A Utilitarian Assessment of the Relevance of Genetic Therapies for HIV-AIDS in Africa, with Special Reference to the Situation in Kenya

by

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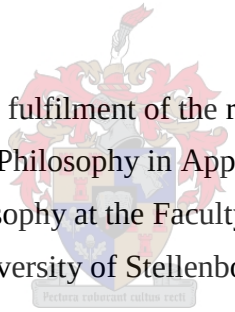

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DECLARATION

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by the University of Stellenbosch will not infringe any third party rights, and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

As African countries continue to bear the largest global burden of HIV-AIDS, the use of Highly Active Antiviral Treatment (HAART) for suppression of viral multiplication is the best available treatment option in which one is advised to take a dose at least once a day for the rest of his or her life. Of the HIV-infected number people globally, some are well into their second decade of treatment with these antiretroviral drugs. Although the survival rates and the quality of life for HIV-AIDS patients have been significantly improved by the intervention, missing the pills for a number of days unleashes a rapid viral replication. Additionally, some patients experience adverse effects which may interfere with their usual daily activities or lifestyles, leading to poor adherence for some, thereby posing risks of treatment failure of the drugs in use. In other words, with continued treatment interruptions, resistance to these drugs may occur. This means there is still no cure for HIV-AIDS, hence the need to consider alternatives that may become available through emerging technologies such as genetic therapies.

This research titled "A Utilitarian Assessment of the Relevance of Genetic Therapies for HIV-AIDS in Africa, with Special Reference to the Situation in Kenya," seeks to establish if genetic therapies would be suitable for treating HIV-AIDS which affects millions of patients in the world, 70% of whom are in Africa. Kenya is among the ten leading countries in Africa in the prevalence of HIV-AIDS, hence a review of the country's healthcare system, especially in relation to the problem of HIV-AIDS, including some on-going research. A comprehensive review of genetic therapies shows a distinction between somatic and germline genetic therapies as different but potentially effective cures for the illness. Special attention has been given to CRISPR Cas9 because, so far, it is the only technology close to providing real treatment for HIV-AIDS although there is need for caution and further development.

Based on the ethics theory of utilitarianism, the dissertation concludes that genetic therapies are the most appropriate solution to the HIV-AIDS scourge that will have justifiable benefit-sharing for the people, with minimum negative consequences. The therapies are most likely to turn misery into good health, pain into happiness, and shame into dignity. From a utilitarian perspective, when genetic therapies will be made available for the treatment of HIV-AIDS, the patient will be cured, the descendants of the patient will be prevented from inheriting the disease, and future societies will be saved from a deadly disease. Therefore, there is sufficient utilitarian justification in investing both technologically and scientifically in the on-going research into genetic therapies.

The dissertation recommends that there be

- collaborative effort in supporting on-going research into genetic therapies,
- propagating a positive understanding of genetic therapies,
- commitment to using the therapies once fully developed, and
- governments agreeing to take final responsibility with regard to results, whether negative or positive.

In view of the discussions, findings and recommendations of this research, genetic therapies are viewed as the most viable solution to the effects of HIV-AIDS.

OPSOMMING

Aangesien Afrika steeds die grootste wêreldwye las van MIV-vigs dra, is die gebruik van Hoogs Aktiewe Antiretrovirale Terapie (HAART) vir die onderdrukking van virale vermenigvuldiging die beste beskikbare behandelingsopsie, waarin ‘n mens aanbeveel word om minstens een maal per dag ‘n dosis te neem vir die res van sy of haar lewe. Van die mense wat wêreldwyd met MIV geïnfekteer is, is sommige reeds in hul tweede dekade van die behandeling met hierdie antiretrovirale medisyne. Alhoewel die oorlewingsyfers en die lewensgehalte van MIV-vigs-pasiënte aansienlik verbeter is deur die ingryping, word ‘n vinnige virusreplikasie veroorsaak wanneer die pasiënt die pille vir ‘n aantal dae nie gebruik nie. Boonop ervaar sommige pasiënte nadelige gevolge wat hul gewone daaglikse aktiwiteite of lewenstyl kan beïnvloed, wat vir sommige tot ‘n slegte nakoming daarvan kan lei, wat die risiko vir behandelingsmislukking van die medisyne in gebruik, kan inhou. Met ander woorde, met voortgesette behandelingsonderbrekings kan weerstand teen hierdie middels opgebou word. Dit beteken dat daar nog steeds geen geneesmiddel vir MIV-vigs is nie, en dus moet daar gekyk word na alternatiewe wat beskikbaar mag word deur opkomende tegnologieë soos genetiese terapieë.

Hierdie navorsing, met die titel “’n Utilitêre Beoordeling van die Toepaslikheid van Genetiese Terapieë vir MIV-vigs in Afrika, met Spesiale Verwysing na die Situasie in Kenia,” wil vasstel of genetiese terapieë geskik is vir die behandeling van MIV-vigs wat miljoene pasiënte regoor die wêreld affekteer, waarvan 70% in Afrika is. Kenia is een van die tien voorste lande in Afrika in die voorkoming van MIV-vigs. ‘n Oorsig word gebied van die land se gesondheidsorgstelsel, veral met betrekking tot die probleem van MIV-vigs, insluitend deurlopende navorsing. ‘n Uitgebreide oorsig van genetiese terapieë toon ‘n onderskeid tussen somatiese en kiemsel genetiese terapieë as verskillende, maar potensieel effektiewe geneesmiddels vir die siekte. Spesiale aandag word gevestig op CRISPR Cas9 omdat dit tot dusver die enigste tegnologie is wat naby kom aan die behandeling van MIV-vigs, hoewel versigtigheid en verdere ontwikkeling nodig is.

Deur middel van die aanwending van die etiek-teorie van utilitarisme, kom die proefskrif tot die gevolgtrekking dat die genetiese terapieë die mees geskikte oplossing vir die MIV-vigs-plaag is wat regverdige bevoordeeldeling vir die mense sal inhou, met die minimum negatiewe gevolge. Dit is waarskynlik dat die terapieë ellende in goeie gesondheid, pyn in geluk en skande in waardigheid kan verander. Vanuit ‘n utilitaristiese perspektief, wanneer genetiese terapieë beskikbaar gestel sal word vir die behandeling van MIV-vigs, sal die pasiënt genees word, dit sal voorkom dat die nasate van die pasiënt geïnfekteer is en toekomstige

samelewings sal gered word van ‘n dodelike siekte. Daar is dus voldoende utilitaristiese regverdiging om te belê in die deurlopende navorsing, beide tegnologies en wetenskaplik, van genetiese terapieë.

Die proefskrif beveel aan

- dat daar gesamentlike pogings aangewend word om deurlopende navorsing oor genetiese terapieë te ondersteun,
- ‘n positiewe begrip van genetiese terapieë bevorder word,
- ‘n verbintenis tot die gebruik van die terapieë sodra dit volledig ontwikkel is aangegaan word en
- dat regerings instem om finale verantwoordelikheid te neem ten opsigte van resultate, hetsy negatief of positief.

In die lig van die besprekings, bevindings en aanbevelings van hierdie navorsing, word genetiese terapieë beskou as die mees lewensvatbare oplossing vir die gevolge van MIV-vigs.

