

A Reformed Christian Bioethical Response to Genetic Modification for Therapeutic use and Human Enhancement

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To God, in whose image and identity we were created, without whom nothing is possible, yet in Him everything is possible.

ABSTRACT

Humans are creative beings who constantly endeavor to improve and overcome limitations and challenges. The last century saw an unprecedented number of technological advancements across all areas of life including biotechnology. Through biotechnological advancements humanity can edit and modify the building blocks of life, which provides the ability not only to heal genetic diseases but have the potential to enhance humanity. Prevention of disease can be achieved through gene editing, but this opens the door to germline gene editing, which in turn can lead to human enhancement. Human enhancement is not necessarily negative, but it carries an existential risk.

The recent advancements in the form of gene editing tools such as CRISPR cas9 and gene sequencing makes it possible to edit genes in a short time frame. Although advancements are progressing at a staggering rate, ethical discussions relating to the use or abuse of the technology are lagging behind. This is especially true when it comes to Christian bioethics. Discussions around transhumanism and posthumanism is essential, especially from the Christian perspective.

A clear gap exists between Christian bioethical views and secular ethical views. The main reason for this is the differing perspectives on human dignity. Secular bioethicists are of the opinion that human dignity should not form part of bioethical debates as it slows down the adoption of technology. From a Christian bioethical perspective, human dignity is at the core of the debate due to the belief that humanity was created in the image of God.

The concept of *Imago Dei* or created in the image of God is at the forefront of the Christian bioethical debate. Although there are many interpretations of *Imago Dei*, "*Imago Dei* as human identity" provides a holistic foundation for Christian bioethicists to work from. Viewing bioethical challenges from this perspective can provide guidance relating to challenging questions on human dignity, human rights, eugenics, and the use of the technology for therapeutic use and human enhancement.

OPSOMMING

Die mens is 'n kreatiewe wese wat streef na vooruitgang om uitdagings te oorkom. Gedurende die laaste eeu was daar ongekende tegnologiese vooruitgang in alle areas van die lewe insluitend biotegnologie. Deur dié tegnologie het die mens die vermoë om die boustene van die lewe te kan verander, wat kan lei tot genesing van genetiese siektes en ook die potensiaal het om die mens as wese te verbeter. Die voorkoming van siektes is 'n fokuspunt, maar kan net gedoen word deur die genoom te verander. Deur dié verandering word die deur oopgemaak vir menslike verbetering, wat nie noodwendig negatief is nie, maar wat wel eksistensiële risiko's dra.

Vooruitgang in die vorm van genetiese manipulasie deur die CRISPR cas9-tegnologie asook genetiese volgordebepaling maak dit moontlik om genetiese materiaal in 'n kort tydperk te verander. Alhoewel biotegnologie vinnig ontwikkel, is die etiese debatte nie so ver gevorderd nie. Dit blyk veral dat Christelike bioëtik nie deelneem aan die huidige debatte nie. Gesprekke rondom transhumanisme en posthumanisme is uiters belangrik, veral vanuit 'n Christelike perspektief.

Daar blyk 'n gaping te wees tussen Christelike bioëtik en die sekulêre bioëtik. Die rede hiervoor is menswaardigheid wat sentraal is aan Christelike bioëtiese gesprekke. Die sekulêre bioëtiese gemeenskap is van mening dat menswaardigheid uit die debat gehaal moet word omdat dit die toepassing van die tegnologie verhinder. Die Christelike perspektief is dat menswaardigheid sentraal is aan die debat as gevolg van die feit dat die mens geskape is in/na die beeld van God.

Die konsep van *Imago Dei*, geskape in God se beeld, vorm deel van die Christelike bioëtiese basis. Alhoewel daar baie interpretasies van *Imago Dei* is, is "*Imago Dei* as menslike identiteit" 'n holistiese siening wat kan help om bioëtiese vrae te beantwoord. Voorbeelde hiervan sluit in die gebruik van die tegnologie wat betref menswaardigheid, menseregte en eugenetika asook vir terapeutiese doeleindes en menslike verbetering.

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CHAPTER 1: INTRODUCTION

In this chapter, the researcher will cover introductory matters, including a description of the background, problem statement, aim and objectives of the study, the introduction of key terminology and major aspects to be investigated⁷, a description of the research methodology to be employed and an overview of the structure of the study.

1.1. TITLE AND KEYWORDS

1.1.1. TITLE

A Reformed Christian Bioethical Response to Genetic Modification for Therapeutic use and Human Enhancement.

1.1.2. KEYWORDS

Keywords: Theological bioethics, bioethics, genetic manipulation, germline modification, human enhancement, post human, gene modification, gene editing.

Sleutel Woorde: Teologiese bio-etiek, bio-etiek, genetiese manipulasie, genetiese modifikasie

1.2. BACKGROUND AND PROBLEM STATEMENT

1.2.1. BACKGROUND

As creative beings we are constantly endeavouring to improve and overcome challenges we face. History is a good indicator that as the human race we are excellent at finding solutions to problems we face. This is true in all aspects of life, which includes the medical sphere. One of the problems scientists are tirelessly working on is finding cures for diseases caused by what is perceived as genetic defects.

Biotechnology, focusing on genetic editing and modification, is advancing at an unprecedented pace. A few years ago research projects focusing on genetic modification took many months, if not years, to complete. The reason for this was due to the availability and cost of genetically modified mice and test subjects. In contrast to this, today a study can take a matter of weeks (Ledford, 2015). There are a few catalysts that propel these advancements, which include the progress in DNA sequencing (Bamanga, *et al* 2018:110); rapid advancements in synthetic bio-engineering tools such as CRISPR cas9 (Doudna & Sternberg, 2017:15) as well as general bio-informatic advancements that assist with the analysis process (D'Agostino, *et al.* 2018:79; Mallawaarachchi, 2017). Another important reason for the rapid advancement relates to a lower cost of research. The reduction of cost and the realisation of the potential impact of this technology are driving an appetite for investment from pharmaceutical companies (Doudna & Sternberg, 2017:15). Das (2017) highlighted in a recent study, conducted by Forbes that the CRISPR cas9 industry will be worth twenty five billion US Dollars by 2030.

The reality is that synthetic biology focusing on the modification of DNA is rapidly advancing and ethical debates whether to alter human DNA are lagging behind. This is especially true from a Reformed theological perspective. Although non-religious ethical debates are in process, it is vital to understand why the religious community should engage in this discussion. Tollefsen (2011:49) is of the opinion that there are gaps between secular bioethics and specifically Christian bio-ethics. One of these relates to human dignity. While Christian bio-ethicists incorporates human dignity in the discussion, secular ethicists tend to shy away from this. However, the distinction between secular and Christian bio-ethicists are much more complex. Cole-Turner (2008:2) points to the fact that most human beings are religious in some way or form and religion brings about a different dimension to the debate. This is achieved by drawing on the rich traditions of religion and beliefs which add a moral complexity in a non-political way. Engaging in this debate from a religious perspective forces us to look at the ethical problem in a different way. It is for this precise reason that religious ethicists are invited to add their voice to scientific debates.

In 2015 Chinese researchers published research claiming they were able to successfully edit human DNA in non-viable embryos (Liang, *et al.* 2015: 363). Chilling news broke at the end of November 2018 when it was announced that the first genetically modified twins were born in China (Sherman, 2018; Regan, *et al.* 2018). This in itself raised major ethical questions with regard to the alteration of human DNA. According to the scientist concerned, the twins are theoretically immune against HIV, although an oversight from the research team was that the individuals would have less resistance against Influenza (Regan, *et al.* 2018). And while the specific experiment raises ethical concerns with regard to the human dignity of the twins, there are other unanswered questions that need to be discussed.

1.2.2. PROBLEM STATEMENT

Philosophically, especially from a Reformed theological perspective, the argument is made that humanity is playing God (Kotze, 2018:2; Cameron & DeBaets, 2008:98). While altering the source code of the human genome might elicit this response, the actual question reaches much deeper. Ethically, it would be wrong to look away and not assist someone in need if we have the means to assist an individual. Not many individuals will look away while a child is suffocating. We will rush to the aid of the child as soon as possible, and in fact some might place themselves in danger to save the child. Theoretically, if a child has sickle cell disease, which affects the transportation of oxygen in the blood to vital organs, he/she is in essence suffocating. Should we look the other way if we have the technology to alter their DNA? Should we not use the technology as therapy to assist those in need?

The theological argument, conviction and confession exists that we are created in the image of God and part of Jesus' incarnation was to show us how God would like us to act, which included healing of the sick (Waters, 2012:179). A good example of this, is Francis Collins, the director of the U.S. Human Genome Project from 1992 to 2008, who stated that the project is founded in Jesus' ministry of healing, calling it a "matter of discipleship, a natural extension of our commitment to heal the sick" (Verhey, 2003:159). This might point to the possibility that if we are able to heal someone through specific technology, it becomes our responsibility to use the technology for healing purposes.

In fact, the argument might come to the fore that it would be unethical not to use the technology to treat a specific disease.

Once we established that we have the responsibility to provide this therapy through altering the DNA, we can focus on the next question: “What is constituted as ethical therapeutic human gene modification and where does human enhancement start?” This is the fundamental question and the main topic for the study.

In an attempt to clarify this grey line, there needs to be an in-depth review and understanding of the different type of cells where the modification of genetic code can be done and the impact on this both on the humanity from an ethical perspective. Waters (2012:176) indicates that there is a more tolerable outlook with regards to gene therapies applied to the somatic cell structure, while changes affecting the germ line is frowned upon. This is also the official view of the World Council of Churches (Granberg-Michaelson, 1989).

When dealing with the ethical issues, the distinction between germ line and somatic gene therapy is of particular importance - germ line therapy, by affecting the reproductive cells, impacts on the individual and his/her children, thereby affecting the gene pool. Somatic gene therapy affects only the cells of an individual. However, the risks of somatic therapy includes that the cells introduced into the body can recombine with other viruses and infect the germ cells, and accordingly, both somatic and germ line therapy leads to a greater concentration of a mutated gene in the gene pool, allowing patients both survival and reproduction of the flawed gene (Chadwick, 2001:189; Green, 2007:55). This being said, it is believed that if we allow the DNA in germline cells to be altered we stand a chance of eradicating some genetic diseases completely.

A vital point that should also be discussed is the impact of this technology on the human race as a whole. Depending on the view with regards to the right to health care, there is a possibility that DNA modification technology will only be available to those who can afford it. This in itself is an ethical challenge – not only could this cause genetic diseases to be associated to a specific “class”, but it also opens the door for the rich to engineer a superior human race with enhanced intellectual and physical abilities. (Cahill, 2008:145; Kotze, 2013:139; Green, 2007:135)

In order to move towards a discussion with regard to finding resolutions to the questions raised, attention should be given to specific topics during the study. From a Reformed theological perspective, we need to understand our relationship with God with regard to *Imago Dei* and being co-creators with God. Cerry (2017:220) highlights that the confession of *Imago Dei* expresses our foundational relationship with God and this has consequences on all areas of life, which includes bio-ethics. Rheeder (2014:9) adds to this and is of the opinion that the concept of *Imago Dei and Creatio Continua* helps us to comprehend new technologies. A doctrinal investigation should be critically conducted in relation to how we should respond to the modification of human DNA. It also warrants an anthropological discussion from a theological point of view. It is vital to come to an understanding of what it means to be human and discuss the topic of human dignity. To adequately articulate and rationalise the main question of the research, a good understanding and definition should be attained with regard to human enhancement. This can only be achieved if both arguments for and against human enhancement is truthfully represented and a baseline definition can be established.

1.2.3. RESEARCH QUESTION

The research question of this study is: From a Reformed theological perspective, what is accepted as ethical therapeutic genetic modification and where does human enhancement start? Answers to the following sub questions must be addressed if the research question is to be successfully answered:

- What is genetic modification and its history?
- What is considered therapeutic gene modification and what is defined as human enhancement?
- What are the rational ethical arguments for and against the use of gene modification for the purposes of therapy and human enhancement?
- What Reformed doctrinal principles can be derived from Scripture that will assist in the ethical response of gene modification during therapy and/or human enhancement?

1.3. AIM AND OBJECTIVES

1.3.1. AIM

The aim of the study is to evaluate the ethical responses to gene modification and create theological-ethical guidelines for its therapeutic use and/or human enhancement.

1.3.2. OBJECTIVES

The objectives of the research are:

- To investigate and describe what constitutes as gene modification.
- To investigate and describe what is therapeutic treatment and human enhancement through gene modification.
- To describe and ethically assess the arguments for and against gene modification used for treatment and/or human enhancement.
- To develop an ethical response when dealing with gene modification during therapeutic use and/or human enhancement from a Reformed perspective.

1.4. CENTRAL THEORETICAL ARGUMENT

The premise is that, from a Reformed perspective, genetic modification is acceptable to use as a form of treatment of disease. Enhancing humanity through genetic modification is the greater ethical challenge, however necessary to prevent disease. Reformed theologians confess that human beings are made in the image of God, which forms the foundation of human dignity, thus to withhold any form of treatment and/or enhancement will question a person's human dignity.

1.5. RESEARCH METHODOLOGY

The research will be conducted from a Reformed theological perspective whereby the Bible, inspired by the Holy Spirit (2 Timothy 3:16), is accepted as authoritative (De Klerk & van Rensburg, 2005: 3, 4; De Klerk & De Wet, 2013:300).

In an attempt to answer the posed research questions, a literary research methodology will be conducted and broken down as follows:

- In order to effectively study the origins for genetic modification, a literature analysis will be conducted;
- A literature study will be conducted to ascertain what is currently defined as therapeutic treatment through genetic modification and what will be considered human enhancement;
- To evaluate and study the arguments for and against genetic modification, a literature analysis will be conducted to determine the most rational argument for or against genetic modification during treatment and/or human enhancement;
- An ethical response for dealing with gene modification during therapeutic use and/or human enhancement from a Reformed perspective will be investigated through a literature study.

The literary study will be completed by drawing on information from various disciplines from a Reformed perspective.

1.6. ETHICAL ASPECTS

The researcher will adhere to the specific ethical requirements as set out by North-West University's Health and Research Ethics Committee. The research will be conducted in the form of a literary study using articles, text books, the Bible and other authoritative sources available to the public domain. Due to the nature of the study and the fact that there will be no human participants the ethical risk level is minimal. The Bible will be accepted as the authoritative Word of God and used within its context (De Klerk & van Rensburg, 2005:3,4,7; De Klerk & De Wet, 2013:300; De Bruyn, 2008:2)

1.7. PROVISIONAL CHAPTER CLASSIFICATION

- **Chapter 1** will cover introductory matters, which includes a description of the background, problem statement, aim and objectives of the study. The chapter will also contain the introduction of key terminology and major aspects to be

investigated, and includes a description of the research methodology to be employed as well as an overview of the structure of the study.

- **Chapter 2** will be devoted to an overview and history of genetic modification. This chapter will explore the current state of technology available for genetic modification and will be conducted by means of literary research.
- **Chapter 3** will, by means of a literary study, attempt to define what is considered as treatment through genetic modification and determine what is human enhancement.
- **Chapter 4** will focus on the arguments for and against genetic modification, by means of a literature research into existing literature presented by the various disciplines within the neighbouring sciences, such as Theology, Anthropology and Sociology.
- **Chapter 5** will evaluate the notion that man is created in the image of God (Imago Dei) and co-creator with Him. This will form the basis of an ethical response with regards to genetic modification from a Reformed Theological perspective.
- **Chapter 6** will conclude with a summary, an explanation of the limitations experienced during the research, as well as recommendations for further research pertaining to the topic.

CHAPTER 2: THE BUILDING BLOCKS OF LIFE: FROM IDENTIFICATION TO EDITING

2.1. OVERVIEW

Chapter two provides an overview and history of genetic editing. Human genetics is a young scientific field with limited historical research. In fact, at the time of this study, many pioneers in this field are still alive (Harper, 2008:3). Although the focus of the research is not on the historical origin of human genetics, a historical review is warranted to fully understand both the evolution of technology, as well as the accompanying ethical arguments.

A focal point in this chapter is the development within the field of heredity that eventually led to the discovery of chromosomes and deoxyribonucleic acid, better known as DNA. Technological advancements led to the identification of the structure of DNA which in turn led to the understanding of how genetic material is passed on from one generation to the next. The Human Genome Project and how it came into existence, is explored as this was a catalyst for human genetic editing as well as bioethics. The second half of the chapter is devoted to current gene editing technologies available at the time of the research, such as TALENs¹ and CRISPR Cas9².

2.2. HISTORICAL OVERVIEW OF BIOLOGICAL INHERITANCE

Although Mendel is considered by some biologists and geneticists as the “father” of genetics it is vital to understand that even before Mendel there were observations made regarding inheritance (Schwarzback, *et al.* 2014:43). Herring (2006: 15) is of the belief that one of the earliest references showcasing a rudimentary understanding of heredity appears in the Bible. Genesis chapter 30: 25-43 tells the story of Jacob, who worked for Laban. After 14 years he wanted to return to his father in Canaan. Laban did not want Jacob to leave as God blessed Jacob and Laban became wealthy due

¹ Transcription activator-like effector nuclease, referring to a gene editing tool (Joung & Sander, 2013:49).

² Clustered regularly interspaced short palindromic repeats, a gene editing tool (Merriam-Webster, 2023).

to Jacob's hard work/ efforts. Laban asked Jacob what he would request as payment to stay. Jacob came up with a clever plan and advised Laban that he will separate all the speckled and spotted sheep from the rest (van Der Watt, *et al.* 2003:118). Through this separation Jacob's flock grew tremendously and he became wealthy. What is unclear is whether he understood hereditary principles. While not a definitive indication of an understanding of heredity, Herring (2006: 15) suggest that it may reflect a rudimentary understanding. This view is controversial as the text was not intended to explain hereditary, nor an understanding of how traits are passed down from one generation to the next.

The ancient Greeks were intensely interested in human reproduction, especially when it came to gender determination and familial likeness. Aristotle recognised in his own primitive way that both the male, through semen, and the female, through menstrual blood played a major role in the formation of an embryo. There are some ontological challenges to his philosophical arguments with regard to the formation of the embryo, but overall, he managed to identify the existence of a hereditary process and that traits are passed down from one generation to the next (Vinci & Robert, 2005:216).

Aristotle went as far as stating that a theory on reproduction can only be recognised if at least 8 different phenomena can be explained namely (Henry, 2006:428):

- Why offspring resemble their parents more than other of the same species?
- Why some offspring resemble the father while other in the same family resemble their mother?
- Offspring have more resemblance to their parents than their ancestors?
- Why offspring resemble their ancestors more than other individuals of the same species?
- Why males usually resemble their fathers while females resemble their mothers?
- Why males sometimes resemble their mothers and females their fathers?
- If offspring fail to resemble their father, mother or ancestors, why do they still resemble a specific species, in this case humans?

- Why are there instances where the individual's observable form fails to bear any resemblance to the species it is derived from?

Aristotle attempted to address these eight factors by means of his theory of inheritance (Henry, 2006:428). Another example of a basic understanding of heredity pre-Mendel can be seen in the rudimentary understanding of Shakespeare in his play *Titus Andronicus* (Herring, 2006:15; Harper, 2008:29). Shakespeare's plays provide information on how heredity was observed before modern science could explain the reasons therefore. His plays illustrate hereditary influences, especially when it came to physical characteristics between father and sons. We also find inherited personality traits, which shows an understanding that certain traits, whether physical or personality related, are passed from one generation to the next (Hook, 1987:147).

Regarding human genetics specifically, it is noteworthy that apart from normal biological inheritance, for instance hair colour, facial features and body posture, the inheritance of specific genetic diseases was observed and documented before the 19th century. Harper (2008:14) highlights that as early as 1645, Kenelm Digby documented the presence of a double thumb in a specific family that occurred throughout five subsequent generations. Likewise, Pierre Louis de Maupertuis observed the same in 1753. He documented four generations of a German family with Polydactyly, a condition which results in more than ten fingers or toes. Maupertuis went further to mathematically calculate that the inheritance was equally transmitted between the father and the mother. His calculations also indicated that Polydactyly³ had a frequency of 1 in 20 000, thus the possibility of this happening in more than three subsequent generations is 1 in 8 trillion. It is noteworthy to mention that these observations and calculations pre-dated modern science, but it helped to lay a foundation of understanding to build upon. The below table indicates the earliest documented observations of inheritance of genetic diseases before 1900:

Identified by	Date	Genetic disorder	Inheritance Pattern
Digby	1645	Double Thumb	Autosomal Dominant
Maupertuis	1753	Polydactyly	Autosomal Dominant

³ The condition of having more than the normal number of fingers or toes (Merriam-Webster, 2023).

Martin	1809	Progressive Blindness	Autosomal Dominant
Huntington	1872	Huntington's disease	Autosomal Dominant
Machin	1732	Ichthyosis hystrix ⁴	Autosomal Dominant
Wafer	1699	Albinism	Autosomal Recessive
Wilde	1853	Congenital Deafness	Autosomal Recessive
Adams	1814	Congenital Cataract	Autosomal Recessive
Dalton	1798	Colour Blindness	X-Chromosome Linked
Otto	1803	Haemophilia ⁵	X-Chromosome Linked
Meryon	1852	Duchenne Muscular Dystrophy ⁶	X-Chromosome Linked
Darwin	1890	Hereditary hypo-hidrotic ectodermal dysplasia ⁷	X-Chromosome Linked

Table 2.1: Genetic disorder and inheritance pattern

The rise in the interest in human anatomy, especially with the identification of the gametes, and the invention of the microscope in the 17th century saw increased focus in heredity. William Harvey led the charge in this area and extensively studied the chicken egg as well as the egg of other species (Harper, 2008: 30). Microscopic studies on animals and plants assisted with the understanding of heredity, especially related to plants. One of the main discoveries were the male organs in plants, which, in turn increased the interest in scientific plant breeding. It is against this backdrop Mendel started with his research (Harper, 2008:30).

While observations made during this period is important as it led to further investigation and scientific discovery, the reality is that scientific philosophy related to genetic heredity was frowned upon (Harper, 2008:31). This was a period during which evolution and church doctrines seemed to contradict each other and heredity was seen

⁴ A rare hereditary disease characterized by the formation of brown, verrucose, and often linear lesions of the skin (Merriam-Webster, 2023).

⁵ A rare blood disease affecting the blood clotting mechanism of the human body (Merriam-Webster, 2023).

⁶ A muscle disease characterised by muscle weakness (Merriam-Webster, 2023).

⁷ A group of diseases derived from abnormalities of the skin, nails or hair (Reyes-Real, *et al.* 2018:965).

as part of the evolutionary process. During the Enlightenment in the second half of the 18th century, significant progress in the understanding of heredity was developed. Harper (2008:32) makes the statement that it was only when science was allowed to think independently from the church and politics that real progress was made. He added that it was only when scientists saw life as a whole and that life changed over the course of time that there was a real need to understand how certain traits were inherited from one generation to the next. This thinking brought about two central questions, namely: how species change, and how they remain constant. The second question relates directly to heredity. We have to understand that insight into this question was driven by the theory of evolution. A discussion regarding the evolution and theology debate falls outside the scope of this chapter, and will therefore not be discussed. It is, however, important to acknowledge that without the scientific questions about the origin of life, genetics as we know it today would not have existed. In fact, there is more evidence that religion and science do not contradict each other but complement each other (McGrath, 2010:2).

Several scientists played a role in laying the foundation of genetics and heredity as we know it today. Most of the studies during that period were centred upon the theory of evolution (Harper, 2008:33).

- During this period Mauperius (1753) developed his “concept of heritable mutations”. He theorised that there is equal contribution from the father and the mother regarding inheritance. Mauperius was a mathematical and scientific philosopher and, apart from his identification and report on the inheritance of polydactyly, he theorised that both parents played a role in the process of inheritance. His view was similar to the view Charles Darwin and held that heredity was dependent on different particles from different parts of the body that was responsible for inherited characteristics (Harper, 2008:34).
- Erasmus Darwin, the grandfather of Charles Darwin, was a physician who during 1794 proposed the progressive evolution of life from primordial organisms. Darwin focused on a wide range of topics which included the evolution of plants and animals. Harper (2008:36) indicated that although he was a respected physician, his work did not draw much attention, although he

must have had influence on the thought processes of his grandchildren who undoubtedly made an impact on how we see the world today (Kormondy, 2011:70).

- Lamarck, in 1809, alluded to progressive evolution based upon acquired characteristics. Lamarck's theory on heredity was specific, and although both Lamarck and Erasmus Darwin published their work during the same period, it seems they were not aware of each other's work. Lamarck held the view that certain characteristics are inherited and that this is the basis of evolutionary change (Harper, 2008: 36; Burkhardt, 2013:793).
- Charles Darwin, the grandson of Erasmus Darwin, took this theory one step further with his work on evolution by natural selection. *On the origin of the species*, outlining Darwin's view on evolution, was published during 1859. Although Darwin was reluctant to publish his work due to the reaction by the public, church and political institutions, the publication re-energised the thought process on heredity. His view on heredity was published in 1868 and outlined his hypothesis of pangenesis which implied that particles from various organs and body areas are the driver behind heredity (Harper, 2008:38; Johnson, 2019:50; Streeck, 2018:663).
- Francis Galton, Charles Darwin's cousin and another grandson of Erasmus Darwin, made strides in his law of ancestral inheritance during 1883. His work is known for the quantitative variations within populations (Bulmer, 2003:238). Overall, his research included not only theory but also quantitative measurements that supported his hypothesis (Bulmer, 2003:209). Various studies contributed to the development of genetics, especially his work on twins, finger prints, the analysis of hereditary variations such as height and intelligence (Harper, 2008:65).
- During 1865 Gregor Mendel focused on particular inheritance that follows a clear mathematical ratio. Although his work did not include human heredity, he was able to mathematically determine the dominance of certain traits within the pea plant. His selection of the pea plant gave him the opportunity to accurately collect vast amounts of data. One of the main characteristics that set Mendel apart from the other scientists of his time, was his view that the hereditary traits was not particulate but preserved through generations. Heredity was conducted

through pairs, one from each parent (Harper, 2008:53; van Dijk & Ellis, 2016:1331).

It would be inappropriate at this stage not to mention that, although Mendel's studies were the most advanced of his time, it went mostly unnoticed for at least 35 years. It was not until the year 1900 that Mendel's work was rediscovered. Three individual papers were written in that year on Mendel's work and although his focus was on plant inheritance, scientists such as De Vries used his methods to indicate similar inheritance patterns in humans, especially when it came to mutations (Harper, 2008:53). In 1905 the term *genetics* was used for the first time by William Bateson and is still used today. What is important is that Mendel's work laid the foundation for what we today know as genetics.

2.3. HUMAN GENETICS

2.3.1. A SHORT HISTORY OF THE HUMAN CHROMOSOME

The foundations laid by Mendel, alongside the breeding methods to study heredity, led to the discovery of the chromosome. In order to study heredity, you need large amounts of generational data. Gathering this data is a lengthy process, especially with animals, where the generational lifespan is long and in which case data collection can take years. This started to change when scientists began using the common fruit fly, *Drosophila*, to conduct research on heredity. Unlike other species the fruit fly was easy to maintain and feed, and is bred in large numbers. The gestation period is about 2 weeks and the species turned out to be an excellent choice as they have large chromosomes, which was unknown at the time (Moore, 1983:862). An added bonus is the fact that the fruit flies had X and Y chromosomes that are somewhat comparable to human chromosomes (Moore, 1983:865; Allen, 1966:50).

Thomas Hunt Morgan was an embryologist and was interested in research on mutations. He started using fruit flies for his research in an attempt to replicate mutations for his developmental studies. It took two years before the first mutations appeared in his colony and was a change of the thorax pattern. Unfortunately, this mutation was not easily replicable and he decided to scrap the study of that specific

mutation. He did not have to wait long before another mutation was observed. This time easily replicable and noticeable – the white eye mutant. What distinguished this mutant was that the white eyes were only observed in males, even if the mother was a normal red eye variant. Over the course of the next few years Morgan teamed up with various scientists and linked the white eye variant to the X chromosome. This discovery led to gene mapping which set the stage for human gene mapping (Harper, 2008:84).

During 1923, Hans Winiwarter published a short preliminary report stating that at that stage only 46 human chromosomes had been found. At the same time the number presented by Theophilus Painter was 48 chromosomes (Harper, 2006: 45). It seems as if Painter's research was more authoritative as the scientific community continued to state that there are 48 human chromosomes. No one knows for sure why this discrepancy was never corrected. It was not until 1946 when a paper was released stating that the correct number of human chromosomes are 46 and not 48 (Arnason, 2006:203). Even though Theophilus Painter initially calculated the incorrect number of human chromosomes, his research did provide a foundation for technological advancements in the 30 years that followed. These advancements were critical in the field of cytogenetics. Innovations came from a series of studies, undertaken principally in Russia. Technology proved to be key in the study of cytogenetics, namely:

- colchicine for the arrest of mitosis;
- the squash technique to view chromosomes in a two-dimensional plane;
- the advancements in cell culture techniques;
- the hypotonic treatment to spread chromosomes;
- photomicrography; the use of embryonic tissue with rapid cell growth (Harper, 2008: 146).

This technology led to what we today know about chromosomes and how they function. It assisted scientists to understand that chromosomes contain long strands of DNA that plays the main role in cell replication and contains the hereditary traits (Finegold, 2019).

2.3.2. THE HISTORY OF DEOXYRIBONUCLEIC ACID (DNA)

We will now turn to the history of DNA, as it is an important aspect of the study since DNA is seen as the building blocks of life and the code of which we are currently editing. It is also important to understand the history of the discovery of the genetic code in order for us to enter into an in-depth discussion concerning the ethics thereof. When considering DNA we are tempted only to recognize Watson and Crick for the discovery of the double Helix. The reality is that DNA was discovered years before Watson and Crick discovered the double Helix (Dahm, 2005:278). The following few paragraphs will outline the history and key role players involved in the discovery of DNA.

During 1866, Gregor Mendel published his paper on the basic principles of genetics. During the same time there were numerous studies conducted that specifically focused on Genetics and the role it plays in heredity. According to Dahm (2005:278) the main aim of biochemists such as Adolf Strecker and Felix Hoppe-Styler was to unravel the biochemistry of life. Adolf Strecker was a leading figure in this area of research, and is renowned as the one that managed to synthesize an amino acid. Hoppe-Styler was also a leader in the field and focused his energy on *hemoglobin*, a protein found in red blood cells responsible for carrying oxygen. He was the first person to coin the term *hemoglobin*. Another accomplishment attributed to him was the introduction of the term *proteid*, which in time became known as the protein. It is against this backdrop and under the supervision of Hoppe-Styler that Frederick Miescher entered the field (Hubsher, *et al.* 2010:5).

Miescher's initial work focused on the bare chemical composition of lymphocytes⁸ and the study proved a difficult task (Hubsher, *et al.* 2010:5). He had to source the cells and then manually separate the protoplasm from the nuclei. The nuclei were then examined under a microscope and he held the view that this was an extremely tedious task. It might have been a tedious task to him at that stage, but it proved to be beneficial. It was during this process, in 1869, that he noticed a specific compound with unique properties. When adding acid to the solution the compound precipitated

⁸ A type of white blood cell forming part of the immune system of most vertebrates (Merriam-Webster, 2023).

and when adding alkali, it dissolved again (Dahm, 2005:274). This was the first discovery of what we know today as DNA. Following this discovery, he continued to work on nuclei and theorized on the function thereof during the hereditary process (Harper, 2008:191; Hubsher, *et al.* 2010:5).

Approximately ten years later, during 1879, Albrecht Kossel, while employed as an assistant in Hoppe-Seyler's institute of Physical Chemistry, explored the nuclein further. The twenty years that followed saw his continuous focus on the nuclei and he made astounding discoveries during this time. He managed to isolate the nuclein in a protein free form and suggested the deproteinized term *nucleic acid* – this became known as *deoxyribose nucleic acid* and during the 1930s the term changed to *deoxyribonucleic acid* (Hubsher, *et al.* 2010:5). He managed to identify the structure of the nucleic acids as well as cellular proteins. During this process he discovered the components adenine, cytosine, guanine, thymine, and uracil. Through his research he managed to identify that both thymine and cytosine is present in both DNA and *Ribonucleic Acid* (RNA). He also identified key components that made up the structure of chromatin that supports the chromosomes which in turn supports the DNA (Hubsher, *et al.* 2010:6).

Phoebus Levene further developed the research by Kossel (Hubsher, *et al.* 2010: 8). He identified the main difference between RNA and DNA. During his career he published more than 700 papers on the chemical structure of DNA and RNA. At this stage, although the belief was that DNA played an important role in the cell, DNA was not recognized as the key component in the genetic material. This is mainly due to an incorrect hypothesis from Levene. It was not until the 1930's before scientists recognized that DNA was pivotal in the genetic processes (Hubsher, *et al.* 2010:8). This recognition led to the conclusion of Oswald Avery, during 1944, who stated that cell transformation is due to DNA and not a specific protein.

Only when scientists understood that DNA plays a key role in the genetic makeup of organisms, questions arose about the role of the structure of DNA during cell division. One of the key questions was how exactly DNA is duplicated during the cell replication process. The answer became possible as a result of technological advancements in

the form of x-rays. It was only a few years following the first x-ray of the DNA structure that Watson and Crick identified the double helix DNA structure and proposed the hypothesis that the helix unzipped itself during cell replication (Hubsher, *et al.* 2010:15).

The table below indicates the historic milestones in the discovery of DNA:

Individual	Date	Key Step
Miescher	1869	Identify and isolate DNA
Lavene	1910	Identified chemical structures of nucleic acid
Willian Bragg	1912	Uses x-ray crystallography to study the structure of molecules
Astbury	1929	Study fibrous protein using x-ray crystallography
Avery	1944	Discovers that cell transformation is due to DNA and not protein
Chargaff	1950	Identifies complementary structure of DNA
Pauling	1951	First proposes a double helix structure of DNA
Wilkens	1951	First good x-ray of DNA
Franklin	1952	X-ray supporting the double helix theory (the x-ray was unknowingly seen by Watson and Crick)
Pauling	1953	Publishes an incorrect model of DNA
Watson and Crick	1953	Publish the double helix model

Table 2.2: Historic milestones in the discovery of DNA

The identification of a rudimentary form of DNA to the identification of the Double Helix structure took approximately seventy years. The reality is that the three-dimensional structure that was identified by Watson and Crick opened the doors to our understanding of how the DNA functions (Hubsher, *et al.* 2010:15). The discovery of chromosomes, DNA and how the DNA functions, paved the way for research into the important science of gene mapping.

2.3.3. THE HUMAN GENE MAP

During the first fifty years of the twentieth century major technological and scientific discoveries were made. It was only once the scientific community had the knowledge of the structure of chromosomes, and how genetic traits are passed down from one generation to the next, that scientists were able to effectively study chromosome linked inherited abnormalities and diseases. Early research was done on Down Syndrome and abnormalities related to the sex chromosomes. The challenges in this field stemmed from the major error made during the 1930s, when the incorrect number of human chromosomes were identified. Initially, scientists believed that there were 48 chromosomes and in some instances 47, while the actual number is 46. This meant that the studies conducted for the next 20 years provided limited results. Once the correct number of human chromosomes was established, renewed interest was shown in this field by numerous groups. Shortly thereafter a consistent trisomy of chromosome 21 was constantly identified in individuals with Down Syndrome (Harper, 2008:152). While studies continued on Down Syndrome, another group of scientists focussed on sex chromosome abnormalities and made several discoveries.

Remarkably, it took only five years to move from relative ignorance to almost a full understanding of the number and morphology of human chromosomes. The scientific advancements and discoveries pointed to the fact that chromosome abnormalities could be responsible for developmental disorders as well as at least one type of cancer, namely myeloid leukaemia⁹ (Harper, 2008:153).

While the research on chromosomes continued, some scientists started developing the hypothesis that the genes located on the chromosomes can be mapped. Harper (2008:196) highlights that as early as 1913 one of Morgan's students, who primarily studied mutations using fruit flies, hypothesised that genes appear in a linear fashion on the chromosomes. The importance of this should not be underestimated. For the first time the reality that genes can be mapped was accepted and was the beginning of the process to map out the genes on chromosomes. Scientists first managed to

⁹ A type of cancer affecting the bone marrow and spleen (Merriam-Webster, 2023).

map out the X chromosome of fruit flies. They used cytology in parallel with genetic analysis, which, allowed them to accurately map the physical gene map of the fruit fly.

The historical development of gene mapping was conducted through different approaches, all of them proved to be important. The below table, mapped by Harper (2008:197), provides valuable insight into the historical development of gene mapping:

Linkage analysis of polymorphic markers and genetic diseases	Observable phenotypes such as colour blindness.
	Blood grouping
	Protein polymorphisms
	Natural chromosome variants
	DNA polymorphisms
Physical approaches to gene mapping	Somatic cell hybridization
	Chromosome sorting
	In situ DNA hybridization
	Deletion analysis
Other approaches	Meiotic analysis of chiasmata
	Comparative gene mapping
	Linkage disequilibrium (allelic association)
	Auto-zygosity in inbred families

Table 2.3: Historical approaches to gene mapping

Harper (2008: 198) refers to the remarkable progress that scientists in the early 1900s made with regards to gene mapping. They managed to accurately map the genes on chromosomes of mice and the fruit fly without the help of computer analysis. This progress was made between the 1920s and 1930s with the advancements in linkage analysis, a statistical method used to identify genes on chromosomes which can be inherited. The remarkable feat was that the theories was sound enough so that when the technological advancements of the computer came, scientist could use the theories as foundations to build on. The theories also enabled scientists to predict the occurrence of serious inherited diseases such as Huntington's disease.

World War II was a complex time with Nazi Germany invading most of Eastern Europe. It is important to note that German scientists were at the forefront of genetic research by 1921. In fact, Harper (2018:5) highlights that Erwin Baur, Eugen Fischer and Fritz Lenz published a book on heredity that became an authoritative book in genetic science circles. Lenz and Fisher were part of the Nazi party and while the book seemed fairly standard, some of the longer chapters were mixed with comments on racial characteristics linked with superiority or inferiority. These comments increased in later publications of the book. During 1920 their book was read by Adolph Hitler while in prison and when the party came to power during 1933 the '*Law for the prevention of progeny with hereditary defects*' was passed, which set the stage for the genocide to follow.

The years following World War II saw a time of renewed focus on gene mapping with the USA funding some projects (Herring, 2006:96). At first the focus was mathematical in nature and Lionel Penrose managed to coordinate a group of researchers to assist with increasing the number of biomarkers and worked towards a systematic gene mapping effort. One of the researchers, James Renwick, developed the biomarkers as well as the first computer programme used to assist with linkage analysis. This was a time of great advancement in the understanding of human genetics. Success was achieved through technological advancements together with a close working relationship between immunogeneticists, mathematicians and blood group research units.

By 1970, human genetics and gene mapping developed rapidly. The collaborative efforts seen during the 1950s and 1960s were formalized during 1973 with the first gene mapping workshop. These workshops were vital, and their published records provided much insight into the state of research and the amount of data shared between the scientists. The advancement of the research was on such a scale that during the last workshop held in 1990, it was decided that the speed and amount of data was too much for a hands-on workshop. A new organisation was formed, namely, the Human Genome Organisation (HUGO) through which the subsequent meetings

was co-ordinated with its focus on individual chromosomes and other activities (Harper, 2008:206).

One of the key driving forces for mapping the human genome was human inherited disorders. Although genetic predictions could be made through linkage prediction, scientists were still not able to apply actual protein markers. This all changed with the discovery of linked DNA markers for Duchenne Muscular Dystrophy during 1982. Huntington's disease followed which confirmed that inherited diseases can be mapped, and specific genes identified causing the disease. Unfortunately, the discoveries and mapping of inherited diseases were not well co-ordinated and much of the research was done in isolation. This all changed with the formation of the Human Genome Project, which, supported by the French Muscular Dystrophy Association, co-ordinated the mapping of the complete human genome (Harper, 2008:211).

The fact is that during the 1980s all forms of gene mapping were labor intensive. Before DNA could be sequenced, the DNA needed to be extracted from the cell and grown in bacteria. Thereafter it had to be sliced in two species of varying links and sizes. Following this process scientists had to use radioactive biomarkers as labels, after which the DNA could be x-rayed. The process of mapping a segment within the DNA took scientists a year (Lim, 2002:5). Despite numerous scientific studies focusing on genetics, actual advancements in this field came as a result of technological progress. This is clearly seen with the identification of different structures in the cell when the microscope was first invented. As time went on stronger and stronger microscopes were invented and eventually scientists were able to capture the building blocks of life, known as the DNA molecule. The use of x-ray technology made it possible for Watson and Crick to identify the helix structure of the DNA (Lee *et al*, 2014:6).

By 1988 it became apparent that genome sequencing was going to have a fundamental effect on medicine. This belief stimulated the US government to fund a project called the Human Genome Project. The Research Council recommended a fifteen-year program that would cost 3 billion dollars. During 1990, James Watson, who discovered the structure of the DNA molecule, was asked to head the project. Not

everybody was keen on mapping out the human genome. Some scientists were opposed to this, stating that it would be a waste of money, as 95% of DNA was deemed junk DNA. Those in support of the project argued against the 95% DNA junk concept. They questioned the validity of such a “junk” statement in view of the fact that scientists could not, at that point, give a full scientific account of DNA. The latter part of the 1980s saw two methods being used in genome sequencing. One method, called the Cottage Method, was a very slow and tedious method. Scientists worked individually in smaller labs and came together annually to present their findings. New development came when the pharmaceutical company Bio Systems invented a new sequencing machine using fluorescent tags instead of radioactive methods. Craig Venter used this new machine to randomly sequence DNA fragments, which made faster sequencing possible – he was able to sequence as many genes as all the other scientists combined (Harper, 2008:381; Lim, 2002:8).

The method used by Watson and by Venter was vastly different (Lim, 2002:13). Watson focused on a systematic system to map the genome chromosome by chromosome. Venter on the other hand used a machine-driven shotgun method sequencing DNA in fragments. The systematic approach was a slow and tedious approach while Venter’s approach was much quicker as he took pieces of DNA and then built it up like a jigsaw puzzle. During 1992, Watson left the National Institute of Health and was replaced by acting director Michael Gottesman. Gottesmann reviewed both systems and decided to use the machine-driven method going forward but keep the process systematic (Lim, 2002:13).

This changed during 1999 when Venter managed to sequence the *hemophilus influenza* that causes ear infection and meningitis using the shotgun method. This convinced funders, and the government at that stage, to rather invest in the shotgun method and move away from the systematic sequencing. Francis Collins assumed directorship of the National Human Genome Research Institute and managed to raise 250 million dollars to buy sequencing machines for five laboratories. These machines were able to run 24 hours a day, seven days a week to speed up the process of the sequencing. By the end of the 1990s, private companies saw the potential of genome sequencing in medicine and were able to visualize a future where specific diseases

could be identified based upon genes. This meant new medicines to treat or prevent specific diseases. The impact of this vision caused healthy competition between private companies and government-led projects that were complementary to each other (Lim, 2002:12).

