expressivist would prove that moral language does not describe moral reality because being pro-germline gene editing does not mean being against those who are against germline gene editing. This means that according to expressivism, eugenics is not necessarily morally wrong provided that it is done for defensible reasons such as avoiding suffering in any way even if it means avoiding failure caused by low IQ or avoiding to not be counted amongst the "good looking" people in society. Expressivism in this case has consequential and symbolic harms in that it deprives those who would be said to be inferior, of their moral status and this could consequentially limit their rights and privileges (Gedge, 2010). This means that parents who consent to edit the germline of their future children may contribute to discrimination against those children whose parents did not pursue germline gene editing.

Savulescu and Singer insist that we are morally obliged to breed healthier children as well as to ensure that the children that we bring into this world live the best lives that they possibly could (Savulescu and Singer, 2021). Due to this obligation, parents who consent to germline editing their children are justified in practicing procreative beneficence.

I think that there should be a balance between reproductive choice, advancing medical knowledge, reducing future suffering, and respecting the moral status of all citizens. If everyone edits the germline of their future children, there would be no need to carry out research on some diseases which are prone to the natural gene pool and therefore this would regress our education and innovation progress that we have done so far on the natural gene pool and refocus our

efforts on edited gene pool and eventually lead to extinction of the natural gene pool. This is obviously unnatural and therefore will cause an imbalance in society and may lead to suffering. There are currently no compelling reasons that compel us to adhere to procreative beneficence. Procreative beneficence is based on one conception of “the best life”, therefore, this principle has limited application because the definitions of the best life are different among people. While some people would want a child with a higher IQ, others may prefer one who is less prone to diseases. Even though, a utilitarian might say that there are different higher and lower “best life” from which parents should ensure that their children live the higher “best life”. My response to this is that different people enjoy different things and there will be people who will enjoy painting portraits and carpentry more than leading a big corporation and that would be the best life for them. This means that procreative beneficence is biased in describing what the best life is for individuals. Secondly, the best life is to be afforded your right to choose whether you want to remain in your natural genetic makeup or enhance yourself without anyone assuming what you would like and choose for you. There are no obvious or consistent mental, physical, or psychological traits that guarantees that a child will live the best life, therefore germline gene editing of future children does not guarantee the best life, and this would be worse if future generations whose germline has been edited are unhappy with the genetic editing done to them. Parents consenting to germline gene editing on behalf of future generations removes their ability to choose (in the future) the best option for them to live their best life, as a result, the greatest good for the greatest number is not met, and this is not morally right according to utilitarianism.

Notice that Savulescu and Singer based their support for procreative beneficence on utilitarianism while I also based my argument against procreative beneficence on utilitarianism. The distinction between our approaches to utilitarianism is that my approach is practical because it is realistic and considers collectivism. Savulescu and Singer’s approach is more

theoretical, and overly individualistic in that it disregards the diversity of preference of the best life and ignores social dimensions such as inequality that we are currently faced with. I believe that my approach to utilitarianism in terms of procreative beneficence is more reliable to determine the morality of parental consent to germline gene editing with regards to procreative beneficence.

2.3 Conclusion

Responsible potential future parents are expected to make the right decisions regarding the children that they will conceive and intend to give birth to. In addition to this, everyone has the right to do whatever they want with their bodies and everything that concerns them. For example, if a woman decides to terminate a pregnancy, she should be afforded the freedom to do so provided that her decision was not unduly influenced in any way. However, if a couple decided to conceive a child and give birth to the child, then the parents are expected to be responsible and act rightly to the best of their ability and protect the child from harm. Germline gene editing can result in physical, psychological and social harms. The physical harms include off-target mutations that can cause dangerous mutations that can result in loss of gene function, causing more genetic conditions, they can also aggravate the creation of cancer cells or make an individual to be more sensitive to diseases that they would normally not be sensitive to. The social harms include eugenics which will result in unjust discrimination as well as the ultimate loss of the natural genetic make-up of the affected future generations and interrupt the natural human evolution. The psychological harms include the genetic psychological diseases that can be caused by off-target mutations and psychological conditions that can result from frustrations experienced by generations who are suffering some physical harms caused by the genetic editing or who have lost their natural gene pool without their consent. The benefits of germline gene editing include preventing genetic diseases in the next generations. Parents are expected to not cause harm to their children, and in instances where they cannot prevent the harm, they

should weigh the benefits against harms of all possible interventions. This means that they should always prioritise the benefit of the child. Procreative beneficence states essentially, the parents are expected to make sure that their child lives the best life at any cause. However, the limitation of procreative beneficence is that it is biased in defining what the best life is because the definitions of the best life are different among people. While some people may think that a child with a higher IQ will live the best life, others may think that a healthy child has the best life. In addition to this, children may disagree with parents regarding their ideas of what would make their life the best life, thereby causing harm to the children. From discussions in this chapter, I can conclude that the physical, psychological and social risk of harm outweigh the health and enhancement possible benefits and so the possible harms caused by parents who consent to germline gene editing their babies are not morally defensible, even with possible benefits. This makes it clear that the harms of parents consenting to editing the germline of their future children outweigh the benefits.