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CHAPTER 1: BACKGROUND INFORMATION

1.1. INTRODUCTION

The first chapter of the dissertation provides detailed background information on HIV-AIDS, especially in the context of the African countries where the impact of the disease is greatest. The first section gives a brief general background. The second section provides statistics about HIV-AIDS in Africa in order to show the effect of the disease on the continent. The third section gives information on the infectious disease burden of Africa in general in order to set the stage for the gravity of the health situation with HIV-AIDS in focus. The chapter also gives the statement of the problem under study, outlines the research methodology, and explains the choice and application of the philosophical theory of utilitarianism. The rest of the dissertation is built on the issues raised in this chapter.

1.2. INTRODUCTION TO HIV-AIDS IN AFRICA

One of the most devastating attacks on human health in recent decades is HIV-AIDS, with consequences not just evident on physical health of an infected person, but also crossing over into the socio-economic fabric of societies in the world in general and Africa in particular. The stigma and rejection that patients have experienced upon being confirmed to have been infected with the virus has caused much psychological and physical damage. HIV-AIDS is known to have attacked humanity through its most intimate facet of life, that is, sexuality, thereby ensuring total vulnerability. HIV-AIDS is primarily a sexually-transmitted disease that attacks the infected person's immune system and renders it useless for the purposes of fighting disease invasions. It is also a generally known fact that, despite the best efforts in scientific research, no cure has been developed against the disease. So, whereas remedies, including Anti-Retroviral Treatments (ARTs), have been developed that suppress the impact on the virus on an individual person, and whereas such treatments have become available across the world, Africa continues to bear the greatest burden of HIV-AIDS. It is, therefore, of interest for a study such as this one to seek to provide, not only an understanding of the disease, but also propose alternative scientific solutions to alleviate human suffering on the continent.

As part of the background information, a summary of the history of HIV-AIDS is relevant. According to the AIDS Institute, "…the earliest known case of infection with HIV-1 in a human was detected in a blood sample collected in 1959 from a man in Kinshasa, Democratic Republic of the Congo. How he became infected is not known. Genetic analysis of this blood sample suggested that HIV-1 may have stemmed from a single virus in the late

1940s or early 1950s" (The AIDS Institute, 2011). Since then, HIV-AIDS has grown to become "…one of the most devastating infectious diseases to have emerged in recent history" (Sharp & Hahn, 2011). In an attempt to establish the exact origins of this pandemic, some scientists in 1999 "…identified a type of chimpanzee in West Africa as the source of HIV infection in humans. They believe that the chimpanzee version of the immunodeficiency virus (called simian immunodeficiency virus or SIV) most likely was transmitted to humans and mutated into HIV when humans hunted these chimpanzees for meat and came into contact with their infected blood. Over decades, the virus slowly spread across Africa and later into other parts of the world" (The AIDS Institute, 2011).

The history of HIV-AIDS in Kenya is as long as that of the illness itself. It has been reported that "…in 1982 AIDS was named and vertical (mother to child) and heterosexual transmission were scientifically recognised. The following year 1983 a retrovirus was identified that was suspected to be the cause of AIDS. The virus was named HIV and World Health Organisation (WHO) HIV surveillance started" (Simon, 2014). The first case in Kenya was identified in 1984; in 1985 the government established the National AIDS Committee (Ibid.). In 1988 "…the Ministry of Health issued guidelines stating that patients should be told their HIV status. In 1989, President Moi is said to have ordered the quarantining of people with HIV-AIDS but the order was quietly ignored" (Ibid.). The Kenya National AIDS Control Council (KNACC) report of 2014 says that by the mid-1990s, HIV-AIDS was one of the major causes of mortality in the country, putting huge demands on the healthcare system as well as the economy (Kenya National AIDS Control Council, 2014). According to Bruhns, "HIV-AIDS was declared a national disaster in Kenya in 1999"; this was "15 years after the first HIV-AIDS case had been reported in the country… By that time, more than half a million Kenyans were estimated to have died of the disease, and some 2.5 million adults were infected" (Bruhns, 2006). "HIV prevalence peaked at 10.5% in 1996, and had fallen to 5.9% by 2015. This is mainly due to the rapid scaling up of HIV treatment and care" (AVERT, 2017).

According to a UNAIDS Report of 2016, "Kenya has the joint fourth-largest HIV epidemic in the world (alongside Mozambique and Uganda), in terms of the number of people living with HIV, which was 1.5 million people in 2015. Roughly 36,000 people died from AIDS-related illnesses in the same year, although this figure is steadily declining from its total of 51,000 in 2010" (UNAIDS, 2016). In the same year, there were "660,000 children orphaned by AIDS" (Ibid.). It was estimated that "…30% of new annual HIV infections in Kenya are among people from key populations such as men who have sex with men, people who inject drugs, sex workers, prisoners, transgender people, women, children, young people and

adolescents. This is disproportionate to how many people from these groups exist within the population" (AVERT, 2017)). A report of the Ministry of Health says that "geographic location is also a factor, with 65% of all new infections occurring in the western regions of Kenya, consisting of nine out of the country's 47 counties" (Ministry of Health, 2014).

A research focusing on HIV-AIDS may face the unintended risk of HIV exceptionalism, also known as AIDS exceptionalism, which refers to the deliberate treatment of HIV-AIDS differently from other diseases in both law and policy (Oppenheimer & Bayer, 2009, p. 988).

> HIV exceptionalists emphasize the human rights of people living with HIV-AIDS, particularly their rights to privacy, confidentiality, and autonomy. They also believe that all people seeking an HIV test always require special services, such as counseling with every HIV test, special informed consent paperwork, and guaranteed anonymity in public health reporting. In many places, it is illegal to disclose HIV test results over the phone or over the internet (Veatch, 1997, p. 399).

It is based on the idea that the disease (HIV-AIDS) requires a response above and beyond "normal" health interventions.

> It began as a Western response to the originally terrifying and lethal nature of the virus. More recently, AIDS exceptionalism came to refer to the disease specific global response and the resources dedicated to addressing the epidemic. There has been a backlash against this exceptionalism, with critics claiming that HIV-AIDS receives a disproportionate amount of international aid and health funding (Smith & Whiteside, 2010, p. 1).

Despite the criticism against AIDS exceptionalism, the global community must not lose sight of the fact that AIDS continues to kill millions of people, the majority of whom live in Africa, of which Kenya is a leading host country. It remains without cure and the scientific research community must not forget to seek its possible permanent resolution, including and especially genetic therapies. In any case, problem solving, especially of global scale, normally requires that special attention be given to the specific problem at hand. This applies to widespread calamities, emergency rescue, and relief work, and should apply in serious cases such as HIV-AIDS. When attention is given to a specific problem, even when resources are disproportionately allocated to it, the attempt is to solve an issues which, if not given such attention, would threaten humanity in a significant way.