The first 10 years of the Human Genome Project was a slow and tedious process. The advancement of technology played a major role in speeding up the mapping process of the human genome. In November 1999, only a third of the human genome was sequenced. By March 2000 two thirds was complete, and by the 6th of April 2000 the project was nearly completed. Once the mapping was completed scientists started working on a first draft in 2001 and completed the sequencing in 2003. The whole project officially took 13 years to complete. The table below outlines the timelines of the Human Genome Project from 1985 as illustrated by Lim (2002:14):

Date	Event
1985	The concept of the Human Genome Project is conceived
1986	The USA Department of Energy announces the Human Genome Initiative and pledges 5.3 million dollars
1987	The National Institute of Health starts funding genome projects and the USA Government pledges 28 million dollars to fund a Human Genome Project
1988	Human Genome Organization is founded to co-ordinate genome mapping and start the sequencing process
1990	USA Congress approved a fifteen-year project called the Human Genome Project under the leadership of James Watson
1991	The Genome Database is established
1992	James Watson, Leroy Hood, Maynard Otson Robert Waterson, Bill Gates, Paul Allen met to discuss the HGP and established the University of Washington Human Genome Centre; First Human Genome Map Linkage published; Watson resigns as Director of the HGP following an argument with Venter;

	Venter leaves the NIH and founded the Institute for Genomic Research
1993	Various USA Genome Centers established.
1994	Genetic mapping five-year goal achieved one year ahead of schedule; A Genetic Privacy Act is proposed to regulate genetic mapping
1995	High resolution physical maps of Chromosome 16 and 19 are published; Moderate resolution physical maps of Chromosomes 3, 11, 12 and 22 are published; First nonviral whole genome is sequenced
1996	The sequencing of the genome of yeast completed; <i>Methanococcus Jannaschii</i> genome is sequenced; Healthcare Portability and Accountability Act passed in the USA which prohibits the use of genetic information in healthcare insurance eligibility
1997	<i>Escherichia coli</i> genome is sequenced; High resolution physical maps of chromosomes X and 7 are completed; UNESCO adopts the <i>Universal Declaration on the Human Genome and Human Rights</i>
1998	HGP passes the halfway mark; More genome sequencing of different organisms are completed; Incyte Pharmaceuticals made the announcement that they are about to sequence the Human Genome within 24 months; Shotgun sequencing received 300 million dollars to finish the sequencing within three years; The USA and UK announced the speeding up of the sequencing process to ensure the first draft is ready by 2000, with the final draft published during 2003.
1999	Rice genome is completed within 6 weeks; The Human Chromosome 22 becomes the first completed chromosome to be sequenced;

2000	The USA and UK made a joint announcement that the first draft of the human genome is completed
2001	First Human Genome Data is shared online
2003	Announced that the Human Genome Project has been completed

Table 2.4: Historical milestones achieved during the Human Genome Project

The completed genome mapping provided scientists with an understanding of how the building blocks of life works. The reality is that there are so many questions arising due to this mapping, that it might take awhile for to fully comprehend the real power behind the code. Scientists have discovered that individuals might have genes that have not expressed or manifested in specific instances, causing a possible pre-disposition to a specific disease. The disease might, however, never occur in the lifetime of the individual. It would seem as if the various genes work together in specific instances to express or manifest into what we perceive as diseases, which makes scientific work even more difficult. Gene mapping opened a new scientific world for geneticists. Not only did it provide a new knowledge basis, but it led to major new advances, of which Genome Editing became a major role player.

2.4. GENOME EDITING

2.4.1. THE HISTORY OF GENOME EDITING

Based on understanding of the history of genetics, specifically heredity, the discovery of DNA and the mapping of the human genome, we will now discuss the topic of genetic editing. In order to understand the ethical concerns linked to genetic editing we need to explore and understand what is genetic editing and what its effects entail. Langel (2019:131) defines gene editing as a specific change to the DNA, while Gupta (2008:15) defines it as a deliberate change of the DNA at a specific place. Herring (2006:39) makes an important distinction between genetic editing and cloning. While genetic editing is the deliberate manipulation of the genetic material of a cell with the aim to change an organism, cloning is the attempt to copy the genetic material with the aim to create exact replicas.

Viewed on the surface, genetic engineering or genetic editing seems innocent, but in reality, changes to a person or organism are effected and the dangers thereof quickly comes into perspective once we realise that we are changing ourselves. About twenty years after the discovery of the double helix by Watson and Crick, scientists began to experiment with changing DNA by means of restriction enzymes. The discovery of especially the ligation enzymes was a significant breakthrough in this respect. Up to that point, scientists were not able to make cuts in the DNA and blend the DNA together during the attempted editing (Shuman, 2009:17365). Cutting of the DNA is only one piece of the process. In order to complete the editing process of the DNA, scientists had to figure out a way not only to cut specific DNA, but also find a way to re-attach the DNA once the desired editing was completed. This done by means of another class of enzymes called Ligases. The purpose of these enzymes was to act as the glue to make sure the DNA connects to the original strand (Herring, 2006:40).

Herring (2006: 40) explains the editing process by using the analogy of cutting camera film. Obviously, this was prior to the move to digital cameras, but, it can still be visualised. In essence, if you would like to add scenes to the camera roll, one had to cut the roll at a specific point, add in the new piece or remove the piece and then connect the film together again. Initially DNA splicing resulted in many successful studies and soon focussed on producing genes that can be used for research, as well as industrial uses. Although this process enabled scientists to edit DNA, it is also this exact process that is the cause of great concern. While this editing process gave scientists the ability to edit specific genes, it also opened the door to introduce DNA strands cross species. Scientists discovered that the changes they effected to DNA is transferred to the next generation of offspring. One of the main challenges with this splicing technique comes in the form of accuracy. While the splicing technique works effectively, the accuracy of the editing cannot be guaranteed. It is for this reason that scientists struggled to target specific defective genes in an attempt to replace them with non-defective genes.

The gene-splicing process was developed during the late 1970s and early 1980s. The process is relatively simple and consists of four steps, namely:

- insert preparation;

- ligation;
- transformation;
- selection of transformants;
- screening of the clones.

During the first step of the process the insert is prepared by collecting a large volume of DNA through the process of digesting the DNA using a restriction enzyme. The enzymes recognize short palindromic DNA sequences and split them in a staggered sequence. The result of this staggering sequence is hundreds and sometimes thousands of fragments that are ready for the next step. The ligation step is achieved by using a vector. Most vectors are viruses with the ability to replicate themselves within their hosts. The most common plasmids are derived from bacteriophages¹⁰, especially those found in *E.coli*¹¹. The ligation step is accomplished through another phage prepared from the cells infected with *E.coli*. During the transformation step the *E.coli* phages are introduced to the host and needs to be conducted via chemical or physical treatments in order for the host to accept them (Shuman, 2009:17365). Interestingly enough, the transformation process is the same process that is followed when a virus infects a bacterium – a virus would infect the bacterium and insert a piece of its DNA or RNA into it. When the DNA is replicated the virus' DNA will replicate into the new cell releasing the virus' vectors throughout the host (Herring, 2006:42). The transformation process is critical. It does, however, yield low results, which means the selection of transformants are paramount. *E.coli* bacteria and yeast often provide the best results and is more commonly used. By the turn of the century, great excitement existed in the scientific community when scientists were able to manipulate DNA copies of entire viral genomes in the bacterial plasmids through RNA transcription (Herring, 2006:42).

Molecular biology laid the foundation for genetic editing tools to be developed during the early 1970s (Gupta, 2008:1). Since the discovery of the technologies huge successes followed in developing newer and more accurate editing tools.

¹⁰ A virus that infects bacteria (Merriam-Webster, 2023).

¹¹ Bacteria (*Escherichia coli*) used in public health as an indicator of faecal pollution (water or food). It is also used in medicine and genetics as a research organism. *E.coli* have various strains that may live as harmless inhabitants of the human lower intestines or may produce toxins causing intestinal illness (Merriam-Webster, 2023).

Biotechnology has been applied on an industrial scale since 1976 and its impact caused an explosion of global growth in specific industries, especially the pharmaceutical sphere (Lim, 2002:55). The initial focus of this newer technology was to manipulate or edit DNA of specific bacteria and microbes to support pharmaceutical uses. Another focus area was the agricultural sciences and, as we know today, there are many genetically modified crops grown on an annual basis.

By the 1980s the technology evolved and saw the first transgenic animal and the first genetically engineered human drug – in the form of synthetic insulin (Fraser, 2016). The development of the polymerase chain reaction (PCR) was pivotal and assisted with the availability of DNA to scientists by reducing the cloning time of DNA (Mullis s.a.).

New biotechnological tools were developed rapidly. The available gene editing technologies available in the late 1970s and early 1980s, namely gene splicing, had its limitations. The editing of specific DNA was not accurate enough and by 1985 another breakthrough came with the discovery of Zink Finger Nucleases or ZFN. Zink Finger Nucleases made it possible to effectively target genes in various ways. The process made it possible to recognise DNA, making it possible to create a design for different targets in different type of cells and organisms. Scientists managed to bind ZFN to three base pairs and combined them to recognise longer DNA sequences. By fusing ZFN and another compound called FokI scientists created “genomic scissors” that was able to cut DNA at a specific location. This process meant that scientists were able to target specifically mutated genes previously not possible (Klug, 2010:1). This became the standard of gene editing and during 1986 the first recombinant vaccine for humans was approved. The vaccine was developed for Hepatitis B and set the standard for many vaccines that are available today.

A new editing tool in the form of TALENs was developed during 2011. While ZFN had the ability to provide much more accuracy than gene splicing, it still took a long time to develop and there were often off-target effects. TALENs, on the other hand, can recognise single nucleotides and is easier to design. The technology has fewer constraints and is much easier to target across a genome. The result is less off-target

effects, which makes it more efficient. The other benefit for TALENs is that they can be developed in a matter of days and are easy to duplicate, which has various benefits to researchers. Unfortunately, the TALENs technology also has its disadvantages – the main challenge is that TALENs are much larger than ZFN and is difficult to deliver and express in vivo (Young & Sander, 2012:51).

To understand the in vivo, which is the editing process taking place inside an organism, one has to understand the transformation process. The transformation process that is used in gene splicing, first discovered during the 1970s, works on the same principles as when a virus implants its DNA into a host – in this case a bacterium. A virus would infect the bacterium and insert a piece of its DNA or RNA into it. When the DNA is replicated the virus' DNA will replicate into the new cell, releasing the virus' vectors throughout the host (Herring, 2006:42). Research on this process led to the next discovery in gene editing technology.

One of the questions that arose from researching bacteria and the viral transformation process concerned the manner in which the bacterial immunity work. Bacteria have a primitive form of immunity that prevent viruses from imbed their DNA into the bacteria. Researchers questioned exactly how this happens. What they discovered was astounding. Bacteria have the ability to snip viral DNA at a precise point and imbed that viral DNA into their own DNA to recognize a specific virus when it is trying to infect the bacteria again. The specific adaptive immune system is called Clustered Regulatory Interspaced Short Palindromic Repeats, abbreviated as CRISPR, and can be programmed to make specific targeted DNA cuts. During 2012 scientists managed to programme these cells to make specific DNA cuts and insert DNA accurately. The technology is a massive breakthrough and is currently being used in various research projects with the aim of eradicating disease (Doudna & Strenberg, 2017:165). The success of this technology was acknowledged during 2020, when the scientists Jenifer Doudna and Emmanuelle Charpentier, who first identified and used the technology, were awarded the Nobel prize in chemistry (Ledford & Callaway, 2020).

2.4.2. ACOMPLISHMENTS THROUGH GENE EDITING

Biotechnology provided the opportunity for genetic engineers to support the farming community by creating crops that are immune to specific viruses and bacteria, which was never possible previously (Herring, 2006:62). Lim (2002:58) points to the successful inclusion of an antifreeze protein gene from flounders to the DNA of tomatoes to protect tomatoes from frost (Bruening & Lyons, 2000:6). They also managed to use genes from a firefly to serve as bio-markers on corn plants. Tobacco plants were edited by inserting the genes of a Chinese hamster to increase the production of sterol.

Lim (2002:58) states that one of the major concerns for this transgenic editing is the unknown impact of crossing species boundaries. Scientists are not able to accurately predict what would happen when the genetic code for one animal or organism is added to a totally different species. For thousands of years the agricultural industry used cross pollination of closely related species to breed specific plants to give them desirable traits. With transgenic DNA editing we are now in an unprecedented era where we are introducing animal DNA into the DNA of plants. The concerns raised is linked to the unknown, as we do not understand what the long-term effects will be by making these changes. When looking at microevolution we do see the adaptation of specific species to tolerate certain conditions (Lukas *et al*, 2020:623). This is exactly what farmers and scientists are doing by cross pollenating closely related species. But adding DNA across species, is in reality, and by definition, a type of forced macro evolution. This study is not focusing on the evolutionary debate, especially when it gets to the views from the biological community and the religious community. It would be interesting to see further research and debate on the topic of forced macro evolution. In his novel "*Monster*", Frank Peretti (2005) explores this notion where scientists attempted to find the notorious "missing link" that would link the evolution between Chimpanzees and humans. The result was disastrous to say the least, as it resulted in a mutated chimp going on a killing spree. Although this is only a novel, it does highlight the dangers of attempting to push the boundaries trying to prove macro evolution with DNA editing technology.

Although concerns are raised regarding cross species DNA being inserted into plants or animal models, Lim (2002:59) is of the opinion that technology might be a solution to world hunger. He bases his view on the fact that rice is the staple food for half of the world but it lacks nutritional value. By including specific code into the DNA of rice scientists are able to manipulate rice crops to produce vitamins required for the malnourished. A Swiss laboratory spliced three genes into rice to increase its iron content, as well as the levels of other vitamins. Chinese researchers are currently busy with research that promises better quality meat as well as livestock that is resistant to specific diseases (Cohen, 2019). This will increase the nutrition of many malnourished individuals. Cohen (2019) states that China is aggressively persuading CRISPR research and has a long list of animal studies where the focus is on DNA editing. This list includes monkeys, dogs, mice, rats, pigs and rabbits.

Aqua biotechnology is also at the forefront of research. When we think about genetically modified organisms or GMOs we usually think about plant crops; however, fish is an essential part of biotechnological research. The zebrafish is a good example as it is inexpensive and easy to maintain. It can be housed in small spaces and reaches maturity quickly. The generational gap is approximately three months, which is useful when it comes to research with regards to the impact of DNA changes to later generations (Lim, 2002:83).

The first gene targeted gene therapy to treat myelogenous leukaemia¹² was approved during 2001. During 2006, the first preventative cancer vaccine was introduced. The significance of both these breakthroughs is that both are still in use today. The preventative vaccine against Human Papillomavirus is still the only cancer preventative vaccine on the market. Craig Venter made history again during 2010 with the creation of a bacterial cell controlled by a chemically synthesized genome. This bacterial cell was the first living organism that was chemically created and not cloned or born from another host (Gibson, *et.al*, 2010:52).

¹² A type of cancer affecting the bone marrow and spleen (Merriam-Webster, 2023).

It seems as if genetically modified food, including animals, is slowly but surely being accepted. Genetic editing has also been introduced in human beings. During 2015, Chinese researchers published research claiming they were able to successfully edit human DNA in non-viable embryos (Liang, *et al.* 2015:363). Chilling news broke at the end of November 2018 when it was announced that the first genetically modified twins were born in China (Sherman, 2018; Regan, *et al.* 2018). This in itself raised major ethical questions regarding the alteration of human DNA. According to the scientist concerned, the twins are theoretically immune against HIV, although an oversight from the research team resulted in the twins having less resistance against Influenza (Regan, *et al.* 2018). Further research indicates that the alteration to the gene also improves memory and brain restoration following strokes (Regalado, 2019). If this is the case it will be the first documented case of human enhancement through DNA editing. The jury is still out as to whether improving their memory was the actual reason for the editing of that specific gene. During December 2020, results from a study involving ten patients with sickle cell anaemia¹³ were released. The aim of the study was to use CRISPR Cas9 to target mutated genes in these individuals in an attempt to cure them from this disease. All the individuals reported improvement of the disease which included pain relief. All the individuals who participated in the study required intermittent blood transfusions. Following the gene editing seven out of the ten participants did not require any transfusions as their own bodies were able to produce enough normal red blood cells (Kaiser, 2020). This indicates that the current technological advancements are effective in treating specific diseases.

2.5. HISTORY OF BIOETHICS

The historical overview regarding genetics presented in this chapter will not be complete without an overview of the history of bioethics. Johnson (1998:3) provides historical insight into bioethics. Bioethics appears to be a relatively new field emerging in the late 1950s and early 1960s. Medical ethics however, existed long before bioethics but it changed its focus with the rise of more complex procedures and

¹³ A chronic inherited anaemia that occurs primarily in individuals of African, Mediterranean, or southwest Asian ancestry. It is characterised by episodic blocking of small blood vessels (Merriam-Webster, 2023).

technology. According to Johnson (1998:3) during the mid-1800s doctors were not regarded in the same light as today. During that period some medical doctors were thought of as envious and contentious individuals who took pleasure in mocking their peers. Professionally, medical doctors had a reputation for poisoning and butchering individuals and were not interested in healing people. It was not until medical training improved and the profession organised itself that doctors were respected as medical practitioners.

During 1847 the American Medical Association was established and instituted the ethical code of conduct (Johnson, 1998:7). The code was based on Percival's *Medical Ethics* and adapted to fit the needs of the people. The Medical Ethics code was revised during 1903 and 1912 and became known as the Principles of Medical Ethics (Johnson, 1998:7). By the 1940s they managed to turn around public opinion, which resulted in the profession being held in high esteem. At that stage, Medical Ethics was incarnate to the behaviour of the doctor. The major ethical battles during that time centred around the actual behaviour of the physician and not around moral perplexity, the patient or procedures (Johnson, 1998:5).

The period following World War II was definitive (Johnson, 1998:11). Science advanced at an unprecedented pace and the use of medical machines became the norm. Suddenly the medical fraternity was faced with questions they never had to think about. When do they switch off the ventilator? When to resuscitate individuals and when not? When to prescribe specific treatments and at what point is the treatment stopped? When is a person brain dead? Who dies and who lives? (Johnson, 1998:11). A recent example from the period of the COVID-19 pandemic illustrates this. One of the primary supportive treatments is oxygen and ventilators. With the scarcity of ventilators, doctors had to decide who would get ventilators and who would receive regular oxygen (Boodman, 2020).

By the 1960s conferences focusing on specific ethical questions were at the order of the day. An important point to note is that up to this point, the church and Theology were kept out of the debate. During one of the conferences this changed, and the inclusion of theological scholars brought a new dimension to the discussions.

Conferences in the 1970s became more formal with the creation of ethical centres such as the Hastings Center, the Kennedy Institute and the Society for Health and Human Values (Johnson, 1998:25). It was during this time that the term “bioethics” was born. Since then, the conversation broadened and, in the following decades, morphed into bioethics as we know it today. Eckenwiler & Cohn (2007:25) states that 1986 was an important year for bioethics. As mentioned previously, the official announcement of the Human Genome Project was made, and the USA government pledged funding for the project. This announcement proved to be the catalyst for a funded ethical group, the Society for Bioethics Consultation (SBC), to review the proposed common rule relating to US government funded human subjects. The SBC joined the Society for Health and Human Values and completed the first code of ethics during 1998. This code is constantly under review and the last review during 2002 included a code for the private sector regarding propriety and bioethics (Eckenwiler & Cohn, 2007:30).

It is worth taking note of the fact that Theological Bioethics added richness to the ethical debates and conversations. Johnson (1998:35) alludes to the fact that bioethics reignited questions of morality within the Roman Catholic moral theology. They were forced to re-examine viewpoints and to make sure the response was based upon a Biblical foundation. To plot the changes to Protestant Theological Ethics is a different matter altogether. With the relative rigid structure of the Roman Catholic Church and their doctrine their changes were easier to identify. This is in stark contrast with Protestants, who are diverse, with many structures and institutions, each with their own views and doctrines. Historical examination reveals that Protestant Churches responded in a similar fashion to the Roman Catholic Church in re-examining their responses to the new bioethical challenges. Both the response from the Roman Catholic Church and the Protestant Church in general made a massive impact on the way humanity views the bioethical challenges in the world today. Sadly, it seems as if the voice of the theological ethicist has grown quiet. Levin & Meador (2012:8) points out that until the mid-1980s, theologians were part of bioethical debates. Since then, their voices became quieter on specific issues and topics. Theological viewpoints bring a richness to ethical debates, and this is something ethicists in general should not shy

away from. The Theological Bioethicist has an important role to play in addressing some very specific ethical questions.

Governments and pharmaceutical companies started to use patents in an attempt to gain revenue from medicine that might target specific genes. While this is controversial, we should keep in mind that there is a financial component linked to research and although DNA is the building blocks of life, there should be funding available to further the research. Patents can advance future research and the development of technology. Lim (2002: 20) refers to this as the *Humpty Dumpty* conundrum where the gap between diagnostics and therapeutic medicine is small.

A real fear and anxiety exists that bio companies will use human genetic data for their own profit (Lim, 2002:21). The challenge is finding the balance between a sustainable system that covers research development, together with the empathy required to treat patients. There have been numerous concerns raised with big biopharmaceutical companies having too much genetic data (Song, 2018). Concerns range from data being shared with insurance companies that will impact insurance premiums based upon one's genetic variance, to sharing genetic data on potential leaders and role players within certain industries to handpick the next leader. Companies can also use the data to select employees who will, in theory, give them more hours of work with less sick days, saving these companies millions if not billions. The scenario of an individual with diabetes and cardiac problems serves as an example. This individual not only poses a risk of passing away with intellectual property or experience but also increases the risk of being away from work, being admitted to hospital and slowing down progress. For some companies the reality is that this discrimination can happen on various fronts, even without genetic data. Genetic data will give power to companies or governments to make discriminatory decisions based upon genetic code. Lim (2002:22) indicated that by 2002 there was a backlog of approximately 30,000 genetic patent applications.

Regarding to the Genetically Modified Organism, or the GMO debate, Herring (2006:62) points out that there might be an overreaction to GMOs in general. Biotechnology has been a lifesaver for many farmers who struggle with pests and

diseases. It saves them millions of dollars in chemicals in an attempt to protect crops, not to mention the money saved on lawsuits due to the possible negative effects of these chemicals. An important aspect that Herring (2006:62) touches on, is the fact that the negative effects of not using GMOs for food production might in fact outweigh the positives of not using GMOs. Herring (2006:63) is of the opinion that the answers to the questions and the objections are not easy to address. This is due to the fact that the focus areas of new technology are on two sensitive areas namely food production and health care. Both areas are critical to our existence. Nevertheless, Herring (2006: 65) tries to make a case for the use of GMOs during food production and is critical against countries who have legislation in place to prevent it. He states that the very countries that oppose the use of GMOs are the ones that will benefit the most if they grow GMO crops. He highlights that more than 70% of foods on the shelves in grocery stores in America were produced by using GMO technology. Although the GMO debate is complex and there might be many benefits in using GMO during food production, Herring (2006:63) seems to downplay the ethical debate on whether changing the DNA of an organism for the benefit of a specific species is the correct thing to do. Even though he mentions that we do not understand the negative impact of GMOs on the human body, he still makes the case that it seems safe and the benefits outweigh the possible negative effects.

In my opinion, this is a shallow understanding of the real debate and an underestimation of the slippery slope philosophical argument. Although people are concerned about their food source as well as healthcare, essentially the main concern is linked to the long-term effects of consuming GMOs as well as the unanswered question related to where to draw the line in altering the DNA of organisms. What effect will certain modification to food have on generations to come? We might provide more food to the poor immediately, but what will the impact be later on? Apart from the human body's response to altered DNA, what will the impact be on the environment? It would seem that as soon as we alter the DNA of a specific plant or species, they become an invasive species and, as we have seen throughout history, this has negative consequences. One such example is the cane toad that was introduced during the 1930s in Australia. Farmers during that period struggled with an increased amount of cane beetles and instead of trying to use the available pesticides

they turned to the cane toad from Peru. While initially all indications were that this toad, which grows to a size of two kilograms, was the solution, they soon found that it could not be controlled and had no natural enemies in Australia. The toads have venomous glands that can kill crocodiles as well as humans (Northfield, 2018). Thus, by trying to find a solution to a pest problem, all that was accomplished was the creation of two pest problems. What if we alter the DNA of a specific species, or as Lim (2002:59) suggests, insert the DNA transgenically to secure food resources, and thereby create an invasive species with no natural predator on the entire planet. It might seem improbable that a species can be created for food production and get out of control, but when we linger on this for a while and we realise that species can evolve through microevolution, it does open the door for an unknown pathogen. While scientists might be focussed on producing food for the world, pathogens might evolve in an attempt to infect the new species that was created, which might have detrimental effects.

From a theological perspective, a two-fold question can be asked: should we continue with exploring synthetic technology, especially if it harnesses the power to edit human DNA? The first part of the question relates to the available technology itself and the second refers to what we do with the technology. With regard to the first part of the question, Kruger (2014:44) concludes that Christians should support the development and use of synthetic technology. He bases his conclusion on his belief that humans are co-creators with God, as it is essentially used for the good of humanity and it is a Christian's responsibility to be a good steward on earth (Kruger, 2014:41). The view of humanity as co-creators is not shared by everyone. Peterson (2004:829) highlights that viewing humans as *co-creators* implies that, when it comes to the creation, humans are equal to God and as responsible for creation. A deeper evaluation on the doctrine of co-creatorship will be conducted in Chapter 5. When looking at synthetic technology holistically, there seems to be more benefits for the world and humanity to continue with the development thereof. If one holds the view that Christians are stewards of creation, it implies that Christians should ensure that technology is not used to benefit evil. This is a great responsibility and one that should not be taken lightly. The fact is that whether it is morally right or wrong from a theological perspective, the technology exists and can be used for evil purposes whether it is condoned or not. It is imperative that Christian bioethicists take part in the debates to

ensure a framework is created on how and when the power of this technology is harnessed. The question of where, how and when to use the technology will be the focus in the next chapter.

2.6. PRELIMINARY CONCLUSION

Gene editing is at the forefront of technology today. The revision of the history that led to where we are today indicates the speed of progress and development. Heredity was observed and documented even before Mendel, albeit not in scientific journals but through the pens of historians, philosophers and playwrights. Genesis chapter 30 provides insight into a rudimentary understanding of heredity, with Jacob becoming wealthy by separating Laban's flock. Aristotle's observation on heredity indicates that heredity was a topic that philosophers debated upon. Aristotle indicated that a theory on reproduction, which if interpreted correctly, relates more to a theory of heredity, can only be accepted if eight fundamental questions can be answered, namely:

- Why do offspring resemble their parents more than other of the same species?
- Why do some offspring resemble the father while others in the same family their mother?
- Why do offspring have more resemblance to their parents than their ancestors?
- Why do offspring resemble their ancestors more than other individuals of the same species?
- Why do males usually resemble their fathers while females resemble their mothers?
- Why do males sometimes resemble their mothers and females their fathers?
- If offspring fail to resemble their father, mother or ancestors, why do they still resemble a specific species, in this case humans?
- Why are there instances where the individual's observable form fails to bear any resemblance to the species it derived from?

All eight questions can be answered through genetics. A basic observation relating to heredity traits can be found in secular writings although it is clear that the heredity process was not understood.

Mendel's work on the pea plant provided a breakthrough in the understanding of heredity and opened the window for subsequent scientists to build upon. Through mere observation, he managed to plot a hereditary map that is still used today. Although there were a lot of theories regarding heredity, it was not until technological advancements in the form of the microscope and more importantly the x-ray machine, that scientists moved closer to discovering the real reason for heredity. The discovery of the correct number of chromosomes, the continued focus on DNA peptides, and x-ray technology, paved the way to the identification of the structure of DNA.

Once Watson and Crick identified the structure of DNA, they theorized that the DNA unzips, and is responsible for replicating the necessary information to the new cell. This quickly moved toward an understanding of heredity. Only a few years later scientists were able to splice genes, which made the editing of genetic material possible. This process also aided in the mapping of the human genome, a project that spanned from 1990 to 2004, although a lot of foundational work was conducted from 1986.

The past fifty years saw an unprecedented move towards gene editing technology for the agriculture, aquaculture and pharmaceutical industries. The pharmaceutical industry is one of the main industries capitalizing on the mapping of the human genome. From a technological perspective, the accuracy of new tools in the form of TALENs and CRISPR Cas 9 is making editing of the human genome possible. Various gene therapy clinical trials are currently underway to treat genetic diseases ranging from Sickle Cell Disease to Muscular Dystrophy. The results of clinical trials confirm the success of the technology.

The ethical arguments across the various disciplines evolved alongside the development of the technologies. Bioethics evolved from medical ethics to encompass not only the behavior of medical personnel but also the impact of biomedicine and treatment decisions on an individual and global level. What is evident throughout the history of bioethics is that the theological viewpoint brought richness to the discussions. Unfortunately, the voices of theological ethicists seem to be quiet, especially when it comes to genetic editing of the human DNA.

With the understanding of the history of heredity, genetic engineering and the evolution of bioethics we can now move to the next level of discussion. The next chapter will be devoted to defining the line between treatment through genetic editing and determine what is human enhancement.

CHAPTER 3: TREATMENT AND ENHANCEMENT

3.1. OVERVIEW

The ethical debate regarding the use of genetic editing technology for treatment and enhancement has become more prominent during the last decade. The arguments for and against the use of the technology are not new and overlaps with other ethical debates such as the question about when life begins, the use of in vitro fertilisation (IVF) technology and the use of stem cells. This chapter will focus mainly on the use of genetic editing for therapeutic purposes and the enhancement of the human state.

Critical topics will be explored to gain a better understanding of the ethical discussions relating to genetic editing. Topics include evaluating definitions for health and disease and understanding disease in a genomic age. Gene therapies aimed at treating diseases with the possibility to enhance a human being will be examined, whereafter transhumanism is addressed.

3.2. DEFINING HEALTH AND DISEASE

3.2.1. HEALTH, DISEASE AND ILLNESS

Evaluating definitions of health and disease in detail will assist with determining where genetic treatment ends, and human enhancement starts. This, however, is proving to be a challenge for philosophers. The main challenge is that a condition might be considered a disease in one area of the population while normal in another population. An example is that of the human heart rate. A healthy athlete's resting heart rate can be as low as 40 beats per minute, while this will be considered as a diseased heart in the majority of individuals who are not regularly exercising (MacGill, 2021). The example is simplistic, but when moving into the realms of physiology it gets much more complex, not to mention when we add a genetic complexity. Defining health and disease is complex due to various factors such as cultural contexts and historic changes to what and how we view diseases. Sculley (2004:650) points to the

example of osteoporosis¹⁴, which was seen as a normal aging process until the World Health Organisation (WHO) reclassified it as a disease in 1994. The impact of this resulted in more research into the causes and treatment for this disease.

Nordenfelt (2001:3), in an attempt to define health and disease, highlights two main views. The first view, namely the biostatistical view or naturalist view, aims to define disease in pure biological terms. The second view relates to a value-laden view, often called the normativist view. This view holds that health, disease and illness is intrinsically linked with value (Nordenfelt, 2001:62; Scully, 2004:651; Messer, 2011:165).

The biostatistical view was first proposed by Christopher Boorse during the 1970s. Messer (2011:164) states that Christopher Boorse and other authors such as Thomas Szasz conceptualised a scientific definition of health and disease in response to the value-laden definition adopted by the WHO.

The WHO adopted the following definition into their constitution during 1948:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (Official Records of WHO 2019).

Sartorius (2006:662) states that the WHO could have gone further by defining that a person can live with a lifelong disease or impairment. He added that the definition was extrapolated into three main definitions used today.

- i. Health is the absence of disease or impairment;
- ii. Health is a state that allows an individual to cope with daily demands (implying the absence of disease or impairment);

¹⁴ A condition that affects especially older women and is characterised by a decrease in bone mass (Merriam-Webster, 2023).

- iii. Health is a state of balance that is established within a person and between himself, and his social and physical environments.

The first definition relates to the biostatistical theory proposed by Boorse and fellow naturalists, while the second is a value-laden theory that combines the naturalist and normativist views through descriptive explanations. The third points to the normativist view (Sartorius, 2006: 662; Nordenfelt, 2001:62).

The definition that the WHO adopted during 1948 is the complete opposite of the value-neutral definition proposed by Boorse (Sartorius, 2006:662). In fact, Messer (2011:162) calls the WHO definition an attempt to define health as a theory of everything, thus highlighting his view on how broad the definition is. Boorse (1975:60) holds the same view and states that unless the physiological paradigm can be differentiated the definition adopted by the WHO is too wide.

The biostatistical theory proposed by Boorse is comprehensive and goes as far as distinguishing between disease and illness (Nordenfelt, 2001:61). Fulford (2001:80), a proponent of the value-laden theory, highlights that Boorse and other philosophers, such as Jerome Wakefield, drew clear lines between disease and illness in an attempt to show that while medical practice is value-laden, medical theory is not.

Boorse based his theory on the premise “that biological design is the notion of natural function” (Boorse, 1975:57). He was of the opinion that normal is the natural, and the natural state of an organism is healthy. Regarding health, he makes the point that healthy means that an organism is free of disease, and all systems within the organism functions as per the natural design. Wakefield (2014:649), summarizes his theory stating that the “concept of biological function and dysfunction can be understood in scientific, factual biological terms independent of value judgements”. Boorse called his theory the biostatistical theory based statistic formulated in terms of statistical normality. Kingma (2007:128), continues by stating that according to Boorse, and the philosophers agreeing with the naturalist theory of health, health is the normal

functioning within a species. This normal functioning is achieved through the statistical contribution of all the organism's cells, organs and processes with the main goal of survival and reproduction. Messer (2011:165), outlines it as follows and states that an organism is healthy and not diseased if they fall within the normal statistical realm:

- An organism is diseased if:
 - i. there is interference with the performance of natural function – meaning that some species-typical contribution towards survival and reproduction is lacking. This is viewed in relation to the age and population of the organism; and
 - ii. the interference is not in the nature of the species; thus, the interference is atypical of the species mainly due to environmental causes.

Nordenfelt (2001:61), a critic of Boorse, believes that the above mentioned definition of disease can be characterised as the absence of disease. It is important to note that an organism may be suffering from a disease, but not necessarily mean that it is displaying symptoms of an illness. They outlined Boorse's definition of an illness as follows:

- A disease is defined as an illness only if it is serious enough to be incapacitating, thus meaning that it is:
 - i. Undesirable for the bearer;
 - ii. A title to special treatment; and
 - iii. A valid excuse for normally criticisable behaviour.

Nordenfelt (2001:62), extrapolates on point iii. stating that Boorse's notion of illness belongs to the ordinary conceptual organism, in this case humans, and their actions. It was developed purely to apply to physiological diseases and the relation with the person and their body. He criticised this point with the notion that certain physiological processes such as peristalsis, the movement of food through the intestines, are not wilful actions of the person but autonomous in nature. If something goes wrong with these autonomous processes a person cannot be held responsible and this is classified as a disease. The challenge is if there is a non-responsible relationship between the body and disease, how do we classify mental illness where there is a notion that a person is responsible for their actions? Boorse's response to this critique

is that there is a growing preference for medicine to be used as an excuse for immorality (Fulford, 2001:81; Nordenfelt, 2001:62; Scully, 2004:651).

There are many other critics of the biostatistical theory proposed by Boorse who mainly holds the value-laden definition (Messer, 2011:165). Fulford (2001:82), noted that during Boorse's explanation of the theory as well as in his responses to critics he often wanders into the domain of the value-laden theories while insisting that his views are those of a naturalist. What is clear is that the critics of his theory/definition of health and disease are struggling to reconcile what they are seeing in the medical practice and what his theory offers. Interpreting Boorse's theory from a Reformed theological perspective, Messer (2011:166), struggles to accept the naturalist exposition. He is of the opinion that the terms health, disease and illness are inherently linked to goodness and thus the reason why it can't be separated from a concept of value.

While it seems as if the biostatistical theory offered by Boorse has its challenges, especially when it comes to psychological diseases, the value-laden or descriptive theories have their own challenges. As mentioned, the WHO adopted a definition of health during 1948. This has never been taken for review to be adapted or reviewed since and is completely the opposite to that of the value-neutral definition proposed by Boorse (Sartorius, 2006:662).

Callahan (1973:77) is of the opinion that although the WHO definition seems large and encompassing, it is attractive due to the seeming notion towards a relationship between the good of the body and the good of the self. He continues with the statement that the definition should be understood against the backdrop of history. The World Health Organisation came into existence following the Second World War as one of the first major activities of the United Nations. During 1948 the WHO obtained the necessary amount of signatories to sign its constitution into existence (McCarthy, 2002:1111). The main formative drive in the establishment of the WHO was the belief that improvement in world health will promote world peace. The initial view of the WHO was that health and peace is one concept (Callahan, 1973:79). Callahan (1973:79) disagrees with this and highlights that although there were many theories on how and

why the Second World War started, none of them relates to health. He is of the opinion that the drive to establish the WHO was the relation between health and economic welfare, something desperately needed following the war. One of the most significant themes adopted in the definition was the inclusion of mental health.

Nordenfelt, (2001:62) attempted to narrow the proposed definition adopted by the WHO while being critical of the definition proposed by Boorse. His drive to find a new definition relates to the notion that health is only present when disease is absent (Venkatapuram, 2013:273; Hanson, 2001:26).

Nordenfelt proposed the following theory of health:

“A person is in health if, and only if, he/she has the ability, given the standard circumstances, to realize his vital goals i.e., the set of goals which are necessary and together sufficient for his minimal happiness.” (Nordenfelt, 2001:65).

The criticism from naturalists, or the value-neutral philosophers, of the broad definition adopted by the WHO, as well as the value-laden definitions of health proposed by Nordenfelt, is that it seems to indicate that health and human happiness is linked (Callahan, 1973:79). Messer (2011:163), takes this concept a step further stating that social well-being or values are one of the challenges the value-laden proponents face. Social well-being could be linked to activities such as drinking, smoking, video games, or extreme sports that could be detrimental to an individual's physical or mental health. Hanson (2001:26) agrees with this view and states that the value-laden definition proposed by Nordenfelt imports social values shaped by western liberal philosophical assumptions. He added that it would seem as if Nordenfelt insinuates that health is achieved when an individual realizes their vital goals. Schramme (2007:14), criticises this concept stating that if part of health is reaching specific goals, healing is as easy as lowering one's expectations to meet a different goal. Messer (2011:163), added that there are many individuals who push the boundaries to achieve perceived social

well-being with negative health consequences. Athletes, for example, can push themselves to the point of burnout, a physiological syndrome categorised by physical and emotional exhaustion, reduced sense of accomplishment, and sport devaluation (De Francisco *et al.* 2016:240). Messer (2011:163) added to this thought by highlighting other examples such as the missionary, pastor and priest who died an early death due to the demands of ministry, all in an effort to care for other's social well-being.

Besides the challenge of including social well-being into the value-laden definition of the WHO, it also highlights why health is important and why governments should promote and protect it. The importance of the WHO definition of health can be taken one step further with thought provoking debates and theories such as those proposed by Christopher Boorse and other naturalists. It is also important to understand that the WHO definition of health appeals to Christian theological philosophers such as Messer and Hanson. The main reason for this is the interpretation that it focusses on health and healing, which equates to wholeness and peace (Messer, 2011:163; Hanson, 2001:26).

The different perspectives on defining health provides guidance on establishing a foundation before moving towards the discussion on where genetic therapy stops and human enhancement starts. Boorse's attempt to define health in pure biological terms is admirable. This might make sense from a pure biological or statistical perspective, but the concept of being healthy is more complex than the binary options he provides. Although broad, the WHO definition is closer to a more holistic view of health. Messer (2011) and Hanson (2001) make a compelling case on the definition of health and disease from a theological perspective. While the value of the human being is at the centre of the gospel, the reality is that our body has an expiration date with limitations impacted by disease.

Understanding the issue of health and disease is important not only for clarity sake, but it also impacts the broad health care system – especially when the right to health care is legislated as in the case of the South African Constitution (s.a. 1996). This

implies that all individuals with genetic diseases should have access to treatment, which includes gene editing. Hendricks, *et al.* (2022:1), highlights that 'right' to health care does not mean automatic 'access' to health care as it is dependent on the availability of resources. They continue and state that resources will only be made available if the size of the problem is calculated and this requires education and quality data.

3.2.1. THE PROBLEM OF DISEASE IN A GENOMIC AGE

The genetic advancements made during the last 50 years are paving the way towards diagnosing and treating many diseases. Berman (2018:2) is of the opinion that the advancements seen in the past few decades are redefining disease. He believes that disease was defined by a specific cause or symptom. This however changed with the recent advancements in molecular biology and genome sequencing and analysis. Scientists are now able not only to observe signs or symptoms of a specific disease but who is at a higher risk of falling ill to a specific disease. Berman further states that through observation scientists are able to identify that all disease follows a specific pathway towards a full expression as a disease. The importance of this is profound, as scientists are moving away from causality in disease in an attempt to eradicate disease by breaking the pathway a disease follows before it expresses as an illness. Bostrom (2004:493), an advocate of transhumanism and human enhancement, believes that through genetic editing there will be a point in the future where disease is eradicated completely.

Although Berman and Bostrom are not in direct dialogue with each other, it must be noted that Berman, a scientist and advocate for precision medicine is not as confident that disease will be eradicated. Berman (2018:24) highlights that although many diseases have a genetic origin there are many diseases that cannot be attributed to a person's genetic structure. An example of this is Rheumatic Fever¹⁵ which, according

¹⁵ An acute disease that occurs mainly in children and adolescents following a viral (streptococcal) infection of the upper respiratory tract. It is characterised by fever, inflammation and pain in and around the joints. There is also the inflammation of the pericardium (the membrane that encloses the heart) and heart valves (Merriam-Webster, 2023).

to him, is one of the most studied diseases. This disease is caused by a strain of *Streptococcus pyogenes* and elicits an autoimmune response. The immune response results in a cross-reaction with specific cardiac proteins and causes Rheumatic Heart Disease (Carapetis *et al.* 2016:1). The challenge with this sporadic disease is that scientists are not able to attribute the disease to the *Streptococcus pyogenes* since the disease is an autoimmune response and not every person infected with *Streptococcus* responds in this manner (Berman, 2018:21). The disease also cannot be classified as an autoimmune disease as there is nothing wrong with the immune system. It only happens to cross-react with specific proteins in the heart. Finally, the disease is not a heart disease although the heart is the organ affected and has nothing to do with either the infection or the immune response. This is only one example of a well-known disease where scientists are still attempting to understand its root cause.

Although we will move towards a discussion regarding Transhumanism later in this chapter, an understanding of how disease is seen with the genetic tools at hand is vital at this point. As mentioned Bostrom (2004:493), is of the opinion that disease can be eradicated through genetic editing, but it could be argued that Rheumatic Fever has an external genesis and not a genetic cause. Berman (2018:24), highlights other sporadic diseases with a seemingly hereditary or genetic cause that are also inexplicable at this stage. One example is Schizophrenia¹⁶, which in many cases has a hereditary cause – and in others not. However, he does highlight that just because a hereditary trace cannot be found does not mean it is not a genetic disease. It is very likely that the disease is caused by a phenomenon called a *de novo*¹⁷ gene mutation. Samocha *et al.* (2014:944), explains a *de novo* gene mutation as a spontaneously occurring mutation. These mutations cannot be predicted and depending on where the mutation occur will result in a specific disease. The *de novo* phenomenon does however pose a challenge to the notion of the eradication of diseases through gene editing. Unless there is an adoption of either embryo selection or screening on a global level. When looking at the COVID 19 pandemic and the resistance of simple

¹⁶ A mental illness that is characterised by disturbances in thought (such as delusions), perception (such as hallucinations), and behaviours (such as disorganised speech or catatonic behaviour), by loss of emotional responsiveness and extreme apathy, and by noticeable deterioration in the level of functioning in everyday life (Merriam-Webster, 2023).

¹⁷ Refers to something new (Merriam-Webster, 2023).

preventative measures such as vaccines and wearing masks, it is difficult to fathom a global acceptance of embryo selection/screening.