Chapter 3: Parental autonomy ought to be limited when it comes to germline gene editing

3.1 Introduction

This chapter normatively explores the second objective of this research: To argue that parental autonomy is not justified and ought to be limited when it comes to germline gene editing because it affects future generations. This will be done by first exploring the concept of autonomy, followed by the use of Kant's respect for persons to argue that parental autonomy ought to be limited when it comes to germline gene editing because it affects future generations. I use Kant's deontology to provide the basis of the duty of giving future generations their autonomous rights. I will use the categorical imperatives of treating humanity as an end and not "as a means to an end" to show that parental autonomy ought to be limited when it comes to germline gene editing. I will then discuss a counter argument from deMiguel Beriain who argues that autonomy of future generations cannot be respected by not changing the human genome because the human genetic make-up is not naturally fixed anyway. I will also discuss a counter argument from Savulescu who points out that it does not make sense to consider the autonomy of future generations only when it comes to germline gene editing but not with other inventions. My opinion is that humans grow with their natural genetic make-up and live autonomously with genes that are given to them by chance, rather than design. Therefore, parental autonomy ought to be limited when it comes to germline gene editing.

Germline gene editing is currently illegal in most countries around the world including South Africa. All currently available technologies of germline gene editing are not accurate, meaning that off-target mutations can take place and either cause harmful genetic diseases, cure a genetic disease or enhance the genetic make-up of an individual (Baylis, *et al*, 2020). There is no known information about if the genetic mutations may be pathogenic in the future (Baylis, *et al*, 2020). Aristotle said that we are rational beings, but we are capable of being non-rational. It is rational

for a parent to want to do the best of what they can for their child, however, when it comes to parents consenting to editing the germline of their future children, it is not rational for parents to consent to editing the germline of their future children because they do not know the details and implications of each off-target mutation that can occur and lead to consequences that we have not yet discovered. There are many unknowns about the consequences of germline gene editing and therefore this compromises rational decision making. A compromise in rational decision making such as in this case leads to diminished autonomy because there is not enough information for the parents to give valid informed consent.

3.2.1 The concept of autonomy

The word autonomy is derived from the ancient Greek words *autos*, meaning “self,” and *nomos*, meaning “rule” and it is the ability of a person to make decisions and lead his/her own life according to reasons, values, or desires that genuinely comes from him/her (Lau, 2018).

The concept of autonomy first came into prominence in ancient Greece when philosophers of that time such as Plato and Aristotle had ideas similar in mind to autonomy as they wrote of persons being guided or ruled by reason (Tarnas, 2010). Plato’s notion of holism and care are crucial to medicine today and can be connected to the ethical principles of autonomy and beneficence (Rotaru, 2020). Autonomy today is defined as self-rule, which is the ability to make decisions for oneself without any other form of external interference such as coercion that would defeat the purpose of a genuine independent choice (Rotaru, 2020).

Aristotle, who studied at Plato’s academy, said that humans are rational and social animals, meaning that in addition to growing, being healthy and fertile like animals, we should also use reasoning and get along with other humans (White, 2020). Aristotle says that due to our “calculative” imagination by which we can consider and weigh several goods together, and with a deeper memory and longer sense of the future, we discern many more goods to compare and

weigh (White, 2020). With reason we can recognize the best and decide upon certain goods among many.

Germline gene editing is currently illegal in most countries around the world, all currently available technologies of germline gene editing are not accurate, meaning that off-target mutations can take place and either cause harmful genetic diseases, cure a genetic diseases or enhance the genetic make-up of an individual (Baylis, *et al*, 2020). There is no known information about if the genetic mutations may be pathogenic in the future (Baylis, *et al*, 2020). Aristotle said that we are rational beings, but we are capable of being non-rational. It is rational for a parent to want to do the best of what they can for their child, however, when it comes to parents consenting to editing the germline of their future children, it is not rational for parents to consent to editing the germline of their future children because they do not know the details and implications of each off-target mutation that can occur and lead to consequences that we have not yet discovered. There are many unknowns about the consequences of germline gene editing and therefore these compromises rational decision making. A compromise in rational decision making such as in this case leads to diminished autonomy because there is not enough information for the parents to give valid informed consent.

3.2.2 Applying Kant's deontology to parents consenting to germline gene editing

Unlike utilitarianism, Kant's Deontology does not find rightness in the consequences of our actions (the ends don't justify the means), but rather, it finds rightness in obeying rules and performing duties (Ameriks, 2013). This means that rightness is determined by our actions and consequences are not considered.