1.3. THE IMPACT OF HIV-AIDS ON AFRICAN SOCIETIES

This study reviews the problem of HIV-AIDS in African societies in light of the persistent lack of a cure, and assesses whether genetic therapies, which are currently part of on-going scientific research, may be a permanent solution to the people of the continent of Africa. Besides TB and malaria, HIV-AIDS is the most seriously devastating infectious disease in sub-Saharan Africa in modern times. It is, therefore, appropriate in this section to do a review

of available literature about its impact on African societies. A recent UNAIDS report regarding HIV-AIDS in Africa shows that in the year 2013 "…an estimated 24.7 million people were living with HIV, accounting for 71% of the global total. In the same year, there were an estimated 1.5 million new HIV infections and 1.1 million AIDS-related deaths" (UNAIDS, 2014). The same report indicates that Southern Africa is the worst affected region "and is widely regarded as the epicentre of the global HIV epidemic," with Swaziland standing at 27.4% of the country's total population -- the highest rate in the world -- and South Africa having "5.9 million people living with HIV." It is reported that "…the majority of new HIV infections in sub-Saharan Africa occur in adults over the age of 25 years, and that more than 4 in 10 new infections among women are in young women aged between 15 and 24 years" (Ibid.). It is further reported that since 2009 "…there has been a 43% decline in new HIV infections among children… from 350,000 to 200,000 in 2013…" (AVERT, 2017) although actual decline figures are significantly different when checked per country. According to UNAIDS the average "…HIV infection in sex workers in sub-Saharan Africa is 20·5% compared with the global median of 3·9%..." (UNAIDS, 2014) of the estimated total number of sex workers. Men who have sex with men have an infection rate range of 15% in the countries with lower infection rates, all the way to 57% for the countries with higher infection rates like Mauritania and Guinea (Ibid.).

The HIV infection rates seem not to have changed much in Africa despite treatment efforts and prevention campaigns. Between 1981 and 2005, 23 million people had been documented to have died from AIDS, out of whom 17 million were Africans (Van Niekerk & Kopelman, 2005). By 2005, 39.4 million people lived with HIV, and 25.4 million of them (64%) lived in sub-Saharan Africa (Ibid.). Whiteside has outlined many ways through which HIV-AIDS affects Africa, noting that

> There is no cure and treatment is inaccessible for the majority of infected Africans due to both the cost and lack of health care staff. Impact is felt through the illness (morbidity) and deaths (mortality). Most of those who die will be young adults who have completed education, started families, and begun working careers (Whiteside, 2005).

The effects realised in the population are "increased mortality and decreased fertility" (Ibid.). The impact on fertility is realised due to the fact that "…infected women are less likely to fall pregnant and carry a child to term, and premature mortality means there will be fewer women of childbearing age" (Whiteside, 2005).

Economics experts have observed that HIV-AIDS negatively affects economic growth through its reduction of human capital (Bell, et al., 2003). There is need for properly coordinated intervention for prevention, nutrition, health care and medicine. Greener points out

that, apart from their need for medical care, "people living with HIV-AIDS will be unable to work" (Greener, 2002). He further reports (Ibid.) that, where infection rates are higher, "the epidemic has left behind many orphans cared for by elderly grandparents." When adult parents lose income, or when they die, age profiling becomes difficult in countries, leading to difficulties in human resource capacity. As Greener says, AIDS seriously weakens the taxable population, thereby putting a strain on government finances and slowing down economic development (Greener, 2002). UNAIDS report of 2010 has it that in 2009, "…1.3 million Africans lost their lives as a result of AIDS." In the same year, "…an estimated 14.8 million children in Africa were estimated to have lost one or both parents to become 'AIDS orphans'" (Ibid.). Since AIDS is not normally indicated on the death certificates as the cause of someone's death, the numbers here could be seriously underestimated. As Whiteside has observed, children orphaned due to HIV-AIDS "…face severe stress, they are less likely to attend school, more likely to be exploited and experience premature mortality, and they also have a more pessimistic outlook on life" (Whiteside, 2005).

Various sub-Saharan countries have experienced the negative effects of the disease in various ways and at various levels. By 2015 Botswana had an adult HIV prevalence of 22.2%, which was the third highest "…in the world after Lesotho and Swaziland" (UNAIDS, 2016). Given that in 2005 the rate had been 25.4%, it may be concluded that Botswana's commitment in responding to HIV-AIDS has borne some fruit. As a result of the country's treatment programme,

> …new infections have decreased significantly, from 15,000 in 2005 to 9,100 in 2013, although in recent years they have begun to rise again, with 9,700 reported in 2015. AIDS-related deaths have dramatically decreased from the 14,000 recorded in 2005. They fell to 3,200 in 2015 (UNAIDS, 2016).

It is worthy of note that "Botswana was the first country in sub-Saharan Africa to provide universal free antiretroviral treatment to people living with HIV" (UNAIDS, 2016), thereby setting an example to other countries in the region. According to reports in *The Guardian* (Wednesday, 26th November 2008), the scale-up of treatment programmes in both Botswana and Namibia between 2000 and 2005 led to the saving of lives, unlike in South Africa where "…more than 330,000 people died unnecessarily in South Africa over the period and that 35,000 HIV-infected babies were born who could have been protected from the virus and would probably have a limited life."[1] By comparison, Botswana achieved 85% treatment coverage, while Namibia achieved 71% by 2005, and both countries had 70% coverage with mother-to-

[1] This occurrence in South Africa was really unnecessary, but it happened because of the dire denialism of the South African government at the time. I will give this matter a fuller discussion in a later section.

child transmission programme. “In the case of South Africa, many lives were lost because of a failure to accept the use of available ARVs to prevent and treat HIV-AIDS in a timely manner." South Africa’s rejection -- of ARVs that came through a donation from the Bill & Melinda Gates Foundation -- was informed by the country’s policy of denialism at the time. President Mbeki promoted the notion that AIDS was not directly caused by HIV but by economic factors such as poverty, arguing that AIDS was not as serious as people thought (Whiteside, 2005). This approach in South Africa relegated to the periphery any possible national action on the HIV-AIDS scourge, and left it in the hands of a few Non-Governmental Organisations. Lesotho seems to have had a similar experience, having the second highest HIV prevalence rate after Swaziland. According to UNAIDS, “Lesotho’s HIV prevalence was 22.7% in 2015, and has been around this level since 2005” (UNAIDS, 2016). The same report showed additional statistics:

> …an estimated 310,000 people were living with HIV in Lesotho and 18,000 died from AIDS-related illnesses in 2015. However, HIV incidence is declining, from 30,000 new infections in 2005 to 18,000 new infections in 2015. Lesotho is a small country with a population of just over two million. High levels of poverty and inequality due to a struggling economy have left the country highly dependent on donors for financial support (UNAIDS, 2016).

As a result of poverty and HIV-AIDS, life expectancy has dropped to “just 52 for men and 55 for women” (Ibid.). “Lesotho’s 2014 Demographic and Health Survey (LDHS) reports prevalence among women to have increased from 26% in 2004 to 30% in 2014, while prevalence among men has remained stable at 19% over the same period” (Ibid.) Cultural issues related to strong patriarchy are thought to contribute to this situation.

According to an AVERT report, Swaziland leads with an adult prevalence rate of 28.8%, noting that “…in 2015, 11,000 people were newly infected with HIV, and 3,800 people died of an AIDS-related illness” (AVERT, 2017). Although the country has “one of the highest rates of antiretroviral treatment coverage in sub-Saharan Africa… at 67%”, the high number of individuals living with HIV in Swaziland means “it is still the country’s biggest public health concern” (UNAIDS, 2016). It was also reported that, out of the 220,000 persons living with HIV in Swaziland, 120,000 were women. Yet Swaziland is only leading by percentage of its own population. In terms of real numbers, South Africa leads with “the biggest and most high profile HIV epidemic in the world, with an estimated 7 million people living with HIV in 2015” (UNAIDS, 2016). In the same year, “there were 380,000 new infections while 180,000 South Africans died from AIDS-related illnesses” (Ibid.).