Another challenge with disease in a genomic age relates to a phenomenon that Berman (2018:70) coins as “one-to-many and many-to-one” diseases. This entails that a single genetic mutation could cause many diseases and conversely a single disease might have many genetic causes. Many examples exist of a single genetic mutation causing more than one type of disease. One of these examples is the mutation on the LMNA (Lamin A/C) gene that is the cause of Congenital Muscular Dystrophy¹⁸ or L-CMD, Emery Dreyfuss Muscular Dystrophy¹⁹, Progeria disease²⁰ (premature aging), heart disease and 6 other types of diseases. Berman (2018:70), highlights that the question researchers are facing is how one gene defect can cause so many diseases. He suggests a few possibilities which includes the notion that one gene controls more than one protein. It could also relate to the fact that a single protein has multiple functions, which is the case in mutations of the LMNA gene. The other scenario Berman (2018:71) refers to relates to the scenario where one disease can be caused by more than one genetic mutation. One example he highlights is cystic fibrosis²¹, which can be caused by any one of more than 2000 genetic defects.

Scientists are finding it challenging to identify the root cause of genetic related diseases (Berman, 2018:96). During the last twenty years many researchers conducted studies to attempt the identification and classification of diseases caused by genetic variants. The challenge became apparent when healthy individuals without any sign of disease carried the same mutations. One such example is mutations in the bcr/abl fusion gene that causes myelogenous leukaemia²². During studies on the mutation of this gene several healthy individuals were found with this specific mutation.

¹⁸ An ultra rare variant of a muscle weakness disorder presenting early in life, during infancy and soon after birth. This is a progressive disorder and weakness increases with age (Yaou, *et al.* 2021).

¹⁹ A rare form of progressive muscle disease (Heller, *et al.* 2020:463).

²⁰ A rare genetic disorder of childhood marked by lowed physical growth with signs of rapid aging (Merriam-Webster, 2023).

²¹ A common, progressive hereditary disease that typically appears in infancy or early childhood (Merriam-Webster, 2023).

²² Cancer affecting the bone marrow and spleen (Merriam-Webster, 2023).

Sosnay & Cutting (2014:195), states that research indicates that individuals with genetic variants may not display any sign of genetic disease. Berman (2018:97), points to the reality that like rheumatic fever it is difficult to pinpoint the origin of disease, which could be influenced by numerous environmental factors.

This leads us to the final challenge scientists face: it is difficult to separate genetic diseases and diseases with environmental causes (Berman, 2018:97). He is of the opinion that it is difficult to classify diseases by genetic mutation when there are many genetic diseases that are biologically complex processes with multiple genetic and environmental components. He added that scientists will continue to struggle when attempting to classify disease solely on genetic classification. However, he implores scientists to continue with their work as genetics will play a vital role in precision medicine.

Precision medicine aims to develop processes to identify what medication will work for individuals based upon their genetic makeup. Current advancements and research are focusing on treating cancer through this process (Berman, 2018:97). This study does not include an overview on precision medicine, but it is recommended that further study be done on this topic. Due to the cost of precision medicine, it is suggested to study the effects of this type of treatment on the poor, especially if it is effective treatment against specific life-threatening diseases such as cancer.

The challenges highlighted in this section does not mean that scientists should not pursue genetic editing, but it underscores the complexity faced when it comes to genetic editing and disease. There has been great success with studies involving gene editing such as the treating of myelogenous leukaemia, as well as the successful treatment of sickle cell anaemia as mentioned in the previous chapter (Gibson, *et.al*, 2010:52; Kaiser, 2020). With these challenges in mind, it is necessary to explore what is defined as genetic disease.

3.2.3. GENETIC DISEASE: A DEFINITION

Defining genetic diseases can be complex, as seen in the previous section. It is important to note that genetic defects do not automatically point to disease (Berman, 2018:96; Sosnay & Cutting, 2014:295). Sosnay & Cutting (2014:295) highlight that through current gene sequencing technology available today, it is evident that genetic variants could be the cause of disease, contribute to disease or have no influence on the development of disease. They state that the genome contains many variants and only some of them are linked to disease.

During the previous chapter the complexity of the genome was highlighted and defining genetic disease seems to be just as complex. Padyukov & Alfredsson (2014:xviii) agree with this statement and add that it is difficult to find a simple definition for it. They point to the fact that apart from genetic variants that do not cause disease, diseases caused by genetic influence can be divided into two groups, namely monogenic or single mutation, often referred to as Mendelian diseases, such as Muscular Dystrophy; and polygenic or complex mutations often referred to as common diseases, such as cardiac diseases.

Mendelian diseases are rare but easy to detect and diagnose while common diseases prove to be more difficult (Padyukov & Alfredsson, 2014:xvii). Mendelian diseases are caused by a mutation of a specific gene. By linking the signs and symptoms with the genetic mutation it is possible to reach a diagnosis of the disease. It is important to note that although this process seems simple it is still complex. Padyukov & Alfredsson (2014:xvii) point out that the diagnosis of these diseases is not based on a single test or symptom, but rather a group of parameters and clinical symptoms. This combination of several conditions with similar dysfunctions for a specific organ or tissue group is then grouped together in one disease group. This is referred to as a phenotype. However, Padyukov & Alfredsson (2014:xvii) highlight that the complexity continues as a specific disease group can have several phenotypes due to pleiotropic effects from the same gene. Thus, within the same group of diseases it is possible that the disease present different symptoms, depending on the mutation. While mendelianian

diseases are complex to diagnose it can most often be traced back through heredity patterns, apart from *de novo* mutations.

Complex genetic diseases on the other hand are far more difficult to diagnose or to isolate a root cause. Patterns relating to heredity are not always as obvious. Many times a combination of the environment and genetics plays a role in the genesis of the disease (Padyukov & Alfredsson, 2014: viii; Craig, 2008:184). Craig (2008:284), adds to this by stating that complex diseases do not follow a typical Mendelian heredity pattern. There seems to be a spectrum of combinations which includes external, physiological and genetic prerequisites that cause the disease. Padyukov and Alfredsson (2014:xviii) define complex genetic diseases as follows:

“Complex (genetic) disease is a pathological condition that shows significant features of inheritance, but cannot be explained on a group level by a single genetic risk factor and depends both on environmental and genetic contribution.”

Examples of complex diseases are schizophrenia, rheumatoid arthritis, diabetes and cardiovascular disease (Padyukov & Alfredsson, 2014:xviii; Berman, 2018:96; Craig, 2008:184). Padyukov & Alfredsson (2014:xviii) are of the opinion that most diseases have a genetic predisposition, which includes infectious diseases. On the latter they expand by stating that the strength of the immune system is often determined by genetics and also play a role in whether a person can fight infection before it causes disease. This theory seems to support Bostrom’s (2004:493) view that all disease can be eradicated through genetic editing by enhancing the immune system.

The fact that genetic variants are common amongst individuals as pointed out by Berman (2018:97), as well as Sosnay & Cutting (2014:295), indicates that defining genetic disorders or diseases cannot be made solely based upon genetic variants. It is a combination of genetic mutations and clinical presentation of disease, which is

easier to diagnose and define in Mendelian genetic diseases. This would also imply that single gene disorders will be easier to treat through gene therapy.

3.3. GENE THERAPY

During the previous chapter the accomplishments of gene editing was highlighted. Gene therapy is still in its infancy with many therapies still in research or clinical trial phase (Hanaa *et al.* 2016:1; Mitha, 2020). What is evident is that since 1989 scientists have made progress with gene therapies. Mitha (2020) states that during 1990 the first human trial was launched. A four-year-old girl with a rare genetic disease called Severe Combined Immunodeficiency, a disease that kept her at risk of infection that could kill her, received gene therapy for 12 days. During the trial a correct copy of the defective gene was delivered by means of a virus vector. The trial was a success, and she was able to lead a normal life without fear of infection (Scheller & Krebsbach, 2009:585). This caused excitement and various other genetic trials started globally. The excitement came to a halt during 1999 when an 18-year-old died only hours after he received gene therapy (Hollon, 2000:6). The cause of death was deemed to be an allergic reaction towards the vector that was used (Mitha, 2020; Weiss & Nelson, 1999; Hollon, 2000:6). Following this incident, the American Food and Drug Administration closed 69 clinical trials due to safety concerns (Hollon, 2000:6; Mitha, 2020).

Mitha (2020) states that during 2003 China announced the approval of the first gene therapy to treat head and neck cancer. Pearson, Jia and Kandachi (2004:3) are of the opinion that although China was the first country to approve gene therapy, questions were raised regarding their technology and regulatory boards. China was followed by Russia who approved gene therapy for peripheral arterial disease²³ during 2011 and the European Commission approved gene therapy for lipoprotein lipase deficiency²⁴ during 2012 (Libby & Wang, 2014:47). Russia's gene therapy proved to be deemed successful as patients continued to show improvement even 5 years following the

²³ A disease characterised by the narrowing of arteries restricting blood flow (Merriam-Webster, 2023).

²⁴ A disease that disrupts the normal breakdown of fats in the human body (Balasubramanian *et al.*, 2022)

initial treatment (Deev *et al.* 2018:237). Unfortunately, the therapy approved by the European Commission was discontinued as it became the most expensive therapy in the world, only to be administered to one patient (Mitha, 2020; McConaghie, 2017).

Maldonado, *et al.* (2021:267), states that since 2012 the number of clinical trials and gene therapies have increased exponentially. It seems as if the development of CRISPR CAS 9 technology is playing a major part in this. During 2012 scientists managed to programme cells using CRISPR CAS 9 to make specific DNA cuts and insert DNA accurately. The technology was a massive breakthrough and is currently being used in various research projects with the aim of eradicating disease (Doudna & Stenberg, 2017:165). Maldonado, *et al.* (2021:267), documents that during February 2020 there were more than 4000 ongoing clinical trials. They added that although there are numerous ongoing trials, only a few products make it to market. Most of the trials are focusing on somatic gene therapy and mainly on cancer treatment. The table below indicates the gene therapies approved in Europe since 2012:

Approval Date	Product Trade Name	Condition
2012	Glybera®	Lipoprotein lipase deficiency
2015	Imlygic®	Regionally or distantly metastatic unresectable melanoma
2016	Strimvelis®	Adenosine deaminase deficiency (ADA)
2018	Kymriah®	Relapsed or refractory B-cell acute lymphoblastic leukemia
		Relapsed or refractory diffuse large B-cell lymphoma
2018	Yescarta®	Relapsed or refractory DLBCL and primary mediastinal large B-cell lymphoma

		Some types of non-Hodgkin lymphoma
2018	LUXTURNA®	Inherited retinal dystrophy caused by biallelic RPE65 mutation.
2019	Zynteglo®	β-thalassemia with regular blood transfusions

Table 3.1: Gene therapies approved in Europe since 2012

Maldonado, *et al.* (2021:273) support the view that new technologies such as CRISPR created a new sense of optimism amongst researchers. They are of the opinion that by 2024 the FDA should have approved no less than 40 new gene therapies in the United States and Europe should expect the same number. Maldonado, *et al.* (2021:273) added that scientists, doctors and health administrators should work together to prepare the general society for these types of treatments and warned that acceptance by society at large could be a major hurdle if not done so.

3.4. SOMATIC AND GERMLINE GENE THERAPY

When referring to gene therapy it is important to understand that genes can be altered through germline editing during the embryonic stage or in individuals at a later stage following birth called somatic gene editing (Resnik, 2016:190). We will deal with both types during this study as both have its own ethical challenges.

Somatic gene editing is less controversial than germline editing, and the main reason is the difference between somatic gene editing and germline editing. During somatic gene therapy only the localised cells of the individual who is being treated are affected. Thus, in theory the individual will not pass on the edits to another generation. However, Resnik (2016:190), points out that certain somatic changes can affect the germline. An example is where the stem cells that generate sperm cells are edited it will be passed on to its offspring.

Germline editing is different in the sense that it occurs on embryonic cells and affects nearly every cell in the body, including reproductive cells which makes it possible to pass on the changes to the next generation. One of the main challenges of germline editing is that the changes are extremely difficult to predict (Bergman, 2019; Resnik 2016:190).

Editing embryonic cells in the laboratory can assist researchers with identifying off-target edits and raises the question as to why this can't be used as part of research (Bergman, 2019). She adds that by editing embryonic cells in a controlled environment researchers can identify what health benefits germline editing can have as well as how future risks can be reduced. There are scientists that support this view, and question why editing of the germline can not continue as the benefits outweigh the risks. This view holds that if the germline can be edited in a safe environment, it will greatly speed up the scientific process of gene editing. Resnik (2016:190) does highlight that the goal of genetic therapy is morally acceptable because the aim is to treat or cure a disease. This is a controversial statement and not held by many ethicists and will be discussed during the next chapter. One of the major objections to gene editing relates to the notion that it can be used not only for curing diseases, but also to enhance the capabilities of a person, thus enhancing humanity as a whole.

3.5. HUMAN ENHANCEMENT

Through the course of this study we have reviewed the history of genetics as well as how health and disease are viewed. The latter included various views on value-laden definitions which could influence our reasoning on human enhancement. Cole-Turner (2011:1) states that we use technology to enhance ourselves on a daily basis. He added that these enhancements are modifying our human traits and capacities. The examples provided include athletes that use drugs to enhance strength and stamina, cosmetic surgery to improve physical appearance, and university students taking medication to enhance their mental abilities.

The common denominator amongst all of the examples is that technology is used for the purpose of enhancement. Almeida & Diogo (2019:183) corroborate this and state that there are countless examples where technology have improved the lives of individuals. One example Almeida & Diogo (2019:183) provide is the enhancement of the eye. The spectacle was invented around the 13th century (Fox, 1890:1) and since then there have been remarkable progress. Most of the examples do however point towards external enhancement and not internal changes to DNA. The notion of enhancement as we understand it today is not new. During 1923, Haldane published a paper in which he argues the benefits of human enhancement through technology. These enhancements included genetic enhancements making humans taller and healthier, and increasing intelligence (Bostrom, 2005:5).

3.5.1. HISTORIC OVERVIEW OF HUMAN ENHANCEMENT

Throughout history there is evidence of farmers and botanists using specific techniques to enhance or improve livestock or plants. Breseghello (2013:8278) points to the genetic changes that were made to teosinte, a type of grass with kernels. The constant selection and planting process changed the genetic makeup of the grass to what we know today as maize. He highlights that this “plant enhancement” process was practiced since the beginning of agricultural history.

During the 1760s hybridization experiments indicated that specific traits from different sub-species can be selected and produce specific results. This was further developed with the understanding of heredity that was derived from Mendel's work, as outlined in chapter 2. Breseghello (2013:8278) states that most plant breeding programs today involve some form of hybridization. Groeneveld (2010:6) is of the opinion that selective breeding has created great diversity within a given species. This escalated during the past few centuries with well-defined breeds being used for specific purposes, such as race horses and specific dog species.

It is thought that dogs were the first animal to be modified through selection (Rangel, 2015). Rangel (2015), indicates that this practice seems to have started during the

hunter gatherer period. From historic accounts they seem to have domesticated wild wolves to aid them with the hunting process. With time the wolves were selectively bred which caused a diverse genetic pool with specific traits. The same process was followed with farm animals. Mei, *et al* (2019:1201) state that cattle are one of the most important livestock species in the world today. Milk, meat and leather is some of the products derived from cattle and through selection farmers and scientists were able to breed cattle that maximise specific production. Essentially this is nothing more than eugenics, where an individual, business (economics) or the state, decide on what organism should be paired with another – and if they do not have specific traits, they are essentially discarded.

There is evidence throughout history that points to humans trying to expand their own limitations (Bostrom, 2005:2). He added that there are individuals that constantly strive to remove obstacles and limitations in the pursuit of human happiness. He points to the search for the mythical fountain of youth and the search for longevity through alchemists. The alchemists invented various compounds that supported technology such as improvements to metallurgy.

The conflict between individuals who advocate change of the current human state and those opposing this view is an age-old debate (Bostrom, 2005:2). Many scholars during medieval Christianity opposed the experimental teachings and believed that alchemy was demonic. However, other Christian scholars were pro-alchemy and Martin Luther even used a process utilised during the experiments to teach on eschatology (Nummedal, 2013:311).

The Renaissance ushered in a change in perspective on philosophy. One of the main perspectives that was changed was the focus on the human, which in turn led to humanism and modern thought (Blum, 2010:1). Bostrom (2005:2), believes that during the Renaissance the human being and the natural world became the object of legitimate study. During the Renaissance people were encouraged not to take everything to the religious authorities, but to rely on themselves and their own judgement. Bostrom (2005:2), adds that the Age of Enlightenment started following a

publication by Francis Bacon during 1620. Bacon proposed an empirical scientific methodology instead of relying on faith for the unexplained. This can be seen as the birth of rationalism which advocates human reason (Mendz & Cook, 2021:106). Mendz & Cook (2021:108) add their anthropologic view and states that rationalism aimed to segregate human reason from the known world. The subsequent result was that human reason was seen as reality and different from the world. They continued stating that a dualism exists within rationalism in the sense that “I” was not part of the body, but rather the body is possessed, or occupied by “I” who is seen as the actual person. It is against this backdrop that human enhancement should be understood. According to Bostrom (2005:2), Bacon advocated using science to master nature and improve the condition of the human being. Tollefsen (2015:104) seems to agree with Bostrom and states that Bacon was concerned with the wellbeing of the human condition and proposed relief through scientific means. When assessing the proposals made by Bacon and his peers during this period against the backdrop of the growing rationalism, it becomes evident that nature is reduced to physical and biological dimensions that limit the true person.

Bacon’s concern included the suffering from disease, disability and mortality (Tollefsen 2015:104). This seems to coincide with the view of transhumanism (Mendz & Cook, 2021:108). Bostrom (2005:2) emphasises that evidence exists that during the 18th and 19th centuries individuals started to realise that science can be used as a tool to enhance human beings. He added that Darwin’s publication of the “*On The Origin of Species*” points to the thought process of the time. Philosophers and scientist were seeing humanity not as the end point, but humans are only part of evolution which could be in an early phase. Bostrom (2005:3) believes that the scientific physicalism views of the time contributed to the thought that technology can be used to augment and improve the human state.

During the Enlightenment Francis Galton, influenced by Darwin’s theory on natural selection, proposed a form of selection of human beings based on specific traits. It would seem that this was the start of the eugenics movement (Galton, 1998:263; Lombardo, 2011:1; Aubert-Marson, 2009:641). Mendz & Cook (2021:109), highlight

that transhumanism and eugenics are not the same, but they do have the same ambitions namely, enhancing the human or a specific population. Galton proposed this type of selection as a form of selective enhancement and called it a science of improving inherited stock (Galton, 1998:263; Lombardo, 2011:1). According to Galton (1904:1), eugenics deals with all influences with the aim to improve inborn qualities of a race. He continued stating that there is a difference between goodness of several qualities and character. The term character refers to the proportion of these qualities that are considered as good. When it came to the topic of eugenics Galton (1904:1) acknowledged the challenge to include morals into the discussion and believed morals should not be included as it complicated the discussion. Galton & Galton (1998:99) highlighted that Francis Galton's main motivation for promoting eugenics to "breed" better races was the focus on inherited factors such as intelligence, energy level and cognition. They continued stating that he was of the belief that eugenics would give the "superior" race the advantage to prevail over the less suitable.

Francis Galton is seen as the father of eugenics. However, the notion of eugenics was not new as it was proposed by the Greek philosopher Plato as early as 427 BCE (Galton & Galton, 1998:264; MacKellar & Bechtel, 2014:15). According to MacKellar & Bechtel (2014:15), it would seem as if there was another kind of eugenics in the city of Sparta even before the notion was brought forward by Plato. In Sparta they selected babies based on physical traits and babies were left unattended outside the city borders to test their strength. Those too weak did not survive the period and died of exposure. This practice did not last long and was rejected by the community.

Plato drafted a blueprint for the ideal society and proposed eugenic principles to ensure "judicious mating". Galton & Galton (1998:264) indicated that Plato proposed that the class status that was prevalent during his time needed to be abolished and provision made that a man and a woman who have the same natural capabilities be allowed to mate. His proposal included an explanation of the selective breeding similar to those with sporting dogs and horses. By selective breeding the desired properties within a population can be retained. In order to produce the perfect offspring with the

most desirable qualities Plato proposed that men should only be allowed to have children once they reach the age of 25 and women 20 years.

He suggested instituting two classes, the guardian class being the class with the most desirable qualities, and the civilian class who were those with less desirable traits. Within the guardian class he recommended that the individuals with less desirable or inferior qualities should be discouraged to have offspring. He continued with the notion that only the best offspring should be kept in the guardian class while the inferior individuals should be relegated to the civilian class, whose main role is to focus on farming and crafting (Galton & Galton, 1998:264).

In order to achieve this Plato suggested that the selection between the best men and women should be conducted via a lottery system. The aim for this process was to take away the feelings people might harbour regarding awareness of the selection process (MacKellar & Bechtel, 2014:15). These notions of “selective breeding” diminished with the rise of monotheistic faiths such as Judaism and later Christianity. These religions were not in favour of either infanticide nor the notion that the state should interfere in the marriage between a man and a woman. It was only again during the rise of the Enlightenment that scientist reconsidered these notions (MacKellar & Bechtel, 2014:16).

It was at this junction that Francis Galton, who was influenced by his cousin and grandfather, proposed eugenics again. MacKellar & Bechtel (2014:16) is of the opinion that the principles of natural selection influenced eugenics, especially the notion that humans should not be viewed differently than any other animal. Galton believed if humanity could implement a breeding strategy like the ones used to breed domestic animals it would enhance desirable human traits. This included “breeding” stronger individuals for specific tasks and intellectual individuals who would be able to advance the scientific field. Galton recognised that specific gifted individuals fathered offspring with similar gifted traits, and he suggested a ranking system, like Plato’s, to favour desired genetic heritage (MacKellar & Bechtel, 2014:17). When looking at both Plato and Galton’s theories there are distinct parallels with eugenics and selective breeding.

This can be seen with plant and animal breeding programmes aimed to produce an enhanced species. Thus, the process is focussed on the natural and neglect the spiritual human element.

The early twentieth century saw the adoption of eugenic policies in most of Europe, Canada and the United States of America. During the 1920s these countries developed programs that would sterilize individuals who were deemed unfit to procreate. The aim was to reduce social degeneration and enhance the population (MacKellar & Bechtel, 2014:18). Marshall (s.a.) concludes that the same principles used during selective breeding in animals are used during eugenics. Thus in theory, if the principles are applied over an extended timeframe the outcome will be a society with “desirable” traits. Bostrom (2005:5) highlights that these eugenics policies were state sponsored and violated many individual rights. He added that more than 65, 000 individuals were forcefully sterilized in the United States alone, including individuals who were mentally disabled, the deaf, and the blind. This even included the homeless in some instances. Lombardo (2011:21) demonstrates the level of acceptance of eugenics during the 1920s by referring to a legal case in the state of Indiana. He refers to a case of *Buck v. Bell*, where the practice of forced sterilization was challenged. During his ruling the judge upheld the state forced sterilization and stated that “*three generations of imbeciles are enough*”. This seems to indicate that the practice was not only acceptable but also deemed necessary without considering the ethical consequences.

Various ethical arguments exist against the practice of eugenics and this topic will be explored further during the next chapter. MacKellar & Bechtel (2014:38) are of the opinion that there are various forms in which eugenics can be implemented. These range from non-intrusive country legislation to the recent biotechnological discoveries that enable man to essentially practice eugenics on cellular level. MacKellar & Bechtel (2014:38) provide an overview of how they believe eugenics can be practiced in various forms:

Eugenics through migration: An example of this is the US government immigration law implemented during 1917, which excluded immigration rights for all “*idiots, imbeciles, feeble minded persons, epileptics and insane persons*”. This was done on the basis that they may be detrimental to the heritage of the country. During 1929 origin quotas were implemented to ensure limited individuals from a specific country can enter the United States, thus attempting to control the genetic diversity within the country. Many countries still have quotas that limits the influx of immigrants but at the same time grants access to certain individuals who are viewed as an asset to the country even if the limit has been reached. Although the exclusion or inclusion of these criteria are not decided based on biology, one can argue that biology or genetic heredity do have an influence on the policies (MacKellar & Bechtel, 2014:38).

Eugenics by selection of a reproductive partner: Although controversial, a suitable partner is selected by one or the other individual due to perceived suitability or positive traits. A woman can choose a husband on the basis that he might have specific traits she would like to see in her offspring. MacKellar & Bechtel (2014:39) state that selection of a partner might occur as part of *assortative mating*. This implies that a person would look for a partner who is similar to them. For example, an athlete might only be interested or attracted to other athletes in the hope that their offspring will have desirable traits, or a specific person with an exceptional IQ is only interested in other individuals with a specific IQ. Although this type of eugenics is not forced, it still constitutes selection, due to the perception that specific desired traits will be passed on to their offspring. MacKellar & Bechtel (2014:41) highlight that there were countries that implemented methods for selecting reproductive partners:

- Nazi Germany:

During 1931 a decree was passed that men in the SS can only marry if the woman is of the German race and is of “healthy stock”. SS troops could only marry following approval from the National Leader or the Race and Settlement Main Office. The approval process included an extensive test and physical examinations from SS doctors. The application also required photographs of the man and the woman in bathing suits from three different angles and they

had to have proof of ancestry dating back to the 1800s. During 1935 this law was expanded and stipulated that Jews and (Aryan) Germans were not permitted to have any form of sexual relations, even if married.

- Premarital certificates:

The outcome of a study conducted in Cyprus during the 1960s and 1970s indicated that a large percentage of individuals were genetic carriers of a disorder called beta-thalassemia. This is an autosomal-recessive disorder that raises the risk of anaemia and other internal disorders. Due to the fact that it is autosomal recessive, the affected individual must have two copies of the specific gene to be affected. Following the outcome of the study the Church in Cyprus approved the use of premarital certificates. The certificates indicate carrier status of the individual and allows individuals to view the status of their potential partner before marriage. While this document does not prevent couples from getting married, it does provide the couple with the opportunity to decide if they are going to have children at risk of carrying the disease. At this stage there is not enough evidence to indicate that the process worked, but it would seem that the Church was in favour of premarital certificates in an attempt to curb diseases that are genetically transferred.

- “Generation of the Upright”:

Tay-Sachs disease is commonly found within the Jewish community. The disease is a degenerative disease that causes children to die within the first four years of their lives. Studies indicate that 1 in 29 individuals in the Ashkenazi Jewish population are carriers of the disease (Rozenberg & de Velga Pereira, 2001:146). The advancement of human genetics saw the establishment of *Dor Yeshorim* an orthodox Jewish organization who tests teenagers and keep a data base if they are carriers of various genetic diseases, including Tay-Sachs. When the individual reaches an age where they plan to marry, the organization can be contacted to obtain recommendations. If one of the individuals are carriers, they are advised against the marriage. The impact of this process saw

a decline of babies born with Tay-Sachs within the communality in the United States of America and Canada. Before the process the number of babies born with Tay-Sachs were between 30 and 40 per year, and currently only 3 to 4 babies with Tay-Sachs are born per year. It seems as if this process is achieving its goals, but it is not without controversy.

Eugenics by selection of the number of offspring: Although limiting the number of children might not be an obvious practice of eugenics, MacKellar & Bechtel (2014:46), include this as a possible means of eugenics. There are various reasons parents might decide not to have children, especially if the children are at risk of genetic diseases. They are of the opinion that this also falls under the definition of eugenics as the aim of eugenics is to create life with a positive outcome. Thus, deciding not to have children due to possible negative outcomes, such as possible diseases, is the same as selecting not to have a child with another undesirable trait. This point is controversial as the opposite can also be true. A specific society, population or country can encourage certain individuals to have many children to increase a specific trait in that population. One example is Nazi Germany, where specific individuals were encouraged to have many children. Another example is the Oneida community in New York.

During the 1800s John Humphrey Noyes founded the Oneida community. The aim of the community was to become a super race through perfectionism (Barnard, 2007). Richards (2004:46) highlights that partners were matched by intellectual, physical and spiritual characteristics. Noyes was a preacher and believed that through science and Darwinian principles a perfect human being could be “bred”. He conducted “breeding” experiments within the community and scientifically selected parental partners. The community was encouraged to have children with that specific partner to enhance the desired traits. This continued for ten years, and the experiment ended a year before the community dissolved.

Richards (2004:59) points to seemingly positive results from the experiment. He stated that follow up studies and reviews of the children born during the experiment indicates

that their growth was superior to those in the normal Boston school system. In conjunction with this a higher percentage of children had successful educational and professional careers. Further studies indicated that their death rates were lower than comparable US populations. Overall, the experiment of the ideology of “breeding” human beings like other animals seems to have been a success on certain levels. MacKellar & Bechtel (2014:46) indicate that this is called positive eugenics and the aim is to positively enhance the population through bearing children.

3.5.2. ENHANCEMENT TECHNOLOGIES

While gene editing in somatic and embryonic cells does have the potential to enhance the current human state, we should acknowledge that this is not the only technology that could be used to enhance human beings. Harris (2007:34) & Kourany (2014:984) are aligned with many scholars who insist that humanity is already enhanced and there is a clear distinction between current and previous generations.

Harris (2007:34) draws a line and uses Boorse’s definition of health and disease to indicate that the current enhancements are more than therapeutic. He adds that technology such as the microscope, binoculars and the telescope are clear examples of enhancing vision for non-therapeutic use. Technology that enhances human abilities can be classified into five groups, namely chemical, cyber, bio-technological, genetic and nano-technological enhancements:

- Chemical enhancements:

There are many pharmacological agents that are used globally to enhance the human being. Kourany (2014:984) points out that stimulants are used daily to enhance concentration, to prevent sleep and improve working memory. Other examples are anabolic steroids as well as “blood doping” to enhance endurance. Kourany (2014:984) highlights the use of beta-blockers²⁵ and other medication to block painful memories, using growth hormone to increase height, libido enhancers, potential

²⁵ Medication that decrease heart rate and the force of heart contractions (Merriam-Webster, 2023)

lifespan extenders and medication that enhance learning and memory. Not to mention the use of caffeine in search of the energy this provides.

- Cybernetic enhancements:

Cyber enhancements offer the opportunity to enhance the current state of the human being. Enhancing the human through cyber technology involves an interface to allow the technology to intergrade with a person. Kourany (2014:984) indicates that there are current therapeutic procedures that involves the integration of technology through electrodes in the brain. During 2016 Elon Musk started a company called Neuralink whose goal it is to develop high-bandwidth implantable brain interface technology to allow individuals to integrate with artificial intelligence (Lewis & Stix, 2019). Elon Musk indicated that their brain interface chips will move to human trials during 2022 (Goodwin, 2022). These devices enable individuals who are not able to communicate, to communicate with others. Other implants used during therapy includes cochlear implants that allow individuals who are deaf to hear again. By definition, using these implants means that these individuals can be classified as “cyborgs”. Bostrom (2005:5), is of the opinion that implant technologies will be used to enhance communication and interaction in the able bodied. The aim is to connect individuals directly to the internet which will allow a person to access any information they require in a specific situation. This will produce an unimaginable level of intelligence to ordinary individuals.

- Genetic/Biotechnological Enhancements

Biotechnology is used daily. Harris (2007:35) indicates that human immunity is enhanced through vaccinations which contributes to the decline in infectious disease and results in longer lifespans. Harris (2007:35) points to the eradication of polio and smallpox through vaccination and adds that vaccination is preventative in nature and not a treatment. Thus, it is classified as an accepted form of human enhancement.

Genetic enhancements can be made by editing the DNA of the individual. Recent technology is not only allowing scientists to sequence DNA but allows them to make

accurate changes to the genome which could lead to enhancement of the human being as we know today. Kourany (2014:985) highlights that genetic editing goes much deeper than embryo selection. Reference is made to studies that produced stronger, larger muscles and increased longevity (Goodman, 2009:240). Technology available to perform enhancement was discussed in depth during chapter 2.

- Nano technology

Kourany (2014:985) is of the opinion that nano technology is most promising for human enhancement. The reason is that it is believed to integrate with biology on a nano scale. The technology can also be used to treat and repair structures within the human body that would require surgery under normal circumstances. Kourany (2014:985) expands on this and states that nano technology can also be used to augment the cognitive functions.

What is evident is that recent technological advancements paved the way not only to select children but with editing technology it could become possible to select, edit and introduce new traits enhancing the current human state. Apart from the various technological advancements highlighted in this study, we will turn our focus on specific enhancements that have a direct enhancement effect to the human being. The majority of enhancements start off as treatment for a disease or overcoming a limitation and, according to Harris (2007:34) then moves into the realm of enhancement.

3.5.3. TRANSHUMANISM / POSTHUMANISM

Transhumanism is an intellectual movement that is advocating the enhancement of the current human state through technology. Porter (2017:237) points out that the transhumanist movement is not only an intellectual group, but also a socio-political movement. He highlights that the transhumanist movement encourages the use of biotechnology, nano technology and technology in general to enhance the human ability in order to overcome current limitations. Bostrom (2004:493), an advocate of transhumanism, concurs with Porter's view and states that transhumanism aims to

enhance the human condition by promoting an interdisciplinary approach towards technology. Mendz & Cook (2021:108) are of the opinion that the transhumanists feel they have a moral obligation to enhance and advance humanity. In order to achieve this their focus is both on current technology, which includes genetic engineering as well as future technology such as molecular nano technology (Mendz & Cook, 2021:106).

Transhumanists view the current human state as a work in progress and part of the evolutionary process. Their view is that the human state will change inevitably, however, by using technology the evolutionary process this can be controlled (Mendz & Cook, 2021:106). One of the points highlighted by Bostrom (2004:493) is that transhumanism aims to use technology responsibly to become post-human, with greater abilities than current human beings. It is noteworthy that there is a difference between transhumanism and posthumanism. Transhumanism attempt to enhance the human state through technology. Posthumanism on the other hand deprives the human of ethical, legal and ontological status (Merzlyakov, 2022:475). Porter (2017:238) provides more context by stating that to be post-human means that the being will be totally different in terms of physical, cognitive and mental abilities. The enhanced human will be notably different from the current human being to the point where it requires a new term to describe the being (Bohan, 2018:11). This view seems to be aligned with the views of Rationalism that gave rise to humanism.

Transhumanists seems to be of the opinion that by changing the human condition either through biological or technological advancements, human beings will overcome their natural limitations (Mendz & Cook, 2021:106). Bostrom (2004:493) continues on the topic of post-humanism and states that some transhumanists are taking active steps in an attempt to increase the probability that they will live long enough to become post-human. This includes leading healthy lifestyles and making provision to be cryogenically frozen. This is corroborated by Dvorsky (2008:63), a transhumanist who changed his eating habits in an attempt to live long enough to see longevity technology come to fruition. He is of the opinion that the technology should be available by the turn of the century.

Transhumanism aims to use technology to live longer, healthier lives, enhance the memory of the human, redefine the human emotional experience and increase a sense of wellbeing. Cognitive enhancements could also lead to an enhancement of morality (Gordon & Ragonese, 2022:1). Ultimately the aim is to provide a person, or humanity more control over their lives (Bostrom, 2004:394; Wolfe, 2010: xiii; Mendz & Cook, 2021:108; Kourany, 2014:983). Mendz & Cook (2021:108) add to this stating that the broad scope of enhancement includes simple activities such as learning to use specialised biotechnology such as genetic engineering.

The current transhumanist thought is more focused on changing the human nature than on preservation (Bohan, 2018:12). Bohan (2018:12) continues, stating that transhumanism is open to changing the current values that define morality and shape the current human nature. Bostrom (2005:8) is of the opinion that there might be greater values that are not yet defined. He continues pointing to the dispositional theory of value, which according to Egan (2012:557) are theories whereby a value is identified with a dispositional property. Bostrom (2005:8) clarifies the theory and states that something is only seen as of value if a person wants to acquire it and if you are adequately aware of all aspects of the value while clearly thinking and contemplating it. He continues stating that humanity has various values that are not desired and when referring to posthumanism he is of the opinion that philosophers are not acquainted with all aspects of future values, or that it has not been contemplated. Thus, humanity is struggling to appreciate possible future values. Plainly stated, humanity does not understand the unknown and theoretically an enhanced human race can have enhanced values. One example of how values changed is how we view slavery. During the time of Jesus, slavery was a normal part of life. Slaves and their possessions were “owned” by their masters (Kirchschlaeger, 2016:68). Today, this practice is seen as unethical and while modern slavery is continuing on the black market, various efforts are undertaken by governments and Non-Governmental Organizations to curb the trend (Hodal & Kelly, 2016).

The fact that humanity is not able to comprehend future values is an important vantage point for transhumanists. Bostrom (2005:8) states that exploring future values does

not mean that the transhumanist should forego the current values. He continues by stating that future values can be added to transhumanist thought although certain values cannot be fully comprehended. The transhumanist should not value the life of the post human as higher than current human beings as humans possess the ability to rationalise and through this rationalisation transhumanists are able to theorise and realise ideals that are not accessible at this point in time (Bostrom, 2005:8).

Wading into theological realms, Bostrom (2005:8) focusses on transhumanist values and states that critics might see a resemblance between transhumanist thoughts about the future and Christianity. He highlights that in Christian theology individuals of the faith will be allowed to go to heaven. During that process certain physical and biological attributes will change before they enter heaven, including the purification of their minds. Some sceptics, according to him, argue that if the mind of an individual is changed it might indicate that the person will not be the same individual. In parallel, transhumanism is facing the same challenge. The challenge he is referring to relates to the question whether posthumans will be seen as human due to the possibility that they will not be seen as a person. Bostrom (2005:8) is of the opinion that although a person will be enhanced in future, which includes cognitive enhancement, longevity, the ability to interact with artificial intelligence and be disease free, the person will not cease to exist. He continues by stating that if a human being enhances intelligence through education or is cured through medicine it does not mean that the person ceases to exist, it only means the person was enhanced through acceptable measures. This is an important aspect for transhumanists as they advocate research to upload human consciousness to technology, which begs the question: When the person is uploaded to a computer, does the person still exist, or is it only a copy of the person's behaviour and thought processes?

When it comes to value, Bostrom (2005:9), is of the opinion that preservation of identity is not important. Value according to him can be obtained through external means and is content if some values fall to the wayside in the name of enhancement, even if it results in being classified as not being the same person. In theory an enhanced individual will not be the same person as before the enhancement, similar to someone

whose views, actions and values changes following enhancement through education. Whether this means a person is a completely new person is debatable, but it does correlate theologically to someone who was reborn in the Christian faith. It can be debated that Paul was not the same person following his Damascus experience as seen in Acts 9. A proper exploration of what values humanity is willing to trade in order to obtain an enhance state should be considered (Bostrom, 2005:13). He is of the opinion that humanity may favour a posthuman society to that of the current human state. Bostrom (2005:13) articulates the core value for transhumanism of “*Having the opportunity to explore the transhuman and posthuman realms*”. In order to achieve this certain conditions need to be met.

Three conditions should be met before the transhumanists will be able to progress whereby to realize their vision of an enhanced society (Bostrom, 2005:10). The first condition relates to global security, which, mainly relates to the topic of existential risk. The theory of existential risk implies that enhancing humans could culminate in an outcome where earth is annihilated or where intelligent life or its potential is permanently reduced. Bostrom (2005:10) indicates that this condition is non-negotiable as extinction will result in ultimate enhancement not being realised.

The second condition he highlights relates to technological progress. The limitations to be overcome are complex, especially biological limitations. Advanced technology is required to overcome these limitations. According to Bostrom (2005:10), economic development, growth and productivity are key drivers to ensure technological enhancement. He provides an example where the economic growth during the past few decades had a drastic impact on technological advancement. When referring to technological progress, the focus is not on a single technology, but on technology as an industry.

The third and final condition Bostrom (2005:10) highlights relates to accessibility. One of the core values is that human enhancement should be available to all. He is of the opinion that it would be sub-optimal if becoming an enhanced species is only available to an elite few. In order to gain support for the ideals of transhumanists inequality

should be reduced and suffering should be alleviated. This will accelerate the ideals of the transhumanist to which Bostrom (2005:10) adds is a moral obligation to save lives. He supports his view stating that a hundred and fifty thousand people die every day, which could have been prevented if technology was available to them.

Transhumanism focuses on individual freedom (Bostrom, 2005:11). He explains that through this freedom they do not limit the choice of enhancement technologies. From a transhumanist perspective each individual has their own opinion on what they consider as enhancement and what perfection should look like. Bostrom (2005:11) states that each person should choose if they would like to be enhanced or stay the way they are. The challenge with this view is that once enhancement is accepted as a trend in the mainstream, individuals might buckle under peer pressure to get irreversible enhancement procedures. Bostrom (2005:11) highlights that if the enhancement poses a risk to other people, it should be regulated. He continues by highlighting that disgust or offence should not prevent a person to use technology to enhance themselves.

Transhumanism value enhancements and improvements both from an individual and collective perspective. They are of the opinion that they will need to use technology to ensure that the enhancement debate moves forward and to implement the techniques. Enhancement drugs might be used to increase intelligence and technological memory chips could be used to show the efficacy of the technology (Bostrom, 2005:11). Bostrom is of the opinion that transhumanists should educate themselves, use critical thinking, artificial intelligence and cognitive enhancing techniques to take part and expand on democratic responsible discussions for the implementation of human enhancement. He concludes that the current level of intelligence and means of debate might not be adequate for the enhancement in future.

From an anthropological perspective, Mendz & Cook (2021:108) state that rationalism aims to segregate human reason from the known world. The subsequent result was that human reason was seen as reality and different from the world. They highlight a dualism within rationalism in the sense that a real person is not seen as part of the

body, but rather that the body is possessed, or occupied by the person. Both Bostrom (2004:494) and Porter (2017:238) agree that transhumanism is a continuation of rationalism started during the Enlightenment.

While the transhumanist still focusses on the traditional values of rationality and autonomy, they do differ in the sense that humanists rely on education and culture to refine humanity while transhumanists apply medical and technological advances to enhance and refine themselves (Bostrom, 2004:394; Porter, 2017:238; Wolfe, 2010:xiii). Bohan (2018:12) highlights that while transhumanists see their beliefs as an extension of humanism, the humanist view is more conservative and does not align with the progressive views of transhumanism.

Bohan (2018:17) provides insight on the themes most transhumanist thinkers align upon, namely:

- Desire to become post-human
- Scientific and evolutionary world view
- Existential risks
- Space colonisation
- Augmented intelligence
- Life extension
- Extending health span
- Cryonic suspension
- Optional death
- Conscious evolution
- Morphological freedom
- Accelerating evolution
- Technological singularity
- Nanotechnology, biotechnology, information technology and cognitive science

Mendz & Cook (2021:106) add that the landscape of interventions is large and includes possible recalibration of pleasure centres to enhance lifelong happiness.

They continue stating that due to the broad scope of transhumanism a systematic overview is almost impossible.

Transhumanists acknowledges that the technology is used to enhance the human state can be used for harm (Bostrom, 2004:494). Bostrom (2004:494) is of the opinion that the technology could cause the end of intelligent life. Mendz & Cook (2021:106) echoes Bostrom's view and add to it by stating that the technologies used for enhancement can be regulated to limit the existential risk. The question should be asked whether the scope of transhumanism is not too large to provide a systematic overview (Mendz & Cook, 2021:106). They question whether it is going to be difficult to regulate. Although there are suggestions that the advancements should be regulated, what is evident is that there are not answers regarding the social regulation of human enhancement technologies while balancing an individual's rights. Further research and discussion is recommended on this topic. While there is a real threat that technology could be misused or abused, it seems as if the benefit of overcoming the current human limitations outweighs the existential threat.