There are two categorical imperatives which are tests that can be used to judge whether an action is in accordance with the moral duty of Kant's deontology (Baylis, *et al*, 2020). These tests include universality of actions (meaning that if the law was to be universalised, would

anybody like to live in that world) and treating humanity as an end and not “as a means to an end” (meaning that we should recognise the humanity of people and realise that each person has their own goals and desires) (Baylis, *et al*, 2020).

The ethics of respect for persons, conveniently adheres to the principle of universalisation as well because respect for persons also mean that you should treat people equally, so these principles are actually different versions of the same idea and they cannot contradict one another (Baylis, *et al*, 2020). The two principles are consistent because the basic idea is the same for both; all people are equal and deserve to be treated as such. This idea lies at the centre of morality, and it therefore means that treating others as means to an end is disrespectful to ethics (Baylis, *et al*, 2020).

I will discuss only treating humanity as an end and not “as a means to an end” because it is often referred to as the principle of respect for persons which is applicable for establishing the morality of parental autonomy when it comes to germline gene editing.

Respect for persons is the concept that all people deserve the right to fully exercise their autonomy (Baylis, *et al*, 2020). Showing respect for persons is a system for interaction where every being is ensured and enabled to make an independent choice.

Parental consent to editing the germline of their future children for different reasons, I will analyse some of those reasons using the categorical imperative of respect for persons. Reasons why parental consent to editing the germline of their future children include to prevent the possibility of their children and future generations from getting genetic diseases that they carry the genes for or to prevent them from getting a particular disease (similarly to vaccines), to improve physical capabilities such as performance in sports (gene doping), to improve mental capabilities such as memory and intelligence and to change their appearance (make them taller, change skin tone or the colour of the eyes etc.) (Baltimore *et al*, 2015).

Consenting to editing the germline of future children cannot be compared to vaccination of children because it takes on average 10 to 20 years for vaccines to pass through relevant clinical trial phases to determine the quality, safety and efficacy of the vaccine before they can go into the market (Pronke *et al*, 2013). Studies are still carried out even when the vaccines are in the market, pharmacovigilance studies are carried out where patients report their experiences with the vaccines to their healthcare practitioners or the manufacturers of the vaccines so that they can be improved to prevent dangerous adverse events and minor adverse events are communicated to patients for their information (Pronke *et al*, 2013). Furthermore, the vaccines used in humans do not alter the germ cells of the individual, therefore any mutations on the genome will not affect future generations. If parents who want to prevent their children from getting genetic diseases, were to consent to editing the germline of their future babies, this would be disastrous because if any quality or safety deficiencies are identified, then they would affect future generations, without any opportunity to correct the deficiencies contradicting the motive of parents wanting to prevent their children from suffering from genetic conditions. This would potentially put future generations in danger of some genetic diseases or even non-existence, should the results lead to death of the embryos involved. The notion that parents today are choosing the fate of their descendants is a frightening one, not to mention that we are still unsure what consequences these alterations will have on future generations. This is where respect for future generations is violated, because future children would potentially be born with those genetic conditions for the rest of their lives and never get the opportunity to have their say regarding this procedure.

Consenting to germline gene editing for the purpose of enhancing physical appearance can be a threat to the natural evolution of the human species. Scientists tell us that humans have evolved naturally (through natural selection) throughout the years to now homosapiens and we

have also changed in bodily features (Storm, 2001). This means that as the climate and environment continues to change, humans also change to adapt to the changing climatic conditions and environment (Storm, 2001). Parents who consent to editing the germline of their future generations for enhancement are acting irresponsibly because these changes will go against the natural human appearances and lead to inequality and discrimination in the human race as we will have two types of humans: the natural looking humans and those whose appearance have been altered. Parents who consent to editing the germline of their future children to enhance their physical and mental capabilities are posing a threat to personhood and human dignity. The human genome is the heritage to humanity because it determines who belongs to the human species; including all the naturally possible physical and mental capabilities; and being part of the human species confers dignity (Raposo, 2019). Dignity is an intrinsic value shared by all human beings by virtue of belonging to the human species (Raposo, 2019). To enhance the physical and mental capabilities of future generations would mean to create a new type of human species that have extraordinary/ unhuman abilities. Unlike animals and plants, we have reasoning capacities that results from our principles, values and opinions. This means that even the future generations will have their own desires and reasoning and not all of them may be happy to have unnatural abilities or features or to be extraordinary human beings because they may have beliefs, desires, reasoning, etc. that are against this. A disrespect to human dignity in this case means that the future generations affected would be deprived of their natural human genome and autonomous right to consent or not consent to genetic editing (Raposo, 2019). This altering of genetic makeup could be the beginning of a downward spiral leading to the destruction of individuality and uniqueness, resulting in an abuse of respect for persons.