A review of the history of HIV-AIDS in South Africa reveals slow progress towards a realistic and comprehensive response. South African History Online provides a review article,

"HIV-AIDS in South Africa Timeline 1940s-2009" in which it reports the first deaths from AIDS to have occurred in South Africa in 1985, and that in 1987 "the apartheid government recognised that HIV and AIDS had the potential to become 'a major problem', even though there were few reported infections" (South African History Online, 2017). That was also the year in which the African Research and Educational Puppetry Programme (AREPP) was founded "as a community-based educational trust… to break down racial, cultural, language and educational taboos and barriers on HIV-AIDS…" in South Africa (South African History Online, 2017). In 1988 the AIDS Foundation of South Africa was "established as an agency seeking to identify and develop initiatives, which reduce the impact of AIDS in under-resourced communities." In January 1992 the Department of Health requested the South African Law Commission "to investigate how the law relates to HIV-infected persons." The Commission later in 1993 reported that "the Constitutional Act 200 regulates the protection of the fundamental rights of the individual and prohibits unfair discrimination against any person infected or affected indirectly or directly by HIV-AIDS" (The Guardian, 2008). In 1999 when Manto Tshabalala-Msimang became the new Minister for Health (until 2008) AIDS in South Africa became a controversial issue because she emphasised on "treating South Africa's AIDS epidemic with vegetables such as garlic and beetroot, rather than with western medicines…" (The Guardian, 2008). On the other hand, religious leaders took their campaigns on AIDS to the pulpit and other worship places.

Between 9th and 14th July 2000 South Africa hosted the 13th International AIDS Conference in Durban during which "Nkosi Johnson, an eleven year old HIV-positive boy, gave a speech in the opening of the conference and called for the government to give AZT to pregnant HIV-positive women" (The Guardian, 2008). At the same conference President Thabo Mbeki stressed "the role of poverty in explaining the problems faced by Africa." In an interview with the Time Magazine, President Mbeki said,

> Clearly there is such a thing as acquired immune deficiency. The question you have to ask is what produces this deficiency. A whole variety of things can cause the immune system to collapse. But the notion that immune deficiency is only acquired from a single virus cannot be sustained. Once you say immune deficiency is acquired from that virus your response will be antiviral drugs. But if you accept that there can be a variety of reasons, including poverty and the many diseases that afflict Africans, then you can have a more comprehensive treatment response (The Guardian, 2008).

This assertion by President Mbeki caused both national and international outcry and confusion on the official response of the South African government to the epidemic of HIV-AIDS. In October he actually admitted that his statement had caused confusion in South Africa. On 4th July 2001 South Africa officially commented on the United Nations' session on HIV "by

declaring highlights of poverty, underdevelopment and illiteracy as the main contributing factors to the spread of HIV-AIDS" (The Guardian, 2008). The government's commitment remained fairly weak over the years until September 2008 when Thabo Mbeki resigned from the Presidency and his immediate successor Kgalema Motlanthe "immediately committed government to a concerted and decisive response to the epidemic."

It is in the context of the above information that South Africa's treatment policy on HIV-AIDS took a slow path and took long to become operational. However, in recent years South Africa has had "the largest antiretroviral treatments (ART) programme globally and these efforts have been largely financed from its own domestic resources. The country now invests more than $1.5 billion annually to run its HIV and AIDS programmes" (UNAIDS, 2016). In 2013, an estimated 360,000 children aged 0 to 14 were living with HIV in South Africa (Ibid.).

The rest of sub-Saharan Africa fares no better. UNAIDS reports that "…an estimated 60% of new infections in western and central Africa in 2015 occurred in Nigeria," a country that had "3.5 million people living with HIV in the same year" (UNAIDS, 2016). In Malawi, "an estimated 980,000 people were living with HIV in 2015 and 27,000 Malawians died from HIV-related illnesses" (Ibid.). The same report says "that young people account for 50% of new HIV infections in Malawi" (Ibid.). In Tanzania in the same year "…1.4 million people were living with HIV, while 54,000 people were newly infected… and 36,000 people died from an AIDS-related illness" (AVERT, 2017). The heavier burden is on the women population, out of whom 780,000 aged 15 years and above live with HIV. In Uganda about 1.5 million people were living with HIV in 2015, while there were 28,000 deaths from AIDS-related illnesses (UNAIDS, 2016). There were "1.2 million people in Zambia living with HIV in 2015" when "55,000 adults and 5,000 children became newly infected" (Ibid). Out of the 1.2 million people, 640,000 were women. Zimbabwe stood at "1.4 million people living with HIV in 2015, including 77,000 with new infections at 64,000 and AIDS-related deaths at 29,000." The number of women living with HIV was about 790,000 in Zimbabwe (Ibid.).

Discussions about HIV-AIDS causes reflections of some of the world's past epidemics, perhaps the worst of which were the Black Death of the 14th century and the Flu Epidemic of 1918-1919, both of which wiped out huge sections of the world's population. According to Britannica Online Encyclopaedia, Black Death originated in China and Inner Asia in 1347, from rat fleas living on black rats that lived on merchant ships, before swiftly moving into parts of Europe. According to Alchon, "the Black Death is estimated to have killed 30-60% of Europe's total population at the time." He says the plague "may have reduced the world

population from an estimated 450 million down to 350-375 million in the 14th century" (Alchon, 2003). The devastation of Black Death can be deduced from the following explanation:

> The Black Death arrived in Europe by sea in October 1347 when 12 Genoese trading ships docked at the Sicilian port of Messina after a long journey through the Black Sea. The people who gathered on the docks to greet the ships were met with a horrifying surprise: most of the sailors aboard the ships were dead, and those who were still alive were gravely ill. They were overcome with fever, unable to keep food down and delirious from pain. Strangest of all, they were covered in mysterious black boils that oozed blood and pus and gave their illness its name: the Black Death. The Sicilian authorities hastily ordered the fleet of "death ships" out of the harbour, but it was too late. Over the next five years, the mysterious Black Death would kill more than 20 million people in Europe – almost one-third of the continent's population (History.com Staff, 2010).

There seems to be variance of figures from one historical source to another. The Norwegian historian Ole Benedictow gives an estimate of 50 million people (which may have been 60% of Europe's population at the time) to have died of the Black Death (Benedictow, 2005). There was evidence of desperation in the reactions of the people. It is reported that "…healthy people did all they could to avoid the sick. Doctors refused to see patients; priests refused to administer last rites. Shopkeepers closed stores. Many people fled the cities for the countryside, but even there they could not escape the disease. It affected cows, sheep, goats, pigs and chicken as well as people" (History.com Staff, 2010). It seems the situation was worsened by the fact that "no one knew exactly how the Black Death was transmitted from one patient to another…" (Benedictow, 2005). Black Death was indiscriminate in its attack, killed with speed, and left grievous devastation behind it.

In modern history, there was the influenza epidemic, which was also known as the flu epidemic or the Spanish Flu, from 1918 to 1919. It is reported to have "infected an estimated 500 million people worldwide – about one-third of the planet's population at the time – and killed an estimated 20 million to 50 million victims" (History.com, 2010). Billing says, "More people died of influenza in a single year that in four years of the Black Death Bubonic Plague from 1347 to 1351" (Billings, 2005). This disease attacked the human population indiscriminately. The symptoms are described as follows:

> Influenza, or flu, is a virus that attacks the respiratory system. The flu virus is highly contagious: When an infected person coughs, sneezes or talks, respiratory droplets are generated and transmitted into the air, and can then be inhaled by anyone nearby. Additionally, a person who touches something with the virus on it and then touches his or her mouth, eyes or nose can become infected (History.com Staff, 2010).