Humanity can be enhanced considerably and what we know as human today is only a small part of what is possible (Bostrom, 2005:4). Bostrom's (2005:4) hypothesis is based upon the belief that just as other animals, humans have intrinsic limitations that they might not be aware of. This evolves into the belief that currently humans do not understand what is possible should enhancement be pursued. He aligns with Bohan (2018:17) on the topic and highlights five specific limitations that can be overcome through human enhancement:

- Increasing the human life span

Human beings have a relatively short lifespan (Bostrom, 2005:5). Bostrom is critical of the length of the human lifespan and indicates that tortoises live longer than the average human, while the human has an intellectual capacity much higher than the reptile. He continues with the fact that the human lifespan is much shorter than other geological or cosmological comparisons. According to the WHO the average global

life expectancy is rising steadily. The current life expectancy of men is sixty-eight and a half years, and seventy-two years for women. However, in Hong Kong the life expectancy for both males and females are eighty-four (WHO, 2020). Bostrom (2005:6) is of the opinion that if the lifespan of a human could be longer it will benefit humanity. Examples he provides are the lives of Beethoven and Goethe stating that they would have been able to contribute more to the arts and culture if they were able to live healthy longer lives. With the key emphasis on healthy lives.

One challenge to increasing life expectancy relates directly to disease. Rae *et al*, (2010:1) highlight that it is evident that a person is more susceptible to disease, especially chronic disease as the body ages. Research seems to indicate that the reason for this is the accumulation of toxin and changes at cellular level. Rae, *et al* (2010:1) are of the opinion that this aging damage is side effects of a normal metabolism and aggravated by toxins and unhealthy lifestyles. Meta-research seems to indicate that life spans are not fixed and can be increased by diet manipulation which include calorie restriction. Editing of the human genome is one of the suggested methods to lengthen the human lifespan (Mendz & Cook, 2021:109). This can be achieved by eradicating or lowering an individual's predisposition to a specific disease. Bostrom (2004:498) is of the opinion that being free of disease will not only lengthen the life span of an individual, but theoretically speaking, also ensure they have a better quality of life. Zoppi (2019) refers to a study conducted by the University of East Anglia and Uppsala University that found lifespans could double with gene editing. Lind, *et al* (2019:214), who conducted the study also found evidence that by editing the insulin/IGF-1 gene, the offspring of the individuals who underwent somatic gene editing, might be healthier.

It seems as if technological advancements, such as gene editing, can support the transhumanist vision to extend life. Although this is the case, it has to be highlighted that it seems as if an extended lifespan might be as a result of using gene editing in an effort to treat or cure a specific disease. Thus, it can be concluded that, similar to other drugs for cancer treatment today, curing or eradicating disease through gene editing technology, even somatic editing, will increase the human lifespan. Increasing

the human lifespan is one of the key goals of the Methuselah Foundation founded by Aubrey de Grey (Palmer, 2009:45). Palmer highlights the effect on the economy, especially pensions. However, the impact on the ecology might be as great as the economy.

- Intellect

Increasing the intelligence of the human being is one of the goals of transhumanists. Although the human brain is already the most developed of any other organism, transhumanists hold the view that the current human intelligence is limited and propose technological and biotechnological solution to increase intelligence. Bostrom (2005:5) is of the opinion that, although there are limitations to the current human brain, it is not a barrier to human development. He continues by highlighting that our current limited human intellect might not be able to compute and understand problems that post-humans in the future will be able to grasp. Some of the key limitations he highlights concerns memory. Although a person is able to train a brain to increase intelligence, it is a slow and tedious process (Sternberg, 2019:6791). Healthy living and frequent memory training can improve this limitation, but it is not able to eradicate the possibility of forgetfulness. Bostrom (2005:5) is of the opinion that perfect memory will be possible in the future.

Future cognitive enhancement is possible through genetic editing (Lavazza, 2018:390). Numerous studies are being conducted in an attempt to isolate the gene(s) responsible for cognitive function. One study indicated that the COMT gene regulates the dopaminergic system and is responsible for long term memory and multitasking. Lavazza (2018:390) continues that cognitive enhancing through genetic editing techniques face challenges in the form of safety. While great strides are made in identifying the genes responsible for intelligence, editing these genes will take time. One of the key ethical challenges highlighted was the uncertainty of what to expect when editing these genes.

The first genetically modified twins were born in China (Sherman, 2018; Regan, *et al.* 2018). The team responsible for the editing commented that the aim of the research was to develop a cure for HIV through editing the CCR5 gene. New research indicates that the gene that was edited has a role to play in cognitive function and the twins could have enhanced cognitive abilities (Regalado, 2019). Although the ethical question should be asked whether the twins should be part of further studies. Should they show enhanced cognitive abilities, it will indicate that gene editing technology can be successful to enhance cognitive function.

A key aspect highlighted by Bostrom (2014:55) is that cognitive function can be enhanced by either embryo selection or selective “breeding”. Apart from the ethical challenges with this suggestion, the reality is that these programs will require a number of generational changes to make a substantial impact, something that is not feasible. He does offer a possible biological solution through the use of Stem cells and genetic editing. The suggestion is to derive gametes from stem cells, then select the best gametes and create embryos via in vitro fertilization (IVF). Once the embryo is at a specific stage, stem cells are selected again, and gametes are derived from these cells to start the process again. Bostrom is confident that this process will speed up the process of increasing biological cognition (Bostrom, 2014:57).

The challenge with this proposal at this stage is the assumption that the embryos will in fact have enhanced cognition. There are numerous external factors that impacts cognitive functions as alluded to by Bostrom (2014:55) with his statement that nutrition plays an important role in cognitive development. Bostrom is of the opinion that this process will take a few years to achieve and will be costly, but any genetic change only need to be made once to make a large-scale impact. Although the theory sounds impressive, the reality is that apart from being a costly exercise there, will be a dilution of genes if the “enhanced” population mixes with “normal” individuals. This raises ethical questions. For example, racial questions, questions of social class and if the already marginalized will become even more marginalized. A factor to keep in consideration is the fact that whoever will control this “experiment” will essentially be able to select and change a person to something exactly what they would like the

person to be. Additionally, due to the cost implications these embryos will receive the best treatment and all the opportunities to ensure success. This against a backdrop of poor people without enough resources to sustain themselves.

- Body function

There is an existing debate whether biotechnology is already used for human enhancement. The primary argument is that the natural immune system is enhanced through vaccinations and thus improving the quality of life as well as enhancing lifespan (Bostrom 2005:7). Other examples of enhancement include stronger, larger muscles and enhanced endurance. Shao, *et al* (2021:2) add to Bostrom and state that enhancement of body function can be obtained in numerous ways such as the use of enhancement drugs. They believe there are four types of enhancement drugs used widely in the world today, namely stimulant drugs, aesthetic analgesics, blockers such as propranolol and precool and synthetic steroids.

- Sensory modalities, special faculties, and sensibilities

The current human sensory function can be enhanced with magnetic orientation, sensors of electric vibration, better smell, and better eyesight (Bostrom, 2005:7). He adds that humans will not be limited to the current senses known today, as it might be possible to attain telepathic abilities or to interpret radio waves and see in infra-red. Shao, *et al* (2021:2) indicate that virtual reality is already used to provide sensory training in specific instances, such as reaction time of special policing units when facing physical danger.

- Mood, energy and self-control

Mood, energy and self-control is not usually associated with human enhancement, but Bostrom (2005:7) highlights that it is a critical part of human enhancement. The sense of well-being is imperative to attain human happiness. He added that chronic well-being seems to be genetically determined, which means that through genetic editing a person might be able to be happier. When it comes to energy and will power it becomes more difficult as this is dependent on a person's circumstances. It is

envisaged that through technology, which includes pharmacological agents, an individual could attain more energy and self-control.

The enhancement debate brought forth by the transhumanist movement seems to have good intentions. The moral argument is that enhancement will overcome the current limitations relieving suffering and pain. The question has to be asked, who makes the decision on what aspects should be enhanced? Not all human limitations are limitations, although it seems as if obvious diseases should be treated – which might give rise to the acceptance of enhancement.

3.6. DRAWING THE LINES: THERAPY VERSUS ENHANCEMENT

Although it might seem easy to draw the line between therapy and enhancement, this is not the case. Decisions in health care are made, based on the distinction between therapy, preventative care and enhancement. The magnitude of the debate cannot be underestimated as specific actions require specific moral considerations. The current medical view is that it is focused on providing a cure and relieve suffering and not to enhance a person's abilities to perform at a higher-than-normal level (Bruynseels, de Sio & van den Hove, 2018:5). Although the curative of medicine today is applies to various technologies, the focus here will be on genetic editing.

Green (2007:55) explains the difference between gene therapy or treatment and enhancement in the following table:

	Treatment or therapy	Enhancement
Somatic genetic editing	Somatic treatment or therapy	Somatic enhancement
Germline genetic editing	Germline treatment or therapy	Germline enhancement

Table 3.2: Gene editing options

The box is divided into four squares, the top left indicates what is considered as somatic gene editing for treatment purposes. The bottom left corner indicates the possibility of germline treatment through gene editing. The top right corner refers to the choice of enhancement through somatic gene editing and the bottom right the parents' or scientist's choice to edit a specific germline. A possible explanation of this box is:

	Treatment or therapy	Enhancement
Somatic genetic editing	Somatic gene therapy to treat inherited retinal dystrophy caused by biallelic RPE65 mutation	Somatic changes to enhance a specific capability such as muscle strength
Germline genetic editing	Editing of the germline to eliminate inherited retinal dystrophy caused by biallelic RPE65 mutation from a specific gene pool	Changing a specific germline to alter the muscle strength of all offspring in a specific gene pool

Table 3.3: Genetic interventions

This might allude to the possibility of clear lines between therapy and enhancement. However, this is not the case. Bostrom & Roach (2008:120) outline the challenges with this as follows:

- It is difficult to link therapies and enhancement to corresponding standard contemporary medicine and the type of medicine that will be practiced in future: Although there are interventions that are focussed on a cure in contemporary medicine, there are many other types of medicine focussing on prevention, fertility treatments, cosmetic procedures, palliative care, obstetrics, sports medicine and many more. Some of these overlap with what can be considered as enhancements. In contrast with this there are many non-medical interventions that focus on enhancement. These include coffee to be more efficient at work, makeup to enhance a person's appearance and vitamins or exercise to enhance the mood of a person. Hotze, *et al.* (2011:6) indicated during a study that 62% of physicians surveyed indicated that they receive requests to prescribe interventions that they would consider as enhancement on a monthly basis while 12% indicated they receive these types of requests daily. This seems to underscore the challenge Bostrom highlights.
- It is challenging to classify interventions that reduce the probability of disease or death: Bostrom & Rouche (2008:120) are of the opinion that vaccination can be seen as the enhancement of the immune system on the one hand, or preventative therapeutic intervention on the other.
- Defining normal is a challenge: When describing normal, there seems to be a distribution range and can be averaged with relative normal limits. Bostrom & Roche (2008:121) provide the example of cognitive capacity. When attempting to define an abnormality as falling too two standard deviations below the population average, is arbitrary as it lacks any fundamental medical or normative significance. One person might have a neurological disease that

reduces cognitive capacity and while this condition causes them to drop one standard deviation, they might still be within the average normal range due to them starting off at the higher end of the scale. Another individual might not have any signs of neurological disease but starts off one standard deviation below normal. While a therapy might cure the first person, the same therapy would enhance the second person's cognitive ability and push them into the normal range. They are of the opinion that in many instances it is unclear if there is a set of complex factors that determine a person's cognitive capacity as pathological or normal.

- It is difficult to define normal in a specific population, even within one person's lifespan: Capacities constantly change within a population and a person's lifespan. As a person advances in age their physical and mental capacities increase up to a point and then start to decline. The question Bostrom & Rouché (2008:121) pose is: If there is an intervention that enables an eighty-year-old person to do similar tasks than when they were in their twenties, will that constitute as enhancement? This serves as an example of the complexity to define normal.
- It is difficult to determine how "internal" an intervention must be before it is constituted as enhancement: When looking at enhancement, there are various examples that can be provided. Spectacles were mentioned earlier, but what about Lasik Surgery? In certain instances vision is enhanced following the surgery. It is quite murky whether enhancement can only be viewed if the intervention is "internal". Bostrom & Rouché (2008:123) are of the opinion that this needs to be clarified in order to discuss.

Green (2007:61) seems to agree with Bruynseels, *et al.* (2018:5) regarding the notion that the prevention of disease blurs the line between genetic treatment and enhancement. Lagay (2001:38) indicates that the enhancement of the human immune system through genetic intervention will be of great benefit and save millions of people

annually. Considering this “grey” line between therapy and enhancement, Green (2007: 61) offered a modified version of the genetic choices, which seems more accurate:

	Treatment or therapy		Enhancement
Somatic genetic editing	Somatic treatment or therapy	Prevention	Somatic enhancement
Germline genetic editing	Germline treatment or therapy		Germline enhancement

Table 3.4: Altered gene editing options

The proposal to “name” the grey line could assist with further discussions. However, calling the grey line prevention could initiate debates on its own. Lagay (2001:37) points out that apart from prevention there is another hypothesis that will not fall into the category of therapy, prevention or enhancement. Their hypothesis relates to the first point Bostrom (2008:120) makes regarding the challenge of not knowing what medicine or tests will be available in the future and states that remediation should be included. When referring to remediation Lagay (2001:37) is of the opinion that it might be possible to identify the gene(s) responsible for certain behaviours. For example, if the gene(s) responsible for aggressive, violent behaviour or the gene(s) that make a person prone to sexual violence can be identified, it could be edited and prevent the person from victimising others. This could remediate the person even before the violent act takes place.

Clarifying the meaning of enhancement is important before attempting to identify the difference between treatment, prevention and enhancement. Cole-Turner (2011:1) asks this question regarding the definition of enhancement. He is of the opinion that human enhancement is not easy to define. Hoffman (2017:1) provides a simple

definition on enhancement. He states that enhancement can be defined as any genetic, biomedical or pharmaceutical intervention aimed at improving the human state and where there is no pathology to be treated. Bostrom & Roache (2008:120) are aligned with the definition of Hoffman and state that enhancement is easier to define if it is contrasted with therapy. They are of the opinion that where therapy aims to “fix” something, enhancement aims to improve the state of an organism or its normal healthy state.

Not all philosophers agree with the definitions provided by Bostrom, Roache and Hoffman. Contrary to their view, Cole-Turner (2011:1) states that if the definition was so simple as improving or increasing performance, ability or capability, the next question arises: what is meant by improvement or increase? He continues by stating that an athlete might think increasing his strength is enhancement, but at what cost? If he enhances his strength but impairs his overall health, does this constitute as enhancement?

The challenge with defining enhancement comes in the form of the value it might bring to a person and the fact that every person differs in their estimation of value. To use the example of the athlete, they might value the addition of their strength to achieve Olympic success at the expense of their health. Someone else might value their health much more than Olympic success. Cole-Turner (2011:2) states that the best way to define enhancement is to leave it to the individual. Thus, if the individual is of the opinion that the technology made an improvement or enhanced themselves, that should be considered enhancement. He adds that it is the only way society can settle on a potential endless debate regarding this topic.

The problem with Cole-Turner's view is that it only creates more questions and debates. What if the person is influenced or is under pressure to make the decision to “enhance” themselves? Does this still represent an enhancement? Summerfield & Tsetsos (2015:27) state that it is difficult to determine what biological and computational mechanisms are used for decision making. The major hurdle is to what

extent choices are optimised to account for prior beliefs and uncertainty in environment, or whether human choices are biased or irrational.

Summerfield & Tsetsos (2015:27) provide three scenarios ranging from simple to complex decision-making:

- I. A footballer deciding whether to angle a penalty shot in the left or right corner of the goal.
- II. A medical practitioner diagnosing a patient with chest pain.
- III. A politician deliberating whether a country should go to war.

All three require reasoning before a decision can be made. In the first example the footballer has to take into account many factors before making the call. The should be made easier if there is prior knowledge about the strengths and weaknesses of the opponent or if the footballer understands his own strengths and weaknesses. The second scenario also requires considering multiple factors before treatment options can be prescribed. The training and experience should guide the medical practitioner to make the correct decision. Evaluating the third scenario the same decision-making processes are at play as with a complex decision (Summerfield & Tsetsos, 2015:28). They claim that the challenge is not making the decision, but in deciding whether the decision is good or bad. By studying human behaviour scientists were able to prove that people make inconsistent decisions due to irrelevant contextual factors. To illustrate this the example of the well-known anchoring effect is used.

During 1974, Tversky & Kahneman conducted experiments on decision making and found that individuals make irrational decisions on a regular basis (Zeng, *et al.* 2020:1011). Teovanovic (2019:8) explains that the conclusion of the Tversky & Kahneman study pointed towards what is now known as the anchoring theory, or cognitive bias. He explains that the initial experiment used a simple two-step procedure where people were asked to make a judgement on how many African countries were part of the United Nations. During the experiment a “wheel of fortune” predicted the amount in percentage, after which the participants had to manually provide an answer. The result indicated a direct correlation between the random answers the “wheel of fortune” provided and the manual answers. If the random selected number was high, the manual answer was high and vice versa (Teovanovic,

2019: 8; Zeng, *et al* 2020:1012; Summerfield & Tsetsos, 2015:28; Bahnic, 2021:131). Zeng, *et al.* (2020:1011) state that since this initial study from Tversky and Kahneman, many other studies concluded that the anchoring effect exists in many fields such as general knowledge, probability estimates and negotiation. Summerfield & Tsetsos (2015:28) provide an economic example of cognitive bias. They state that consumers will bid higher for a house whose initial price is deliberately inflated. Lebowitz (2020) gives another example where during negotiations offers made first will be the anchor to any counteroffer. Other examples of cognitive bias are the “bandwagon effect” or “heard behaviour” where a person adopts a belief and/or act in a specific way purely on the basis that those around them have a specific belief or acting in a certain way (Banerjee, 1992:800; Bahnic, 2021:131).

From the preceding paragraphs it would seem as if decisions are influenced by many factors. This can cause bias-based decisions that could be incorrect and irrational. In an attempt to define human enhancement Cole-Turner (2011:2) suggests that enhancement is determined by the individual who receives the enhancement. From the view that cognitive bias could influence a person, Cole-Turner proposed that a solution to define human enhancement will not suffice. Through scientific studies it is evident that it is easy to influence an individual's decision. Take for example a study conducted by Huber, *et al.* (1982:95) that proved they can influence consumer choices by manipulating prices. If people are influenced towards a specific view, they might view an enhancement as something that is not actually an enhancement for them at all. It might also be that they opt for human enhancement because other individuals within a specific community are enhancing themselves, thus acting irrationally in a way that could be detrimental to their long-term health.

Another aspect that is challenging with Cole-Turner's view of letting each person define enhancement for themselves lies in the difficulty of predicting the future outcomes of decisions. Poon, *et al.* (2014:207) state that people often try to predict their future and these predictions have widespread consequences. They are of the opinion that people often overestimate their future which can lead to choices they later regret. They added that the reason individuals make optimistic predictions is because

they take and “inside approach” where they construct a mental model of the specific target or event. A person would be better off to step back and take an “outside approach” based on relevant and past experiences (Buehler, *et al.* 1997:245). Thus, if individuals are prone to make decisions based upon a flawed view of their predicted future, their view of enhancement might change in time.

The Nuffield Council of Bioethics appointed a working group to explore the ethical challenges posed by human genome editing (Gyngell, *et al.* 2019:514). The conclusion of the working group was a report titled “*Genome editing and human reproduction*”. An interesting element highlighted by Gyngell, *et al.* (2019: 517) is that the report does not differentiate between treatment of diseases and human enhancement. According to the report it is too challenging to find a clear distinction between treatment of diseases and human enhancement, thus they suggest the focus should rather take a principle approach than debating whether editing the human genome is for therapeutic or enhancement purposes. They suggested principles should be based on the future welfare of a person in conjunction with social justice and solidarity. While this is an interesting approach, the risks highlighted by those opposing human enhancement remain a reality.

3.7. PRELIMINARY CONCLUSION

The ethics of genetic editing is complex with opinions and views on all ends of the spectrum. Defining what is health and disease are central to grapple with the ethical challenges genetic editing brings to the table. Defining normality is proving to be a challenge of its own. It seems as if the definition of normality is a moving target as is evident in the example of osteoporosis which was only classified by the WHO as a disease in 1994 (Sculley, 2004:650). Understanding what is health and disease assists with discussions relating to human enhancement. Although not perfect, the WHO suggests a value-laden definition of disease. Opponents such as Boorse (Messer, 2011:164) disagree with the value-laden definition and proposed statistical methods to assist with the definition. The value-laden definition proposed by the WHO appeals with theological philosophers as it is closer to the teachings of wholeness and peace (Hanson, 2001:26). It is noteworthy that that the South African constitution

legislate that every individual has the right to access to healthcare. The “access” to treatment is dependent on resources and does not mean that a person automatically qualifies for any treatment, which is challenging in cases that require genetic therapy.

The technological advancements during the last decades are redefining the way scientists are viewing disease. Previously only signs and symptoms could be observed, but with the advancements it is possible to identify if a person is genetically at higher risk of a specific disease. Biotechnology makes it possible to edit an individual genetically and some are of the view that disease can be eradicated completely (Doudna & Strenberg, 2017:165). While this seems to be a noble cause it does bring ethical challenges that will be a focus area during the next chapter.

The possibility to make changes to the DNA does highlight the potential that the technology can be used to enhance the human state (Cole-Turner, 2011:1). Cole-Turner (2011) indicated that technology has been used throughout history to enhance the wellbeing of humanity. Thus, using biotechnology to enhance the human state is actually a natural part of development. The concept of human enhancement is not new and was a key driver during the Enlightenment (Tollefsen, 2015:104). Francis Galton popularised the concept of eugenics by suggesting the selection of specific human beings based on desired traits. The focus of the eugenics movement was to attempt to improve inborn qualities of a specific race. Eugenics policies were adopted by various states with the aim to reduce social degeneration and enhance the population (MacKellar & Bechtel, 2014:18).

Population enhancement through eugenics seems to be a slow and unpredictable method, not to mention the ethical challenges linked to this method of enhancement. However, enhancement could be achieved by using technology. This is advocated by transhumanists as well as post-humanists. The difference between the two ideologies is that transhumanists aim to enhance the human state while the focus of the post-humanists is to use various technologies to move to a post-human state. While the aims of transhumanism and post-humanism differ, they share the common goal of using technology for enhancement purposes. These enhancements range from

increasing lifespan, increasing intellect, and enhancing the function of the body, to enhancing sensory abilities and controlling emotions.

Through gene therapy specific diseases can be cured or treated. However, it is challenging to ascertain where therapy stops and human enhancement starts. If enhancement can be defined as endowing an individual with higher than normal capabilities, it is seemingly easy to identify. The challenge with enhancement is that according to some humanity is already enhanced through vaccines, as the immune system is enhanced through vaccines. Another possibility is to prevent specific diseases through genetic identification and editing. This would fall in the realm of prevention of disease and not treatment, but due to prevention the human is enhanced with higher than normal abilities (Lagay, 2001:37).

Enhancement could also lead to making incorrect decisions that are detrimental to an individual. With current enhancement technologies such as chemical enhancements, athletes can enhance performance, but it might be detrimental to their health. In these instances the question should be asked if this is truly enhancement. The Nuffield Council of Bioethics suggested a principled approach should be taken based on the future welfare of a person in conjunction with social justice and solidarity. This seems to suggest that changes to DNA are permissible and it does not matter if it is for therapy or enhancement, as long as it promotes the welfare of the person and society (Gyngell, *et al.* 2019:514). The focal point of the next chapter will be on the ethical debates surrounding gene therapy for treatment and human enhancement.

CHAPTER 4: ETHICAL ARGUMENTS FOR AND AGAINST GENE EDITING

4.1. OVERVIEW

Ethical debates are well documented throughout history and although technological advancements prompt specific discussions, most of the debates are not new. The debates concerning genetic editing are more prominent during the past few decades as gene editing has the potential to change the human genome, seemingly without reversal. While this is the case, there are various debates for and against the use of this technology.

Safety is one of the debates against this technology, but this concern will dissipate once the technology is proven safe. The use of the technology should not only be subject to whether it is safe to use or not. It is likely that the consequences of genetic editing will only be evident decades following the original edit. However, it could be debated that gene editing is humanity's moral obligation as it will not only prevent disease, but also enhance the abilities of the human race. This chapter will focus on both the arguments for and against gene editing.

4.2. ETHICAL REASONS FOR AND AGAINST GENE EDITING

There are two gene-editing techniques, namely somatic editing and germline editing. Somatic editing refers to editing of specific cells and only affects one individual, thus the changes made to the DNA is not passed on to another generation (Resnik, 2016:190). Changes made during germline editing, however, is passed on from one generation to the next. Due to the distinct difference between the two applications there seems to be different ethical responses. Schaefer (2015) states that risk is the reason for the different ethical responses. He continues with the notion that germline editing is not as advanced as somatic editing and that the unknown causes anxiety. Generally, it seems as if regulatory bodies are in favour of gene editing, especially somatic editing.

An example of this observation appears in a statement following the *International Summit on Human Gene Editing* during 2015 (National Academies of Science, Engineering and Medicine, 2015). The statement is overwhelmingly in favour of gene editing, and contends that, subject to the appropriate legal and ethical guidance, research should continue. There are, however, differences in the approaches between somatic and germline editing. A conclusion reached during the summit was that editing somatic cells can be used clinically if the changes to the DNA is not passed on to the next generation. It would apply for instance to the treatment of specific diseases such as Muscular Dystrophy, Sickle Cell disease or the modification of white blood cells to target a specific cancer (National Academies of Science, Engineering and Medicine, 2015).

One of the surprising conclusions made during the summit was that germline editing should be permitted in principle to prevent severe inherited diseases in order to “*enhance our species*”. The following current risks associated with germline editing highlighted during the *International Summit on Human Gene Editing* during 2015 are:

- Inaccurate editing;
- Incomplete editing of embryos which can result in Mosaicism;
- The difficulty in predicting the long-term effects of editing;
- The changes passed on from one generation to the next will be difficult to reverse.

The moral and ethical consideration of purposefully evolving the human species through technology is also highlighted in this report (National Academies of Science, Engineering and Medicine, 2015). However, their conclusion concerning germline editing outlined the irresponsibility to continue with the clinical application of germline editing without adhering to the following criteria:

- i. The current safety issues have been resolved;
- ii. Broader consensus on the topic of germline editing;
- iii. Any germline treatment should only be conducted under appropriate regulatory guidance.

It seems as if many within the scientific community understand the dangers of genetic editing, especially with reference to germline editing. This is apparent from the response to the first genetically modified twins born during 2018. The debate for and against gene editing has been ongoing for the last 50 years and according to Evans (2021:1) much of the debate was influenced by the historic backdrop of eugenics during the 20th century.

The Ethical debate concerning gene editing technology to alter the human genome for the benefit of man is not new. However, the biotechnological advancement in the last decade indicates that the possibility of genetic editing is becoming a reality. While there are various scholars warning that genetic editing could lead to irreversible changes and damage to the human genetic pool, there are those who believe that genetic editing should continue, and that it should be used not only for treatment purposes, but also in non-treatment situations (Savulescu, 2016:1; Bostrom, 2004: 97; Gyngell *et al*, 2019:514; MacKellar, 2012).

Certain arguments relating to the risk of gene editing do not make sense when viewed in isolation (Bostrom, 2004:497). However, Bostrom (2004:497) is of the opinion that, when looking holistically at human genetic editing, the benefits far outweigh the risks. This seems to be true when gene editing focuses on curing or eradicating diseases.

To comprehend the ethical arguments for both somatic as well as germline gene editing, it will be helpful to gain an understanding of the benefits of editing the human genome. An overview of the benefits of genetic editing is discussed using Savulescu's (2016:1) list of benefits as guideline.

- Curing genetic diseases:

Curing genetic diseases is one of the obvious benefits and an argument in favour of genetic editing, which both sides of the debate are in agreement on. It should be noted that both those in favour of gene editing and the majority of those opposing genetic

editing agree that where the technology can be safely applied it should be used to cure genetic diseases. Resnik (2016:191) points out that genetic editing has moral grounds as it promotes the overall goal of health. The technology can and should therefore be used to treat and cure less complex genetic diseases.

- Curing and treating complex genetic diseases:

Chapter 3 addressed the difference between single genetic disease and more complex disease. Savulescu (2019:1) highlights that while selecting an embryo without a genetic mutation is feasible with single gene mutations, it is not that easy where complex mutations such as heart disease presents itself. Rana *et al.* (2020) indicate that the top two causes of death in the world between 2011 and 2018 was heart disease and cancer. Both are complex genetic diseases. It stands without reason that if there are tools available to interpret genetic tests and rectify faulty or mutated genes the benefits will be tremendous. Resnik's (2019:191) point relating to treating or curing a person aligns with this view as well.

- Delaying or stopping ageing:

Although the major cause of death globally is heart disease, more than thirty million people die from aging every year (Savulescu, 2019:2). If genetic editing can provide a sustainable solution to combat aging, it will limit the amount of age related death. This concept is only feasible if the individual can live a healthy pain-free life while aging. Savulescu (2019:2) continues by stating that aging is the most under researched cause of death. Green (2007:103) points out that through various technological and medical advancements life expectancy has been increased. During 1900 life expectancy was a mere forty-eight years, however, it should be noted that the mortality rate of babies skews the statistics. What is evident though is that if a girl reached the age of 10, her life expectancy would be 62. This figure increased to 81 years a century later. The point Green (2007:103) makes, is that while there are valid arguments against certain elements when it comes to gene editing, no one is currently complaining about the 31% increase in life expectancy during the last century. Chances are that no one will complain about an increase in life expectancy if

technological advancements continue. In fact, it could be debated that if we have the technological means to delay death it would be morally wrong not to use it.

- Controlling the “genetic lottery”:

The fact to consider is that no one really knows what to expect from the genetic composition passed on through heredity. While there are certain Mendelian principles that can be followed, the reality is that when a child is born, no one knows for certain what traits will be inherited or what *de novo* mutations could have happened during conception. Savulescu (2019:2) is of the opinion that selecting embryos or editing the embryo will eliminate the genetic lottery. He adds that the argument against this type of editing or selection process is concerned with fairness and eugenics.

In response to this, he highlights the lengths to which parents and the governing authorities are going to, when nature dictates what he calls the unfair “genetic lottery”. In response to the genetic disposition of some individuals, parents often change their children’s diet, enlist special educators or arrange specific social interventions. He states that approximately 10% of children in the United States of America are placed on Ritalin due to a lack of self-control. He concludes this topic with the suggestion that gene editing should form part of public health care (Savulescu, 2019:2).

- Lowering the cost of treatment

The perception exists that gene editing will only benefit the rich, but Savulescu (2019:3) disagrees with this and believes that research on genetically edited embryos will lower the cost of treatment across the board. He is of the opinion that through research and the identification of disease-causing genes scientists will be able to develop cost effective treatments. Thus, while the initial genetic editing process might be expensive, the long-term economic benefits of this will offset the initial investments (Savulescu, 2019:2).

- Cognitive enhancement

Savulescu is not the only scholar to highlight the benefits of genetic editing. Bostrom (2005:5) highlights the benefits of increasing intelligence, while Jones & Schneider (2006:71) highlight the economic benefit of increasing intelligence. Their study indicates that an average IQ increase of 1 point equates to an increase of 0.11% of a country's annual GDP. Thus, if a population increases its intelligence through genetic editing it will have an impact on the global GDP, directly impacting poverty.

4.2.1. MORAL OBLIGATIONS

From an ethical perspective, the argument exists that the human population has a moral obligation to continue with gene editing. This argument is central to Savulescu's (2016:4) reasoning. An analogy of neglectful parents forms the basis of his argument. He is of the opinion that parents of a child with an incredibly high intellect have a moral duty to ensure the child is nurtured in such a way that his intelligence is developed. Neglecting the child will result in an average intellect, which is clearly wrong. He further states that if another child with a normal intellect can achieve higher cognitive ability through a specific diet and the parents do not provide this diet in order for him to enhance his cognitive ability, it will be equally wrong. Thus, the negligent parent and the other non-providing parent both have the moral duty to ensure that their children have the best cognitive ability possible. He uses this analogy to argue that if the diet of the child with a normal intellect is replaced with "biological technology" we will have the same moral outcome. Savulescu (2016:4) argues that if technology was available that could enhance children's ability cognitively, psychologically or physically, then parents have a moral duty to enhance their children.

Continuing with the moral argument, Savulescu (2019:519) highlights the success of diagnosing single gene disorders. An example of this is the diagnosis of phenylketonuria, a genetic disorder that prevents the body from metabolising specific proteins. The inability to metabolise these proteins causes severe intellectual disabilities. During 1962, a simple test was developed to diagnose this disorder at birth. Once diagnosed, the children are placed on a special diet, which enables them

to develop normally without any intellectual disabilities. He further states that if medication was discovered that could substitute the protein in the diet, it would mean that the child could have a normal diet. This would be considered a breakthrough in science and the medical community would have a moral obligation to prescribe this medication to the child. He takes this argument further and states that if we have the technology to prevent the disease in the first place, we have the same moral obligation. Thus, promoting the moral obligation to use gene therapy both on somatic and germline level. During the past few decades, the role of the medical doctor and science has been moving steadily from curing disease to preventing disease (National Academies of Science, Engineering and Medicine, 2017:166). It would seem that there are grounds to use biotechnology, specifically gene editing technology, not only to cure disease, but also to prevent it.

4.2.2. SAFETY

While gene editing has the potential to be used in therapeutic and enhancement scenarios, ethical concerns exist relating to the safety of the technology. Doudna (2020:233) explains that one of the key concerns of gene editing is the accuracy of the edit. She adds that with currently available technology, especially with CRISPR, the accuracy of the edits has improved. However, “off target” editing does occur and when it does, it can cause cancer. During 2021 the WHO released new guidelines in an attempt to regulate the research and the administration of gene editing applications (WHO, 2021:8). It seems that the main objection from a medical ethical perspective focuses on safety.

The Nuffield Council released their report on genome editing and reproduction during 2018. The Council’s view is that genome editing could be ethically acceptable if it were used for the purpose of consistent welfare of the unborn and could be permitted if it did not have a negative impact on society in the form of division or marginalisation within society (Nuffield Council, 2018). This is in line with views from the National Academy of Science and Medicine (Chen, 2019:538). Drabiak (2020:224) argues that although the Council stated that gene editing could be permitted if the purpose is the

consistent welfare of the unborn, it failed to take into account the potential adverse outcomes that might not be immediately visible.

The researcher is of the opinion that the Council has failed to recognize the initial period of experimentation before the process of embryo gene editing can begin. The challenge is that the first genetically edited individuals will be an experiment, due to the long-term uncertainties of editing the germline such as with the Chinese twins born in 2018. Drabiak (2020:224) is of the opinion that safety and welfare of individuals who are born following genetic editing of the embryo, cannot be guaranteed and due to this he believes that it should never be permitted. According to Drabiak (2020:224), once changes are made it would be impossible to reverse the process. An example of this is the first genetically edited babies born in China. The genes that were targeted mutated into new CCR5 genes never seen before. While the function of the gene is related to HIV immunity, it also has other functions such as increasing cognitive abilities (Gorvett, 2021). This seems to indicate that genome editing might introduce new genetic diseases never seen before.

The Nuffield Council appear to be ignorant of the long-term safety of individuals born following editing of their germline (Drabiak, 2019:224). He argues that the Council glossed over the fact that the child might be born healthy, but with an increased risk of cancer, infertility or shortened lifespan as a result of off-target effects. This view is echoed by Cyranoski & Reardon (2015:594) who state that scientists routinely find off-target mutations that could have long-term harmful effects. George Church on the other hand is of the opinion that the technology is still immature and in time these off-target mutations will be limited (Church in Cyranoski & Reardon, 2015:594). Tou (2020:18) and Gyngell *et al.* (2017:504) agree with Church and highlight that improvements in the technology will eradicate off-target mutations, thus rendering the technology safe to use.

While safety is paramount, it also seems as if the welfare of the individuals who may be born following genetic editing of the embryo cannot be guaranteed. Apart from this, there is the reality that the first individuals who are born following these edits will be

experiments (Gorvett, 2021). This is a major hurdle for researchers as the embryo's undergoing the editing has not provided consent to make changes to their DNA. This is a topic that requires further research. The researcher, however, asks the question as to who will determine when it will be safe to start germline editing.

4.2.3. RIGHTS

There is consensus amongst researchers that germline editing is ethically the most troublesome. The WHO's report stated that it would be irresponsible to continue with clinical trials with any germline editing and suggested a global review approach when any study moves into a clinical trial phase (WHO, 2021:2). Apart from safety concerns there are concerns relating to consent and the rights of the unborn. Resnik (2016:194) indicates that the debate concerning the unborn pivots around three main points:

- The procedures violate the unborn due to the fact that they are experimental and the unborn individual cannot provide informed consent relating to the risks involved.
- Every child has the right to be born without a genetically modified germline.
- The procedure would deny the child the choice of an open future.

This argument assumes that the embryo is a person and that all unborn children have rights. It also assumes that the rights are violated due to the editing of the germline. When reviewing these points in more detail there are basic flaws in the arguments. The first statement that the procedure violates the rights of the unborn since the treatment currently is experimental and they are not able to provide informed consent, is not well structured. Resnik (2016:194) points out that various procedures are performed on babies and foetuses, some of which are experimental in nature in order to save their lives or enhance their quality of life. This is achieved through implied consent or parental consent where a proxy consents to the procedure. The researcher therefore agrees with Resnik. If the welfare of the child is the primary focus it should in theory not be an obstacle.

The second argument is also troublesome, as rights usually have a specific interest at heart (Resnik, 2016:194). Resnik (2016:195) is of the opinion that parents of children might have the desire to have children without an edited germline due to doctrinal or religious reasons, but the child generally does not have this conviction yet. An important element Resnik (2016: 195) highlights is that the possibility is greater that the child would like to have a healthy life, or better opportunities than having unedited genes with the risk of living a lower quality of life due to an inherited disease.

The right to an open future relates to the ability of the child to make his or her own choices. We have to acknowledge that adults impose their own choices on children every day. Resnik (2016:195) highlights that while genetic editing might take parental choices to the extreme, especially during enhancement, the possibility exists that the changes to the genes could provide the child with more choices. On this topic, Resnik (2016:195) seems to agree with Savulescu (2019:519) that every parent should have the best interest of their child at heart. This seems to indicate that if the technology is available and safe it is the moral obligation of the parents to choose the best outcome for the child.

A unique viewpoint from a theological perspective relates to the right to life. Theologically the topic is challenging since the Bible was not composed to provide scientific guidelines. For the researcher, the challenge when it comes to genome editing lies in the question concerning the ethical status of the embryo. While many scientific scholars view the pre-implanted embryo as cells with the potential to become a human being (Gyngell *et al.* 2017:504), the question from a theological perspective is when does life begin. Ling (2017:5) indicates that this question is at the heart of bioethics. He adds that from an ethical perspective this has an impact on abortion, assisted reproductive technologies such as invitro fertilization (IVF), stem cell research, human embryo research and experimentation, prenatal screening as well as certain forms of contraception.

From a Roman Catholic perspective, the church made statements regarding their view on the starting point of life. Before IVF was possible, the Roman Catholic Church had

accepted the doctrine of Thomas Aquinas, who stated that the rational soul is only infused forty days following conception (Benagiano & Mori, 2007:163). Following the technological advancements of IVF the Church changed their stance and is currently teaching that life begins at conception.

According to Zuradzki (2014:442) it would seem as if the embryo's right to life is seen as lesser than the right to life of a more advanced foetus, child or adult. This is evident in the social use of the morning after pill, as well as the amount of ongoing research performed on embryos. Zuradzki (2014:446) does highlight that the Catholic Church bases its current view on the uncertainty of when an embryo becomes a *person*. The Church's approach is that it will be a "*grave sin to dare to risk murder*" making it clear that the Church is against research involving the use of embryos. While this is the official Catholic Church response, the Protestant view is much more complex.

The challenge with the Protestant church's view is that churches function autonomously and each denomination, and sometimes each congregation, has their own opinion on how they view the status of an embryo (Gribkov & Minchenko, 2020:2). The Council of the Community of Protestant Churches in Europe (CPCE) issued guidelines during 2017 to assist Protestant Churches with certain bioethical debates. The problem of the moral status of the embryo was briefly touched upon. They highlighted that the concept of "person" has traditionally been used to try and address the problem. This concept distinguishes between the "person" and a "human being" with a "person" being seen as a member of the moral community. This implies that the "person" has moral regard from other humans within the community (CPCE, 2017:49). To simplify this, philosophers created a checklist containing criteria to define when someone is a person:

- A person is rational;
- A person is self-aware;
- A person has the capacity to relate and engage in relationships;
- A person has the capacity to have interests of preferences.

The CPCE (2017:49) highlights that this view seems to indicate that if a non-human entity met all the conditions, it would be considered a “person” while the opposite would be true for a non-human entity that does not. Morgan (2013:22) indicate that this is a gradualist view, and the main argument is that the embryo develops into a “person”. The CPCE (2017:50) agree with this and continue to recognise that gradualists tend to view embryos not as a “person” due to the fact that they do not meet all the criteria. Birkhauser (2013:957) indicates that the Protestant gradualist hold this position for as long as the embryo does not have a nervous system, does not have organs and pain receptors. The implication of this is that embryos are not treated by the same moral standard as a “person”. The gradualist view also allows for the destruction of embryos used during research, fertility treatments or genetic screening based upon the justification of the benefits gained or prevention of harm. This seems to be aligned with outspoken transhumanists such as Gyngell *et al.* (2017:504), who argue that due to the nature of an embryo it cannot be harmed. They view an embryo as a cell, or cells that do not have the capacity of feeling and thus cannot be harmed.

However, not all Protestants agree with the gradualist view of the embryo. Saunders (2006) highlights that passages in the Bible place value on the embryo and refers to passages such as Psalm 139: 13-16. He is of the opinion that the passage refers to God’s creation and communion with the foetus or embryo in the womb and implies continuity between life before birth and after birth. He aligns with the Roman Catholic view of the embryo, stating that life begins at fertilization, or conception. Harle (2011:253) also agrees with the view that life begins at fertilization and is of the opinion that human dignity should be bestowed on all embryos.

While there seems to be an argument for life starting at conception the main challenge does not lie with the notion of when life begins, but rather with the definition and concepts of a person (CPCE, 2017:51). The CPCE (2017:51) acknowledges this and highlights the challenge that both arguments on the two spectrums use hermeneutical proof to provide each group’s desired results concerning the status of an embryo. They are of the opinion that the reason for this is the complex nature and history of the Trinitarian and Christological argument, which was not designed for use in modern-

day ethical debates. The statement of the CPCE (2017:52) points out that the first argument, which states that the embryo should be able to be rational, self-aware, be able to engage in relationships and have capacities to have interests, is a similar argument used to marginalise women, people of colour and severely disabled people. They add that this does not mean that the argument is incorrect – just that it should be used mindfully as it could lead to a form of eugenics.

4.2.4. EUGENICS

Another concern relating to genetic editing comes in the form of eugenics. It is stated earlier in the chapter that eugenics seems to be prevalent in our day and age, but the only difference is that it is not institutionalised. There is a real concern that allowing editing of the germline will form part of a eugenics movement, which could lead to a state attempting to establish a superior race (Doudna & Strenberg, 2017:55). Resnik (2016:195), reminds us that the aim of eugenics is to control the human gene pool. He continues by asking a key question, relating to the morality of eugenics, namely: is it wrong? In order to understand his reasoning, we need to understand that eugenics can be positive or negative. He highlights that negative eugenics equates to the removal of a specific trait from a gene pool. Positive eugenics on the other hand, attempts to promote desirable traits. The question the researcher poses is who decides what traits should be removed or promoted? This is a topic requiring further research from an ethical perspective.