Therefore, parents should not arrogate to themselves the power to alter the genome of their future generations. Respect for persons means that we recognise and respect that each person

has the right and capacity to make his or her own decisions. Respecting a person ensures that dignity is valued.

3.2.3 Counter arguments and response

Some bioethicists argue that respect for autonomy does not mean preserving the human genome. de Miguel Beriain says that if the autonomy of future generations is respected by not changing their genome; then we should not accept any new mutation in the human genome—regardless of whether it is produced by human invention or whether it happened naturally (de Miguel Beriain, 2018). Many arguments that are against gene editing ignore the fact that the human genome is subject to mutations like any other genome, therefore the human genome is not a fixed entity, which is why evolution will continue to take place with time (de Miguel Beriain, 2018). Savulescu argues that it does not make sense to consider the autonomy of future generations only when it comes to decisions involving germline gene editing but ignore the autonomy of future generations when it comes to inventions that have long term effects which will drastically change humans way of living such as cell phones (Savulescu and Singer, 2021). Savulescu says that this shows that it is ridiculous and unrealistic that we do not develop risky novel technologies just because they will affect future generations without their consent (Savulescu and Singer, 2021). It is obvious that every invention created now will affect the future generations positively or negatively. The sooner the inventions are explored, the sooner any negative effects can be identified and mitigated as best as possible and the benefits can be enjoyed by many other people (Savulescu and Singer, 2021). The important point with all risky interventions that will affect non-consenting individuals is that they will also possibly enjoy the benefits and not whether they would consent to the intervention (Savulescu and Singer, 2021). If the individuals who bear the risk of our pursuing of germline gene editing technologies would exist even if we did not pursue it, then they will not enjoy their life compared to if we had

pursued the technology (Savulescu and Singer, 2021). Life in the midst of possibilities that one does not pursue is not enjoyed (Savulescu and Singer, 2021).

I think that parental autonomy is not justified when it comes to germline gene editing because it deprives future generations of their autonomy. In genetic engineering research that involves embryos, the embryo whose genetic make-up is being edited is not autonomous, making it acceptable for the scientists involved to decide how the embryos can be destroyed after the research and so the embryos are not carried to full term and born (Lau, 2018). In the case where parents consent to editing the germline of their embryos, which they intend to carry full term and give birth to, then the future autonomy of the child and future generations should be considered because the children will grow, become sound minded and fit to make personal decisions but application of respect for persons will not be possible if decisions regarding their genetic make-up have already been made for them before they were born. People are different and different people have their own dreams, goals, desires, visions and intentions and therefore decisions made by other people other than our own selves can prevent us from living that satisfying, fulfilling life of our dreams. When a person makes a decision about editing their own genetic make-up it is easier for them to accept the outcome if the gene editing goes wrong compared to if someone else had made the decision for them (Ameriks, 2013). Self-chosen dreams create intrinsic motivation as opposed to living out a dream that has been chosen by a great ancestor that one has never met. Autonomy is important because it ensures that the individual involved is actively involved in decisions that will affect them. Respect for autonomy should be taken seriously and highlighted above other principles because it enables people to be themselves, follow their dreams, and live by their preferred principle and values while they also allow others to do the same and be their unique selves (Ameriks, 2013).

We grow from nature and live autonomously with genes that are given to us by chance, rather than design (Gyngell *et al*, 2017). This makes it possible and acceptable for anyone who is autonomous and would like to edit their own genes somatically, to have the right to consent to their own genetic editing. However, when it comes to germline gene editing, this means that parents who consent to germline editing their unborn babies, undermine their future autonomy (Gyngell *et al*, 2017). Unborn children have no rational capacity or ability to make decisions and therefore all rational capacity is delegated to the parents, therefore unborn children are merely means to their parents' ends. Even if the parents may have consented to the germline gene editing with the intention of giving their child a better life, the child may feel betrayed in that the parents have extended their parental authority to their future generations and therefore depriving them of their autonomy.

The effects of new inventions and medical interventions can be minimized or avoided to some extent. When it comes to editing the germline of the future generations, the effects cannot be avoided as they will be embedded in their genome. To give the children an opportunity to exercise their autonomy, there are other gene editing techniques such as somatic gene editing that can be considered which can allow children of every generation to exercise their autonomy. This shows that there is just no need for parents to consent to editing the germline of their future generations while they can afford their children the right to make their own autonomous decisions. This means that children and generations whose germline would be edited will feel deprived of their dignity and their autonomy undermined by the parents. Therefore, the autonomy of children whose parents have consented to editing their germline has been undermined.