In mild stages, victims experienced "chills, fever and fatigue"; in stronger waves, "their skin turned blue and their lungs filled with fluid that caused them to suffocate…" (Ibid.). According to CDC (November 2016), "…mortality was high in people younger than 5 years old, 20-40

years old, and 65 years and older. The high mortality in healthy people, including those in the 20-40 year age group, was a unique feature of this pandemic." Apparently, modern science is yet to adequately explain the properties that made the virus so destructive within such a short time.

It may be concluded that, while the Black Death Plague had been bacterial in nature, the influenza pandemic was viral. And while the Black Death had progressed from one place to another for almost five years, the flu epidemic struck instantly in several places almost at the same time. Also, whereas age had not been a relevant factor in the Black Death attacks, it was a factor observed in the flu epidemic. Both epidemics can be contrasted with HIV-AIDS. One of the worst aspects of HIV-AIDS is that, unlike the other two epidemics, it targets a specific age group of the human population – the ages between 18 and 35 -- exactly the group that is economically most active and productive, whereas the other epidemics had been generally hitting indiscriminately.

From the UNAIDS statistics reviewed earlier, it becomes clear that the disease burden of HIV-AIDS is overwhelming for African countries. As Boutayeb observes, "AIDS does not only cause sickness, incapacity or death of workers, and severe emotional and economic upheavals for families; it also increases the cost of doing business" (Boutayeb, 2009). Boutayeb continues, "It (HIV-AIDS) has also continued to diminish the chances of alleviating poverty and hunger, achieving universal primary education, promoting gender equality, reducing child and maternal mortality, and ensuring environmental sustainability" (Boutayeb, 2009). In many countries of Africa the negative effects of HIV-AIDS are evident in the health care sector:

> Some of the most affected countries have lost more than 15% of their healthcare workforce due to AIDS and, in many other countries, midwives and health workers are living with HIV. It should also be stressed that the HIV-AIDS epidemic worsens the situation of other diseases like cardiovascular diseases, diabetes and tuberculosis. For instance, 80% of tuberculosis patients are HIV positive in countries with high prevalence of HIV (Boutayeb, 2009).

The point raised by Boutayeb on the relationship between HIV and TB may be explained by the statement from the AIDS Centre that "TB is the leading cause of death among HIV infected people; the WHO estimates that TB accounts for up to a third of AIDS deaths worldwide. When someone is infected with TB, the likelihood of them becoming sick with the disease is increased many times if they are also HIV-positive" (UNAIDS, 2002-2010). This line of thought is supported by CDC (2016) whose report says, "People living with HIV are more likely than others to become sick with tuberculosis (TB). This is because HIV weakens the immune system, which makes it harder for the body to fight TB germs" (CDC, 2016). Hence,

Boutayeb's statement with regard to the big percentage of TB patients being at the same time HIV-positive in countries with high prevalence of HIV should raise concern.

The situation may be considered desperate if evaluated in the context of generally poor economic power of many African countries, thereby not prioritising the challenges posed by HIV-AIDS. One such grim picture is portrayed by Van Niekerk in his work 'Moral and social complexities of AIDS in Africa' as follows:

> The fact of the matter is that sub-Saharan Africa generates no more than one per cent of the total wealth produced in the world. The buying power of all the countries south of the Sahara, excepting South Africa, in total just about matches that of a country such as Norway. The developed world can no longer ignore the fact that Africa is the home of ten per cent of the world's population, lives on one per cent of the global economy, and carries 70 per cent of the world's HIV-AIDS burden. Furthermore, annual per capita expenditure on health care is less than US$10 in many African countries, as compared with between US$2000 and $4200 in industrialised nations (Van Niekerk, 2005).

In other words, the burden is such that the developed nations can no longer ignore the HIV-AIDS burden for Africa. There is a call for a global approach to seeking and finding solutions to the problem. Such a global approach will necessarily require collaboration among nations at government level, and among scientists and researchers at institutional and individual levels as well.

Controlling HIV-AIDS remains a major challenge in Kenya where new infections continue to rise. According to AVERT, in June 2014, the Ministry of Health published a report called Kenya HIV Prevention Revolution Roadmap, in which the government explained its aim of strengthening prevention, hoping to reduce new infections to zero by the year 2030 (AVERT, 2017). According to an official report from the National AIDS Control Council, "…Kenya has an average HIV prevalence of 6%, with about 1.6 million people living with HIV infection" (Kenya National AIDS Control Council, 2014). This makes Kenya one of the six "high burden" countries in Africa, the others being Swaziland, South Africa, Lesotho, Botswana, and Mozambique. The report further reveals that counties[2] in the western part of Kenya, such as "Homa Bay, Siaya, and Kisumu are the most affected with HIV with rates of 25.7%, 23.7%, and 19.3% respectively," followed closely by the neighbouring Migori and Kisii at 8% and 7.6% respectively (Ibid.). Ironically, the same report indicates that in these five counties ART is being received by about 65% of the adult individuals who should receive it, far less than the expected 97%. Recent reports from the Global Burden of Disease showed that "Kenya had the fastest-growing number of new HIV infections in sub-Saharan Africa in the

[2] A county in Kenya is a devolved government unit, with its own governor and a legislative assembly. The five counties specifically mentioned here as leading in HIV infections are of interest to me because their ethnic composition is primarily of the Luo, the community to which I belong by origin.

last decade… between 2005 and 2015, the number of new HIV cases grew by an average of 7.1 per cent per year… one of the highest in the world" (Muchangi, 2016). This makes it possible to conclude that, given the numbers and the ages involved, HIV remains a serious threat to the people of Kenya, the efforts against the pandemic notwithstanding.

The situation discussed above should cause the government and other stakeholders to invest additional effort and resources into preventing new infections, besides carrying out treatment and care for those already infected. That is one way of seeking to solve or resolve the problem. Another way is that the situation should also cause policy-makers to support new research to move into the direction of seeking to develop relevant genetic therapies for HIV-AIDS. In human history there have been devastating diseases which have been effectively turned preventable through the development and application of medical vaccines which make the human body resistant to either the bacteria or the virus that causes the disease. It can be argued that a vaccine is a form of changing the capacity of the human body to respond to a source of potential harm, hence it is a form of modification. Vaccines do not change the structure of genes in the body; rather, vaccines alter and enhance the capacity to react in a certain way. This is how medical science has controlled polio, smallpox, and yellow fever. The Kenya AIDS Vaccine Initiative (KAVI) was established with the goal of developing a vaccine for HIV-AIDS, and has carried out reasonable research into the matter. However, in recent years, KAVI has diverted its attention to other issues other than the AIDS vaccine. But perhaps the original focus can be recovered. Or maybe there is need to think beyond the possibility of a vaccine, and start thinking of the possibility of genetic enhancement therapies, some of which have already been developed, and are undergoing trials, in the developed world. The possibility exists for human genes to be scientifically modified and enhanced to possess capacity to resist infection from HIV.