An example of negative eugenics is the holocaust in Nazi Germany while an example of positive eugenics is the Oneida community where partners were selected to enhance positive traits (Richards, 2004:46). According to MacKellar & Bechtel (2014:47) another example of negative eugenics is when a person or a couple decide not to have any children. There are various reasons for not having children, but according to MacKellar & Bechtel (2014:47) the decision usually concerns preconception genetics. The Jewish Orthodox *Dor Yeshorim* organization is an example, as they perform genetic testing within the community and dissuade non-compatible couples from getting married.

Although society understands why a couple could decide not to have a child due to the risk of passing on a gene that has the potential of causing a serious genetic disorder, it is still a form of eugenics (MacKellar & Bechtel, 2014:47). The foundation for MacKellar & Bechtel's (2014) argument is that the couple would abstain from reproducing to avoid "undesired" genetic heritage. Thomas & Rothman (2016:406) agree with this view and state that deciding not to have children based upon genetic information is a form of eugenics as it is aligned with the notion to promote the reproduction of individuals with a desired outcome. They underscore their argument stating that one of the foundational principles of eugenics is the concept that the world will be a better place if everyone is healthy and without defect. One of the key challenges to what MacKellar & Bechtel (2014) calls pre-conceptual eugenics, is that people born with genetic diseases can be seen as inferior and undesirable. In essence, the challenge lies with value of human life and if a decision is made not to conceive based upon the possibility of negative genetic traits, then what is the value of the person with the genetic disease or disability (Brown & Schippers, 2019:122).

There seems to be the notion amongst researchers that eugenics can occur through adoption. MacKellar & Bechtel (2014:52) discuss that the possibility to select a child or an embryo in an unregulated manner could provide a platform for eugenics. Adopting an embryo is still relatively new and not common practice, but there is evidence that this is on the rise with the amount of embryos available following fertility treatments (Lester, 2019). One of the key aspects MacKellar & Bechtel (2014:52) point to is that the focus of adoption should be the welfare of the child. As soon as there is a shift to the focus of what the parents want in a child it becomes eugenics. Decisions can be made on various factors that relate to the racial or ethnic background of the donors of the embryo or on genetic information that might be available to the adoptive parents.

Selecting the sex of an embryo can be seen as a form of eugenics, as the parents are in the pursuit of specific genetic characteristics. MacKellar & Bechtel (2014:58) explain that it becomes an eugenic "act" when the parents are selecting the sex of a child purely to satisfy their own aspirations. This is especially true in certain societies or

populations where one sex is preferred above another. Rai *et al.* (2018:548) state that the science of sex selection was initially developed to prevent specific genetic diseases, but there is a growing social demand for selecting the sex of a child. This can be achieved through various means, namely:

- Preconception: Dahl (2003:380) indicates that this form of selection is aimed at selecting sperm that only contains the desired sex chromosome. This is conducted through an identifiable difference between spermatozoa (Savulescu & Kahane, 2008:275).
- Pre-implantation: During this method the selection of the sex is conducted following IVF (MacKellar & Bechtel 2014:58). Dahl (2003:380) is of the opinion that the selection of a specific sex of an embryo became possible with the arrival of preimplantation genetic diagnosis (PGD) (Savulescu & Kahane, 2008:275).
- Post-implantation: This method entails the abortion of the foetus if the sex of the foetus is not the desired sex for the parents (MacKellar & Bechtel, 2014:58; Dahl, 2003: 380; Rai *et al.* 2018:540; Savulescu & Kahane, 2008:275).

It seems as if MacKellar & Bechtel (2014:58) are of the opinion that, although not formalised, eugenics is as prevalent as ever. Vizcarrondo (2014:240) states that the main aim of the original eugenic thought was to enhance or eliminate certain traits by controlling reproduction of individuals. He adds that the “new” eugenics movement is based on good science, involves consent and flows from a desire to improve society. Savulescu & Kahane (2008:275) are of the opinion that new technology provides parents the opportunity to select certain traits at an early stage of pregnancy. They add that genetic testing is conducted in various parts of the world to detect abnormalities within the genome. Examples they provide are single gene disorders such as Down Syndrome (Trisomy 21), Cystic Fibrosis, Huntington's Disease, Alzheimer's and inherited cancer. Included in the tests are the ability to select the sex of the embryo. Kovacs (2013:1105) alludes to the fact that there are a few countries

that do not have any legislation against the selection of the sex a child. These include the United States of America, Thailand and Cyprus.

Savulescu & Kahane (2008:275) do not see a reason why embryos should not be selected on any genetic basis. They indicate that behavioural geneticists study the genetic components that are not seen as diseased states, which include cognitive and physical abilities. These traits include personality traits, predisposition to addiction and sexual orientation. Savulescu & Kahane (2008:276) highlights that selecting embryos based upon principles that are not related to disease is controversial. They are of the opinion that any parent who intends to have a child would like to have the best future for the child. They extrapolate, stating that if this is the case, the parent should be allowed to genetically select the child to give them the best possible chance of success. Savulescu & Kahane (2008:277) are of the opinion that parents have the same right to select a child free of rubella than the parent who must consent to cure their child of rubella. They believe that if the technology exists to map the genome of an embryo and the DNA that is responsible for certain traits are identified, parents should not only be allowed to select the best embryo, but it is their moral duty to do so. Their view is that the parent has the same moral obligation to select the best embryo, as if they would have if the embryo had a disposition to a genetic disease.

Resnik (2016:195) points towards an important distinction on the historical implementation of eugenics. Previously, eugenics were state sponsored programs where the government tried to control the gene pool. He stated that with parental eugenics, parents will have the choice of what to edit and what not, thus it is not centralised. Another concern relating to genetic editing comes in the form of eugenics. We highlighted earlier in the chapter that eugenics seem to be prevalent in our day and age, the only difference is that it is not institutionalised. There is a real concern that if allowing gene editing of the germline, it will form part of an eugenics movement (Doudna & Strenberg, 2017:55). Resnik (2016:195) reminds us that the aim of eugenics is to control the human gene pool and usually controlled by a specific group of people. The challenge is that once this is allowed, state institutions can easily pass a law preventing and/or promoting certain traits. If the genes are discovered that is

responsible for violent behaviour it could be exploited for military purposes. A government could reinstate a state sponsored eugenics that allows only certain edits to ensure economic wellbeing or ensure that they are recognisable by specific traits.

4.2.5. HUMAN DIGNITY AND INEQUALITY

When it comes to germline editing, there are concerns that inequality and social norms will be negatively impacted (WHO, 2019:9; Cyranoski & Reardon, 2015:173; McKibben, 2003). One of the key benefits of editing the human genome relates to extending lifespan, but there are drawbacks, and it has its own risks.

Savulescu (2019:2) points to the benefits of extending lifespan, while Bostrom (2005:5) indicates that this is a key agenda point for the transhumanists. There might be a moral argument towards extending lifespans, but it also has risks. Green (2007:05) is of the opinion that increasing the age of the human population will have a global economic impact. Another concern is that if humans live longer healthier lives, will there be an appetite to make room for younger generations? Rationally, by increasing the lifespan of individuals family relationships will be affected, social justice will change, and the possibility exists that generational gaps would increase which could lead to other problems such as a lack of innovation and change (Green, 2007:104). Pijnenburg & Leget (2007:586) add to this view and state that arguments in favour of extending life is often based upon the assumptions of liberalism. They base their view on anthropological views that the human species are communal in nature and by extending life the possibility exists that generational challenges will be enhanced. They add that the challenge on a social level is how social conditions could be improved when it comes to life extension. However, one must acknowledge the comment from Bostrom, who indicates that life is already extended from previous generations and albeit a slow process, socially humanity has adapted (Bostrom, 2004:497).

Another ethical challenge regarding life extension is addressed by Pijnenburg & Leget (2007:585). They are of the opinion that life extension will have an impact on global

justice. Their belief is that the first world countries will benefit from life extension while the third world countries will suffer the most. However, they do note that there are sceptics who do not agree with their view and are of the opinion that bioethics should not be politicised. They refer to the role of politicians and governments to look after the social welfare of their citizens and bioethics should not focus on this. While this might be the case, the reality is that it does reduce bioethics to applied ethics and should be avoided. The impact of the actions from rich nations should not be underestimated. Pijnenburg & Leget (2007:585) address another argument against their view that third world countries are going to suffer if life extension is possible. The argument is that one cannot deny the people who can afford these technologies access to treatment solely based on the fact that some individuals cannot afford the treatment.

Evidence in favour of this seems to be found in an article by Chokshi (2018:113) who indicates that low-income communities have been a key driver in advancing public health. Albeit the case, he asks the question if it is the responsibility of the health care worker to address poverty and poses a view that is in direct opposition of Pijnenburg & Leget. Sherman (2017) agrees with Chokshi's view and states that the type of genetic editing does not really matter when it comes to inequality. The poorer communities and countries will always be negatively affected, even if the aim is to ensure its affordability. He bases his argument on several genetic tests that are available and performed at birth in some countries, while not available in poorer countries. The challenge with inequality takes the debate back to the notion of eugenics. If a specific population manages to edit genes either for treatment purposes or enhancement, the world might get to a stage where specific genetic diseases are eradicated in some parts of the world and due to cost implications individuals from other parts might be excluded. The real question relates to human dignity, and the value a society places on a person.

The term human dignity is enigmatic and difficult to define (Segers & Mertes, 2020:33; Beriain, 2018:1). Beriain (2018:1) states that the vagueness of the definition has an impact on the application of technology, to the point where some scientists remove

human dignity from the debate and see it as an obstacle. Segers & Mertes (2020:33) point to the fact that while the concept of human dignity was central in the creation of human rights post World War II, it was not properly defined due to political reasons. The challenge with this unclear definition, as far as genetic editing is concerned, is that it opens the debate regarding what is considered as human dignity. An example of this is the challenge with disabilities caused by genetic diseases. On the one side of the debate, the individuals who are pro-genetic editing will state that a person's human dignity is affected by the disability and impacts their quality of life. The other side of the debate states that human dignity is not measured according to what a person can do, but rather who they are (Sufain & Garland-Thompson, 2021).

Diversity strengthens human community (Sufain & Garland-Thompson, 2021). They are convinced that diversity opens discussions related to different life experiences and promotes the belief in equal value between individuals. One of the key aspects they highlight is that a person's worth should not be determined by social judgments. Their article concluded that while genome editing is powerful and can achieve near impossible feats, it can harm human diversity and increase inequality. They believe that the genomes selected for editing will be shaped by society, thus labelling the disabled as undesirable. They highlight the fact that "bad" genetics is not necessarily an indicator of quality of life, just like "good" genetics is not a good indicator of the same.

In an attempt to demystify and simplify the concept of human dignity relating to genetic editing, Segers & Mertes (2020:33) reject any form of metaphysical explanation of human dignity. They are of the opinion that adding metaphysical beliefs to the discussion complicates the discussion. They suggest two principles to focus on instead, namely:

- dignity does not have fixed references as in the case with metaphysics;
- human dignity is complex and should not be disqualified as a point of discussion based upon this complexity.

While the notion of simplifying the debate is commendable, they might actually have complicated the debate even more. However, they do argue that one of the problems with defining human dignity is the fact that people are viewed as objects and not as subjects. While this is not a new argument and aligns with concepts suggested by Aristotle relating to belonging, it does provide some perspective especially when looking at germline editing.

4.2.6. SUMMARY

There is sufficient proof that the Bible can be used in this research to present a reliable research outcome. The Bible offers an authoritative source of information. In spite of the various views regarding its authority, the general consensus is that it is authoritative to address life issues. It is also a book accepted as being divinely inspired. Its inspiration is based on the influence of the Holy Spirit upon the writers of the various texts, and it also recognises that the human element was present in writing the various books of the Bible. Its inspiration and authority has led to it being a book of major influence in many areas of life. The Bible is considered, throughout the ages, as a book of influence. These characteristics of the Bible make it a valuable source in determining the normative task of this research.

4.3. PRELIMINARY CONCLUSION

There are distinct ethical approaches to the different forms of gene editing techniques. The *International Summit on Human Gene Editing*, held during 2015, concluded in favour of gene editing as long as conducted safely. A distinction was made between somatic gene editing and germline editing. Somatic gene editing was encouraged for treatment of genetic diseases if the changes to the DNA are not passed on to the next generation (National Academies of Science, Engineering and Medicine, 2015). However, the summit report made a controversial statement in the favour of germline editing if it prevents inherited diseases. The controversy caused was not concerning germline editing, but rather the statement that through germline editing the inherited disease can be prevented and the human race “*enhanced*”.

Benefits of germline editing cannot be denied. Savulescu (2016:1) highlighted several benefits of germline gene editing, namely:

- Curing genetic diseases;
- Curing and treating complex diseases, such as cancer;
- Delaying or stopping aging;
- Controlling inherited traits;
- Lowering cost of treatment;
- Cognitive enhancement.

Based on the benefits, it seems there is a moral argument to allow both germline and somatic genetic editing. This seems to be especially true when looking at genetic diseases. Savulescu's (2016) argument extends to more than treatment of disease though. He is of the opinion that if the technology exists to enhance a person's cognitive functions it would be morally wrong not to use the technology.

Ethical concerns are raised relating to the safety of the current technology, especially with the potential of inaccurate gene editing (Doudna, 2020:233). While the CRISPR technology has improved the accuracy, any inaccurate editing has the potential to cause cancer. The WHO (WHO, 2021:8) released guidelines during 2021 in attempt to govern the research and enhance safety.

The Nuffield Council concluded that genome editing should be permitted as long as it is conducted with the welfare of the unborn in mind. There are some scholars who oppose this view with concerns for the long term effects of gene editing (Drabiak, 2019:224; Gorvett, 2021). Additionally it seems as if the welfare of a child born with defects following the use of the technology can also not be guaranteed (Cyransoski & Reardon, 2015:594).

The rights of the unborn is also a concern for ethicists and pivots on three points:

- The procedures violate the unborn due to the fact that they are experimental and the unborn individual could not provide informed consent relating to the risks involved.
- Every child has the right to be born without a genetically modified germline.

- The procedure would deny the child the choice of an open future.

It would seem as if the debates that centre on these points assume that the unborn have rights. It also assumes that the unborn is capable of providing consent, which as can be seen with treatment of minors, is not the case. Resnik (2016:195) highlighted that it is more realistic to assume that the unborn will consent to genetic editing if it improves their quality of life.

The right to life seems to be a unique religious viewpoint. Main challenges from this perspective, especially the theological perspective, relates to the question of whether the embryo is considered alive or not (Gyngell, *et al.* 2017:504). The Roman Catholic Church is taking a conservative stance regarding when life begins and is of the opinion that no research should be permitted on embryos as there is uncertainty on when life begins. The Protestant view is not as simple to determine, as denominations are autonomous. In some instances, a gradualist approach is taken and while an embryo has the potential to become a person, it is only cells with potential. Many are of the opinion that an embryo becomes a person when specific criteria are met (CPCE, 2017:49):

- A person is rational;
- A person is self-aware;
- A person has the capacity to relate and engage in relationships;
- A person has the capacity to have interests of preferences.

This is a gradualist view that believes an embryo becomes a person once a nervous system is developed. Their argument is that before the nervous system is developed, embryos can be used for research as there is no co-ordinated pain stimulus and can therefore not be harmed. Although there seems to be a debate amongst Protestant Christians on whether an embryo is alive or not, the real debate is when an embryo can be defined as a person.

Eugenics is a concern amongst bioethics as the technology can be used to create a superior race. It seems as if various forms of eugenics exists, such as couples deciding not to have children in order to avoid passing on undesirable traits (Brown & Schippers,

2019:122). Many researchers are of the opinion that if specific traits can be selected during embryo selection it will be a form of eugenics. Savulescu & Kahane (2008:275) are not convinced that this is a negative aspect as specific traits can enhance the genetic pool as well as prevent undesirable traits within a community.

Inequality is a major concern. Although there seems to be focus on extending the life of a person, there are however, associated risks. Apart from potential generation gaps, living longer will have an economic as well as an ecological impact (Green, 2007:497). It is possible that inequality will increase with genetic editing and/ or embryo selection (Pijnenburg & Leget, 2007:585). Poorer countries do not have the financial means to provide genetic editing to the majority of their population, which means they will not benefit from the technology.

Human dignity is difficult to define, and due to the vagueness of the definition is prompting scientists to remove the term from bioethical debates (Segers & Mertes, 2020:33). Human dignity was central to the creation of human rights following World War II but not properly defined due to political reasons. Sufain & Garland-Thompson, (2021) is of the opinion that selecting or editing genes will have an impact on the human dignity of those who were not edited. The potential exists that individuals without an edited genome might be seen as lower than those with edited genomes. Human dignity is central to the debate on genome editing as it has far reaching consequences.

CHAPTER 5: REFORMED THEOLOGICAL RESPONSE

5.1. OVERVIEW

The focus of this chapter is to respond to gene editing for therapeutic use and human enhancement from a Reformed Christian perspective. The basic principles for biblical interpretation and the authority of the Bible will be explored. Throughout history the Bible has influenced and shaped culture – and this includes the way we think about bioethics. The ethical challenges presented with biotechnology today is not addressed in the Bible. An alternative method from a doctrinal perspective will be investigated with focus on the doctrine of *Imago Dei*. This topic will be explored in relation to gene editing and the use of biotechnology. The chapter will conclude with a response towards the use of biotechnology with reference to gene editing for therapeutic use and human enhancement.

5.2. BASIC PRINCIPLES FOR BIBLICAL INTERPRETATION

Establishing principles for Biblical interpretation is vital as it provides guiding principles in an attempt to resolve the research question. The Reformed Christian view is that the Bible is authoritative. It is therefore important to address specific issues regarding the role of the Bible and to establish its use in bioethical matters. To ensure the reliability of this research the following issues are addressed: the authority of the Bible, inspiration of the Bible, the influence of the Bible, and interpretation of the Bible.

5.2.1. AUTHORITY OF THE BIBLE

The researcher is of the opinion that the Bible is authoritative based on the view that the Bible is the word of God, inspired by the Holy Spirit (2 Timothy 3:16) (Nullens, 2013:39; De Klerk and Van Rensburg, 2005:3, 4; De Klerk and De Wet, 2013:300; Cowan and Wilder 2013:XV). It would be ignorant to assume that this view is accepted by all as highlighted by Conradie (2005:86-88), a Reformed theologian. Therefore, the issue relating to the authority of the Bible will be addressed.

Within the Christian tradition various scholars view the Bible as authoritative (Lee, 2010:111). This view is also held by various historical figures such as Galileo. Galileo's work is misinterpreted by some to show that he did not see the Bible as authoritative, however the statements in his work actually indicates that he saw Scripture as the ultimate authority (Lee, 2010:112). A meta study by Lee (2010:112) indicates that Galileo believed that Scripture addresses issues that transcend human understanding and explained issues that cannot be explained through science, but only through the Holy Spirit (Lee, 2010:111; Carroll, 1999:158).

Divine authority was attributed to the Bible by Thomas Aquinas who viewed Scripture as the ultimate authority and addresses God's salvation of man (Levering, 2008 72; Selden 1984:186). Aquinas held similar views to Galileo and stated that the Bible is the only truth and has the authority to salvation (Carroll, 1999:158). Levering (2008:73) is of the opinion that the effect of the authority of the Bible on man is that it commands and attains a faith response. Three reasons are attributed to this: the Bible originated with God, Scripture requires a faith response and it is predisposed to the restoration of the relationship between God and man.

There are many objections to the authority of the Bible, one of which is the perspective that for anything to be authoritative it should be without error. In light of this Porter (2014:304) is not convinced that the Bible is authoritative based on the view of inerrancy of Scripture. His view is based on errors found in the texts, as well as contradictions within the biblical text. One of the contradictions highlighted pertains to the command given by Jesus to his disciples regarding what they had to take with them when he sent them to minister in surrounding areas. In Matthew 10:10 they are instructed not to take a staff, sandals, coat or a purse with them. In Mark 6:8-9 they are instructed to only take a staff and sandals. Luke 9:3 corresponds with Matthew 10:10 and points towards an interesting contradiction as it is assumed by some scholars that Luke composed his work based on the gospel according to Mark (Knight, 1998:12; Marshall, 2004:29; Poirier, 2009:181). Porter (2014:305) clearly points out that Biblical authority cannot be built on inerrancy. He concluded that the real challenge lies with the interpretation of the text. While this is an important element, interpretation leads to a problem of inerrancies and contradiction (2014:318). Cowan

and Wilder (2013:8) is of the opinion that it is easy to make claims of contradiction and the challenge lies with proving the contradiction. They are of the opinion that different is not necessarily a discrepancy and not a reason to discredit the Bible from an authoritative perspective.

Concerning interpretation, Fretheim (2006: 365) agrees with Porter (2014) regarding the interpretation of Scripture. He is of the opinion that interpretation leads to contentious issues relating to the authority of the Bible. For Fretheim the authority of the Bible does not reside in the interpretation or inerrancy of the Bible but rather in the directive nature towards Christians regarding Christian living (Fretheim 2006:366).

Fretheim (2006:370) highlighted various textual uncertainties found in the Bible and cites the following examples:

- Grammatical ambiguity: words can have more than one meaning, which makes translation challenging. This is influenced by the reader's conviction on how the ambiguity is dealt with;
- Genre and historicity: He refers to the book of Jonah as an example. Should it be dealt with as a parable, history, or something else?
- Metaphor: He indicates that readers are allowed to unpack these metaphors. An important aspect of the interpretation of the metaphors are that every metaphor has a "yes" and a "no" or a "like" and an "unlike". He concludes with a crucial question as to how the reader deals with the metaphors describing God as human;
- Voids (openness). The reader can use imagination during the interpretation process.
- Silence and gaps: There are instances where the Bible does not contain all the information a reader would like to know. Fretheim provides the example of Cain and Able: why did God choose Abel's offer and not Cain's (Genesis 4:1-17)?

Fretheim (2006:372) concludes that although there are differences in opinion pertaining to the above mentioned matters, it is not enough to nullify the authority of the Bible. This view is supported by Cowan and Wilder (2013:8) who state that some gaps relate to the fact that the original audience did not require the level of information

expected from readers 2000 years later. The audience understood the texts and the authors did not see a need to explain certain concepts.

Although extrabiblical texts can provide insight into the period and the culture during biblical times, it should not be used as a source to prove the authority of the Bible (Bouman 1984: 171). Bouman (1984:171) is of the opinion that the authority of the Bible comes “from within” the Bible. External factors, such as the age of the Bible, the geographical spread of the Bible over the centuries, excavated documents of antiquity or rational proof, do not prove the authority of the Bible. Walton (2006:20) is of the opinion that using extrabiblical texts assists the reader in understanding the culture of the intended audience. This does not necessarily mean the authority of the Bible is based on external sources, but these sources can bring deeper meaning to the text.

Bouman (1984:171) indicates that the authority of the Bible can be ascertained as outlined below:

- Self-authentication:

Self-authentication or *autopistia* implies the Bible itself indicates its authority (Van den Belt, 2008:330; Nullens, 2013:39). According to Bouman (1984:171) the view described by Nullens as evangelical *sola scriptura*, which can only be attained if the Holy Spirit testifies that the words are divine in the heart of the reader. This seems to underscore the problem Fretheim (2006) and Porter (2014) refers to, as it does not prove the authority of the Bible. The notion of self-authentication of the Bible can only be possible if the reader believes that the Bible has authority (Bouman, 1984:171), which is problematic. Van den Belt (2008:332) expands on this concept and states that *autopistia* should be maintained without withdrawing into irrationalism.

- Divine authority of the Old Testament was acknowledged by Jesus:

Jesus frequently referred to the Old Testament, especially to the prophets as individuals who received the word from God (see Luke 4:3 where Jesus referred to the words of Isaiah). Bouman (1984:173) points out that if the passages referred by Jesus are compared, a compelling argument can be made for the authenticity of the Old Testament.

- The Apostles recognise the divine authority of the Old Testament:

The Old Testament was the point of departure for all the apostles. Part of the reason for this was that they only had the Old Testament texts as reference. Their knowledge of the Old Testament meant they were able to refer to the Old Testament in order to support, or explain their teachings. The letter to the Romans is a prime example of how the Old Testament is referenced, thereby confirming their view of its authority (see Romans 1:17; 3:21; 4:17; 5:12). It is evident that Paul based his teachings on the Old Testament and not the personal teachings of Jesus, as he was not in the position to do so. His use of the Old Testament indicates his view on the authoritative Scripture (Romans 4:3). All the other New Testament writers refer to the Old Testament prophets, for example Matthew 2:23 and 4:14. (Bouman, 1984:173).

- The witness of Jesus and the self-testimony of the apostles concerning the divine authority of the oral and written Apostolic Proclamation.

The New Testament writers used their names and refer to themselves as “Apostle of Jesus Christ”, thereby implying that they were authorised by Christ to write the accounts. Most of which were eyewitnesses of all that transpired concerning Christ (example I John 1:1) (Bouman, 1984:174). The only exception is Paul who refers to himself as an apostle through the will of God (I Corinthians 1:1). Paul claimed that the content of his writing was given by God, which stand in direct contrast to the words of men (2 Thessalonians 2:13). Furthermore, Peter claims that they should call on the writings of the Old Testament prophets and the teachings of Christ (2 Peter 3:2) (Bouman, 1984:174).

- Holy Scripture itself substantiates its divine authority.

This statement is troublesome and refers to direct revelation and the self-substantiation could be based upon rationalism. In an attempt to address this, Bouman (1984:175) refers to the accounts of miracles listed in the Gospels. He believes that one miracle can substantiate another, which in turn is sufficient ground for self-substantiation. He is of the opinion that substantiating authority for the sake of faith is different from rationalism. His foundation for his argument lies in the miracle that the Son of man became flesh and dwelt amongst us and the ultimate sacrifice, and the

miracle of man's redemption (Bouman, 1984:175). This argument supports the view of the researcher that the determining factor of the authenticity of the Bible lays within the Christian community.

The Bible as an authoritative source is important as it provides ultimate guidance for humanity. One challenge though is that the Bible does address various ethical conundrums in our modern society, such as human genetic editing.

5.2.2. INSPIRATION OF THE BIBLE

Christian tradition views the Bible, as a written text, as the inspired word of God. (HaCohen, 2010:25; Williams, 2004:14, Nullens 2013:39). The implication of this view is that the entire Bible is the ultimate truth. However, this view is not held by all Christian scholars and there is a debate concerning the nature of the truth the Bible depicts (HaCohen, 2010:25). This also extends to the manner in which truth is interpreted and extracted from the text (Nullens 2013:42). HaCohen (2010:25) makes reference to Silva who is of the opinion that *"relinquishing the assumption of divine inspiration means relinquishing the assumption of truth"*.

Williams (2004:12) is of the opinion that the Old Testament prophecies concerning Christ and the fulfilment of these prophecies are proof that the Bible in its entirety was divinely inspired. Researchers and scholars such as Williams are convinced that the rapid spread of Christianity is directly related to the divine inspiration of the Bible.

Trembath (1987:5) is of the belief that the inspiration of the Bible should not be based on empirical characteristics of the Bible. For Trembath inspiration does not have to be miraculous or extraordinary as the inspiration is a matter to be dealt with within the Christian community. He is of the opinion that those outside the Christian community should not have an influence on the inspiration of the Bible. Similar views are expressed by Levering (2008:93) with the addition that it was not only the written text that was inspired by God but also the compilation of the Canon. He also highlights the belief that the topic of the inspiration of the Bible is a faith matter and should be debated and treated within the faith community. Levering (2008:93) continues and

states that to read the Bible without spiritual insight concerning inspiration equates to the reading of the Bible as plain literary text depicting a portion of history.

Möller's (1998:49) discussion regarding the inspiration of the Bible points towards the assumption regarding the *autopisty* of the Bible. The term is derived from two Greek words, *auto* which means self, and *pistis* which can be translated as faith or trust. Examples of this can be found in both the Old and New Testaments: Exodus 17:14; Deuteronomy 31:19; Isaiah 8:1 and 1 Thessalonians 5:27. For Möller the *autopisty* of the Bible is backed up by the historic and normative authority of the Bible. He argues that the historic and normative authority lies in the fact that throughout history there has been numerous attempts to discredit the Bible and yet it still carries the same historic and normative authority despite the onslaughts (Möller, 1998:51).

Möller provides a summary of the existing inspiration theories (Möller, 1998:55):

- Mechanical Inspiration

This theory holds that God dictated the Bible word for word and the authors of the Bible had to narrate every single word as they heard it from God. This is problematic in the sense that the authors of the Bible are reduced to a role of composing texts without any influence. The influence of the individuals is clearly visible when analysing the texts critically. This influence can be seen in Acts 1:1 and reference is made to the use of other sources as seen in 2 Samuel 1:18 and 1 Kings 11:41. In addition, there are clear differences in narrating style and characteristics in Scripture which do not align with this view (Möller, 1998:55).

- Dualistic Inspiration

According to dualistic inspiration there is a clear distinction between humanity and the divine and exists next to each other. Portions of the Bible that reference to the salvation and faith is canonical and all other portions of the Bible might contain errors as they are attributed to the human influence. This view struggles to indicate what portions of the Bible can be attributed to the divine and what cannot (Möller, 1998:57).

- Dynamic or personalised inspiration

The emphasis of this view is that the inspiration by the Holy Spirit is replaced by the concept that the authors of the Bible narrated their own experiences in relation to God. When evaluating this view the inspiration of the Bible can only be attributed to the authors themselves and not to God. This deprives the authority of the Bible as it is based upon human insight alone (Möller, 1998:59).

- Inspiration of essential ideas

The theory of inspiration of essential ideas holds that God inspired the biblical authors with ideas on which they expanded. This theory is challenging as it seems to hold that the author's style and character was also inspired (Möller, 1998:60). Möller argues that once the ideas were inspired the authors could narrate the work as they see fit. However, this can create the opportunity for the narrator to imprint their own character on the text.

- Organic inspiration

This theory states that the Bible contains both divine and human elements. They do not exist apart from each other, but assimilated with the divine and is submissive to the divine. Man's role in authoring the Bible was not a passive role but God used each person uniquely according to his own personal abilities, linguistic skills, knowledge and surroundings. This view describes the inspiration of the Bible the best as it contains active human elements submissive to the divine inspiration (Möller, 1998:63).

The organic inspiration theory negates all the challenges presented by the other theories and provides the necessary authority regarding inspiration of the Bible. The authority of the Bible is validated on the basis that it acknowledges the origin of the Bible with God, but also incorporates the human factor in the narration process.

5.2.3. INFLUENCE OF THE BIBLE

The authority and the inspiration of Scripture was determined in the foregoing section and the focus will now shift to the influence of the Bible within history. The Bible was not accessible to the public before the Reformation, thus the influence was fairly

limited and subject to the interpretation of the church. It was only during the post-reformation period that individuals were encouraged to read the Bible (Spencer, 2013:52).

Williams (2004:11) attempts to determine the influence of the Bible by referring to comments made by Origen. He highlights that Christianity is the only philosophy that manages to draw large populations within countries to accept the teachings of one philosopher, often at the cost of persecution and death. Williams (2004:12) is of the opinion that for Origen the influence of the Bible is unprecedented. The influence of Jesus can be seen in the spread of Christianity before the narration of the New Testament. The majority of texts were only penned during the first century by Paul (Koester, 2000:7)

While the purpose of this section is not to study the development of the canon, it is worthwhile mentioning that the influence of the philosophy of the Christian tradition was strong enough for individuals to die for (Whitworth, 2018:129). Kannengiesser (2004:5) sums up the influence of the Bible and views the first Christian community, and their adherence to the teachings in the Bible, as the main reason for the restructuring within the society of the Roman Empire. During that period, the Roman Empire consisted mainly of the territory known today as Europe and the Bible was a key influencer in the development of the territory as it progressed to the Western Middle Ages. Kannengiesser (2004:5) asserts that the Bible was a major influence upon the entire Western culture.

Although the Bible can be seen as a major influence of culture and thought during history, science and politics, its influence is not restricted to the past (Chan and Ecklund, 2016:54). Presently, at the time of this research, the Bible is still a major influence in the social life of many. Especially within the Reformed Christian tradition, where the Bible is seen as a key part of life. The following list reflects examples of the social influence the Bible has:

- Family life;
- Politics;
- Education;

- Science literacy;
- Opinions of science and scientists.

When viewing this from a bioethical perspective it is evident that there is tension concerning the role the Bible has within science (Chan and Ecklund, 2016:54). The influence of the Bible in bioethics can be seen during debates concerning genetic editing of the human genome, the concept of playing God and the controversial discussion surrounding human dignity (Dilley & Palpant eds. 2013:7; Peters, 2017:9). The Prometheus argument is not isolated in religious circles, but also made by non-religious philosophers (Peters, 2017:9). It would seem that these arguments, although not religious in nature, are influenced by the concept of a creator as depicted in the Bible or as Dilley & Palpant states, they have their roots in metaphysics. Arguments exist that this is not due to a direct influence of the Bible but because there are many religions that advocate the existence of a god. The reality is that while this might be true, the major monotheistic religions, and Christianity in particular, had the most influence on Western philosophical thought (Kling, 2006:5). The Q'uran for example, was only composed a few hundred years after the acceptance of the Biblical Canon, was influenced by numerous portions of the Bible, and concentrated on the Middle East (Thomas, 2008:385). Chan and Ecklund (2016:55) allude to the fact that there is tension between scientific views and the Bible. This relates to the relationship the Bible has with other sources, but despite the prominent tension the influence that the Bible has on science is evident.

Politics plays a major role in the world and this is one of the areas where the influence of the Bible is clearly visible. Eisenstein (2008:2) points towards the religious clauses within various constitutions. In a report by Chancey *et al.* (2014:1), he points to statements from the then president, Ronald Reagan, during 1983:

of the many influences that have shaped the United States of America into a distinctive nation and people, none may be said to be more fundamental and enduring than the Bible.

This might have been a subjective statement, but it does highlight the influence of the Bible amongst law makers in America. Reagan continued and stated that the Bible

offered more than technology, education and weapons. More recently, the mayor of Flowermound, Texas, Tom Hayden, announced 2014 as the “Year of the Bible” in the city (Chancey *et al.* 2014:2).

In the United Kingdom, the parliament is filled with Biblical references and Christian symbolism. The mosaic floor in the foyer of parliament, contains the words of Psalm 127:1 “*Except the Lord build the house, they labour in vain that build it*”. The galley floor contains the Latin text found in Proverbs 21:1 “*The king’s heart is in the hand of the Lord*”. In the Commons Lobby the words of 1 Peter 2:17 “*Fear God, Honour the King*” are edged in the floor (Spencer, 2013:51). While it may seem that the Bible is absent from the rest of the political system in the United Kingdom, Spencer (2013:51) highlights that the house is opened in prayer and the majority of the political system was built upon biblical principles. Spencer (2013:51) does however warn that whole political system was not built on biblical principles nor Christian principles, but the influence the Bible had on the political system in the United Kingdom is apparent. He draws on the basic principles of the English political system and points out specifically that nationhood, justice, democracy, equality and toleration are some of the principles directly influenced by a biblical view (Spencer, 2013:65).

With this backdrop, it is no surprise that Ronald Reagan referred to the Bible during a speech in 1983. America is still a relatively young country and built by pioneers and descendants from the United Kingdom (Klein, 2012:35). More recent examples of how the Bible is still influential in the political system is found in the recent American Presidential elections. Major points relating to the moral compass of society was one of the key agenda points during former President Donald Trump’s election campaigns (Kivisto, 2017:92).

South Africa’s previous dispensation referred to the Bible extensively in an attempt to persuade the white minority that Apartheid was biblical (Richardson, 1986:1). During 1994 the African National Congress took over the regime, and referred to the Bible on numerous occasions during speeches and letters (West, 2010).

America's foreign policy relating to Israel and the Middle East is referenced in Chancey's *et al.* (2014:5) report. Additionally, the social eschatological interpretations of the Bible, especially how America views current affairs in the Middle East, can be seen in statements of both political and social influencers.

Chancey *et al.* (2014:8) highlights the influence of the Bible on Popular Culture. Major films have references to either scripture or use specific scripture as part of the script. In the recent Marvel episodes of *Flash* the statement is made by one of the characters that "*the truth shall set you free*", a direct quote of John 8:32. The film *The Sixth Day* (2000) relates to cloning and the title is referring to the biblical creation account of humanity's creation on the sixth day. *Gattaca* on the other hand uses the term "*faith birth*" to refer to children who were born naturally without an altered genome. *Valley of Elah* (2007) draws upon Biblical values in which America plays the role of the saviour during the Iraq war (Chancey *et al.* 2014:8).

The Bible also influenced literature and music within the Western culture (Exum, 2007:i). Classical music, such as Handel's masterpiece "Messiah", is one example. This can also be seen in recent Pop Culture with the rendering of Psalm 137, *By the rivers of Babylon*, which according to Chancey *et al.* (2014:8), became an anthem for resistance during the African American antiracism struggle. More recently, non-Christian bands and rappers are openly advocating the influence the Bible has on their songs (Chow, 2019).

Although the influence of the Bible is well documented, there seems to be a gap in research outside the United States and the United Kingdom. What is important to understand is that both these countries have a major sphere of influence. Consequently their cultures and influences permeate boundaries.

It is apparent that the influence of the Bible is vast, and that it is important to refer to the Bible to provide guidance regarding ethical matters. Chapter 2 explored the history of genetic engineering and references were made to the Enlightenment and the scientific advancements during the 18th and 19th centuries. Although the Bible was not the primary reference point in the scientific research, there is the notion that the

Enlightenment was a response to the beliefs and interpretation of the Bible during that period. From this, it can be deduced that the Bible influenced the scientific community in the search for truth (Sheehan 2003:1064).

5.2.4. CHALLENGES OF THE BIBLE AND MODERN BIOETHICS

From a Reformed Christian perspective, the Bible is seen as normative and authoritative. There are however, various views regarding its authority. In spite of this, there is general consensus that it is authoritative and can address life issues. The challenge with bioethics however, is the fact that the majority of technologies available today was not available when the Bible was composed (Verhey 2003:37). This means that there are various aspects of bioethics not addressed directly in the Bible. Genetic editing and human enhancement are relatively new topics of discussion and the authors of the Bible were not aware of genetics to be the wiser. It does however pose the question of how the Bible can be used as an ethical reference for Christians (O'Mathunda, 2014:6). O'Mathunda (2014:5) states that the present complex medical and biotechnological questions did not exist in biblical times, thus the Bible was not composed to address these issues. That does not mean that sickness and disease are not addressed in the Bible, although they viewed this in a manner that is unfamiliar to contemporary readers. An example of this is how God opened wombs and how disease is often linked with demonic activity (O'Mathunda, 2014:5).

O'Mathunda (2014:5) makes a valid observation that modern Christian bioethicists are facing new challenges that philosophers in previous generations did not face. Although the challenges are different, it would seem the same thought processes are used when providing responses. This can be seen in the amount of philosophers, such as Aristotle, Locke and Kant who are presented during modern bioethical responses while never facing the modern issues (O'Mathunda, 2014:6).

Verhey (2003) makes a valid attempt to provide guidelines for using the Bible as a reference point for bioethical questions. In his book, "The strange world of the Bible and medicine", Verhey (2003) proposes methods for addressing bioethical questions. To comprehend the methods proposed, he lays the foundation with the notion that the

Bible should be read and used humbly. Verhey (2003:43) extrapolates his view with the concept that the Bible should not be read as the definitive answer to difficult bioethical questions (Verhey, 2003:42). He continues with the idea that the Bible should not be a source of moral criticism, nor should interpretation of Scripture substitute Scripture itself. He implies that the community plays a significant role in how the Bible is used, and proposes the following six methods:

- The Bible should be seen as the *canon* and authoritative to the Church. It should not be seen as a collection of ancient texts. It is also important for the Christian community to understand that the Bible is considered as authoritative within the Church and not necessarily by the secular community (Verhey, 2003:45).
- Scripture should be viewed without the dualism of body and spirit. Verhey (2003:47) makes it clear that the Bible should be read and interpreted as the canon and avoid any dualistic views.
- The Bible should be read according to the creed of the apostles, which denotes the story of the canon. The creed of the apostles provides a sound doctrinal guideline on the canon and is vital to the interpretation of the text (Verhey, 2003:47).
- Care should be taken when the Bible is interpreted and must be read within the context it was written. Interpreting the text compels the interpreter to understand that the canon was documented at a specific time for a specific audience, and therefore interpreting Scripture within context is vital (Verhey, 2003:48).
- The Bible should not be read in isolation, and within the community, the various gifts and voices should be allowed to hear each other's voices. Different views result in different interpretations of Scripture, which allows better understanding and provides clarity (Verhey, 2003:49).
- Finally, scripture should be read prayerfully. The focus should be on God with respect, humility and hope. Prayer is an action learned within a Christian community and teaches the individual to focus on God (Verhey, 2003:50).

Kotze (2013:39) critically assesses Verhey's (2003) proposed methods of using the bible during bioethical discussions. She highlights that while the methods are meaningful it is too vague, and proposes another way of using the Bible within

Christian Bioethics. The reality is that Scripture itself does not address the bioethical issues seen in the world today – certainly not when we are referring to genetic editing. It is also noteworthy that while important ethical frameworks were established by philosophers such as Kant, Barth and Aquinas, the technological advancements compel Christian bioethicists to expand on and change the thought processes of the past. Kotze (2013:43) suggests that the Bible should be used as guidance during bioethical discussions in the form of Christian doctrine. She correctly assesses that the methods Verhey (2003) proposes are vague and states that the most useful tool provided is the use of the Apostles' Creed as a guideline. Christian doctrine, similar to the creed, is based on Biblical interpretations and on the view that the Bible is an authoritative source. Using doctrine during bioethical responses provides a broader foundation as doctrine is built upon Scripture. Ericson (2015:4) highlights that Christian doctrine deals with truths as well as reality. He states that doctrines are derived from the Old and the New Testaments and address timeless truths that shed light on contemporary issues (Ericson, 2015:5). With this understanding of the use of doctrine as a response to bioethics, the researcher will adopt this method to formulate a Reformed Christian bioethical response to genetic modifications for therapeutic use and human enhancement. A focal point will be the doctrine of *Imago Dei*.

5.3. *IMAGO DEI*

To move towards a Reformed Christian response to gene editing and the use of the technologies, we will consider Christian doctrine as our main vantage point. Christian doctrine is used as the framework for this response as the Bible does not address contemporary bioethical issues. The focal point will be on the doctrine of *Imago Dei*, or man created in the image of God. From this is derived the concept of *Imitatio Dei* that leads to the role man plays in the world by acting as a co-creator. The implication of the doctrine of *Imago Dei* within the context of genetic editing for treatment and human enhancement will be explored in this section, but in order to do so we need to understand *Imago Dei*. Various views are presented and Peterson (2016) offers an alternative view on *Imago Dei* that can be used as a framework for a response to genetic editing for the purpose of treatment and human enhancement. Before critically

evaluating Peterson's work, an understanding of the main approaches to *Imago Dei* needs to be ascertained.

5.3.1. APPROACHES TO *IMAGO DEI*

The theological topic of *Imago Dei* has been debated amongst scholars for centuries. Middleton (1994:8) supports this view and states that for nearly two thousand years Genesis 1:26-27 is singled out as one of the foundations of the doctrine of *Imago Dei*. He adds that there are only three references to the concept of *Imago Dei* in Genesis which can be found in Genesis 1:26-27; 5:1 and 9:6. It is notable that all these references are found within the first section of Genesis, commonly called the "primeval history" and attributed to the priestly writers. Middleton (1994:8) highlights that the concept of *Imago Dei* is central to the Christian tradition and the notion that humans are created in God's image only really resurfaces in the New Testament as can be seen in Romans 8:29, 1 Corinthians 11:7, 2 Corinthians 3:18, 2 Corinthians 4:4, Ephesians 4:24, Colossians 1:15 and James 3:9. One of the key challenges in the debate relating to the meaning of *Imago Dei* can be attributed to the scarcity of the texts referring to the creation of humans in the image of God (Middleton, 1994:9; Jancovic, 2019:185).