3.3 Conclusion

An unborn child is not autonomous because he/she cannot comprehend, process any information and cannot make decisions or communicate in any way. For this reason, parents are given the responsibility to make decisions for their children and can be easily treated as means to their parents desires. In the case where parents consent to editing the germline of their embryos, which they intend to carry full term and give birth to, then the future autonomy of the child and future generations should be considered. The human genome is the heritage to humanity because it determines who belongs to the human species and being part of the human species confers dignity (Raposo, 2019). Humans have reasoning capacities that results from our principles, values and opinions. This means that even the future generations will have their own desires and reasoning which may be against this. The potential parents cannot know what the desires of their future generations will be and therefore cannot make the best decisions for the child and future generations. This means that children and generations whose germline would be edited will feel deprived of their dignity and their autonomy undermined by the parents. Therefore, parental consent cannot be justified when it comes to germline gene editing because it affects future generation

Chapter 4: Shared liability between parents and scientists involved in consenting to germline gene editing

4.1 Introduction

This chapter normatively explores the third objective of this research: To argue that there should be shared liability for consenting to germline gene editing between parents who consent to germline gene editing of their unborn babies and the scientists involved. First, I will share information on how Dr. He Jiankui was held liable for medical malpractice after editing the germline of twin babies. I explain medical malpractice and medical liability, followed by the current legal status on performing germline gene editing and proxy decision makers for the non-autonomous. I then use the nasciturus fiction which was used in the case where a child who was born with brain damage as a result of an accident that his mother was involved in while he was still a foetus, to show that parents who have consented to germline gene editing should be held liable for consenting to germline gene editing.

4.2.1 Medical malpractice and liability

Dr. Jiankui and his postdoctoral fellows obtained consent from a couple to edit the germline of their embryos to make their offspring resistant to HIV (Shaw, 2020). On 30 December 2019, Dr He Jiankui was sentenced to 3 years in prison for medical malpractice after he used the CRISPR-Cas9 technology to edit the germline of embryos which were carried till full term and born (Cyranoski, 2020). The couple was not punished for consenting to editing the germline of their children and future generations illegally (Cyranoski, 2020). Dr. Jiankui tried to justify his actions by claiming that he wanted to spare children of HIV-positive parents from the stigma that the parents are suffering by drastically reducing their risk of ever being infected with HIV (Shaw, 2020). This forced professionals in the scientific field to admit the uncomfortable truth

that regulations and the scientific community's efforts to control CRISPR's powers are not working (Shaw, 2020).

Medical malpractice is a legal cause of action that takes place when deviation of healthcare standards as a result of healthcare professionals omitting or neglecting their duty to a patient, thereby causes harm to the patient (Sloan and Chepke, 2008). An example of medical malpractice is when a doctor performs an unnecessary surgery and it results in an injury or damage or the standards of care not being met (Sloan and Chepke, 2008). The negligence referred to in medical malpractice might arise from errors in diagnosis, treatment, aftercare or health management (Sloan and Chepke, 2008). When parents consent to editing the germline of their future children, the scientists involved would deviate from their profession by violating medical regulations since germline gene editing abuses the rights to psychological and bodily integrity of future generations and germline gene editing is illegal in many countries including in South Africa. The parents would be illegally permitting the scientists to edit the germline of their future children and generations.

Dr Jiankui illegally performed germline gene editing on the embryos of the couple and the gene editing caused the children to have mosaic cells but he was not held liable for this result (Cryanoski, 2020). Medical liability is legal accountability for damage inflicted to a patient by a health service provider (Mello *et al*, 2014). Parental liability is when parents are held liable for damages caused by their children (Van der Bijl, 2018). Parental liability is not enforced in South Africa and it does not apply to this discussion. Shared liability in this discussion, means that the scientists and the consenting parents are both liable for their actions and it does not mean that the liability is split equally between parents and scientists. When parents consent to editing the germline of their future children even after possible outcomes have been disclosed to them, the scientists involved cannot be held liable just like Dr. Jiankui

was not held liable for his procedure causing mosaic cells. This leaves the autonomy of future generations in the hands of the parents and the parents consenting to a genetic editing that will affect the future children and generations without their consent.

4.2.2 Proxy decision makers and autonomy

In a situation where parents consented to editing the germline of their future children and generations, the parents cannot demand liability to damages from the scientist because they are the ones who consented to the gene editing and the possible outcomes have been disclosed to them (Mello *et al*, 2014). This is only if the scientist did not omit some information or falsify some information (Mello *et al*, 2014). In the case where a patient is not autonomous, the proxy decision maker which can be a spouse, care giver, the courts or parent makes medical decisions for the individual based on his or her best interest (Parsapoor *et al*, 2014). However, the supremacy of the best interest of the child does not apply the law when it comes to unborn babies because in South Africa the constitutional rights only apply to children who are born alive and not to foetuses and embryos (Strode, 2011). This therefore makes it possible for parents to consent to editing the germline of their unborn babies which can affect their future generations and not be held liable for that decision because an unborn child is not a legal entity.