1.4. THE IMPACT OF INFECTIOUS DISEASES ON AFRICAN SOCIETIES

The transmission and control of communicable diseases continue to pose major economic and health challenges to nations in sub-Saharan Africa. Recent studies revealed that infectious diseases increased in rates during economic recessions due to "…infectious contact under poorer living circumstances, worsened access to therapy, or poorer retention in treatment" (Suhrcke, et al., 2011). Although the study was worldwide, its negative conclusions focus strongly on Africa where it identified "…certain high-risk groups, including migrants, homeless persons, and prison populations, as particularly vulnerable conduits of epidemics during situations of economic duress" (Suhrcke, et al., 2011). The situation is worsened by the

identification of "16 new infectious diseases… in the past two decades…" between 1990 and 2010 by the United States National Institutes of Health (Fonkwo, 2008). Although smallpox and poliomyelitis had been more or less removed from nature, many infectious diseases continue to afflict human societies. This is because "…microbes have shown a tenacious ability to adapt, re-adapt, survive, and challenge the human ingenuity" (Ibid.). In sub-Saharan Africa particularly, the challenge seriously affects various sectors of national and societal life, including loss of qualified human resources due to HIV-AIDS, tuberculosis (TB), and malaria. As Fonkwo points out, "…these and other infectious agents not only take an enormous physical toll on humanity, but also cause significant economic losses both directly in the developing world and less directly in the developed world" (Fonkwo, 2008).

The problem of infectious diseases is not only a public health problem; it is also an economic one, which needs "an internationally coordinated strategy to fight… or at least bring under control" (Fonkwo, 2008). One would have thought that the challenge of such diseases would be easy to solve by simply eliminating the "…pathogens and their vectors from their natural hosts" (Ibid.). But Fonkwo explains that

> Pathogens constantly change their genetic make-up, which challenges the development of vaccines against infectious diseases. This genetic flexibility allows many infectious agents to mutate or evolve into more deadly strains against which humans have little or no resistance: the HIV and influenza viruses, for example, constantly mutate and recombine to find their way through the host defence mechanisms (Fonkwo, 2008).

The complex behaviour of the pathogens necessitates international scientific collaboration in order to develop viable permanent solutions. Evidently, there is need for scientific explanations on the mutations of pathogens in relation to infectious diseases in order to develop appropriate control systems.

> When humans live in close contact with animals, pathogens are sometimes able to change hosts and infect humans. The new host – in this case a human – is often not as adapted to these zoonic diseases as the original host. The past outbreaks of avian influenza, severe acute respiratory syndrome (SARS), hanta-virus, Nipah virus, and the HIV epidemic were all due to pathogens that were normally found in animals, but which subsequently found a new, susceptible host in humans (Fonkwo, 2008).

The lesson in this phenomenon is that, when infectious conditions are not properly addressed at their earliest possible stages to prevent escalation, the negative impact can have serious global consequences, some of which may take decades to resolve. This is confirmed by a recent Harvard research report[3] which pointed out that "…while modern medicine and technology

[3] The research was carried out by thirty of the world's leading infectious disease researchers -- including those from Nigeria, Senegal, South Africa, Tanzania, and Uganda -- who gathered at the Radcliffe Institute for Advanced Study at Harvard University in October 2015 under the theme of *Focus on Africa: Infectious Diseases from Basic Science to New Technologies.*

have diminished the threat of many infectious disease pathogens in high-income countries, infectious diseases account for more than 17 million deaths worldwide every year. A significant number of those deaths occur in sub-Saharan Africa" (Harvard Research Report, 2015). The research concluded that "…while sub-Saharan Africa bears the burden of most major infectious disease pathogens, the prevention and control of new outbreaks is a global problem that requires global cooperation" (Harvard Research Report, 2015). This conclusion reinforces the need for collaborative research at the global level, with strong networks between scientists from Africa and those from Western research institutions.

The most prevalent infectious diseases are malaria, tuberculosis (TB), and HIV-AIDS, although there are numerous others in existence as well. The Centre for Disease Control (CDC) reports that "…approximately half of all deaths caused by infectious diseases each year can be attributed to just three diseases: tuberculosis, malaria, and AIDS. Together, these diseases cause over 300 million illnesses and more that 5 million deaths each year" (CDC, 2017). The report says that many infectious diseases are "endemic to developing countries" due to the fact that medical care largely remains inaccessible, unaffordable, or ineffective, among other factors. In the case of malaria, for example, although it "…is found in 90 countries of the world… 90% of all cases are found in sub-Saharan Africa" (Ibid.). The report (Ibid.) further states that "…in 2015 an estimated 214 million cases of malaria occurred worldwide and 438,000 people died, mostly children in the African Region." CDC describes the symptoms of malaria:

> The first stage consists of shaking and chills, the next stage involves high fever and severe headache, and in the final stage the infected person's temperature drops and he or she sweats profusely. Infected people also often suffer from anaemia, weakness, and a swelling of the spleen (CDC, 2017).

It may be calculated that, going by the estimate that 90% of the 214 million malaria infections in the world in 2015, more than 192 million occurred in sub-Saharan Africa. The disease burden for the continent, even from malaria alone, is disproportionately heavy, and should be cause for global concern.

The impact of malaria on women is worthy of review, since, as Gerberding (2004) explains, it causes "…serious illness in pregnant women and children below 5 years of age… mostly in Africa." She further explains:

> Pregnant women suffer decreased immunity to malaria, which more than doubles their chances of contracting and dying of the disease. Pregnant women who contract malaria have an increased risk for severe maternal anaemia. The consequent impaired foetal growth contributes to low birth-weight in new-borns. Malaria during pregnancy causes as many as 10,000 maternal deaths each year, 8%-14% of all low birth-weight babies, and 3%-8% of all infant deaths in certain parts of Africa (Gerberding, 2004).

The continued negative impact of malaria on women in sub-Saharan Africa is, in the long run, a threat to the population of the continent.

The tuberculosis (TB) bacteria often affect lungs, and lead to pain in the chest and bloody coughs. "Other symptoms of the disease include fatigue, weight loss, appetite loss, chills, fever and night sweats" (CDC, 2017). In South Africa a study of 618 TB patients established that TB patients bore a heavy burden in diagnosis and treatment, such that

> Patients incurred the greatest share of TB episode costs (41%) prior to starting treatment, with the largest portion of these costs being due to income loss. Poorer patients incurred higher direct costs during treatment than those who were less poor… Indirect costs accounted for 52% of total episode cost (Foster, 2015).

These challenges are prevalent, despite the fact that South Africa provides free TB diagnosis and treatment (Ibid.), and despite South Africa running one of the strongest economies on the continent. The researchers in this case warned that this state could drive up what they called "the medical poverty trap" where medical costs far exceed income levels (Foster, 2015). A similar study across Africa concluded that "…the costs for hospitalization, medication, transportation, and care in the private sector were the largest" for TB patients (Barter, et al., 2012). Since "…the patient costs incurred commonly amounted to 10% or more of per capita incomes…", it is important for governments to develop "… policies to decrease direct and indirect TB patient costs… to prevent poverty due to TB treatment and care for those affected by the disease" (Barter, et al., 2012).

TB is a killer disease in Africa. In 2009, "…tuberculosis (TB) was the world's 7th leading cause of death, resulting in 1.7 million deaths worldwide, more that 9.4 million new infections, and 14 million prevalent cases" (Barter, et al., 2012). It was further reported that "…26% of all TB cases are in sub-Saharan Africa" where poor communities are also the most vulnerable due to "…overcrowded living or working conditions, poor nutrition, smoking, alcoholism, diabetes, exposure to indoor air pollution, and HIV…" (Ibid.) combine in various measures to further complicate the situation. The vicious cycle then persists because TB, in turn, contributes to poverty by reducing labour productivity, as patients now lack physical strength and ability to work in order to contribute to the family, community and the nation's economy.