Apart from the paucity of texts other challenges includes the interpretation of these texts. However, while there seems to be various interpretations of the texts there appears to be an agreement on the fact that Genesis 1 indicates that humans are created in God's image (Peterson, 2016:1; Bentley, 2017:2). Peterson (2016:1) highlights that the debate between theologians is not the act of being created in God's image, but the meaning of being created in the image of God. He states:

"The orthodox Christian tradition is unanimous that God is ontologically distinct from creation. Yet, in treatments of the Imago Dei it has been difficult for interpreters to describe just how humans are like God without assuming some kind of ontological kinship" (Peterson, 2016:23).

What Peterson is referring to is that the meaning of the concept of being created in the image of God is interpreted in many ways. We will now explore three specific interpretations of *Imago Dei* namely the substantialist, rational and functional interpretations.

5.3.1.1. SUBSTANTIALIST

The primary focus of the substantialist view is that it singles out a specific attribute within the substantial form of human nature. This specific attribute is usually something that distinguishes a human from other creatures such as reason, conscience, dominion emotional awareness, spiritual awareness, form and personhood. (Tarus, 2016:19). Jancovic (2019:196) and Tarus (2016:19) point to the fact that rational abilities and intelligence were attractive attributes to western theologians. Tarus (2016:19) provides clarity on the origin of the substantialist view. He states that engagements between theological, philosophical and anthropological thought of specifically Greek and Jews led to this view.

Philo believed the mind was created in the image of God, while Aristotle held the view that rationality was the attribute that distinguishes human beings from other species. For philosophers such as Augustine, Aquinas and Athanasius the ability to think and apply rational intelligent thought was what sets man apart from other creatures. These views heavily influenced the theological concept that the mind and rationality was what it meant to be created in the image of God (Tarus, 2016:19; Jancovic, 2019:196).

One of the key challenges of this view is highlighted by Tarus (2016:19). He is of the opinion that individualism and its dualistic dichotomy of the mind and body is posing a unique problem. The internal focus and the degradation of the human body seem to be problematic especially when referring to individuals with disabilities (Reynolds, 2008:175; Creamer, 2009:85-96).

Another challenge relates to how substantialists manage the problem of sin. If humanity is created in the image of God and it only refers to our intellectual abilities, then what exactly changed following the fall of man? To address this challenge,

substantialists differentiate between image and likeness (Tarus, 2016:19; Garner, 2006:76). According to Garner (2006:76), the main proponent of this was Justin Martyr, who saw the mortal soul and mortal body as distinct entities with the gift of life provided by the spirit God. Irenaeus further developed this dichotomous view and stated that before the Fall Adam possessed both the image of God and His likeness. For Irenaeus *Imago Dei* meant that man is created with the ability to reason and possesses free will in an innocent form. Likeness can be related to a supernatural gift, *donum superadditum*. The supernatural gift pointed to the righteous acts of man, the ability to extend grace and possess the ability to make ethical decisions. Irenaeus argued that the likeness of God was lost following the Fall, but man kept the image of God (Garner, 2006:77; Tarus, 2016:19). Tarus (2016:19) points to the fact that Irenaeus' theology influenced Eastern Orthodox traditions, although they later abandoned the supernatural gift theory for a relational-Christological approach (Tarus, 2016:19).

Augustine later explored and popularised the rational approach with the concept that being created in the image of God means that you have the ability to reason. He was of the belief that the mind, reason or intelligence possessed three basic faculties in the form of memory, intellect and will. This he equated to the trinity. Thomas Aquinas not only adopted Augustine's rationale, but also advanced it with the notion that humans can love God. Aquinas strongly advocated rationality as the meaning of bearing the image of God and held the stance that pre and post the fall humans still bear the image of God. He was however, of the opinion that redeemed Christians bear the image of God in greater capacity than the unredeemed (Tarus, 2016:19).

Peterson (2016:28) is critical of the substantialist view on *Imago Dei*. He argues that from an ontological perspective no distinction is made between the soul and the body. He highlights that according to Aquinas the mind or soul has its own operations, which was alluded to previously, the mind has memory, intellect and will. Peterson (2016:29) argues that the body also has its own operation; it has sensation and is just as complex as the mind. Recent studies also show that the body contains muscle memory that is separate from the mind, which suggests that Peterson has a sound argument even from a scientific perspective (Gundersen, 2016:235). Peterson is of the opinion that

body and soul can be distinguished, but both is required to complete human nature. While the question can be asked if a body is required to display human nature, the reality is that without a body the soul will not understand specific limitations. This is further explored later in the chapter during the response to transhumanism and the post-human state. What needs to be highlighted is that Peterson is referring to human nature and not *Imago Dei*.

In Peterson's (2016:29) response, he points out that Aquinas was aware of the objections to his positions that include the following: the whole human creature was created in the image of God and not only the mind; God made humanity male and female, which indicates that image refers to more than just the mind; generally, image refers to a shape, or a form and thus must include a body. This is in line with the Near Eastern background of the time (Middleton, 1994:18; Peterson, 2016:6).

5.3.1.2. RELATIONAL VIEW

The relational view focuses on the relationship aspects of *Imago Dei*, especially the relationship between man and God. Miller (2011:324) indicates that relationship between God and man is what sets humankind apart from the rest of creation. Tarus (2016:21) highlights that although Martin Luther focussed on the relational aspect of *Imago Dei*, he was not able to completely distance himself from the substantialist view. Luther emphasised that reason was the main part of being human and through reason man is able to build a relationship with God. The relationship with God is central to the relational view and it is this relationship that was lost through the Fall of man (Tarus, 2016:21).

Luther believed man existed in perfect relationship with God before man sinned against God and corrupted their relationship. It is through Jesus Christ and man's faith in him where the grace of God is displayed. Humankind's relationship with God is restored through the redemptive actions of Christ. John Calvin had a similar view and built on Luther's work by stating that it is through Christ that the relationship between humankind and God is restored (Tarus, 2016:21). Tarus (2016:21) highlights that Calvin's focus was on redemption and restoration from sin. The difference between

Calvin and Luther was that Calvin seems to affirm that man was created in God's image to glorify God, thus not only focussing on the image itself, but also on the reason for creation.

While Calvin focused on the restoration of relationship with God, Karl Barth had a different view. Barth viewed the relationship not in the individual sense, but in relationships in general. This is evident in his position that man's creation in the image of God enables him to have relationships with other individuals. Although Barth's work concentrated on the relationship between individuals he did not neglect the relationship between man and God. For Barth, God invites humanity to enter into a relationship with Him and this can only be done through Jesus Christ. Thus, Barth is clear that *Imago Dei* points directly to Christ the redeemer (Tarus, 2016:21; Otto, 1992:507). Peterson (2016:43) agrees with the view that Barth's interpretation of *Imago Dei* lies in a Christological context. Peterson argues that by extension this means it is a Trinitarian context.

As part of his study, Peterson (2016:43) evaluates Barth's specific relational view of *Imago Dei*. He critically reviews Barth's work and notes that Barth's view has various strengths, but also weaknesses. Key strengths in Barth's argument is that he refrains from relating *Imago Dei* to any specific human power, possession, or activity. The interaction is always directed from God towards humanity and not the other way around. Another element is that Barth refers to the whole of humanity as created in the image of God, while distinguishing between soul and body. Peterson (2016:44) points out that Barth went as far as tracing the image of God to the covenant relationship with Israel. Key to Barth's Christological view is that *Imago Dei* was fulfilled in Jesus Christ according to the New Testament texts. Peterson highlights that Barth correctly described the relationship between being created in the image of God and having dominion. He is of the opinion that rule is a consequence of image. While Peterson highlights the strengths in Barth's view, he is however critical of Barth's exegesis.

Barth's interpretation of Genesis 1:26-27 and Genesis 5:1 is a topic of contention. Influenced by Bonhoeffer, Barth was confident in his interpretation of Genesis 1:27,

since Genesis 5:1-2 repeats the same material. He believed the text explains itself by stating that man was created in God's image as "male and female". The challenge to Barth's interpretation lies in the interpretation of "male and female." For Barth it is a clear indication that there is a relational element included in the creation account. While this might be the case, the challenge to his interpretation is that it is possible that the text is not referring to relationship, but that all humans are created in the image of God. There is an argument that Peterson bring forth, namely, that male and female can be a democratising clarification and not necessarily pointing to meaning (Peterson, 2016:47).

There are also other implications relating to the Genesis 5 exegesis. Barth and Bonhoeffer both linked the text used in Genesis 1:26-27 with a poetry construction where the three lines of poetry is brought together by a word, in this case *bara*. The implication of this is that the first two lines should be interpreted by the information provided in the third line. Peterson (2016:48) indicates that if this method of interpretation is used in Genesis 1:26-27 and the same affirmative text are contained in Genesis 5:3, the same method of interpretation should be used. He continues with the statement that Claus Westermann compellingly argued that the third line in Genesis 1:27 is the foundation of a blessing in Genesis 1:28 and then worked out in Genesis 5. This reading was confirmed by scholars such as Paul-E, Dion. Dion argued that Genesis 5:1-3 should be interpreted as the transmission of the human divine likeness (Peterson, 2016:49). Apart from the interpretation of the text in Genesis, Peterson (2016:50) does not agree with Barth's view on sin and redemption. For Peterson it is challenging to accept the relational view of *Imago Dei* due to the evidence of misinterpretation of specific texts. It seems as if Peterson's disapproving view of the relational view is influenced by the Barth's theology as a whole and not only the exegesis of Genesis. He does point out that Barth's thinking is remarkable, but still seems at odds with his view, especially relating to *Imago Dei*.

5.3.1.3. FUNCTIONAL VIEW

This view holds that dominion is the main fundamental significance of being created in the image of God. The functional view rejects the substantialist view of *Imago Dei*

in the sense that it relates to rationality. Being created in the image of God refers to man exercising dominion over creation. Tarus (2016:22) highlights that the image of God refers to the task of ruling in authority over creation. Middleton (2005:27) states that the meaning of *Imago Dei* relates to the divine authority that has been given to humanity to rule over creation. Middleton's functional view is that God's image is the mediation of power onto creation. He is basing his view on a thorough exegesis of Genesis in conjunction with other Old Testament and New Testament texts. What gives substance to his exegesis is that he couples his exegesis with the Near Ancient view on image in historical time (Middleton, 2005:30).

Tarus (2016:22) indicates that the functional view is based on two main arguments. He argues that the view emerged from the historical-biblical method of exegesis, as can be seen in Middleton's work. The interpretation deals with "*in our image*" and "*let them rule*" found in Genesis 1:26 in close relationship. By interpreting the text in this manner a link is created between *image* and *rule* or dominion. This implies that to bear the image of God, man should rule over creation, for without this rule humanity cannot bear the image of God (Tarus, 2016:22; Barth, 1991:27). The second argument, also prominent in Middleton's argument, is that this view refers heavily to historical views from the Near East (Middleton, 1994: 18). Christophe Barth (1991:27) highlights that ancient extra-biblical texts point to kings being shaped into gods. Due to this he is of the opinion that it would be common in that era to use *Imago Dei* to exert power attributed to the image to rule creation. He further states that in ancient Egypt "image of God" usually is an equivalent of "son of God." The functional view refutes other interpretations of the texts and Barth (1991:28) provides the following reasons:

- There is no point in arguing for a literal interpretation. God is transcendent over creation and any outward appearance will be unlikely;
- A substantialist interpretation of the text is speculative and has little basis in the text;
- The relational interpretation is also refuted. Although there is merit in the statements that God is not alone and humans need relationships, they argue that there is little textual evidence for this approach.

To summarise, this view holds that the image of God is found in the act of ruling over creation. Ruling over creation does not mean that humanity can be abusive towards creation, but that man should be servants and stewards of God's creation (Tarus, 2016:23; Barth, 1991:28; Middleton, 2005:34).

While Barth and Middleton's arguments are strong there are some areas they neglect to address, especially from a New Testament perspective. Peterson (2016:14) accepts Middleton's argument as the best interdisciplinary argument. However, he objects to the functional view both logically and exegetically. His focus is on the work of Middleton as He is a contemporary theologian who draws on various sources which includes the Old and New Testaments. Peterson (2016:38) indicates that if image is equated with rule, then it opens the options that not all of humanity is created in the image of God. From a propositional logic perspective, it means that if a person does not exercise rule, they are not in the image of God. This is problematic as it means a person can be in the image of God when exercising rule, but not be in his image when not. Peterson (2016:38) provides an example of this by stating that if a person needs to breathe to survive, one cannot equate breathing itself as the condition for human existence. There are many factors that determine this and not only one factor. He gave a second analogy to refute the functional claim: if by implication, only a man can be a father it means one cannot be a father without being a man. This however does not mean that all males are fathers, as it is only a prerequisite to be one. Therefore, if humans can only be considered to be in the image of God when exercising rule, not everyone is in the image of God and by implication downgrades the worth of a person. Logically this argument does not make sense.

Peterson (2016:39) also objects to this view from an exegetical perspective. The main challenge he proposes is that Middleton and Barth are referencing the New Testament but are careful not to speculate about the meaning of *imago Dei* in the New Testament. Due to this, Peterson is of the opinion that the link between the Old Testament and New Testament references are not addressed. He continues by highlighting that the term *rule* should not define if a person is created in the image of God or not. The reality is that rule is an attribute that can be exercised or not at all, as it is the choice of an individual if they want to exercise that authority or not.

5.3.2. AN ALTERNATIVE APPROACH TO *IMAGO DEI*: HUMAN IDENTITY

During the previous sections, the prominent views and interpretations of *Imago Dei* were discussed. None of these views encapsulate the true meaning of being created in God's image. Peterson (2016:1) offers a different view on what *Imago Dei* means. He equates the image of God to humanity's identity and states that this identity is basic to all humans. He continues by pointing to the fact that man was created as the earthly image of God and bound to God's purposes. He believes that to understand what it means to be created in the image of God one needs to know who God is and what God is like. According to Peterson (2016:1) man needs to know the identity of God before he can understand his own identity.

Peterson (2016:1) is of the opinion that both the Old Testament and New Testament texts should be relied upon to provide a true reflection of God's identity. It is only when we understand God's identity that we will be able to conceptualise *Imago Dei*. One aspect of God's identity is that he is particularly interested in human beings and humanity's dependence on Him for identity. Peterson (2016:1) points to the fact that Jesus is fully divine, yet was fully human. Through his incarnation he brought the full image of God to the world and instead of bringing new intention to the world, he fulfilled God's intention.

In Peterson's work "*The Imago Dei as human identity*" he outlined *Imago Dei* as more than just man created in the physical image of God, which includes the body, soul and spirit. Although his interpretation of *Imago Dei* is not specifically related to genetic editing it does provide a good foundation to work from. Peterson's view on the *Imago Dei* seems to be holistic in the sense that he considers various angles. The holistic view he offers include that the image of God refers to the human soul as God is spiritual. It also refers to the human mind since God is rational and it refers to the human body since ancient Near Eastern philosophy thought gods had physical forms. He further includes human domination over creation since God rules all things, human relations since God is triune, human virtue since the God is good as well as human existence since God exists (Peterson, 2016:3).

Peterson indicates correctly that the Genesis 1:26 - 28 reference to *Imago Dei* is not limited to a specific aspect of humanity, as can be seen in the other interpretations of image. The implication of this view is that God created humans holistically in His image. Peterson points to three specific areas relating to the creation of humanity:

- humans are created in the image of God;
- humans are created to rule over the earth and other creatures;
- humans are created male and female.

The argument Peterson is making with these points is that there the spheres of humanity do not function in a silo. In other words, it is not a specific attribute that reflects the image of God but everything that makes a human, human. Peterson (2016:53) is attempting to combine various interpretations of *Imago Dei*. Thus humans are made in the image of God and should rule in an analogous way. God created a person with the ability to reason, to live in relationship not only with other humans but also with God and finally through Jesus Christ and his redemptive work we are able to see God's true image.

Some context is required to fully comprehend the problem Peterson is attempting to solve. Scholars such as Christophe Barth and Middleton believe that human creation in the image of God is solely contained in Genesis, and therefore they do not attempt to interpret the meaning of the New Testament texts. Other scholars believe that the image of God is exclusively found in Christology, with condensed reference to Genesis, as in the case with Karl Barth. Peterson makes the point that in both instances the conclusions are based upon one testament with limited complimentary interactions between the Old and the New Testaments. While most theologians see the concept of *Imago Dei* as central to their theological anthropology, redemption and sanctification, their definition of *Imago Dei* is vague and lacks explanation of what they are referring to. He argues that if *Imago Dei* is to be used as a central theme in theological arguments, it is imperative that a detailed explanation of *Imago Dei* is presented (Peterson, 2016:16).

For Peterson (2016:16) the dominant interpretations of *Imago Dei* lack fullness in the sense that it does not account for the meaning of *Imago Dei* in the real world. Most interpretations reflect on the conditions for the possibility of imaging God. When looking at Genesis, Peterson poses the question of why the author of Genesis refers to humanity by calling man the *Imago Dei*? He elaborates with a follow-up question, asking what warrants the attribution of *Imago Dei* to humanity. The answer to these questions could be any of the dominant interpretations of Genesis 1, namely, soul, physical shape and posture, rationality and the ability to build relationships.

One of the key aspects Peterson (2016:17) addresses is the concept that could arise from an attempt to interpret God's identity by looking at human identity. God was not created in man's image, but humanity was created in God's image. Therefore the identity of the creature is in the image of the maker. If it was the other way around it would imply that man existed before God. As seen in Genesis 1, this is not the case (Crouch, 2010:1). God created man in his image with abilities and attributes that reflect the image of God.

Peterson continues with this notion and asks a profound question: "*What does it mean for God that he created humankind in his image?*" During his interpretation, Peterson is clear that God was determined to create an image of Himself as a representative on earth. As a result, a humanity was created in God's image which means a similar identity than God. The implication of this is that God created man with specific abilities and attributes to reflect Gods image on earth. It is noteworthy that Peterson does not isolate any ability or attribute as the main reflection of God's image, instead he focuses on the holistic human being.

The definition of identity is key to Peterson's argument and he considers various definitions before motivating a specific one. He defines identity as "*the condition or fact that a person or thing is itself and not something else.*" The reasoning behind this definition is that God determined what humanity should be and subsequently created man in his image. Thus, image is what makes humans what they are and not something else (Peterson, 2016:54). He continues and states that it is also important to define how identity is determined. Peterson defines it as follows: "*recognition of a*

thing as being what it is.” He adds that in Genesis 1 God defines what humanity is for humans, and specifically that the people of Israel may recognize who they truly are. He concludes that the fact that man is created in the image of God motivates God’s interest in humans (Peterson, 2016:55). It is notable that Peterson’s definition of identity is problematic for social sciences as it is very direct and does not leave room for interpretation. This is exactly why he uses this term. If the image of God is human identity, it means that all of humanity has this identity and not a specific group of individuals. He continues and state that Genesis 1:26-30 makes God’s people aware of their identity within creation and if individuals substitute it with an alternative identity instead of understanding their God given identity, they do not understand or are not aware of their identity (Peterson, 2016:55).

Moving towards Peterson’s interpretation of *Imago Dei* as human identity from a theological perspective, an understanding of his foundations relating to the use of biblical exegesis needs to be attained. He is of the opinion that scripture is to be read theologically and canonically. Peterson highlights that the topic of *Imago Dei* is a complex problem due to the different interpretations of scripture (Peterson 2016:20).

Peterson (2016:65) concludes that *Imago Dei* is a common identity shared by all humanity. God, who is transcendent, determines this identity and all humanity possesses this identity whether they know it or not. Awareness of this identity is obtained through an understanding of the narrative identity of humanity as depicted in the Old and New Testaments. The image of God as human identity can be discerned in a similar way than Jesus’ divine identity – through the careful studying of the identity in biblical texts. While Peterson does not highlight a specific attribute of man as the image of God, he does advocate that careful understanding of identity, function and ontology should be obtained to ensure the proper theological order of *Imago Dei* can be attained (Peterson 2016:66). Ultimately, he suggests that the question should not be “what” constitutes as *Imago Dei* but rather “who” is *Imago Dei*.

While this is an attractive way of looking at *Imago Dei* there are areas that are not addressed by stating *Imago Dei* is human identity. Peterson’s approach is to state that identity means to be something that is not something else – and this opens the

question to what human identity is. It is this logic Peterson attempts to avoid by stating that the search for human identity should not start with an investigation into human identity, but rather with an investigation into God's identity (2016:17). Peterson's goal is not to answer this question, but to build a framework to recognise that created in the *Imago Dei* is a holistic term. Isolating one human attribute, power, function or action as the image of God is incorrect as being the image of God is much more than reason, authority or the ability to live in relationship with other humans. However, humanity's true identity can only be understood in God's identity and central to this is Jesus Christ who, by being fully human, was the perfect example of *Imago Dei* (Colossians 1:15; John 10:30; John 14:7-9).

If we equate human identity as *Imago Dei*, there is a probable basis for *Imitatio Dei*. Peterson (2016:112) explores this concept and is of the opinion that imitation of God is part of *Imago Dei*. His reasoning on this topic is that the imitation of God is the partial realization of God's image. He continued with the statement that humanity was created in God's image and humans become like what they worship. This according to Peterson was the intention of God from the beginning of creation "*to become like God through knowing God.*"

The concept of *Imago Dei* through the lens of *Imitatio Dei* is important to explore especially when it comes to bioethics and specifically to gene editing. During the next section the focus will turn towards the implications of *Imago Dei* as human identity for gene editing and bioethics in general.

5.3.3. IMAGO DEI AS HUMAN IDENTITY AND ITS IMPLICATIONS

When evaluating all the views on *Imago Dei* from a bioethical perspective, especially focusing on genetic editing, it is evident that a holistic approach should be followed. The view presented by Peterson (2016) is convincing and does provide a framework for an ethical response to the current challenges outlined in the previous chapters. The substantialists view does not provide an adequate framework as the view states that the image of God relates to the rationality or the mind of a person. This implies that, from a simplified perspective, any form of genetic editing can be conducted as long as

a person can rationally think, stay intelligent and is able to communicate. The relational view has similar challenges. As long as an individual's relationship with God and those around him is not affected, any genetic editing or enhancements are permissible. The functional view provides the freest reign, as it states that image relates to dominion. It can be argued that gene editing and human enhancement is the ultimate form of dominion over creation and by not exercising the dominion over creation a person cannot be the image of God as stated by Christophe Barth (Barth, 1991:27).

The view of *Imago Dei* as human identity implies a holistic approach as the true image of God is found in God's identity. The researcher is of the opinion that with this view it is possible to move towards a Reformed Christian bioethical response to genetic modification for therapeutic use and human enhancement.

In order to understand *Imago Dei* as human identity in relation to the research question, we need to explore God's identity. One of the key attributes of God that needs to be investigated can be found within the creation account. The first point relating to creation is that God is the *ex nihilo* creator, in other words God created out of nothing (May, 2004:ix). While the purpose of this study is not to discuss the doctrine of *creatio ex nihilo* it does provide a foundation on which later concepts will be build. Ho (2020:199) opposes this doctrine. However, he does provide a clear understanding of the doctrine. The doctrine implies that there was a stage that nothing except God existed. God was responsible for creating a natural world out of nothing and declared it good and perfect (Creel, 2014:31). The challenges brought forth by Ho and other scholars is that if God created a perfect world out of nothing, He also created evil out of nothing. This is a profound statement if read in isolation. Essentially, what Ho is implying is that God is responsible for all evil in the world including pain, disease and death. According to Creel (2014:25) this pantheistic view holds that God could not make the world out of nothing and elements were in existence from which all was created. Ho (2020:199) does not state that his view is pantheistic, but rather points to modal rationalism as his rational foundation.

Creel (2014:28) explores the notion of deism in the creation account. He states that while pantheism believe that God did not create from nothing, deism holds the notion

that God created out of nothing and during creation set specific rules in place that governs daily life. According to this philosophy God is not actively involved in daily life (Lucey, 2022). Lucey (2022) points to modern deism, which believes that God created the world and is only involved in certain instances and only if there is favour on a person. Creel (2014:28) is aligned with this view and states that deism believes that God is aware of what is going on in the world and man will be judged based upon his works and obedience to the moral law of God.

In Creel's (2014:31) exploration of the different creation accounts he summarises the traditional biblical view of creation by a God who is transcended and created *ex nihilo*. Following the creation account God is involved in the world, meaning He cares for His creation. This view is in line with Jurgen Moltman's trinitarian view (Gunton 2004:89). Moltman's view on *creatio ex nihilo* is that it is an outward act from God. For the purpose of this study we will accept the doctrine of *creatio ex nihilo* in line with the traditional biblical view of creation.

The importance of laying the foundation of *Creatio ex nihilo* in this study can be found in the act of creation. God created the world according to Genesis 1, but the creativity God displays during creation transcends the human mind. We are not able to fathom how something new can be created from nothing, without any reference points. Robson (2008:156) aligns himself with this view and states that the entire creative process cannot be rationally explained. The main reason for this is the unknown. As humans we can only relate to creativity that is born from something we know, or something we emulate. For instance, if a potter wants to make a pot, the potter would require clay in order to mould it into a specific form. The substance used is known to the potter, as well as the attributes of the clay, its consistency and how the clay responds in certain conditions. With the creation account it is different, as God did not have the proverbial clay to mould into a form. He created the clay with the attributes and then used it as part of His creation. Robson (2008:156) indicates that Plato insisted on something similar when referring to art. Plato insisted that art is non-rational and cannot be explained, for instance where the words come from a poet uses to write a poem cannot be explained. Although this might highlight the challenge that creativity is inexplicable and non-rational, it does fail to recognise how sophisticated

the creativity of God is. If God's creation was a poem, He not only had to be creative enough to write the poem, but also creative enough to construct a language framework and create individuals to understand the language used in the poem.

Continuing with this creative narrative, it is important to acknowledge the amount of creativity it took to create something as complex as DNA. As highlighted during the previous chapters, human DNA consists of three billion base pairs and one can all but stand in awe of a God who is able to create from nothing such complex organisms functioning with DNA as its building blocks, (Christmann *et al.* 2003:3). The Psalmist clearly states in Psalm 19:1 that "*The heavens declare the glory of God; the skies proclaim the work of his hands*". This verse not only refers to the greatness of God but can also be interpreted as an indication of God's creativity. In Paul's letter to the Roman church he reminds the reader that God's invisible qualities, his eternal power and divine nature have been seen and understood from creation (Romans 1:20). Bawulski and Watkins (2012:174) points out that God exhibits creativity in the product (creation) as well as the process of creation. In their work, they make it clear that a relationship exists between humanity's creativity and God's creativity. They justify the fact on the basis of God's revelation of his own creativity. This divine creativity was fully revealed in the incarnation of Jesus Christ. When analysing their thought process it is clear that they, similar to Peterson (2016), start with God as the source of creativity. By implementing this method, they avoid mistakes of transposing human attributes on God's character.

In summary, if humanity is created in the image of God, and that image is human identity, then humans will naturally imitate God. With God's transcended creativity it is natural that man will be creative as well. This natural creativity is evident in children whose creativity can amaze parents, creating whole storylines from nothing and role playing for hours. If humans are naturally creative then it makes sense that humanity can be seen as created co-creators with God.

5.3.4. CREATED CO-CREATORS

The term *created co-creators* was coined by Philip Hefner, who interacted with various disciplines before concluding that humanity is co-creators with God (Lorrimar, 2017:727). Hefner (1993:27) pointed out that:

“Human beings are God’s created co-creators whose purpose is to be the agency, acting in freedom, to birth the future that is most wholesome for the nature that birthed us – the nature that is not only our own genetic heritage, but also the entire human community and the evolutionary and ecological reality in which and to which we belong. Exercising this agency is said to be God’s will for humans”.

Peterson (2004:829) is of the opinion that the term co-creator implies that, when referring to creation, humans are responsible for creation. The term co-creator might be interpreted incorrectly as co-creator with God, meaning humans have free reign to create similar to God. Due to the potential misunderstanding one should explore other terms to describe this action.

Molhoek (2022:4) suggests two possible terms that could be used for co-creators in order to eliminate some ambiguity. The first term Molhoek (2022:4) proposes is the *subordinate created co-creator*. This term implies that humans are created by God, in God’s image and due to this fact that we are creative co-creators. However, the difference is that God created *ex nihilo*, while humans are not able to so. In other words, humans are able to take God’s creation and rearrange specific aspects to create new things. Molhoek (2022:4) provides the analogy of Lego blocks. If God created the Lego blocks the subordinate co-creator can rearrange the blocks to create something new. The other term Molhoek discusses is *truly cooperative created co-creators*. This term implies that human beings has the ability to create novel creations as God does.

While Molhoek attempts to clarify the term created co-creator, it is important to note that Hefner (1993:36) never implies that human beings have the same creative power

as God. He states that humans are created within creation and thus are dependent on antecedent factors such as ecology, biology and culture. He continues and points to the fact that humanity was created and given a place within creation by God. It is this ordination from God that makes the discussion a theological discussion. A key concept of created co-creator is that man can only function within the realm of creation where as God transcend creation and function both within and outside creation. Due to the fact that humans are not able to create *ex nihilo*, and can only create within the matrix of creation the researcher aligns with Molhoek's first term, but will refer to created co-creator as the explanation by Hefner (1993:36) will suffice. Humans are however subordinate to God and cannot create matter out of nothing. Due to the implications of *Imago Dei* though, humans have the natural inclination to create. This creative action is performed within the matrix of creation by taking existing matter and rearranging it to create something new.

5.3. REFORMED THEOLOGICAL RESPONSE

The following section focuses on a Reformed theological response to gene editing. Responses will be constructed based on the framework of the doctrine of *Imago Dei* as human identity. Before an ethical response can be constructed regarding gene editing, the question should be answered if it is ethical to create and use biotechnology.

5.4.1. A SHORT RESPONSE TOWARD BIOTECHNOLOGY

During the preceding section, it was reasoned that creativity forms part of God's identity. It was also highlighted that man is created in God's image, therefore humans are naturally inclined to be creative. We also concluded that humanity can be seen as created co-creators and use existing matter to create something new within the matrix of creation.

Kruger (2014:41) states that Reformed theology and ethics are not opposed to the development and use of biotechnology. Cole-Turner (2011:6) is aligned with this view and indicates that there are more proponents of using biotechnology in the church than against it. What seems to be evident is that biotechnology similar to other

technologies are to be embraced. However, Drees (2002:647) warns that while humans are the creator of technology and that technology has the ability to shape humanity. An example of this is electricity, as man is so dependent on electricity that it seems archaic when there is no electricity. Another example is the internet and the mobile phone – a few years ago, information was found in libraries and books, whereas today an individual can connect to the internet via a mobile device. The challenge with all of these technologies is that it shapes human behaviour and creates a dependency on the technology.

Shatzer (2015:87) points out that the majority of Christians and theologians view technology as an external tool that can be used to produce a specific outcome. For example, if a person needs to fasten a screw, a screwdriver can be used. This creates the impression that there is not any issue with technology, but there might be an issue with how technology is used as the same screwdriver can be used to injure someone intentionally. This line of thought is explored by Shatzer (2015:90) who asks whether technology should be celebrated or feared. The reality is that any technology can be used for good or evil.

The researcher considers technology as part of the creative process that forms part of the role humanity is playing as created co-creators. It is however vital to acknowledge that technology can be used or abused and thus the study of the ethical use of technology is necessary. This is especially true when it comes to biotechnology. One question that requires further research is linked with how technology is shaping humanity's identity and what the impact of this is on the view of *Imago Dei*. To clarify this point, essentially the creation of the created co-creator is shaping the created co-creator who continues to create. This is especially true in the case of genetic engineering.

5.4.2. HUMAN DIGNITY

The term human dignity has been growing in popularity during the past century. Sensen (2011:1) highlights that human dignity is the cornerstone of many states, political manifestos and is the foundation used by the United Nations for human rights.

This statement is backed up by Barilan and Caplan (2012:2) who are of the belief that clarification of human dignity is urgently required as the term appears in the constitution of 157 countries which represent 81% of sovereign states belonging to the United Nations. Sensen (2011:1) is of the opinion that this creates the impression that every human has specific value attributed to them and implies that respect should be shown to every individual.

However, recently the term seems to have fallen out of favour, especially amongst ethicists and bioethicists who are of the opinion that human dignity prevents fruitful discussions and progress. The term “human dignity” is attributed negative labels such as “useless”, “vacuous” and “stops conversations” to the point that some ethicists want to remove it from any bioethical discourse. It seems as if this view is far reaching and shared by more than the bioethical communality. During 2008 the Supreme Court of Canada voiced its disappointment at the role of human dignity in constitutional law (Barilan and Caplan, 2012:2; Segers and Mertes, 2020:33; Beriain, 2018:1).

A possible explanation of this might be the historical derivation of human dignity and the mainstream culture of today. Aroney (2021:1211) highlights the historic origins of human dignity and states that important distinctions should be drawn to the historic approaches to the concept. Although dignity has its traces in Greek philosophy, dignity was attributed to specific classes within the community. This meant that some individuals seemingly had more worth than others. It was only with the rise of Christianity that this changed.

The advent of the Church era brought new focus to the topic of human dignity and its meaning, especially with the view that humans were created in the image of God. Genesis 1:26 was the basis of this view and meant that the Christian Church paved the way to ensure all had equal dignity no matter what class or how wise a person was. The grace Christ extended on the cross for all humanity was seen as a double reason for human dignity (Aroney, 2021:1217). Thomas Aquinas took this concept further and attempted to explain that humanity’s uniqueness lies in the ability to reason. This was his view of *Imago Dei* and the reason a human has value. Aquinas was of the opinion that a status of high dignity should be attributed to anyone who has

the ability to reason. He concluded that sin could never take away the human dignity, but dignity can be enhanced through a relationship with God (Aroney, 2021:1222).

The view that human dignity is grounded in *Imago Dei* have been held throughout the centuries. It was not until the modern age when Kant suggested that human dignity is grounded in morality (Aroney, 2021:1233). Kant was of the opinion that morality is derived from rational concepts and not from human nature or divine revelation. During the post-modern era Fredrich Nietzsche (1923) suggested a totally different view of human dignity. He was of the opinion that human dignity does not exist and pointed to the fact that from the Greek era throughout the middle ages some classes had more dignity than others. This means that theoretically the concept of the same human dignity for all is not a realistic concept. Nietzsche is of the opinion that equal rights is a myth and the majority will always be subjected to “slavery” for the benefit of a few (Andorno, 2011:967).

It is against this backdrop that several bioethicists are recommending to remove human dignity from bioethical discussions. Nussbaum, a renowned ethicist is also of the opinion that introducing religion into ethical debates slows down progress and does not recommend doing so (Owens 2017:48). There are individuals who believe that human dignity is purely rhetoric and political (Andorno, 2011:967). Macklin (2003:1419) is of the opinion that references to human dignity in bioethics are vague restatements of other or slogans not adding any substance to the topic. She concluded that dignity is a futile notion and can be eliminated without any loss of content. Hoffman (2020:603) highlights that the removal of human dignity by some philosophers are based on a lack of clarity, that it is redundant as a moral idea and has religious overtones. It would seem that the challenge for theological bioethics is to stay in conversation with scientists and philosophers as the theological viewpoint brings another dimension to the discussion.

The concept of *Imago Dei* adds to the discussion of human dignity within the bioethical sphere. Although human dignity based upon *Imago Dei* is not new, as seen in the work of Aquinas, the view that our identity is linked with God’s identity brings a new dimension to the table (Voster 2012:3). When looking at human dignity through the

lens of *Imago Dei*, especially from the holistic view as presented by Peterson (2016:119) the question should be asked what moral compass science will use if human dignity is removed from the conversation? The critique from philosophers such as Macklin who views human dignity as a stumbling block to progress is unwarranted, especially when looking at it from a different perspective. Removing human dignity from the conversation, especially with regards to gene editing, opens the door for regulated eugenics programmes in the name of science. This is a slippery slope, as the power will belong to those who has the financial means to control the experiments and ultimately control and shape humanity as they see fit. Another question that can be asked is who decides what elements within humanity will be deemed good to keep and enhance?

Voster (2012:3) highlights that Christianity basis its understanding of human dignity upon the teaching of *Imago Dei* since the time of Ambrose of Milan. The foundation of human dignity lies in the fact that human beings are created by God and has a special relationship with Him. Voster (2012:4) concluded that the right to life, autonomy and equal respect are the basic theological components of human dignity. He points to Genesis 2:7 as foundation that life has divine origin and that God sustains the earth. In line with Peterson (2016:116) he is of the opinion that God is the source of life and due to this God is offended by anything that destroys life. This is backed up with the view that humans are the representatives of God as part of the doctrine of *Imago Dei* and is based upon Genesis 9:6. Thus, theologically human dignity is attributed to every person whether they are a Christian or not. This is based upon the view that all human beings are created in the image of God (Peterson, 2016:116; Voster, 2012:6; Middleton, 1994:9). Thus what is clear from a theological perspective is that the human is created in the image of God, which is the basis for human dignity.

The researcher is of the opinion that the term human dignity can be explored further as there seems to be non-equal values ascribed to individuals. An example of this is the value society ascribe to the poor against the rich. Friedrich Nietzsche (1923:123) observed this and was extremely vocal on this point criticizing Christianity for its doctrines of equality amongst other things. He was of the opinion that this would ruin civilization and that human dignity and equality is a lie within the faith. Nietzsche

argued that within Christianity this equality is non-existent (Nietzsche 1923:123). While this should not be the case a brief observation within Christianity seems to support this view. There are many instances where Christian communities degrades other individuals, whether in the community itself or individuals from other faiths. Take for example the notion of Aquinas that through the death and resurrection of Christ, some individuals bear the image of God in greater capacity than others, thus implying that some have more value than others (Tarus, 2016:19).

While there are arguments to remove human dignity from bioethical discussions it is impossible to do so from a theological perspective. The ontological view of theology implies that humans are formed in the image of God, bear the identity and represents God in creation. Thus With this as foundation we can now move the focus to gene editing for therapeutic use and human enhancement.

5.4.2. CHRISTIAN BIOETHICAL RESPONSE TO GENE EDITING FOR THERAPEUTIC USE AND HUMAN ENHANCEMENT

The Bible itself does not provide enough guidance to properly respond to gene editing for therapeutic use and human enhancement. Thus, as suggested by Kotze (2013:45), specific doctrines are used to provide guidance on this topic, specifically the doctrines of *Imago Dei*, *imitatio Dei* and *created co-creators*. We now turn to a response for using gene editing for therapeutic use.

Chapter 3 pointed to the definition of health from a non-Christian perspective. While the value-laden definition of the WHO has its critics it does find appeal with theological philosophers (Messer, 2011:163; Hanson, 2001:26). When looking at health from a perspective of *Imago Dei* it seems as if wholeness is at its core. Hanson (2001:28) is of the opinion that wholeness is a state of perfect health. This can only be achieved through the perfect reconciliation with God. He supports this argument with the view that spiritual health and physical health are in unity and goes as far as asking the question: “*Can you have physical health without spiritual health? Or vice versa?*” (Hanson, 2001:28). Hanson is of the opinion that health from a theological perspective should be broad and refer to the total wellbeing of an individual. The main challenge

with these broad definitions relates more to determining what is typical for a specific species. Questions raised opposing the value-laden concept of the theological Reformed perspective is similar than that of the non-Christian views except for the notion on wholeness on the physical body and spirit (Messer, 2011:166).

Galvez (2010:23) is of the opinion that the human body was created as a whole, sinned as a whole and will be resurrected as a whole, which implies that perfect health can only exist following the death and resurrection of a believer. Hanson (2001:27) is aligned with this view but cautions that it does not make sense to view health as something that humans can only attain in eternity; however it does provide a vantage point to work from. He states that perfect reconciliation with God and perfect wholeness would be a perfect state of health and added that death will be no more (Hanson, 2001:28). In this context the meaning of health for the Christian means that health is more than the absence of disease. This is a concept that differs from the value neutral proposal of Boorse as well as the value laden definitions of the WHO and Nordenfelt. Messer (2011:166) expands on this and states that health must be understood as a real but limited human good. He is of the opinion that both health and disease are intrinsic value laden teleological concepts.

The question of how important physical health is, is key. If physical health is less important than spiritual or emotional health it would be challenging agreeing with the amount of time, money and resources that is spent on gene editing for therapeutic purposes. Hanson (2001:28) does recognise that there is an important biological element to health. In the current clinical environment, health is largely focused on the well-being of the biological component. He added that when individuals refer to a cure, it is aimed at a biological cure. He extrapolates on this concept and warns that Christians should recognize that the overall biological health is a relative condition and teleologically is pointing towards salvation. Hanson (2001:29) is of the opinion that psychological health or physical health does not ensure complete health which will only be achieved through salvation. This sheds light on the term “wholeness” as a concept of health that is used by various scholars such as Messer, Hanson and Galves (Messer, 2011:166; Hanson, 2001:29; Galves, 2010:23).

Hanson (2001:27) points out that Jesus is often portrayed as a healer of physical ailments. In reality this healing was more than physical, as the healing was spiritual, emotional and physical. This points to the wholeness of an individual and affirms the relationship between healing and having a right to have a relationship with God. Hanson is a proponent of salvation as a form of healing. While Hanson (2001:28) does not address the topic of gene editing, it is noteworthy that biological healing and health is an important factor in the relationship between God and man. This can be seen in the Gospel accounts where Jesus healed physical disease (Luke 18:42; Mark 2:9). Messer (2011:171) correctly states that physical healing should be viewed as a genuine but limited human good and should not be confused with total human well-being.

Against this backdrop of physical health from a theological perspective, we turn to gene editing for therapeutic use. From a theological ontological position humans are created in the image of God as described by various philosophers including Irenaeus, Aquinas, Luther, Calvin, Moltmann, Middleton and Barth (Middleton, 1994:9; Jancovic, 2019:185; Peterson 2016:1; Bentley, 2017:2; Gunton 2004:89). Although there are differing views on what is meant by *Imago Dei*, there seems to be consensus that according to the Old and the New testaments, humans were created in the image of God. The holistic argument presented by Peterson (2016) seems to be the most comprehensive. There also seems to be consensus that Jesus' incarnation fulfilled the perfect image of God in human form. If this is the case, an argument can be made towards physical and psychological healing in our current state by looking at the example of healing acts performed by Christ. What we can deduce is that through relationship with God, God wants people to be healthy. From the perspective of gene editing for therapeutic purpose this understanding is crucial. If we state that God wants us to use technological advancements to heal people, gene editing technology can be used for therapeutic use. This, however, brings about its own challenges regarding access to healthcare, which is seen as a basic human right and based upon human dignity.

The cost of providing gene therapy is a contentious issue. At the time of this study gene therapies are extremely expensive due to the individual precision required to edit the correct genes. For example, Zolgensma, the one-time gene therapy for Spinal Muscular Atrophy costs 2.2 million US dollars. The long-term use option, needs to be administered four times a year for life with the cost of 750 000 US dollars for the first year, and thereafter 350 000 US dollars per year (Fookes, 2022). At this price the treatment is inaccessible to most of the people it is intended to help. This treatment is not affordable for the majority of individuals. The question should be asked whether governments such as that of South Africa, which through its constitution is obliged to provide medical care, has the funding to support the treatment (Lategan, 2017:27). From a theological perspective, the question can be asked concerning the role of the collective church in providing care for those in need. This is a practical problem that requires further discussion regarding the role of the church in healthcare, especially in the post-church era (Lategan, 2017:29). The cost of the treatment could create disparity not only between the rich and poor, but also between first world and third world countries. It is noteworthy that this disparity already exists in the current context when it comes to treating diseases.