Research shows that decisions made by healthcare proxy decision makers, as well as parents are not always reliable because they are usually based on the personal beliefs of the proxy decision maker or the healthcare provider and therefore they are rife with consequential variability and uncertainty (Krick, *et al*, 2020). These decisions are most likely to contradict the desires or best interest of the patient, thereby depriving the patient of his/her autonomous decision (Krick, *et al*, 2020). You will recall that in chapter 2, I highlighted harms which my occur from parents consenting to germline gene editing and these harms include psychological

and bodily harm. Section (12)(2) of the Bill of Rights of South Africa states that “Everyone has the right to bodily and psychological integrity”. This shows that the principle for respect for autonomy is coded in the constitution of South Africa. When parents consent to editing the germline of their future children, they are depriving them of their future autonomous rights by not considering their bodily and psychological integrity. Therefore, parents who consent to editing the germline of their future children could be making a decision that contradicts the desires of their children and future generation, thereby depriving them of their autonomous right.

4.2.3 The Nasciturus Fiction

The nasciturus fiction is derived from Roman law and it states that “an unborn child, if subsequently born alive, will acquire all the rights of the born children whenever its own advantage is concerned” (Mankga, 2008). According to section 11 of the constitution of South Africa, everyone’s right to life is guaranteed. However, a foetus or embryo is neither a legal subject, nor a bearer of rights and duties enforceable in a court of law (Smit, 2015). The high court, in the *Christian Lawyers Association vs Minister of Health and Others (2005)* case ruled that the word ‘everyone’ in section 11 does not apply to unborn babies, since they do not have legal personality under our Bill of Right (Smit, 2015).

In the case between the RAF (Road Accident Fund) and Mxolisi, where a child who was born with brain damage as a result of an accident that his mother was involved in while he was still a foetus, the nasciturus fiction was applied to argue that the child can take action against RAF (Road Accident Fund) (Mankga, 2008). The case went in favour of the child and the child was compensated for the damages. This means that although there is no charge for the nasciturus fiction in South Africa a child can take legal action against those who caused harms to him/her while he/she was still a foetus once he/she becomes a legal entity, which is when the child is born and born alive (Mankga, 2008). We have established from chapter 2 and 3 that parents who consent to editing the germline if their future children are exposing them to harms such as

physical harm and psychological harm. Section (12)(2) of the Bill of Rights of South Africa states that “Everyone has the right to bodily and psychological integrity”. This shows that the principle for respect for autonomy is coded in the constitution of South Africa. When parents consent to editing the germline of their future children, they are depriving them of their future autonomous rights by not considering their bodily and psychological integrity. This means that, using the nasciturus fiction, future children whose parents have consented to editing their germline can take legal action against their parents for consenting to germline gene editing and thereby disregarding their rights to bodily and psychological integrity and depriving them of their autonomous rights.

Drawing from section 57 (1) (a) of the National Health Act, which states that a person may not manipulate any genetic material, including genetic material of human gametes, zygotes or embryos (National Health Act, 2003), parents should be held liable should they consent to an illegal practice in South Africa. The nasciturus fiction was used to take action against the RAF, the fiction can also be used to take action against the parents who consent to editing their childrens’ genes while they were still unborn whether the gene editing is successful or not. According to section 150 and 154 of the Children’s Act, it should be ensured that children are protected from harm and danger and section 9 states that the child’s best interest is of paramount importance (Children’s Act, 2005). Using these sections of the Children’s Act, parents who consent to editing the germline of their future children can be held liable because they are abusing the childrens right to psychological and bodily integrity and depriving them of their future autonomy. This is also disregarding their best interest because the future psychological and physical well-being is disregarded.

4.2.4 Using ethics to justify shared liability between parents and scientists

One justification for making parents liable for consenting to editing the germline of their future generations is the notion of justice for the children and future generations (Krick, *et al*, 2020). If a parent knows that they will be held liable for consenting to editing the germline of their future children and generations, then they will avoid making decisions that will potentially harm their future children and generations. Ethics can be associated with liability in a normative or empirical way (Flight and Pardew, 2017). Normatively, liability is ethical when responsibility of the harm caused is placed on the parents consenting to editing the germline of their future children (Flight and Pardew, 2017). Liability is fundamentally about assigning responsibility; hence the parents should take responsibility of their actions. Therefore, in the case where parents consent to editing the germline of their future children, the parents should be held liable for exposing their children and future generations to harm and not seeking the best interest of their children and future generations. Empirically, Liability is ethical when it aligns with the utilitarian framework, which is if it maximizes social utility. The consequences of parents consenting to germline gene editing may vary from unintended beneficial to unintended burdening mutations and the children as well as future generations contesting for their autonomy when they are born upon discovering the germline gene editing that has been done to them when they are told. When generation upon generation have to live with burdening mutations that were caused by germline gene editing which great parent have consented to, physical, psychological and social harms are most likely to take place as a result and this does not maximise social utility. The parents have violated their future children's rights to psychological and bodily integrity, this is unlawful and it is ethically justifiable to have shared liability between consenting parents and the scientists involved in germline gene editing.