Infectious diseases affect African peoples in a variety of ways. Fonkwo who reports that the "…misuse and overuse of antibiotics is eroding our ability to control common infections. Many bacteria have become resistant to even the most powerful antibiotics or combinations of antibiotics; similarly, the once first-time drugs against malaria are now almost

useless" (Fonkwo, 2008). Fonkwo, quoting a WHO report of 1999, notes that 68% of deaths in Africa in 1999 had been due to infectious diseases, adding that

> …TB prevalence – a good indicator of overall quality of life – correlates strongly with political instability, even in countries that have already achieved a measure of democracy. The severe social and economic impact of infectious diseases is likely to intensify the struggle for the political power to control scarce resources. Health must therefore be regarded as a major economic factor and investments in health as a profitable business (Fonkwo, 2008).

In other words, part of Africa's political instability is caused by desire to control scarce resources, including resources useful for the control of infectious diseases in societies. TB affects working hours in "…the formal and informal economies, as well as within households…" The loss is estimated to be the equivalent of between 3 and 4 months of work time for each patient each year, and 20% to 30% of household income. Fonkwo says, "Families of people who die from the disease (TB) lose approximately 15 years of income." Similarly, families in Africa "spend up to 25% of income on malaria treatment, with infected children suffering cognitive damage and anaemia" (Fonkwo, 2008).

The future impact of infectious diseases has been predicted to be dependent on three variables:

> …the relationship between increasing microbial resistance and scientific efforts to develop new antibiotics and vaccines; the future of developing and transitional economies, especially with regard to improving the basic quality of life for the poorest people; and the success of global and national efforts to create effective systems of surveillance and response (Fonkwo, 2008).

These variables will determine how infectious diseases affect humans. On the one hand, it is quite possible that there will be "significant improvements in health care and medical research…" such that "infectious diseases will be replaced by non-infectious diseases such as diabetes, heart disease and cancer, as major health challenges" (Fonkwo, 2008). On the other hand, poverty and infectious diseases may combine effort, and viruses may spread throughout populations "…as a result of increased resistance to multi-drug treatments and the unavailability of expensive treatments in developing countries, which face the majority of the problem" (Fonkwo, 2008). The better option would be for better planning and the investment of finances into programmes that will help prevent and control infectious diseases through the use of new medicines and vaccines.

1.5. RATIONALE FOR THE STUDY

HIV-AIDS continues to pose major threats to human life and health in sub-Saharan Africa, with casualties persistently increasing despite efforts in medical science aimed at finding effective treatments. New infections continue to occur, and people continue to suffer, especially where Anti-Retroviral Treatment (ART) is not easily accessible. As African

countries seek to find solutions to the challenges that arise from HIV-AIDS, the severity of the shortage of resources leads governments into justifying resource allocations to apparently more common, urgent and effectively treatable problems, such as malaria, tuberculosis, bilharzias, typhoid, cholera, and reproductive health issues. It is still argued that investment in HIV-AIDS research remains a luxury that Sub-Saharan African governments cannot afford out of their own inadequate budgets. Generally, expenditure on AIDS in Africa remains an issue of concern. Most African countries receive funding from Western donors in order to support HIV-AIDS programmes, including research. It is reported that "… the three upper-middle-income countries (Botswana, Namibia, and South Africa) are the only ones to fund most of their AIDS programmes from domestic sources. Nigeria and Kenya contribute about 20% of their total national AIDS spending, whereas all other countries account for less than 15% of the total. Excluding the three upper-middle-income countries, external funding covers an average of 87% of all AIDS spending in Africa. This emphasises the heavy dependence of the high-burden by low-income African countries on donor aid" (Resch, et al., 2015). In the case of Kenya, specifically, "…external resources continue to dominate HIV-AIDS financing" (UNAIDS, 2016). A UNAIDS report stated that international "… organizations accounted for over 56% of funds. The public sector agents accounted for between 25% and 27% while local private organizations managed between 16% and 19% of the total funds" (UNAIDS, 2014). And these are general figures that include treatment, advocacy, administrative support, as well as research. Therefore, it is reasonable to conclude that, given the lack of internal financial support within Africa, for a huge undertaking like genetic research, they would rather wait until a scientific solution is found in Western countries; even then, there is likely to be a tendency to wait until cheaper provisions become available.

Evidently, the HIV-AIDS malady remains a great threat to health in sub-Saharan Africa. Presently governments in Africa remain focused on prevailing treatment and prevention options. When the developed countries have moved ahead to modern technological interventions, Africa remains inhibited by a perennial lack of resources to invest in such technologies. As van Niekerk observes, this reveals "…a kind of exclusion from the advantages of modern medicine", a situation he fears might reinforce prejudice against the continent (Van Niekerk, 2014). But we need to ask, what kind of technologies should Africa seek? Well, the answer, or at least a significant part of it, lies in genetic therapies, especially those that also promote enhancement. In the developed countries, genetic science now holds the promise of providing therapies for this fatal disease through enhancing the human capacity to resist

infections. As research develops in this regard, it may seem wise for governments in Africa to invest some of their resources in the scientific efforts towards a solution.

Research in the developed countries is currently creating the hope that genetic therapy for HIV-AIDS is possible, and may soon be a common reality. For example, "…in 2012, HIV patients treated with genetically modified T cells" were reported to have remained "healthy up to 11 years after initial therapy" (Colovos, et al., 2012). This was a result of the work of scientists from the Perelman School of Medicine at the University of Pennsylvania who released their report in the *Science Translational Medicine.* "The results provided a framework for the use of this type of gene therapy as a powerful weapon in the treatment of HIV, cancer, and a wide variety of other diseases. The patients showed long term persistence of the modified T cells in their bodies" (Colovos, et al., 2012). Presently, patients have access to anti-retroviral therapy for their lifetime, a treatment that remains expensive and often comes with adverse side effects. With this new genetic modification and therapy, there is potential for both curative and preventive approaches to the problem. Apart from enhancement therapies, there is also the new technology known as "clustered regularly interspaced short palindromic repeats (CRISPR)," which can change the genetic code of cells in an HIV-positive patient, thereby providing treatment. Scientists have reported that technologies for editing genes, "…including CRISPR/Cas9, now offer us the ability to directly modify or correct the underlying disease-associated changes in our genome. Successfully editing or correcting a gene that encodes the dysfunctional or missing protein can in principle result in the expression of a fully normal protein and full correction of the disease" (CRISPR Therapeutics, 2015). Through this new technology, there is potential for a cure for AIDS. Therefore, research in genetic therapies must necessarily include this dimension as well, and will receive attention in this research at a later stage.