While there seems to be limited concern for safe gene editing focusing on therapeutic use on somatic cells, there are arguments against the editing of embryonic cells from theological philosophers (Bergman, 2019; Resnik, 2016:190). The main concern remains the dangers of using the technology to change the germline. One question that should be asked is if germline editing can lower the overall frequency of genetic diseases, especially single gene disorders. From a cost perspective it might be cheaper to limit the frequency of the disorders than paying exorbitant amounts for treatment, not to mention the psychological and financial cost of the families caring for loved ones. This relates more to the prevention of disease than curing a disease and has its own challenges. It also points to the wholeness Messer, Hanson and Galves refer to when speaking about health (Messer, 2011:166; Hanson, 2001:29; Galves, 2010:23).

However, this does raise other concerns relating to the rights of the unborn and a unique viewpoint from a theological perspective concerns the right to life. Theologically the topic is challenging since the Bible was not composed to provide scientific guidelines. The challenge when it comes to genome editing lies in the question of the ethical status of the embryo. While many scientific scholars view the pre-implanted embryo as cells (Gyngell, *et al.* 2017:504), the question from a theological perspective is when does life begin. Ling (2017:5) indicates that this question is at the heart of bioethics. He added that from an ethical perspective this has an impact on abortion, assisted reproductive technologies such as IVF, stem cell research, human embryo research and experimentation, prenatal screening as well as certain forms of contraception.

From a Roman Catholic perspective, the church made statements regarding their view that the starting point of life is at an early stage. Before IVF was possible, the Roman Catholic Church had accepted the doctrine of Thomas Aquinas, who stated that the rational soul is only infused forty days following conception (Benagiano and Mori, 2007:163). Following the technological advancements of IVF the Church changed their stance and is currently teaching that life begins at conception. According to Zuradzki (2014:442) it would seem as if the embryo's right to life is seen as lesser than the right to life of a more advanced foetus, child or adult. This is evident in the social use of the morning after pill, as well as the amount of ongoing embryo research. Zuradzki (2014:446) does highlight that the current view of the Catholic Church is based upon the uncertainty of when an embryo becomes a *person*. The Church's approach is that it will be a "*grave sin to dare to risk murder*". While this is the official Catholic Church response, the Protestant view is much more complex.

The challenge with the Protestant church's view is that churches function autonomously and each denomination, and sometimes each congregation, have their own view on embryos (Gribkov and Minchenko, 2020:2). The Council of the Community of Protestant Churches in Europe (CPCE) issued a guideline during 2017 to assist Protestant Churches with certain bioethical debates. The problem of the moral status of the embryo was briefly touched upon. They highlighted that the concept

of “person” has traditionally been used to try and address the problem. This concept distinguishes between the “person” and a “human being” with a “person” being seen as a member of the moral community. This implies that the “person” has moral regard from other humans within the community (CPCE, 2017:49). To simplify this, philosophers created a checklist containing criteria to define when someone is a person:

- A person is rational;
- A person is self-aware;
- A person has the capacity to relate and engage in relationships;
- A person has the capacity to have interests or preferences.

The CPCE (2017:49) highlights that this view seems to indicate that if a non-human entity met all the conditions, it would be considered a “person” while the opposite would be true for a human entity who does not. Morgan (2013:22) indicate that this is a gradualist view, and the main argument is that the embryo develops into a “person”. The CPCE (2017:50) agree with this and continues to recognise that gradualists tend to view embryos not as a “person” due to the fact that they do not meet all the criteria. Birkhauser (2013:957) indicates the Protestant gradualist hold this view for as long as the embryo does not have a nervous system, do not have organs and pain receptors. The implication of this is that embryos are not treated with the same moral standard as a “person”. The gradualist view also allows for the destruction of embryos used during research, fertility treatments and genetic screening based upon the justification of the benefits gained or prevention of harm. This seems to be aligned with outspoken transhumanists such as Gyngell, Douglas and Savulescu (2017:504) who argues that due to the nature of an embryo it cannot be harmed. They view an embryo as a cell, or cells that do not have the capacity of feeling and thus cannot be harmed.

However, not all Protestants agree with the gradualist view of the embryo. Saunders (2006) highlights that passages in the Bible place value on an embryo and refers to passages such as Psalm 139:13-16. He is of the opinion that the passage refers to God’s creation and communion with the foetus or embryo in the womb and implies there are continuity between life before birth and after birth. He continues and aligns with the Roman Catholic view of the embryo, stating that life begins at fertilization, or

conception. Wilfred Harle (2011:253) also aligns with the view that life begins at fertilization and is of the opinion that human dignity should be bestowed on all embryos.

While there seems to be an argument for life starting at conception the main challenge does not lie with the notion of when life begins, but rather with the definition and concepts of a person (CPCE, 2017:51). The CPCE (2017:51) acknowledged this and highlighted the challenge that both arguments on the two spectrums use hermeneutical proof that will give the results they desire on the status of an embryo. They are of the opinion the reason for this is the complex nature and history of the Trinitarian and Christological argument, which was not designed to use in modern day ethical debates. The statement of the CPCE (2017:52) highlights that the first argument, which state that the embryo should be able to be rational, self-aware, be able to engage in relationships and have capacities to have interests, is a similar argument used to marginalise women, people of colour and severely disabled people. They added that this does not mean that the argument is incorrect, just that it should be used mindfully as it could lead to a form of eugenics.

This also moves the discussion towards using gene editing for prevention, which leads to human enhancement. As discussed in previous chapters, humanity has been in a state of enhancement for thousands of years. The main difference in this day and age is the fact that the technology is available to make irreversible changes to the uniqueness that makes us human. This discussion is not an easy one to have and one of the main reasons are the different views of *Imago Dei*. If there was a clear definition of what it means to be created in the image of God the discussion would have been much different. The theological advocates for human enhancement argue that the ability to enhance gives meaning to be created in the image of God (Garner, 2006:215). The argument exists that through human enhancement suffering and pain will be alleviated in the world, which is inline with Savulescu's (2016) moral arguments. Mellon (2017:270) on the other hand points to the fact that God sometimes allow human weakness as it creates an opportunity to glorify God. From the biblical narrative it is evident that God uses illness and disease to bring hope and draw people to him.

An example of this can be seen in Matthew 15:31 where Matthew articulates the amazement of the people when they saw the healing of people. This however should be seen in context and to be understood as God using weakness to glorify Himself and not God creating weakness to glorify Himself. This in itself is not reason to believe that God is against enhancing the human state.

Cole-Turner (2011:195) is of the opinion that the theological question should not be if humanity should be enhanced, but rather how far humans should enhance themselves through gene editing and technology. The reality is that you do not have to do a specific action because you can. Hardin (2019) seems to agree with this statement and is of the opinion that humanity is more prone to sin and based his view on Romans 3:23. He has an interesting view regarding the human nature and states that humanity was restraint on their knowledge and contained within set boundaries even before the Fall (Genesis 2:16-17). This does make sense when taking into account the doctrine of created co-creator. Humans were created in the image of God, not to be God, but to represent God within creation. Genetic editing will bring ethical challenges such as equality, human dignity, the right to life, the impact on the world if lifespans are lengthen and various other questions. The researcher is of the opinion that this representation includes using wisdom when referring to genetic editing even for therapeutic use.

5.5. PRELIMINARY CONCLUSION

Gene editing has major implications for humanity and answers to ethical challenges should be pursued with wisdom. A Reformed theological response brings a different view and should be included in bioethical debates. This implies that the Bible is seen as authoritative and the inspired Word of God. Interpretation of the text is seen as a challenge as many interpretations exist. What is evident is that Christian bioethical responses should be holistic and thus a Canonical interpretation was used as the main method of biblical interpretation. Although there are different interpretations of the Bible, one area that cannot be denied is the influence of the Bible throughout history. Some might argue that the Bible is not relevant during the current day and age, but in reality the Bible still influences various spheres of life, namely:

- Family life;
- Politics;
- Education;
- Science literacy;
- Opinions of science and scientists.

Modern day bioethics seems to be a challenging topic when using the Bible as foundation. The main reason for this is the fact that the modern challenges we face are not addressed in scripture. This can be overcome by referring to doctrine as doctrine is based on scripture and provides clarity to major theological concepts, one of which is *Imago Dei*.

Imago Dei concerns teaching that man is created in the image of God and based upon Genesis 1:26-27 as well as various New Testament texts such as, Romans 8:29, 1 Corinthians 11:7, 2 Corinthians 3:18, 2 Corinthians 4:4, Ephesians 4:24, Colossians 1:15 and James 3:9. Throughout history, there has been various interpretations of *Imago Dei* and the major views were discussed such as the substantialist, relational and functional views.

The primary focus of the substantialist view is that they single out a specific attribute within the substantial form of human nature. This specific attribute is usually something that distinguishes a human from other creatures such as reason, conscience, dominion emotional awareness, spiritual awareness, form and personhood.

The relational view focuses on relationship aspects of *Imago Dei*, especially the relationship between man and God. This relationship between God and man is what sets humankind apart from the rest of creation.

According to the functional view, dominion is the main fundamental significance of being created in the image of God. This view rejects the substantialist view of *Imago Dei* in the sense that it relates to rationality. Created in the image of God is to exercise dominion over creation.

An alternative view of *Imago Dei* was presented as a holistic view that incorporates both Old and New Testament interpretation namely, *Imago Dei* as human identity. This view, as suggested by Peterson (2016), focuses on God's identity as the origin for understanding human identity. This is a holistic interpretation that acknowledges the fact that humans are created as physical beings with the ability to rationalise with a spiritual element. Our identity is what sets us apart from creation as it reflects our creator. One of the characteristics of being created in God's image is the fact that humanity imitates God. Due to this desire to imitate God, humans naturally create which is according to the *created co-creator* concept depicted by Hefner (1993). This implies that human beings are created within creation and co-create by using created material to create new things. This includes biotechnology that can be used to alter the created DNA of human beings amongst other things.

The tension between bioethics and the role the Bible plays is evident during debates, especially when referring to human dignity. It seems as if the mainstream bioethicists want to exclude the discussion pertaining to human dignity as it is derived from theological concepts. There is a belief that the discussion around human dignity slows down technological advancements. The challenge with removing human dignity from discussions is that the discussion will lose the human element and disregard human rights.

Human rights in itself is a challenging concept. Human rights is a concept adopted by various governments, but implementing services relating to human rights is still lacking. Access to medical care is one area governments are failing, especially when it comes to gene therapies to treat diseases. Part of the challenge is not necessarily access to the technology, but the cost. Governments would rather spend finances on providing more care to individuals than expensive care to one person. Unfortunately, this violates the human dignity of the person who is not able to receive the treatment. An area that needs to be explored more in-depth is the role of the church in the post church age.

Gene editing for treatment purposes seems to be acceptable amongst theologians and bioethicists alike, as long as it is somatic treatment of a disease. Prevention of disease is a topic that requires more discussion that could involve germline cell editing. This seems to be a challenging ethical debate as proponents of germline editing are also advocating human enhancement. Prevention of disease, especially single gene disorders could also be seen as a form of eugenics.

Prevention of disease does open the door towards human enhancement. The debate concerning human enhancement is critical because with the current technology humans have the ability to potentially alter the human race. From a Reformed theological perspective, especially *Imago Dei* as human identity, this might be permitted as long as our core identity, which represents God's identity, is not changed.

Human rights and dignity will remain a challenge in the enhancement debate. Proponents of human enhancement through gene editing has moral arguments, but it does not address the human rights of the unborn, or the right to choice. Exactly where enhancement should stop is another question that requires further research. A suggested starting point for this discussion from a Reformed theological perspective should start with God's identity. If we better understand His identity we will better understand human identity that could provide guidance. This topic should be approached with wisdom and caution and not recommended until more certainty can be achieved on the outcome of any changes to DNA.

CHAPTER 6: SYNOPTIC OVERVIEW, CONCLUSIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

The aim of the study was to provide a Christian bioethical response towards gene editing for therapeutic use and human enhancement. The research started with an overview of the historical aspects related to heredity, the identification of DNA, gene editing and the emergence of bioethics. The focus shifted towards defining health and disease, the problem of genetic disease, gene therapies and current gene editing technology. The ethical debates for and against the utilisation of gene editing technologies was discussed and concluded with a problematic view on human dignity.

A theological response towards the research question was provided which started by recognising the Bible as the authoritative inspired Word of God. The Bible, however, does not address modern ethical challenges and therefore the recommended use of doctrines during bioethical discussions was presented. This led to an overview of the doctrine of *Imago Dei* and culminated in the recommendation to use the doctrine of “*Imago Dei* as human identity” as presented by Peterson (2016) to support bioethical responses. Once this was established, Hefner’s (1996) suggested doctrine of “created co-creator” was critically reviewed. Considerations regarding safety, human dignity, human rights and the dangers of eugenics were presented. This chapter concludes with final remarks, recommendations and themes for further study.

6.2. SUMMARY OF CHAPTER 2-5

This section provides a synoptic overview of Chapters 2-5 of the study:

6.2.1. SUMMARY OF CHAPTER 2

The history of DNA and inheritance was the main focus of chapter 2. Observations regarding heredity was documented long before Mendel’s observations and documented through historians and playwrights (Schwarzback, *et al.* 2014:43). Genesis chapter 30 seems to indicate that there existed a rudimentary understanding

of heredity during biblical times. Jacob became wealthy by separating Laban's flock, however, it is unclear if Jacob understood the heredity principles (Herring, 2006:15).

Aristotle's work on heredity indicates that the ancient Greeks were interested in reproduction focusing on gender determination and familial traits (Vinci & Robert, 2005:216). He indicated that a theory on reproduction can only be accepted if eight fundamental questions can be answered, namely (Henry, 2006:428):

- Why does offspring resemble their parents more than other of the same species?
- Why does some offspring resemble the father, while others in the same family resemble their mother?
- Why does offspring have more resemblance to their parents than their ancestors?
- Why does offspring resemble their ancestors more than other individuals of the same species?
- Why do males usually resemble their fathers while females resemble their mothers?
- Why do males sometimes resemble their mothers and females their fathers?
- If offspring fail to resemble their father, mother or ancestors, why do they still resemble a specific species, in this case humans?
- Why are there instances where the individual's observable form fails to bear any resemblance to the species it derived from?

Modern technology indicates that all eight questions can be answered through genetics.

Mendel's observations on heredity provided the breakthrough in the understanding of heredity traits, which opened the door for subsequent scientists to build upon. He was able to plot the hereditary map that tracks dominant hereditary traits. This laid the foundation that guided further research on DNA and chromosomes following the invention of the x-ray machine and the microscope. The x-ray machine proved to be instrumental in the discovery of the structure of the DNA.

Watson and Crick theorized that DNA unzips and is then able to replicate the information to create another cell. This was based primarily on the structure they identified through x-ray images. The discovery and their theory prompted renewed interest in heredity and scientists quickly moved toward an understanding of heredity (Hubsher *et al.* 2010:15; Lee *et al.*, 2014:6). It only took a few years for scientists to splice genes, which made the editing of genetic material possible. This process also aided in the mapping of the human genome, a project that officially spanned from 1990 to 2004, although a lot of foundational work was conducted between 1986 and 1989 (Harper, 2008:381; Lim, 2002:8).

The discovery of gene editing technology prompted a move towards the use of the technology for commercial use in the agricultural, aquacultural and pharmaceutical industries. A key driver of the technology is the pharmaceutical industry who is capitalizing on the mapping of the human genome (Lim, 2002:83). Modern biotechnological tools, such as TALENs and CRISPR Cas 9, is making more accurate editing possible. The implication of this is the adoption of the technologies to edit the human genome. Various gene therapy clinical trials are currently underway to treat genetic diseases ranging from Sickle Cell Disease to Muscular Dystrophy. It would seem as if the technology is successful, and during 2018 the first genetically edited twins were born (Sherman, 2018; Regan, *et al.* 2018).

The historical aspects of bioethics were briefly discussed during this chapter. Bioethics evolved from medical ethics and includes the behavior of medical personnel, as well as the impact of biomedicine and treatment decisions on an individual and global level. Theology has played an ever-present role during the history of bioethics and it would seem as if their voices are silent during modern debates (Levin & Meador 2012:8). The reason for this could be that the majority of the science community does not see the foundation for their argument as scientific. While this might be the case, one cannot deny the richness the theological view brings to bioethical debates.

Commercial gains of insurance and pharmaceutical companies play a major role in the fear that biotechnology can be used or abused for personal gain. DNA data collection can increase life insurance premiums for individuals with a genetic

disposition towards illness or disease. Pharmaceutical companies are already focusing on precision medicine in order to cure or treat diseases. While pharmaceutical and insurance industries are a focal point in the use of DNA data, food production is another industry already using the technology. In America, 70% of the food is derived from GMO's which indicates that the use of gene editing technologies might be more advanced than the average person would like to believe.

The chapter concluded with a brief view on the use of the technology from a Reformed Theological perspective. The conclusion being, that the use of the technology should be encouraged as it could be used for the good of humanity and towards the glory of God.

6.2.2. SUMMARY OF CHAPTER 3

The focal point of this chapter was on the use of genetic editing techniques for therapeutic use and the enhancement of the human state. To shed light on the use of the technology the chapter started with an overview of health and disease. The various methods of defining health and disease were discussed. Although not perfect, the WHO suggests a value-laden definition of disease with opponents such as Boorse (Messer, 2011:164) who disagrees with the value-laden definition and proposed statistical methods to assist with the definition. The value-laden definition proposed by the WHO appeals with theological philosophers as it is closer to the teachings of wholeness and peace (Hanson, 2001:26). It is noteworthy that the South African constitution legislate that every individual has the right to access to health care. The "access" to treatment depends on available resources and therefore does not mean that a person automatically qualifies for any treatment, which is challenging in cases that require genetic therapy.

Disease is being redefined through the advancement of technology. A few years ago a disease could only be observed through its signs and symptoms and currently a "simple" genetic test can provide information about an individual's propensity towards disease. Through biotechnology, genes can be edited, not only to cure a disease, but

has the potential to nearly eradicate specific diseases (Doudna & Strenberg, 2017:165).

The ability to edit the DNA of an individual makes it theoretically possible to enhance the human state. Historically humans have used technology to enhance their well-being and it will be short sighted to think that biotechnology will not be used to enhance individuals (Cole-Turner, 2011:1). Some philosophers such as Cole-Turner (2011) and Bostrom (2005) are of the opinion that enhancement is a natural part of development. The concept of human enhancement is not new and was a key driver during the Enlightenment (Tollefsen, 2015:104). Francis Galton popularised the concept of eugenics by suggesting the selection of specific human beings based on desired traits. The focus of the eugenics movement was to attempt to improve inborn qualities of a specific race and by doing so enhance a specific race. Eugenics policies were adopted by various sovereign states with the aim to reduce social degeneration and enhance the population (MacKellar & Bechtel, 2014:18).

Eugenics proved to be a controversial, slow and unpredictable method to enhance a population. New gene editing biotechnology can speed up the process and in theory provides more accurate results. This is advocated by transhumanists as well as post-humanists. The difference between the two ideologies is that transhumanists aim to enhance the human state while the focus of the post-humanists is to use various technologies to move to a post-human state. While the aims of transhumanism and post-humanism differ, they share the common goal of using technology for enhancement purposes. These enhancements range from increasing lifespan, increasing intellect, and enhancing the function of the body, to enhancing sensory abilities and controlling emotions.

Gene therapy can cure or treat diseases but the challenge concerning where treatment stops and enhancement starts is key. It seems as if there is not much opposition to using the technology for somatic gene editing. Germline editing is proving to be more challenging from an ethical perspective. Green (2007: 55) provides some guidance relating to the ability to draw lines between treatment and enhancement:

	Treatment or therapy	Enhancement
Somatic genetic editing	Somatic gene therapy to treat inherited retinal dystrophy caused by biallelic RPE65 mutation	Somatic changes to enhance a specific capability such as muscle strength
Germline genetic editing	Editing of the germline to eliminate inherited retinal dystrophy caused by biallelic RPE65 mutation from a specific gene pool	Changing a specific germline to alter the muscle strength of all offspring in a specific gene pool

Table 6.1: Summary of genetic interventions

Defining the line between therapy and enhancement was highlighted by Bostrom & Roach (2008:120). They believe that the prevention of disease and defining what is normal are the main challenges. Another debate is that humanity might already be enhanced through vaccines, as the immune system is enhanced through vaccines. It is possible to prevent specific diseases through genetic identification and editing. This would fall in the realm of prevention of disease and not treatment, but due to prevention the human is enhanced with higher than normal abilities (Lagay, 2001:37).

Peer pressure, short-sighted goals or ambitions and incorrect information can lead individuals to make enhancement decisions detrimental to their health. This can be seen with athletes who are willing to jeopardise their long-term health by taking chemical enhancement drugs. If any enhancement has detrimental outcomes, the question should be asked whether it is a long-term enhancement. The Nuffield Council of Bioethics suggested that a principled approach should be taken based on the future welfare of a person in conjunction with social justice and solidarity. This seems to indicate that changes to DNA are permissible and it does not matter if it is for therapy or enhancement, as long as it is based on the welfare of the person and society (Gyngell, *et al.* 2019:514).

6.3.3. SUMMARY OF CHAPTER 4

Different gene editing techniques require different ethical approaches. The distinction is made between somatic gene editing and germline editing. The *International Summit on Human Gene Editing*, held during 2015, concluded in favour of gene editing as long as conducted safely. They encouraged somatic gene editing to treat genetic diseases as long as the changes are not passed to the next generation (National Academies of Science, Engineering and Medicine, 2015). The published report controversially stated that germline editing can prevent inherited diseases to “*enhance the human race*”.

Germline editing has various benefits. These benefits were summarised by Savulescu (2016:1):

- Curing genetic diseases;
- Curing and treating complex diseases, such as cancer;
- Delaying or stopping aging;
- Controlling inherited traits;
- Lowering cost of treatment;
- Cognitive enhancement.

The benefits of genetic therapy seems to indicate that there is a moral argument to allow for germline and somatic gene editing. The researcher is of the opinion that this is especially true when it comes to therapeutic use. However, Savulescu (2016) and other transhumanists such as Bostrom (2005) do point out that benefits to germline editing can enhance cognitive functions. This theory will lead to numerous benefits that are not comprehensible with our current understanding. Savulescu (2016) argues that it would be morally wrong not to use technology to enhance the human genome.

Safety relating to the use of the technology is paramount and one of the main ethical concerns, especially with the potential of inaccurate gene editing (Doudna, 2020:233). New technology, such as CRISPR and TALENs have improved accuracy, but any inaccuracy have the potential to cause cancer. The WHO (WHO, 2021:8) released guidelines during 2021 in an attempt to govern the research and enhance safety.

The Nuffield Council concluded that genome editing should be permitted as long as it is conducted towards the welfare of the unborn. Some scholars oppose this view due to concerns about the long-term effects of gene editing (Drabiak, 2019:224; Gorvett, 2021). Additionally it seems as if the welfare of a child born with defects following the use of the technology is not guaranteed (Cyranoski & Reardon, 2015:594).

Three points relating to the rights of the unborn is a concern for ethicists:

- The procedures violates the unborn because it is experimental and the unborn individual could not provide informed consent relating to the risks involved.
- Every child has the right to be born without a genetically modified germline.
- The procedure would deny the child the choice of an open future.

It would seem as if the debates centred on these points assume that the unborn have rights. It also assumes that the unborn is capable of providing consent, which as can be seen with treatment of minors, is not the case. Resnik (2016:195) highlighted that it is more realistic to assume that the unborn will consent to genetic editing if it improves their quality of life.

The religious view brings a unique perspective. Theologically the question should be asked whether the embryo is alive or not (Gyngell, *et al.* 2017:504). The Roman Catholic Church took the stance that life begins at conception. Their belief is based on the possibility that killing another human is a sin and the possibility exists that by killing the embryo a sin is committed in the form of murder. The Protestant view is not as easy to define as churches are independent and denominations are autonomous. In some instances, a gradualist approach is taken, whereby an embryo has the potential to become a person, it is however only cells with potential. Many are of the opinion that an embryo becomes a person when specific criteria are met (CPCE, 2017:49):

- A person is rational;
- A person is self-aware;
- A person has the capacity to relate and engage in relationships;
- A person has the capacity to have interests of preferences.

The gradualist believes an embryo becomes a person once the nervous system has developed. They argue that before the nervous system is developed, embryos can be used for research, as there is no co-ordinated pain stimulus and can therefore not be harmed. Although there seems to be a debate amongst Protestant Christians on whether an embryo is alive or not, the real debate is when an embryo is defined as a person.

The possibility exists that germline gene editing can be used to create a superior race or class. This ethical concern of eugenics exists across the different ethical views of the debate. It seems as if various forms of eugenics are already taking place. This ranges from couples deciding not to have children and avoiding passing on undesirable traits, to the adoption of embryos with specific traits (Brown & Schippers, 2019:122). Some scholars are not convinced this is a negative aspect as specific traits can enhance the genetic pool as well as prevent undesirable traits within a community (Savalescu & Kahane 2008:275). One key difference between the current form of eugenics and the eugenics of the past relates to the fact that it is not institutionalised. However, there is a risk that allowing gene editing of the germline can prompt an institutionalised form of eugenics (Doudna & Strenberg, 2017:55).

Gene editing technology is expensive and there is concern that the inequality gap will widen. Extending life expectancy seems to be a natural outcome of genetic editing and although there are benefits, pitfalls do exist. Apart from potential generation gaps, there will be an economic but also an ecological impact on living longer (Green, 2004:497). It is possible that inequality will increase with genetic editing and/or embryo selection (Pijnenburg & Leget, 2007:585). Poorer countries do not have the financial means to provide genetic editing to the majority of their population, which means they will not benefit from the technology.

The vagueness relating to the definition of the term “human dignity” is prompting scientists to remove the term from bioethical debates (Segers & Mertes, 2020:33). Following World War II, the United Nations created the bill of human rights. Although based upon human dignity, it was not properly defined due to political reasons. The challenge with this unclear definition, as far as genetic editing is concerned, is that it

opens the debate regarding what is considered as human dignity. An example of this is the challenge with disabilities caused by genetic diseases. On the one side of the debate, the individuals who are pro-genetic editing will state that a person's human dignity is affected by the disability, which impacts their quality of life. While the other side of the debate state that human dignity is not measured according to what a person can do, but rather on who they are (Sufain & Garland-Thompson, 2021).

6.3.4. SUMMARY OF CHAPTER 5

The implications of gene editing for humanity and the ethical challenges should be considered with wisdom. A Reformed theological view is unique in the sense that the Bible is considered as the authoritative and inspired Word of God. It seems as if there are many interpretations of the text, which can be challenging in many instances.

A Canonical approach to the interpretation of the Bible was used during the interpretation of texts. This insured that a holistic approach was followed. Although there are different interpretations of the Bible, the influence of the Bible throughout history cannot be denied. Arguments exists that the Bible is not relevant during the current day and age, however the Bible has influence in various spheres of life, namely:

- Family life;
- Politics;
- Education;
- Science literacy;
- Opinions of science and scientists.

Using the Bible as foundation seems to be challenging when attempting to address modern day bioethical questions. During the composition of the Bible, the authors were not aware of the modern day technology or the ethical challenges that it brings. Due to the fact that doctrines are based on scripture, it can be used to address some of the modern ethical conundrums, one of which is *Imago Dei*.

The doctrine of *Imago Dei* is based upon Genesis 1:26-27 as well as various New Testament texts such as, Romans 8:29, 1 Corinthians 11:7, 2 Corinthians 3:18, 2 Corinthians 4:4, Ephesians 4:24, Colossians 1:15 and James 3:9, and holds that man is created in the image of God. Throughout history, there have been various interpretations of *Imago Dei* and the major views were discussed such as the substantialist, relational and functional views.

The primary focus of the substantialist view is that they single out a specific attribute within the substantial form of human nature. This specific attribute is usually something that distinguishes a human from other creatures such as reason, conscience, dominion, emotional awareness, spiritual awareness, form and personhood.

The relational view focuses on relationship aspects of *Imago Dei*, especially the relationship between man and God. This relationship between God and man is what sets humans apart from the rest of creation.

According to the functional view, dominion is the main fundamental significance of being created in the image of God. This view rejects the substantialist view of *Imago Dei* in the sense that it relates to rationality. Created in the image of God is to exercise dominion over creation.

The researcher believes that an alternative view of *Imago Dei*, as suggested by Peterson (2016), should be applied during Christian bioethical debates. *Imago Dei* seen from this perspective focuses on God's identity as the origin for understanding human identity. This holistic interpretation acknowledges the fact that humans are created as physical beings with the ability to rationalise and contains a spiritual element. Human identity sets humans apart from creation as it reflects God the Creator. One of the characteristics of being created in God's image is the fact that man imitates God. Due to this desire to imitate God, humans naturally create which is according to the *created co-creator* concept depicted by Hefner (1993). This implies that human beings are created within creation and co-create by using created material to create new things. This includes biotechnology that can be used to alter the DNA of

human beings amongst other things. The implication of the doctrine is that humans do have value and relates directly to human dignity.

Human dignity is a contentious issue during bioethical debates. Mainstream bioethicists aims to exclude human dignity as it is derived from theological or metaphysical concepts. They argue that discussions around human dignity slows down technological advancements and the implementation of possible solutions. However, removing human dignity from the discussion could discard human rights, which will make human dignity null and void. The challenge with this is that the implementation of technology without any concern about how it will affect different individuals, or how it might change human identity.

The vagueness of the definition of human rights causes challenges. The term is adopted by various governments, but implementing services relating to human rights is still lacking. Access to medical care is one area governments are failing in, especially when it comes to gene therapies to treat diseases. Part of the challenge is not necessarily access to the technology, but the cost. Governments would rather spend finances on providing more care to individuals than expensive care to one person. Unfortunately, this violates the human dignity of the person who is not able to receive the treatment. An area that needs to be explored more in-depth is the role of the church in the post church age.

Applying gene-editing technology to treat diseases seems acceptable amongst theologians as well as bioethicists, as long as it relates to the editing of somatic cells. Prevention of diseases requires more discussions. It would seem as if there is a moral argument to apply the technology to prevent diseases. However, this will imply that gene editing should be allowed on germline cells. This seems to be a challenging ethical debate as proponents of germline editing are also advocating human enhancement. Prevention of disease, especially single gene disorders could also be seen as a form of eugenics.

Prevention of disease does open the door towards human enhancement. The slippery slope argument of this could be catastrophic and thus the reason for the current critical

debates. Humans possess the technology to not only enhance the human genome, but also alter it forever. Enhancing the human genome could have positive or negative results without any guarantees. Preventing disease, such as single gene disorders, do have a moral argument and from the perspective of *Imago Dei* as human identity, this might be permitted as long as our core identity, which represents God's identity, is not changed.

Human rights and dignity will remain a challenge in the enhancement debate. Proponents of human enhancement through gene editing have moral arguments, but it does not address the human rights of the unborn, or the right to choice. Exactly where enhancement should stop is another question that requires further research. A suggested starting point for this discussion from a Reformed theological perspective should start with God's identity. If we better understand His identity we will better understand human identity that could provide guidance. This topic should be approached with wisdom and caution and not recommended until more certainty can be achieved on the outcome of any changes to DNA.

6.4. FINAL REMARKS

The aim of this study was to develop a bioethical response to gene editing for treatment or enhancement from a Reformed theological perspective. The researcher recommends using the doctrine of "*Imago Dei* as human identity" to respond to bioethical questions relating to gene editing. It provides a holistic doctrinal foundation that facilitates debates and focuses on the human identity found in the identity of God. This presents a conclusion that man is creative due to the fact that God is creative. Humans have a natural inclination to create and through technological advancement is able to care for, and heal individuals. This care that is shown is also found in God's identity and evidently part of human identity. Humanity has a desire not only towards being healthy, but also towards wholeness. Evidence of this can be seen in the amount of resources attributed towards the extension of life expectancy and dying from old age. While this seems to have its own ethical challenges relating to economic, ecological and relational aspects, no one will complain about living longer, with the

condition that quality of life is not neglected. The fact that human identity is found in God's identity is key to the bioethical response of genetic editing.

6.5. RECOMMENDATIONS AND THEMES FOR FURTHER RESEARCH

Based on the research conducted, the researcher recommends using the doctrine of "*Imago Dei* as human identity" during bioethical debates relating to gene editing for therapeutic use or human enhancement. The doctrine can assist with drawing a line when human enhancement is moving too far towards a post-human state. It also helps to address other ethical issues such as human dignity, human rights and eugenics. The *Prometheus* argument viewed from "*Imago Dei* as human identity" also brings a different perspective. The *Prometheus* argument is that humanity is playing God through gene editing. However, while there are dangers associated with playing God, it is clear that man plays God on a daily basis in other areas of life. This can be attributed to the fact that human identity can be found in God's identity. Humans were created to rule over creation, which is demonstrated through the editing of DNA amongst other things. However, one attribute of God is wisdom and if humanity does not use wisdom in utilising the technology correctly the dangers as discussed will become a reality. These include lack of human dignity, human rights violations and eugenics.

The study highlighted areas requiring further discussion. These can be summarised as follows:

- How technology is shaping humanity's identity and the impact on the view of *Imago Dei*;
- A proper definition for human dignity should be explored to assist with bioethical discussions;
- Human value in relation to human dignity is a topic that can be explored as there seems to be a clear divide between the value of the rich and the poor;
- Research should be conducted on the church's ethical responsibility towards health care in a post-church era;
- If human enhancement is permitted what will the impact be on the church and how should the church respond to the new ethical challenges;

- How to reconcile theological bioethical discussions with mainstream bioethical discussion;
- From a theological perspective, where should human enhancement stop.

6.5. CONCLUSION

The theological perspective brings a different viewpoint to bioethical discussions. At first glance, the limited theological input during current bioethical debates seems to point to a lack of interest from theological circles. However, the researcher deduced that theological voices are being silenced. This can be seen in the drive to remove human dignity from bioethical debates. When looking at bioethics from a theological view, it is usually based on human dignity and has an *Imago Dei* element. It seems as if this is not acceptable within secular bioethical discussions.

Regarding health and disease, the researcher is in alignment with the views of Messer (2011) and Hanson (2001). The value-laden theory proposed by the WHO and philosophers such as Nordenfelt (2001) offer a holistic definition of health and disease. The focus should not only be on health and disease, but on wholeness as it includes elements of life including the spiritual aspect.

It is challenging to confidently define the line between treatment and enhancement. The researcher is of the opinion that treatment and prevention of disease through genetic editing should be allowed, with the condition that it is safe and carefully regulated. It would be morally wrong not to use the technology if it can alleviate pain and suffering. It is noteworthy that prevention of disease seems only possible by editing the germline or through embryo selection. "*When life begins*" was not extensively discussed during the study and should be considered before the topic of embryo selection or editing of the embryo can be broached. Prevention of genetic diseases through germline editing can be performed on gametes before conception to limit the ethical concerns.

The benefits of genetic therapy seem to indicate that there is a moral argument to allow for germline and somatic gene editing. The researcher is of the opinion that this

is especially true when it comes to therapeutic use. It does however mean that germline editing will enhance the human population as specific diseases will be less prominent which was highlighted during the *International Summit on Human Gene Editing*. By definition, this means prevention will lead to human enhancement. Savulescu's (2016) argument that it would be morally wrong not to use technology to enhance the human genome depends on whether the enhancements are for preventative measures and if it will move humanity towards a post-human state.

From a Reformed theological point of view, the doctrine of "*Imago Dei* as human identity" provides a strong doctrinal foundation to respond to the bioethics of gene editing. It supports a holistic view of *Imago Dei* and provides a vantage point to discuss the ethical issues at hand. The fact that human identity is found in God's identity is key to the bioethical response of genetic editing.

SOURCE LIST

- Allen, G.E. 1966. Thomas Hunt Morgan and the problem of sex determination. *American Philosophical Society*, 110(1): 8-57.
- Almeida, M., & Diogo, R. 2019. Human enhancement: Genetic engineering and evolution. *Evolution, Medicine & Public Health*, 1:183-189.
- Andorno, R. 2011. The dual role of human dignity in bioethics. *Medicine, Health Care and Philosophy*, 16:967-973.
- Arnason, U. 2006. 50 years after – Examination of some circumstances around the establishment of the correct chromosome number of man. *Hereditas*, 143:202-211.
- Aroney, N. 2021. The rise and fall of human dignity. *Brigham Young University Law Review*, 46(5):1211-1241.
- Aubert-Marson, D. 2009. Sir Francis Galton : The farther of eugenics. *Med Sci Paris*, 25(7):641-645.
- Bahnic, S. 2021. Anchoring without scale distortion. *Judgement and Decision Making*, 16(1):131-141.
- Balasubramanian, S., Aggarwal, P., & Sharma, S. 2022. Lipoprotein Lipase Deficiency. *National Library of Medicine, NBK560795*. [Lipoprotein Lipase Deficiency - StatPearls - NCBI Bookshelf \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/35484441/).
- Bamanga, R. A. Ja'afar, J. N. & Gaili, A. I. 2018. Progress in DBA sequencing. *Bayero Journal of Pure and Applied Sciences*, 11(1): 110-119.
- Banerjee, A. V. 1992. A simple model of herd behaviour. *The Quarterly Journal of Economics*, 107(3):797-817.

- Barilan, Y. M., & Caplan, A. L. 2012. Human dignity, human rights and responsibility: The new language of global bioethics and biolaw. London: The MIT Press.
- Barnard, B. Q. 2007. The utopia of sharing in Oneida, New York. <https://www.nytimes.com/2007/08/03/travel/escapes/03Oneida.html>. Date of access: 13 June 2021.
- Barth, C. 1991. God with us: A theological introduction to the Old Testament. Grand Rapids: William B. Eerdmans Publishing Company.
- Bawulski, S., & Watkins, J. 2012. Possible worlds and God's creative process: How a classical doctrine of divine creation can understand divine creativity. *Scottish Journal of Theology*, 65(2):174-193.
- Benagiano, G., & Mori, M. 2007. The Catholic Church on the beginning of human life. *Ethics, Law and Moral Philosophy of Reproductive Biomedicine*, 2(1): 162-168.
- Bentley, W. 2017. Are we special? A critique of Imago Dei. *HTS Teologiese Studies/Theological Studies*, 73(3),4524. <https://doi.org/10.4102/hts.v73i3.4524>. Date of access: 30 August 2022.
- Berain, I. M. 2018. Human dignity and gene editing. *Science and Society*, 19,e46789. <https://doi.org/10.15252/embr.201846789>
- Bergman, M. T. 2019. Perspectives on gene editing. <https://news.harvard.edu/gazette/story/2019/01/perspectives-on-gene-editing/>. Date of access: 2 June 2021.
- Berman, J. J. 2018. Precision medicine and the reinvention of human disease. London: Academic Press.
- Birkhauser, M. 2013. Ethical issues in human reproduction: Protestant perspectives in light of European Protestant and Reformed Churches. *Gynecol Endocrinol*, 29(11):955-559.

- Blum, P. R. 2010. *Philosophy of religion in the renaissance*. Burlington: Ashgate Publishing Company.
- Bohan, E. 2018. *A history of transhumanism*. Sydney: Macquarie University. (Thesis – Doctor of Philosophy).
- Boodman, E. 2020. Who gets the last ventilator? Facing the Corona Virus, a hospital ponders the unthinkable. <https://www.statnews.com/2020/04/14/coronavirus-who-gets-last-ventilator-hospital-ponders-unthinkable/>. Date of access: 12 January 2021.
- Boorse, C. 1975. On the distinction between disease and illness. *Philosophy and Public Affairs*, 5(1):49-68.
- Bostrom, N. 2004. Human genetic enhancements: A transhumanist perspective. *Journal of Value Inquiry*, 37(4):439-506.
- Bostrom, N. 2005. A history of transhumanist thought. *Journal of Evolution and Technology*. 14(1):1-25.
- Bostrom, N. 2005. Transhumanist values. *Journal of Philosophical Research*, 30:3-14.
- Bostrom, N., & Roach, R. 2008. New waves in applied ethics <https://www.nickbostrom.com/ethics/human-enhancement.pdf>. Date of access: 21 January 2021.
- Bostrom, N. 2014. *Superintelligence, paths, dangers, strategies*. Oxford: Oxford University Press.
- Bouman, H. J .A. 1984. The authority of holy Scripture. *Concordia Journal*, 10(5):171-180.
- Breseghello, F. 2013. Traditional and modern plant breeding methods with examples in rice. *Journal of Agricultural and food chemistry*, 13: 8277-8286.

- Brown, R. I., & Schippers, A. 2019. A quality of life perspective on the new eugenics. *Journal of Policy and Practice in Intellectual Disabilities*, 16(2): 121-126.
- Bruening, G. & Lyons, J.M. 2000. The case of the FLAVR SAVR tomato. *California Agriculture*, 54(4):6-7.
- Bruynseels, K., de Sio, F. S., & van den Hoven, J. 2018. Digital twins in health care: Ethical implications of an emerging engineering paradigm. *Frontiers in Genetics*, 9(31): 1-11.
- Buehler, R., Friffin, D., & MacDonald, H. 1997. The role of motivated reasoning in optimistic time predictions. *Society of Personality and Social Psychology*, 23(3):238-247.
- Bulmer, M. 2003. Francis Galton: Pioneer of heredity and biometry. Baltimore Johns Hopkins University Press.
- Burkhardt, R. W. 2013. Lamarck, evolution, and the inheritance of acquired characters. *Genetics*, 194:793-805.
- Cahill, L. S. 2008. Germline genetics, human nature, and social ethics. (In Cole-Turner. Ed. *Design and destiny: Jewish and Christian perspectives on human germline modification*. Hong Kong: SNP Best-set Typesetter Ltd. P145-165).
- Callahan, D. 1973. The WHO definition of health. *The Hastings Center Studies*, 1(3):77-87.
- Cameron, N. M. D. S. & DeBaets, A. M. 2008. Germline gene modification and the human condition before God. (In Cole-Turner. Ed. *Design and destiny: Jewish and Christian perspectives on human germline modification*. Hong Kong: SNP Best-set Typesetter Ltd. P93-118).

- Carapetis, J. R., Bearon, A., Cunningam, W. M., Guilherme, L., Karhikeyan, G., Mayosi, B. M., Sable, C., Steer, A., Wilson, N., Wyber, R., and Zurhlke, L. 2016. Acute rheumatic fever and rheumatic heart disease. *Nature Reviews*, 2:1-24.
- Carroll, W. E. 1999. Galileo and the interpretation of the Bible. *Science and Education*, 8:151-187.
- Cerry, M.J. 2017. Created in the Image of God: Bioethical implications of the Imago Dei. *Christian Bioethics*, 23(3): 219-233.
- Chadwick, R., 2001, "Gene Therapy", In *A Companion to Bioethics*, H. Kuhse & P. Singer, (eds.), Oxford: Blackwell.
- Chan, E. & Ecklund, E.H. 2016. Narrating and navigating authorities: Evangelical and mainline Protestant interpretations of the Bible and science. *Journal for the scientific study of religion*, 55(1):54-69.
- Chancey, M. A., Meyers, C. & Meyers, E .M. 2014. The Bible in the public square: It's enduring influence in American life. Atlanta: Society of Biblical Literature Press.
- Chen, W. W. 2019. Human germline gene editing: Engineering and unstoppable train. *Southern California Interdisciplinary Law Journal*, 28:523-548.
- Chokshi, D. A. 2018. Income, poverty, and health inequality. *The Journal of the American Medical Association*, 319(13):1312-1313.
- Chow, A. R. 2019. How Kanye West's controversial "Jesus is King" is dividing the Christian community. <https://time.com/5716576/kanye-west-jesus-is-king-gospel-reaction/>. Date of Access: 1 September 2022.
- Christmann, M., Tomicic, M. T., Roos, W. P., and Kiana, B. 2003. Mechanisms of human DNA repair: an update. *Science Direct*, 193:3-34.