4.2.5 Counter arguments and response

There are not adequate articles discussing parental liability due to consenting to gene editing, therefore I will use the constitution of South Africa and LaFollette's idea of licencing parents to infer what they would say regarding parental liability regarding germline gene editing. I will start off by using the constitution of South Africa as the first counter argument. Currently, the Section 12(2)(a) states that, "Everyone has the right to bodily integrity, which includes the right to do as they wish with their bodies (South African Constitution, 1996). This means that the South African constitution does not support holding parents liable for consenting to germline gene editing because holding parents liable for consenting to editing the germline of their future children implies that the embryo has rights which are superior to those of the woman carrying it and providing the necessities required for its existence. Currently, under SA constitutional right to life, the embryo is not a legal person, therefore the pregnant woman can consent to treatment that may affect her future child. Parents who consent to germline gene editing their future children intend to promote the health and well-being of their future children and they do so because they believe that they have a duty to ensure that their children live the best life.

LaFollette argues that if an act requires certain measurable expertise to perform and has a potential to harm others, then this act must be regulated by the government. For example, if installing electric wires requires measurable expertise and has a potential to harm other, then installing electric wires must be regulated by the government. This is the reason why we have licencing programs for those who want to practice medicine, driving a car, manufacture some foods etc. (LaFollette, 2010). According to LaFollette, since children can grow up to become discontent, unhappy and suffer from social disorders as a result of parental abuse, these standards should be applied to parenting to reduce a lot of irresponsible parents from having kids who are likely to become adults who are neither well-adjusted nor happy (LaFollette, 2010). These kinds of harm can lead children to different negative social consequences

(LaFollette, 2010). LaFollette says that parents who expose their children to such kinds of harm should be held liable and the children be taken away from them (LaFollette, 2010). This means that LaFollette would be in support of parents being held liable for consenting to editing the germline of their future children because a parent who consent to editing the germline of their children would be abusing the future children's right to psychological and bodily harm and disregarding their autonomous rights.

I believe parents have the right to raise their children the way they see fit as long as they do not violate the children's rights. In a situation where parents consent to editing the germline of their future children before they are born it is understandable that at that time the foetus does not have rights, however, if the parents are intending to give birth to the child, they should consider the fact that the child will grow up and become autonomous one day. This means that medical treatments that will affect the rest of the child's life and future generations should be carefully analysed.

A responsible and caring parent would ensure that their children have an open future whereby they have options to become whatever they want. This implies that parents who do not take care of their children should be liable because Chapter 3 (18)(a) of the Children's Act 38 of 2005 state that parents have a responsibility to care for the child (Children's Act 39, 2002). Parents who make permanent decisions such as germline gene editing for their future children and generations are closing some options for their children and therefore denying their children of an open future. When parents deny their children an open future, they are violating the autonomy of the adult that the child and future generations will one day become. Therefore, parents who consent to editing the germline of their future generations are depriving them of this right to having an open future so that they can have options to decide what they want to choose. The parents are abusing their parental rights to give or refuse consent in respect of the

child as stipulated in Section 18(3)(c) of the Children's Act (Children's Act 39, 2002). If parents who abuse their children are being held liable according to the law, then surely, parents who consent to editing the germline of their future children should also be held liable for abusing their parental rights to give or refuse consent in respect to the child and abusing the future generations rights to psychological and bodily harm.

4.3 Conclusion

Parents are proxy decision makers to their children, however, the law does not say that parents are proxy decision makers to their unborn baby because they do not have legal status and a human right to life. Therefore, parents can make decisions and consent to medical treatments that can affect the future baby. Research shows that decisions made by healthcare proxy decision makers, including parents are most likely to not be in the best interest or desire of the patient because the proxy decision makers usually have desires, interests or beliefs that are different from those of the patient (Krick, *et al*, 2020). Therefore, once born, children can become victims of the decisions that were made by their parents.

The nasciturus fiction states that “an unborn child, if subsequently born alive, will acquire all the rights of the born children whenever its own advantage is concerned” (Ten Haaf, 2017). When parents consent to editing the germline of their future children, they are depriving them of their future autonomous rights by not considering their bodily and psychological integrity. This nasciturus fiction has been successfully used in the courts of law all over the world. This means that parents can also be held liable for consenting to germline gene editing and thereby disregarding their rights to bodily and psychological integrity and depriving them of their autonomous rights. . If a parent knows that they will be held liable for consenting to editing the germline of their children, then they will avoid making decisions that will expose their children and future generation to harm and deprive them of their autonomy. A rule to hold parents liable for consenting to germline gene editing is ethical because it also places

responsibility on the parents that consented to a genetic editing that will affect their children's genome and therefore their future generations as well.

Chapter 5: Conclusion

The aim of this research is to defend the thesis that morally justified parental consent to germline gene editing on behalf of future children is not possible and parents should be held equally liable as the scientists involved. Each objective of this research has been discussed in the preceding chapters to ultimately accomplish the aim of the research.

In chapter two I discussed the possible benefits and harms of parents consenting to germline gene editing and then weighed them against each other. I argued that the harms of germline gene editing far outweighs the benefits because the harms include death, genetic disorders, susceptibility to other genetic diseases and also eugenics. I also argued that although it is the parents' responsibility to ensure that their children live the best life possible, they should not extend that reason into altering the germline of their future children because the definition of a best life is different for every person. The action that can maximise utility would be to allow the child to be born and afford the child the right to choose if they want to be genetically edited somatically instead of editing the germline. This way, the child and future generations are not genetically modified without their consent and any harms that may occur will be incurred by the consenting child alone and not inherited by their generations. There are other gene editing therapies such as somatic gene editing that can be explored on oneself without affecting future generation. This way, should the gene editing turn out to be pathogenic in future, it does not affect the future generations who will still be born in future and then the principle of utility is followed in that pain or harm is minimised for the greater number of the coming generations.

In chapter three, I used Kant's categorical imperative of treating people as ends in themselves (respect for persons) to show that parental autonomy is not justified when it comes to germline gene editing because it affects future generations. The human genome is an intrinsic feature shared by all human beings just by them being part of the human race. To enhance the physical and mental capabilities of future generations would mean to create a new type of human species that have extraordinary/ unhuman abilities and appearances. Human beings grow up to have different beliefs and reasoning capacities that results from our principles, values and opinions. Unborn children have no rational capacity or ability to make decisions and therefore all rational capacity is delegated to the parents, therefore unborn children are merely means to their parents' ends. The principle of respect for persons requires that we respect these different opinions, beliefs principles etc. A foetus or an under-age child is not autonomous because they are not able to comprehend some information and therefore not able to give proper informed consent, their autonomy is delegated to their parents. This means that parents are given the responsibility to make decisions for their children and the children can be easily treated as means to their parent's desires. However, children grow up to become rational beings and will be able to take decisions for themselves one day. A child whose germline has been edited will not be able to practice their autonomy with regards to gene editing because their genes would have already been edited. The results of the germline gene editing will affect future generations who will live with those edited genes even long after the parents who consented to editing their germlines have passed away. This is unethical as it deprived future generations of their autonomy and therefore robs them of their human dignity of their choice and natural human genome. For this reason, parental autonomy is not justified when it comes to germline gene editing because it affects future generations.

In chapter four, I argue that there should be shared liability between parents who consent to germline gene editing and the scientists involved. Healthcare professional can by law be held

liable for omission or negligently deviating from standards in their profession thereby causing injury to patients. Healthcare professionals have a responsibility to act as a medical proxy decision maker when a decision needs to be made quickly for a patient who is not autonomous, and when next of kin or family are not around and there is no time to approach the courts for a decision to be made. When a child is still a foetus, he/she has no legal rights so the parents can legally make medical decisions that can affect the foetus, for example, abortion. But once a child is born and born alive, he/she assumes the right of any other individual. The nasciturus fiction states that “an unborn child, if subsequently born alive, will acquire all the rights of the born children whenever its own advantage is concerned.” Section (12)(2) of the Bill of Rights of South Africa states that “Everyone has the right to bodily and psychological integrity”. In Chapter 2, we discussed the bodily and psychological harms that can occur when parents consent to germline gene editing. When parents consent to editing the germline of their future children, they are depriving them of their future autonomous rights by not considering their bodily and psychological integrity. Therefore if a child is born with injuries or damages that were caused by parents consenting to germline gene editing, they should be able to lay charges on the parents. There should be shared liability for consenting to germline gene editing between parents who consent to germline gene editing of their unborn babies and the scientists involved.

The possible harms of germline gene editing far outweigh the benefits and therefore it makes it ethically unjustifiable for parents to consent to editing the germline of their future generations because there will be more harm caused than benefit, making this against the utilitarian ethical theory of the greatest good for the greatest number. The human genome is what defines us as humans, humans are also different from other living species in that we have reasoning capacity which enables us to make rational decisions. Once the human genome is altered, then future generations will be deprived of their own human dignity and their autonomous right. Embryo and fetuses do not have constitutional right because they are not legal entities. However, these

embryos will one day be born and grow up to be autonomous individuals with their own beliefs, ideas and dream and will therefore be in a position to make their own informed consent. This means that morally justified parental consent to germline gene editing on behalf of future children is not possible and parents should be held equally liable as the scientists involved.

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