- Cohen, J. 2019. China's CRISPR push in animals promises better meat, novel therapies and pig organs for people. <https://www.sciencemag.org/news/2019/07/china-s-crispr-push-animals-promises-better-meat-novel-therapies-and-pig-organs-people>. Date of access: 21 October 2020.
- Cole-Turner, R. 2008. Religion and the question of human germline modification. *In Cole-Turner. Ed. Design and destiny: Jewish and Christian perspectives on human germline modification*. Hong Kong: SNP Best-set Typesetter Ltd. P1-27).
- Cole-Turner, R. 2011. Transhumanism and transcendence: Christian hope in an age of technological enhancement. Washington: Georgetown University Press.
- Conradie, E. M. 2005. Christian identity: An introduction. Stellenbosch: Sun Books.
- Cowan, S. B., & Wilder, T. L. 2013. In defence of the Bible: A comprehensive apologetic for the authority of Scripture. Nashville: B&H Academic.
- CPCE (Council of the Communion of Protestant Churches in Europe). 2017. Before I formed you in the womb: A guide to the ethics of reproductive medicine from the Council of the Communion of Protestant Churches in Europe. <http://cpce-repro-ethics.eu/>. Date of Access: 15 August 2021.
- Craig, J. 2008. Complex diseases: Research and applications. *Nature Education*, 1(1):184).
- Creamer, D. B. 2009. Disability and Christian theology: Embodied limits and constructive possibilities. Oxford: Oxford University Press.
- Crouch, C. L. 2010. Genesis 1:26-27 as a statement of humanity's divine parentage. *Journal of Theological Studies*, 61(1):1-15.
- Creel, R. E. 2014. Philosophy of religion: The basics. New York: John Wiley & Sons, Inc.

- Cyranoski, D., & Reardon, S. 2015. Embryo editing sparks epic debate. *Nature*, 520:593-594.
- Dahl, E. 2003. Procreative liberty: The case for preconception sex selection. *Reproductive Bio-Medicine*, 7(4):380-384.
- Das, R. 2017. Gene editing with CRISPR-Cas9: The next step in human evolution will be worth \$25 billion by 2030. <https://www.forbes.com/sites/reenitadas/2017/12/14/gene-editing-with-crispr-cas9-the-next-step-in-human-evolution-to-be-worth-25-billion-by-2030/#37b02eb1449f>. Date of access: 3 December 2018.
- Dahm, R. 2005. Friedrich Miescher and the discovery of DNA. *Developmental Biology*:278:274-288.
- D'Agostino, D. Morganti, L. Corni, E. Cesini, D. & Merelli, I. 2018. Combining edge and cloud computing for low-power, cost-effective metagenomics analysis. *Future Generation Computer Systems*, 90(2019) 79-85.
- De Bruyn, P.J. 2008. Die tien gebooe. Potchefstroom: Potchefstroom Teologiese Publikasies.
- Deev, R., Plaska, I., Bozo, I., Mzhavanadze, N., Suchkov, I., Chervyakov, Y., Staroverov, I., Kalinin, R., & Isaev, A. 2018. Results of 5-year follow-up study in patients with peripheral artery disease treated with PL-VEGF165 for intermittent claudication. *Sage Journals*, 12(9):237-246.
- De Francisco, C., Acre, C., del Pilar Vilchez, M., and Vales, A. 2016. Antecedents and consequences of burnout in athletes: perceived stress and depression. *International Journal of Clinical and Health Psychology*, 16:239-246.
- De Klerk, B .J. & De Wet, F. W. 2013. Met die oog op God. Potchefstroom: Potchefstroom Theological Publications.C

- De Klerk, B.J. & Van Rensburg, F.J. 2005. Making a sermon. Potchefstroom: Potchefstroom Theological Publications.
- De Klerk, B.J. & De Wet, F.W. 2013. Met die oog op God. Potchefstroom: Potchefstroom Theological Publications.
- Dilley, S., & Palpant, N. J., eds. 2013. Human dignity in bioethics: From worldviews to the public square. London: Routledge.
- Doudna, J., & Sternberg, S. 2017. A crack in creation: The new power to control evolution. London: Penuin Random House UK.
- Doudna, J. A. 2020. The promise and challenge of therapeutic genome editing. *Nature*, 578:229-236.
- Drabiak, K. 2020. The Nuffield Council's green light for genome editing human embryo's defies fundamental human rights law. *Bioethics*, 34:223-227.
- Drees, W. B. 2002. Playing God? Yes! *Zygon*, 37(3):643-654.
- Dvorsky, G. 2008. Better living through transhumanism. *Journal of Evolution & Technology*, 19(1):62-66.
- Eckenwiler, L.A. & Cohn, F.G. 2007. The ethics of bioethics: Mapping the moral landscape. Baltimore: The Johns Hopkins University Press.
- Egan, A. 2012. Relativist dispositional theories of value. *The Southern Journal of Philosophy*, 50(4):557-582.
- Eisenstein, M. A. 2008. Religion and the politics of Tolerance: How Christianity builds democracy. Waco: Baylor University Press.
- Ericson, M. J. 2015. Introducing Christian doctrine. Grand Rapids: Baker Academic.

Evans, J. H. 2021. Setting ethical limits on human gene editing after the fall of the somatic/germline barrier. *PNAS*, 118(22):1-7.

Exum, J.C. (ed.). 2007. Retellings: The Bible in literature, music, art and film. Leiden: Brill.

Finegold, D.N. 2019. Genes and chromosomes. <https://www.msmanuals.com/home/fundamentals/genetics/genes-and-chromosomes>. Date of access: 21 January 2021.

Fox, L. W. 1890. A history of spectacles. Philadelphia: Medical and Surgical Reporter.

Fookes, C. 2022. Why is Zolgensma so expensive? <https://www.drugs.com/medical-answers/zolgensma-expensive-3552644/#:~:text=by%20Drugs.com%20Zolgensma%20is%20a%20one-time-only%20gene%20therapy,that%20costs%20%242.1%20million%20for%20the%20single%20treatment>. Date of access: 7 September 2022.

Fraser, L. 2016. Cloning insulin. www.gene.com/stories/cloning-insulin. Date of access: 6 January 2021.

Fretheim, T. E. 2006. The authority of the Bible and churchly debates regarding sexuality. *Word and World*, 26(4):365-374.

Fulford, K.W.M. 2001. What is (mental) disease: and open letter to Christopher Boorse. *Journal of Medical Ethics*, 27:80-85.

Galton, D. J. 1998. Greek theories on eugenics. *Journal of Medical Ethics*, 24:263-267.

Galton, D. J., & Galton, J. G. 1998. Francis Galton: and eugenics today. *Journal of Medical Ethics*, 24:99-105.

Galton, F. 1904. Eugenics. *The American Journal of Sociology*, 10(1):1-25.

- Galvez, C. A. 2010. Biblical perspectives on health for the contemporary world. *International Forum*, 13(1):20-29.
- Garner, S. R. 2006. Transhumanism and the *Imago Dei*: Narratives of apprehension and hope. Auckland: The University of Aukland. (Thesis-Doctor of Philosophy).
- Gibson, D.G., Glass, J.I., Lartigue, C., Noskov, V.N., Chuang, R., Algire, M.A., Benders, G.A., Montague, M.G., Ma, L., Moodie, M.M., Merryman, C., Vashee, S., Krishnakumar, R., Assad-Garcia, A., Andrews-Pfannokoch, C., Denisova, E.A., Young, L., Qi, Z., Segal-Shapiro, T.H., Calvey, C.H., Parmar, P., Hutchison, C.A., Smith, H.O. & Venter, J.C. 2010. Creation of a bacterial cell controlled by a chemically synthesized genome. *Science*, 329(5987):52-56.
- Goodman, L. E. 2009. May you live to be 150. *Symposium*, 46:240-246.
- Goodwin, K. 2022. Elon Musk's brain implants move toward in-human trials. <https://www.biospace.com/article/elon-musk-s-brain-implants-move-towards-in-human-trials-/>. Date of Access: 6 February 2022.
- Gordon, E. G., & Ragonese, V. 2022. Cognitive and moral enhancement: A practical proposal. *Journal of Applied Philosophy*, <https://doi.org/10.1111/japp.12619>. Date of Access: 1 October 2022.
- Gorvett, Z. 2021. New technologies may have already introduced genetic errors to the human gene pool. How long will they last? And how could they affect us? <https://www.bbc.com/future/article/20210412-the-genetic-mistakes-that-could-shape-our-species>. Date of access: 2 August 2021.
- Granberg-Michaelson, W. 1989. Biotechnology: Report by WCC subunit on Church and society. <https://www.oikoumene.org/en/resources/documents/wcc-programmes/justice-diakonia-and-responsibility-for-creation/science-technology-ethics/biotechnology>.

- Green, R. M. 2007. *Babies by design: The ethics of genetic choice*. London: Yale University Press.
- Gribkov, E. E., & Minchenko, T. P. 2020. The problems of human embryos genome editing from the position of Christian denominations. http://ceur-ws.org/Vol-2763/CPT2020_paper_s3-12.pdf. Date of Access: 15 August 2021.
- Groeneveld, L. F., Lenstra, J. A., Eding, H., Toro, M. A., Scherf, B., Pilling, D., Negrini, R., Finlay, E. K., Jianlin, H., Groeneveld, E., & Weigend, S. 2010. Genetic diversity in farm animals – A review. *Animal Genetics*, 41(6):6-31.
- Gundersen, K. 2016. Muscle memory and a new cellular model for muscle atrophy and hypertrophy. *Journal of Experimental Biology*, 219:235-242.
- Gunton, C. E. 2004. *The doctrine of creation: Essays in dogmatics, History and philosophy*. London: Bloomsbury Publishing.
- Gupta, P.K. 2008. *Molecular biology and genetic engineering*. Meerut: Rastogi Publications.
- Gyngell, C., Bowman-Smart, H., & Savulescu, J. 2019. Moral reasons to edit the human genome: picking up from the Nuffield report. *Journal of Medical Ethics*, 45:514-523.
- Gyngell, C., Douglas, T., & Savulescu, J. 2017. The ethics of gene editing. *Journal of Applied Philosophy*, 34(4):498-513.
- HaCohen, R. 2010. (Translated into English by Engel, M.). *Reclaiming the Hebrew Bible: Geman-Jewish reception of biblical criticism*. Berlin: Walter de Gruyter GmbH & Co.
- Hanaa, E., Rémuzatb, C., Auquiera, P., & Toumia, M. 2016. *Journal of Market Access & Health Policy*, 5(1):1-9.

- Hanson, M.J. 2001. Defining health and health related concepts: Conceptual and theological considerations. *Word and World*, 21:23-31.
- Hardin, J. 2019. Genome editing and the Christian. <https://biologos.org/articles/genome-editing-and-the-christian>. Date of access: 20 September 2022.
- Harle, W. 2011. *Ethik*. New York: De Gruyter.
- Harper, S. P. 2008. *A short history of medical genetics*. Oxford: Oxford University Press.
- Harper, S. P. 2018. Human genetics in troubled times and places. *Hereditas*, 155(7):1 – 14.
- Harris, J. 2007. *Enhancing evolution: The ethical case for making better people*. Princeton: Princeton University Press.
- Hefner, P. 1993. *The human factor: Evolution, culture and religion*. Minneapolis: Augsburg Fortress.
- Heller, S. A., Shih, R., Kalra, R., & Kang, P. B. 2020. Emiry-Dreifuss muscular dystrophy. *Muscle Nerve*, 61(4):436-448.
- Hendricks, C. L., Alessandrini, M., & Pepper, M. S. 2022. Equitable access to cell and gene therapies in South Africa: opportunities and hurdles. *Gene Therapy*. <https://doi.org/10.1038/s41434-021-00309-y>. Date of access: 20 September 2022.
- Henry, D. 2006. Aristotle on the mechanism of Inheritance. *Journal of the history of biology*, 39:425-455.
- Herring, M.Y. 2006. *Genetic engineering*. Westport: Greenwood Press.

- Ho, P. 2020. The modal problem of *creatio ex nihilo*. *International journal for philosophy of religion*, 88:197-213.
- Hodal, K., & Kelly, A. 2016. Thailand's improved status in US human trafficking report sparks fury. [Thailand's improved status in US human trafficking report sparks fury | Global development | The Guardian](#). Date of access: 21 June 2021.
- Hoffman, B. 2017. Limits to human enhancement: Nature, disease, therapy or betterment? *BMC Medical Ethics*, 18(56):1-11.
- Hoffman, B. 2020. The death of dignity is greatly exaggerated: Reflections 15 years after the declaration of dignity as a useless concept. *Bioethics*, 34:602-611.
- Hollon, T. 2000. Researchers and regulators reflect on first gene therapy death. *Nature Medicine*, 6(1):6.
- Hook, E. B. 1987. Shakespeare, genetics, malformations, and the wars of the roses: Hereditary themes in Henry VI and Richard III. *Teratology*, 35(1):147-155.
- Hotze, T. D., Shah, K., Anderson, E. E., & Wynia, M. K. 2011. "Doctor, would you prescribe a pill to help me ...?" A national survey of physicians on using medicine for human enhancement. *The American Journal of Bioethics*, 11(1): 3–13.
- Huber, J., Payne, J. W., & Puto, C. 1982. Adding asymmetrically dominated alternatives: Violations of regularity and the similarity hypothesis. *The Journal of Consumer Research*, 9(1):90-98.
- Hubsher, U., Spadari, S., Villani, G. & Giovanni, M. 2010. DNA Polymerases: Discovery, characterization and functions in cellular DNA transactions. London: World Scientific.
- Johnson, A. R. 1998. The birth of bioethics. New York: Oxford University Press.
- Johnson, C.N. 2019. Charles Darwin, Richard Owen, and natural selection: A question of priority. *Journal of the history of Biology*, 52:45-85.

- Joncovic, J. 2019. Imago Dei: An Exegetical and theological reappraisal. *ET-Studies*, 10(2):183-206.
- Jones, G., & Schneider, W. J. 2006. Intelligence, human capital, and economic growth: A Bayesian averaging of classical estimates (BACE) approach. *Journal of Economic Growth*, 11:71-93.
- Joung, J. K., & Sander, J. D. 2013. TALENs: A widely applicable technology for targeted genome editing. *Nature reviews molecular cell biology*, 14:49-55.
- Kaiser, J. 2020. CRISPR and another genetic strategy fix cell defects in two common blood disorders. <https://www.sciencemag.org/news/2020/12/crispr-and-another-genetic-strategy-fix-cell-defects-two-common-blood-disorders>. Date of access: 6 January 2020.
- Kannengiesser, C. 2004. Handbook of patristic exegesis: The Bible in ancient Christianity. Leiden: Koninklijke Brill.
- Kingma, E. 2007. What is it to be healthy? *Analysis*, 67(294):128-133.
- Kirchschlaeger, P. G. 2016. Slavery and early Christianity: A reflection from a human rights perspective. *Acta Theologica*, 23:66-93.
- Kivisto, P. 2017. The Trump phenomenon: How the politics of populism won in 2016. Bingley: Emerald Publishing Limited.
- Klein, H. S. 2012. A population history of the United States. Cambridge: Cambridge University Press.
- Kling, D. W. 2006. The Bible in history: How the texts have shaped the times. Oxford: Oxford University Press.
- Klug, A. 2010. The discovery of zinc fingers and their development for practical applications in gene regulation and genome manipulation. *Quarterly reviews of biophysics*, 43(1):1-21.

- Knight, J. 1998. Luke's Gospel. London: Routledge.
- Koester, H. 2000. History and literature of early Christianity. New York: De Gruyter, Inc.
- Kormondy, E.J. 2011. Erasmus Darwin, 18th Century Polymath. *The American Biology Teacher*, 73(2):68-71.
- Kotze, M. 2013. A Christian bioethical perspective on pre-implantation genetic diagnosis (PGD) and genetic manipulation (GM). Stellenbosch: Stellenbosch University. (Thesis – Doctor of Philosophy).
- Kotze, M. 2018. The theological ethics of human enhancement: Genetic engineering, robotics and nanotechnology. *In die Skriflig*, 52(3), a2323. <https://doi.org/10.4102/ids.v52i3.2323>.
- Kourany, J. A. 2014. Human enhancement: Making the debate more productive. *Journal of Analytic Philosophy*, 79(5): 981-998.
- Kovacs, G. 2013. Should couples be allowed to select the sex of their offspring? *Journal of Obstetrics and Gynaecology Canada*, 35(12):1105-1107.
- Kruger, G. 2014. Synthetic biology: A theological-ethical evaluation from a Reformed perspective. Potchefstroom: North-West university. (Dissertation – *Magister Artium* in Ethics).
- Lagay, F. 2001. Gene therapy or genetic enhancement: Does it make a difference? *American Medical Association Journal of Ethics*, 3(2):37-39.
- Langel, U. 2019. CPP, cell penetrating peptides. Stockholm: Springer.
- Lategan, L. O. L. 2017. Church and healthcare: time for a new debate? *Journal for Christian Scholarship*, 53(3):27-44.

- Lavazza, A. 2018. Cognitive Enhancement through genetic editing: A new frontier to explore (and to regulate)? *Journal of Cognitive Enhancement*, 2:388-396.
- Lebowitz, S. 2020. 61 cognitive biases that screw up everything we do. <https://www.businessinsider.co.za/cognitive-biases-2015-10?r=US&IR=T>. Date of access: 5 June 2021.
- Ledford, H. 2015. CRISPR, the disruptor. <https://www.nature.com/news/crispr-the-disruptor-1.17673>. Date of access 3 December 2018.
- Ledford, H. & Callaway, E. 2020. Pioneers of revolutionary CRISPR gene editing win Chemistry Nobel. <https://www.nature.com/articles/d41586-020-02765-9>. Date of access: 15 January 2021.
- Lee, H. J. 2010. Men of Galilee, why stand gazing up into heaven: Revisiting Galileo, astronomy and the authority of the Bible. *Journal of the Evangelical Theological Society*, 55(1):103-116.
- Lee, W.D., Drazen, J., Sharp, P.A. & Langer, R.S. 2014. From x-rays to DNA. London: The MIT Press.
- Lester, C. 2019. Embryo adoption is growing, but it's getting tangled in the abortion debate. <https://www.nytimes.com/2019/02/17/health/embryo-adoption-donated-snowflake.html>. Date of Access: 15 June 2021.
- Levering, M. 2008. Principles of exegesis: Toward a participatory biblical exegesis. *Pro Ecclesia*, 17(1):35-51.
- Levin, J. & Meador, K.G. 2012. Healing to all their flesh. West Conshohocken: Templeton Press.
- Lewis, T. & Stix, G. 2019. Elon Musk's secretive brain tech company debuts a sophisticated neural implant. <https://www.scientificamerican.com/article/elon->

[musks-secretive-brain-tech-company-debuts-a-sophisticated-neural-implant1/](#).

Date of Access: 9 July 2021.

- Liang, P. Xu, Y. Zhang, X. Ding, C. Huang, r. Zhang, Z. Lv, J. Xie, X. Chen, Y. Li, Y. Sun, Y. Bai, Y. Songyang, Z. Ma, W. Zhou, C. & Huang, J. 2015. CRISPR/CAS9-mediated gene editing in human tripronuclear zygotes. *Protein Cell*, 6(5):363-372.
- Libby, A. E., & Wang, H. 2014. An update on gene therapy for the treatment of lipoprotein lipase deficiency. *Orphan Drugs: Research and Reviews*, 4:47-54.
- Lim, H. A. 2002. Genetically yours: bioinforming, biopharming, biofarming. New Jersey: World Scientific.
- Lind, M. I., Ravindran, S., Sekajova, Z., Carlsson, H., Hinas, A., & Maklakov, A. A. 2019. Experimentally reduced insulin/IGF-1 signalling in adulthood extend lifespan of parents and improves Darwinian fitness of their offspring. *Evolution Letters*, 3(2): 207-216.
- Ling, J. R. 2017. When does human life begin? Newcastle: The Christian Institute.
- Lombardo, P. A. 2011. A century of eugenics in America. Indianapolis: Indiana University Press.
- Lorrimar, V. 2017. The scientific character of Philip Hefner's "created co-creator". *Zygon*, 52(3):726-746.
- Lucey, C. 2022. What is deism and what are the deism beliefs. <https://www.christianity.com/wiki/cults-and-other-religions/what-is-deism-what-are-deism-beliefs.html#:~:text=How%20Deism%20Differs%20from%20Christianity%20The%20Genesis%20account,hold%20vastly%20different%20beliefs%20on%20key%20issues.%201>. Date of access: 3 June 2022.

- Lukas, T., Kumaratilake, J. & Henneberg, M. 2020. Recently increased prevalence of the human median artery of the forearm: A microevolutionary change. *Journal of Anatomy*, 237:623-631.
- MacGill, M. 2021. What should my heart rate be? <https://www.medicalnewstoday.com/articles/235710>. Date of access 27 April 2021.
- MacKellar, C. 2012. Paul Ramsey and preconceptive eugenics. https://cbhd.org/sites/default/files/premium_content/Dignitas_V19_N1_Spring_2012_MacKellar.pdf. Date of access: 14 June 2021.
- MacKellar, C., & Bechtel, C. 2014. The ethics of new eugenics. New York: Berghahn Books.
- Macklin, R. 2003. Dignity is a useless concept. *British Medical Journal*, 327:1419-1420.
- Maldonado, R., Jalil, S., & Wartiovaara, K. 2021. Curative gene therapies for rare diseases. *Journal of Community Genetics*, 12:267-276.
- Mallawaarachchi, V. 2017. DNA sequence data analysis – Starting off in bioinformatics. <https://towardsdatascience.com/dna-sequence-data-analysis-starting-off-in-bioinformatics-3dba4cea04f>. Date of access: 28 January 2019.
- Marshall, I.H. 2004. New Testament Theology: many witnesses, one Gospel. Downers Grove: InterVarsity Press.
- Marshall, M. s.a. Eugenics. <https://www.newscientist.com/definition/eugenics/>. Date of access: 13 June 2021.
- May, G. 2004. Creation ex Nihilo: The doctrine of creation out of nothing in early Christian thought. New York: T&T Clark International.

- McCarthy, M. 2002. A brief history of the World Health Organisation. *The Lancet*, 360:1111-1112.
- McConaghie, A. 2017. Glybera, the most expensive drug in the world, to be withdrawn after commercial flop. <https://pharmaphorum.com/news/glybera-expensive-drug-world-withdrawn-commercial-flop/>. Date of access 30 May 2021.
- McGrath, A.E. 2010. Science and religion: A new introduction. Oxford: Wiley-Blackwell.
- McKibben, B. 2003. Designer genes. <https://orionmagazine.org/article/designer-genes/>. Date of Access: 1 Aug 2021.
- Mei, C., Hongcheng, W., Liao, Q., Khan, R., Raza, S. H. A., Zhao, C., Wang, H., Cheng, G., Tian, W., Li, Y., & Zan, L. 2019. Genome-wide analysis reveals the effects of artificial selection on production and meat quality traits in Qincuan cattle. *Genomics*, 111:1201-1208.
- Mellon, B. F. 2017. John Kilner's understanding of the *Imago Dei* and the ethical treatment of persons with disabilities. *Christian Bioethics*, 23(5):283-298.
- Mendz, G, L., & Cook, M. 2021. Transhumanist genetic enhancement: Creation of a 'new man' through technological innovation. *The New Bioethics*, 27(2):105-126.
- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/CRISPR>. Date of access: 19 February 2023.
- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/polydactyly>. Date of access: 19 February 2023.
- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/medical/ichthyosis%20hystrix%20gravior>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/lymphocyte>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/bacteriophages>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/E.%20coli>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/myelogenous%20leukemia>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/sickle%20cell%20anemia>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/osteoporosis>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/rheumatic%20fever>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/schizophrenia>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/de%20novo>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/progeria>. Date of access: 19 February 2023.

Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/cystic%20fibrosis>. Date of access: 19 February 2023.

- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/medical/peripheral%20arterial%20disease>. Date of access: 19 February 2023.
- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/beta-blocker>. Date of access: 19 February 2023.
- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/hemophilia>. Date of access: 19 February 2023.
- Merriam-Webster Inc. 2023. *Merriam-Webster dictionary*. <https://www.merriam-webster.com/dictionary/Duchenne%20muscular%20dystrophy>. Date of access: 19 February 2023.
- Merzlyakov, S. S. 2022. Posthumanism vs. Transhumanism: From the end of exceptionalism to technological humanism. *Herald of the Russian Academy of Sciences*, 92(6):475-482.
- Messer, N. 2011. Toward a theological understanding of health and disease. *Journal of the society of Christian ethics*, 31(1):161-178.
- Middleton, J. R. 1994. The liberating Image? Interpreting the Imago Dei in context. *Christian Scholars Review*, 24(1):8-25.
- Middleton, J. R. 2005. The liberating Image: The Imago Dei in Genesis. Grand Rapids: Brazos Press.
- Miller, D. K. 2011. Responsible relationship: *Imago Dei* and the moral distinction between humans and other animals. *International Journal of Systematic Theology*, 13(3):323-339.
- Mitha, F. 2020. The return of gene therapy. <https://www.labiotech.eu/in-depth/gene-therapy-history/>. Date of access: 30 May 2021. Messer, N. 2011. Toward a

- theological understanding of health and disease. *Journal of the society of Christian ethics*, 31(1):161-178.
- Molhoek, B. 2022. The scope of human creative action: Created co-creators, *Imago Dei* and artificial intelligence. *HTS Teologiese Studies/Theological Studies* 78(2), a7697. <https://doi.org/10.4102/hts.v78i2.7697>. Date of access: 15 September 2022.
- Möller, F. P. 1998. Words of light and life. Volume 1: Understanding the greatest truths. Pretoria: JL van Schaik.
- Moore, J. A. 1983. Thomas Hunt Morgan: The geneticist. *American Zoologist*, 23(4):855-865.
- Morgan, L. M. 2013. The potentiality principle from Aristotle to Abortion. *Current Anthropology*, 54(7):15-25.
- Mullis, K. B. s.a. Polymerase chain reaction. www.karymullis.com/pcr.shtml. Date of access: 6 January 2021.
- National Academies of Science, Engineering and Medicine. 2015. On genome editing: National summit statement. <https://www.nationalacademies.org/news/2015/12/on-human-gene-editing-international-summit-statement>. Date of Access: 1 August 2021.
- National Academies of Science, Engineering and Medicine. 2017. Human genome editing: Science, ethics and governance. Washington: National Academic Press.
- Nietzsche, F. W. 1923. The Antichrist. New York: Alfred A. Knopf, Inc.
- Nordenfelt, L. 2001. Health, Science, and ordinary language. New York: Rodopi.
- Northfield, R. 2018. Top 10 invasive species: when pest control goes wrong. <https://eandt.theiet.org/content/articles/2018/05/top-10-invasive-species-when-pest-control-goes-wrong/>. Date of access: 5 January 2021.

- Nuffield Council. 2018. Genome editing and human reproduction: Social and ethical issues. <https://www.nuffieldbioethics.org/publications/genome-editing-and-human-reproduction>. Date of access: 1 August 2021.
- Nullens, P. 2013. Theologia caritatis and the moral authority of Scripture: Approaching 2 Timothy 3:16-17 with a hermeneutic of love. *European journal of Theology*, 22(1):38-49.
- Nummedal, T. 2013. Alchemy and Religion in Christian Europe. *Ambix*, 60(4):311-322.
- O'Mathunda, P. O. 2014. Christian bioethics and the Bible. *Christian Bioethics*, 20(2):246-259.
- Otto, R. 1992. The *Imago Dei* as familitas. *Journal of Evangelical Theological Society*, 35(4):503-513.
- Owens, J. 2017. Martha Nussbaum on ethics and religion. *Colloquium*, 49(1):4-60.
- Padyukov, L., & Alfredsson, L. 2014. Between the lines of genetic code: Genetic interactions in understanding disease and complex phenotypes. London: Elsevier Science & Technology.
- Palmer, M. 2009. Who wants to live forever? *Corporate Advisor*, 1 Apr., p45.
- Pearson, S., Jia, H., & Kandachi, K. 2004. China approves first gene therapy. *Nature Biotechnology*, 22(1):3-4.
- Peretti, F. 2005. *Monster*. Nashville: WestBow Press.
- Peters, T. 2017. Should CRISPR scientists play God? *Religions*, 61(8):1-11.
- Peterson, G. R. 2004. The created co-creator: what it is and is not. *Zygon*, 39(4):827-840.

- Peterson, R. S. 2016. The *Imago Dei* as human identity: A theological interpretation. Winona Lake: Penn State University.
- Pijnenburg, M. A. M., & Leget, C. 2007. Who wants to live forever? Three arguments against extending the human lifespan. *Journal of Medical Ethics*, 33(10):585-587.
- Poon, C. S. K., Koehler, D. J., & Buehler. 2014. On the psychology of self-prediction: Consideration of situational barriers to intended actions. *Judgment and Decision Making*, 9(3):207-225.
- Poirier, J. P. 2009. The synoptic problem and the field of New Testament introduction. *Journal of the study of the New Testament*, 32(2):179-190.
- Porter, A. 2017. Bioethics and transhumanism. *Journal of Medicine and Philosophy*, 42:237-260.
- Porter, S. E. 2014. The authority of the Bible as hermeneutical issue. *The Evangelical Quarterly*, 86(4):303-324.
- Rae, M. J., Butler, R. N., Campisi, J., de Grey, A. D. N. J., Finch, C. E., Gough, M., Martin, G. M., Vijg, J., Perrott, K. M., & Logan, J. L. 2010. The demographic and biomedical case for late-life interventions in aging. *Science Translational Medicine*, 2(40):1-6.
- Rai, P., Ganguli, A., Balachandran, S., Gupta, R., & Neogi, S. B. 2018. Global sex selection techniques for family planning: A narrative review. *Journal of Reproductive and Infant Psychology*, 36(5):548-560.
- Rana, S. J., Khan, S. S., Lloyd-Jones, D. M., & Sidney, S. 2020. Changes in mortality in Top 10 causes of death from 2011 to 2018. *Journal of General Internal Medicine*,
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7377530/pdf/11606_2020_Article_6070.pdf.

- Rangel, G. 2015. From corgis to corn: A brief look at the long history of GMO Technology. <https://sitn.hms.harvard.edu/flash/2015/from-corgis-to-corn-a-brief-look-at-the-long-history-of-gmo-technology/>. Date of access: 12 June 2021.
- Reardon, S. 2015. Global summit reveals divergent views on human gene editing. *Nature*, 528: 173.
- Regalado, A. 2019. China's CRISPR twins might have had their brains inadvertently enhanced. <https://www.technologyreview.com/2019/02/21/137309/the-crispr-twins-had-their-brains-altered/>. Date of access: 26 October 2020.
- Regan, H. Wright, R. & Field, A. 2018. The scientist, the twins and the experiment that geneticists say went too far. <https://edition.cnn.com/2018/11/30/health/gene-edited-babies-he-jiankui-intl/index.html> . Date of access: 3 December 2018.
- Resnik, D. B. 2016. The moral significance of the therapy-enhancement distinction in human genetics. In: Kuhse, H., Schuklenk, U., & Singer, P., eds. *Bioethics an anthology*. Chichester: Wiley Blackwell Publishing. pp. 189-199.
- Reyes-Realí, J., Mendoza-Ramos, M. I., Garrido-Guerrero, E., Mendez-Catala, C. F., Mendez-Cruz, A. R., & Pozo-Monila, G. 2018. Hypohidrotic ectodermal dysplasia: Clinical and molecular review. *International Journal of Dermatology*, 57(8):965-972.
- Reynolds, T. E. 2008. *Vulnerable Communion: A theology of disability and hospitality*. Grand Rapids: Brazos Press.
- Rheeder, R. 2014. Synthetic biology ethically evaluated: The creating God and co-creating human. *In die Skriflig*, 48(1), a723. <https://indieskriflig.org.za/index.php/skriflig/article/view/723>

- Richards, M. 2004. Perfecting people: selective breeding at the Oneida community (1869 – 1879) and the eugenics movement. *New Genetics and Society*, 23(1): 46-71.
- Richardson, N. 1986. Apartheid, heresy and the church in South Africa. *The Journal of Religious Ethics*, 14(1):1-21.
- Robson, M. I. T. 2008. Ontology and providence in creation: Taking ex nihilo seriously. London: Continuum International Publishing Group.
- Rosenberg, R., & de Velga Pereira, L. 2001. The frequency of Tay-Sachs disease causing mutations in the Brazilian Jewish population justifies a carrier screening program. *Medical Journal of Sao Paulo*, 119(4):146-149.
- s.a. 1996. Constitution of the Republic of South Africa, 1996 – Chapter 1 Bill of Rights. <https://www.gov.za/documents/constitution/chapter-2-bill-rights#27>. Date of access: 20 September 2022.
- Samocha, K. E., Robinson, E. B., Sanders, S. J., Stevens, C., Sabo, A., McGrath, L. M., Kosmicki, J. A., Rehnström, K., Mallick, S., Andrew Kirby, A., Wall, D. P., MacArthur, D. G., Gabriel, S. B., Mark DePristo, M., Purcell, S. M., Palotie, A., Boerwinkle, E., Buxbaum, J. D., Cook, J. H., Gibbs, R. A., Schellenberg, G. D., Sutcliffe, J. F., Bernie, D., Roeder, K., Neale, B. N., and Daly, M. J. 2014. A framework for the interpretation of *de novo* mutation in human disease. *Nature Genetics*, 46(9):944-951.
- Sartorius, N. 2006. The meanings of health and its promotion. *Croat Medical Journal*, 47:662-664.
- Saunders, P. 2006. *The moral status of the embryo*. <https://www.cmf.org.uk/resources/publications/content/?context=article&id=1811>. Date of access: 15 August 2021.

- Savulescu, J., & Kahane, G. The moral obligation to create children with the best chance of the best life. *Bioethics*, 23(5):274-290.
- Savulescu, J. 2016. Genitic interventions and the ethics of enhancement of human beings. *Gazeta de Antropologia*, 32(2):1-15.
- Schramme, T. 2007. A qualified defence of a naturalist theory of health. *Medicine, Health Care and Philosophy*, 10:11-17.
- Schwarzbach, E., Smykal, P., Dostal, O., Jarkovska, M. & Volova, S. 2014. Gregor J. Mendel: Genetis Founding Father. *Czeck J. Genet, Plant Breed*, 50(2):43-51.
- Scully, J.L. 2004. What is a disease? Disease, disability and their definitions. *European Molecular and Biology Organisation*, 5:650-653.
- Schaefer, G. O. 2015. *Why treat gene editing differently in two types of human cells?* <https://scitechconnect.elsevier.com/treat-gene-editing-differently-human-cells/>
Date of Access: 30 December 2021.
- Scheller, E. L., & Krebsbach, P. H. 2009. Gene therapy: Design and prospects for craniofacial regeneration. *J Dent Res*, 88(7): 585-596.
- Segers, S., & Mertes, H. 2020. Does human genome editing reinforce or violate human dignity? *Bioethics*, 34:33-40.
- Selden, J. 1984. Aquinas, Luther, Melanchthon and Biblical apologetics. *Grace Journal*, 5(2):181-195.
- Sensen, O. 2011. Kant on human dignity. Boston: De Gruyter, Inc.
- Shao, S., Wu, J., and Zhou, Q. 2021. Developments and challenges in human performance enhancement technology. *Elsevier*, 12: 1-7.
- Shatzer, J. 2015. Theology and Technology: Mapping the questions. *Ethics & Medicine: An International Journal of Bioethics*, 31(2):87-108.

- Sheehan, J. 2003. Enlightenment, religion, and the enigma of secularization: A review essay. *The American Historical Review*, 108(4):1061-1080.
- Sherman, E., 2017. Genetic editing will make income inequality much worse. <https://www.forbes.com/sites/eriksherman/2017/08/20/genetic-engineering-will-make-income-inequality-much-worse/?sh=2b00de063d75>. Date of Access: 31 December 2021.
- Sherman, E. 2018. Chinese researchers claim to have genetically engineered the first HIV-immune babies. <http://fortune.com/2018/11/26/chinese-researchers-genetic-engineering-babies-crispr-hiv/>. Date of access: 3 December 2018.
- Shuman, S. 2009. DNA ligases: progress and prospects. *The Journal of Biochemistry*, 284(26):17365-17369.
- Song, K. 2018. Four risks consumers need to know about DNA testing kit results and buying life insurance. [4 hidden insurance risks consumers face with at-home DNA testing kits \(cnbc.com\)](#). Date of access: 20 April 2020.
- Sosnay, P. R., & Cutting, G. R. 2014. Interpretation of genetic variants. *Thorax* 69:295-297.
- Spencer, N. 2013. The influence of the Bible on English political thought. *Law and Justice – The Christian law review*, 170(49):49-66.
- Sternberg, R. J. 2019. Increasing fluid intelligence is possible after all. *PNAS*, 105(19):6791-6792.
- Streeck, W. 2018. From speciation to specialization: On the origin of species by means of natural selection, Charles Darwin. *Social Research: An International Quarterly*, 85(3):661-685.
- Summerfield, C., & Tsetsos, K. 2015. Do humans make good decisions. *Trends in Cognitive Science*, 19(1):27-34.

- Tarus, D. 2016. Imago Dei in Christian theology: The various approaches. *Online International Journal of Arts and Humanities*, 5:18-25.
- Teovanovic, P. 2019. Individual differences in anchoring effect: evidence for the role of insufficient adjustment. *Europe's Journal of Psychology*, 15(1):8-24.
- Thomas, D. 2008. Christian doctrines in Islamic theology. Leiden: Brill.
- Thomas, G. M., & Rothman, B. K. 2016. Keeping the backdoor to eugenics ajar?: Disability and the future of prenatal screening. *American Medical Association Journal of Ethics*, 18(4):406-415.
- Tollefsen, C. 2011. Mind the gap: Charting the distance between Christian and secular bioethics. *Christian Bioethics*, 17(1): 47-53.
- Tollefsen, C. 2015. Suffering, enhancement, and human goods. *Quaestiones Disputatae*, 5(2):104-17.
- Tou, C. 2020. Hubris of helpful? Ethics and governance in heritable genome editing. *Penn Bioethics Journal*, 15(49):17-19.
- Trembath, K. R. 1987. Evangelical theories of biblical inspiration: A review and proposal. New York: Oxford University Press.
- Van den Belt, H. 2008. The authority of Scripture in Reformed Theology: Truth and trust. Boston: Brill.
- Van Der Watt, J., Bosman, H., du Rand, J., Janse van Rensburg, F., Nel, M., Smit, D., Venter, P., Die Bybel A-Z. Vereniging: Christelike Uitgewersmaatskappy.
- Van Dijk, P.J. & Ellis, T.H.N. 2016. The full breadth of Mendel's genetics. *Genetics*, 204:1327-1336.
- Venkatapuram, S. 2013. Health, vital goals, and central human capabilities. *Bioethics*, 27:271-279.

- Verhey, A. 2003. Reading the Bible in the strange world of medicine. Grand Rapids: Willian B. Eerdmans Publishing Company.
- Vinci, T. & Robert, J. S. 2005. Aristotle and Modern Genetics. *Journal of the history of ideas*, 66(2):201-221.
- Vizcarrondo, F. E. 2014. Human enhancement: The new eugenics. *The Lincacre Quarterly*, 81(3):239-243
- Voster, N. 2012. A theological perspective on human dignity, equality and freedom. *Open Journals*, 33(1):1-6.
- Wakefield, J.C. 2014. The biostatistical theory versus the harmful dysfunction analysis, Part 1: Is part-dysfunction a sufficient condition for medical disorder? *Journal of Medicine and Philosophy*, 39:648-682.
- Walton, J. H. 2006. Ancient Near Eastern thought and the Old Testament: Introducing the conceptual world of the Hebrew Bible. Grand Rapids: Baker Academic.
- Waters, B. 2012. Christian ethics and human germ line genetic modification. *Christian Bioethics*: 18(2): 171-186.
- Weiss, R., & Nelson, D. 1999. Teen dies undergoing experimental gene therapy. <https://www.washingtonpost.com/wp-srv/WPcap/1999-09/29/060r-092999-idx.html>. Date of Access: 30 May 2021.
- West, G. 2010. The ANC's deployment of religion in nation building: from Thabo Mbeki, to "The RDP of the Soul", to Jacob Zuma. Paper presented at the Forum for Religious Dialogue Symposium of the Research Institute for Theology and Religion held at the University of South Africa, Pretoria, 26-27 March 2009.
- Whitworth, P. 2018. Suffering and glory: The Church from the Apostles to Constantine. Durham: Sacristy Press.

- WHO (World Health Organisation). 2019. *The ethics of human genome editing*. <https://www.who.int/ethics/topics/human-genome-editing/WHO-Commissioned-Ethics-paper-March19.pdf>. Date of Access: 1 August 2021.
- WHO (World Health Organization). 2020. *GHE: Life expectancy and healthy life expectancy*. <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-life-expectancy-and-healthy-life-expectancy>. Date of Access: 20 August 2021.
- WHO (World Health Organisation). 2021. *Human genome editing: recommendations*. <https://www.who.int/publications/i/item/9789240030381>. Date of Access: 1 August 2021.
- Williams, D.M. 2004. *Receiving the Bible in faith*. Washington, D.C.: The Catholic University of America Press.
- Wolfe, C. 2010. *What is posthumanism*. Minnesota: University of Minnesota Press.
- Yaou, R. B., Yun, P., Dabaj, I., Norato, G., Donkervoort, S., Xiong, H., Nascimento, A., Maggi, L., Sarkozy, A., Monges, S., Bertoli, M., Komaki, H., Mayer, M., Mercuri, E., Zanoteli, E., Castiglioni, C., Marini-Bettolo, C., D'Amico, A., Dconinck, N., Desguerre, I., Erazo-Torricelli, R., Gurgel-Giannetti, J., Ishiyama, A., Kleinsteuber, K. S., Lagrue, E., Laugel, V., Mercier, S., Messina, S., Politano, L., Ryan, M. M., Sabouraud, P., Schara, U., Siciliano, G., Vercelli, L., Voit, T., Yoon, G., Alvarez, R., Muntoni, F., Pierson, T. M., Gomez-Andres, D., Reghan, F., Quijano-Roy, S., Bonnemann, C. G., & Bonne, G. 2021. International retrospective natural history study of LMNA-related congenital muscular dystrophy. *Brain Communications*, 3(3),fcab075. <https://doi.org/10.1093/braincomms/fcab075>.

Ulrike Schara, Gabriele Siciliano, Liliana Vercelli, Thomas Voit, Grace Yoon, Rachel Alvarez, Francesco Muntoni, Tyler M Pierson, David Gómez-Andrés, A Reghan Foley, Susana Quijano-Roy, Carsten G Bönnemann, Gisèle Bonne

Young, J.K., & Sander, D.S. 2012. TALENs: a widely applicable technology for targeted genome editing. *Nature Reviews: Molecular Cell Biology*, 14(1):49-55.

Zeng, J., Liu, M., Hou, X., Zhang, Q., Cheng, H., & Su, L. 2020. Can genes modulate anchoring effect? *International Journal of Psychology*, 55(6):1011-1015.

Zoppi, L. 2019. Genetic manipulation can double life expectancy and increase health of offspring. <https://www.news-medical.net/news/20190306/Genetic-manipulation-can-double-life-expectancy-and-increase-health-of-offspring.aspx>.
Date of Access: 8 July 2021.

Zuradzki, T. 2014. Moral uncertainty in bioethical argumentation: a new understanding of the pro-life view on early human embryos. *Theoretical Medicine and Bioethics*, 35(6):441-457.

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