For the Kenya government and other governments in Africa to consider allocating scarce resources to the proposed research into enhancement therapy for HIV-AIDS, there is need for acceptable justification for such an effort. Given the presumed expensive nature of scientific research, even for the developed countries, there is need for collaboration, not just at individual and institutional level, but among nations as well. Professor Sir Kenneth Calman[4] acknowledges that "…eighty per cent of the world's population lives in developing countries,

[4] Professor Sir Kenneth Calman, while serving as Vice-Chancellor and Warden, University of Durham, UK, was the Chairman of the Working Party of the Nuffield Council on Bioethics (2002 - 2012), which was funded jointly by the Medical Research Council, the Nuffield Foundation, and the Wellcome Trust. The Council's official report was published in 2012 as *The Ethics of Research Related to Healthcare in Developing Countries.*

where both healthcare and research related to healthcare are severely constrained by limited financial and human resources and by the lack of appropriate infrastructure to deliver healthcare" (Calman, 2012). Furthermore, health has many determinants, which "…include social, cultural, economic, and environmental factors, genetic variation, and the quality of healthcare available. Research into these factors is an essential component of improving health and healthcare in developing and developed countries alike" (Ibid.). As Van Niekerk explains, "…Africa is the home of 15% of the world's population, lives on 1% of the global economy, and carries 70% of the world's HIV-AIDS burden" (Van Niekerk, 2014). He draws a contrast with the United States which spends more than "50% of the total health care expenditure in the world," yet the US contains "only 5% of the world's population" (Ibid.). Van Niekerk says, "Given Africa's resources crisis, ideas about the possibility of all kinds of genetically induced personal enhancements are far removed from the urgent and immediate health care realities that policy makers have to face on a daily basis, given the prohibitive costs that such research or technologies might imply" (Ibid.). Western nations, with their advanced technology in medical science, especially genetic engineering, should consider it part of their human responsibility to contribute towards the alleviation of HIV-AIDS in Africa. It is an engagement in benevolence and distributive justice at the same time.

In this research, the appropriateness of genetic therapies for the treatment of HIV-AIDS and alleviating the burden created by the disease is investigated, with a view to encouraging the Kenya government and other African governments, together with their partners from the developed world, to carry out research on these technologies and develop them for the benefit of the majority of Africans. Genetic therapies are proposed in the context of the present reality of having no known cure for HIV-AIDS in the whole world. The ARVs in use are not a cure but are a means of reversing the symptoms in order to prolong the life of an infected person. The ARVs do not remove the virus from the body and are, in this sense, only a temporal response. Results of recent scientific research show that combined antiretroviral therapy (cART) never eradicates HIV, but that the virus "persists for years and can re-establish replication if treatment is stopped" (Nolan, et al., 2018). It was found out that "the spleen is an HIV-1 during combined antiretroviral therapy" (Ibid), which means that once the virus hides in the spleen it cannot be affected by ARVs, and the virus then continues to re-infect the body through the circulation system. In other words, as soon as treatment is stopped, the plasma viral loads rebound. This idea is supported by Rose, *et al,* who explain that

> While combined antiretroviral therapy (cART) can result in undetectable plasma viral loads, it does not eradicate HIV infection. Furthermore, HIV-infected individuals while on cART remain at an increased risk of developing serious comorbidities, such as cancer, neurological disease,

> and atherosclerosis, suggesting that during cART, tissue-based HIV may contribute to such pathologies (Rose, et al., 2016).

We can safely conclude that cART, while effective in reducing the plasma HIV to very low levels, is not able to get rid of infection from the body. In their research, Rose, *et al,* used high-resolution evolutionary analyses and found out that "tissue-based HIV continues to replicate, evolve, and migrate among tissues during cART." They also concluded that

> …significant HIV comorbidities, including cancer, lipid disorders, and neurological diseases, develop in cART-treated (cART) patients at a higher rate than in the general population, despite fully suppressed VL (viral load) and restored immunity. Of the major HIV-related comorbidities, cancer is the leading cause of death for HIV-infected (HIV), cART-treated patients (Rose, et al., 2016).

From the foregoing, it is apparent that ARVs are working only to the extent of suppressing viral load and restoring immunity against opportunistic infections, thereby alleviating suffering, but does not cure the disease. In fact, suffering sets back right in as soon as treatment lapses, a situation that puts the patient at greater risk than before. ARVs are not effectively containing the virus. What looks like a solution is actually not a solution at all to the problem of HIV-AIDS. If Africa in general, and Kenya in particular, is going to continue to rely on ARVs for dealing with the scourge, there is going to be continuity in the spread and negative impact on the population. This is precisely why there is need for genetic therapies as a permanent solution for HIV-AIDS.

The research needs to be done in one of the countries with the leading rates of infection, of which Kenya is a significant part. Since Kenya, as an integral part of Sub-Saharan Africa, continues to record higher levels of new infections, besides bearing the burden of loss of young and middle-aged population, there is need for a solution that can effectively and safely prevent the human body from receiving and hosting the virus in the first place. Such a solution would not only prevent human suffering and degradation, but also significantly lower the socio-economic impact of HIV-AIDS on the continent. The proposal in this study is that the solution may be best found in genetic therapies. Given that the virus remains prevalent without a real cure, and given that it affects the working and productive population in Africa, a remedy should be found which leads to great benefit to the infected and the affected people, while at the same time providing economic and health relief to African nations. The solution should bring relief to the suffering and save future generations from the disease burden. In order to maximise health and economic benefits to the people and the countries, while also minimising suffering and pain by preventing recurrence of the disease, I have chosen to address the problem by the ethics theory of utilitarianism, the understanding and application of utilitarianism of which the

fourth chapter of this dissertation is dedicated, although the sixth section of this first chapter makes a preliminary discussion as well.

1.6. PROBLEM STATEMENT

The central problem that this dissertation wishes to address, is whether genetically based enhancement therapies ought to be optimally pursued in Africa's (with special reference to Kenya's) struggle to overcome the human suffering and destruction caused by HIV-AIDS. Such a problem statement in turn raises the question of whether it is justifiable for an African country such as Kenya to allocate a significant amount of its limited intellectual and material resources to this kind of research, and if another model of co-operation with the West for realising the goal of fighting HIV-AIDS in this manner is not rather called for. As has been pointed out, there are very encouraging signs in Western countries that research on genetically based HIV-AIDS remedies can be highly beneficial to persons living with HIV-AIDS, and thus to the societies that must support them. Is this the way to go in terms of curative or preventive HIV research in the future, and if so, to what extent ought African countries become involved in this kind of research? If not, what is a better model for seeking a medical and social solution to the HIV pandemic? In other words, the question arises as to the wisdom or otherwise of paying more attention to research on enhancement, despite the huge costs involved, or treating what is treatable with the little funds available. Whichever choices are made, would they bring more benefits to the peoples of Africa, or would their benefits be minimal?

Let me elaborate a little on the issue as to who should do the research. Should the research be carried out in Africa by African scientists? It is well known that, with the possible exception of South Africa, research facilities in the rest of Africa are few and under-resourced, and that human research capacity is quite limited. The alternative may be to leave the actual research in the hands of the developed countries, where resources for scientific research are already strong and generally well-funded. But this will remove the research from the context in which the disease burden has the biggest impact. Consequently, it may create challenges in attempting to ensure that the benefits of the research actually come to Africa. There seems to be a need for collaborative research between the resource-strong Western institutions and countries on the one hand, and the resource-scarce African institutions and states.

In reflecting on this issue, a number of related problems present themselves. The first, inevitably, has to do with the general moral justification of enhancement therapies as such. In this regard, Alberto Giubilini and Sagar Sanyal, in their article "The Ethics of Human Enhancement," argue that the discussion of the issues related to human enhancement should

"…include whether specific types of enhancement are permissible or even obligatory, whether they are likely to produce a net good for individuals and for society, and whether there is something intrinsically wrong in playing God with human nature" (Giubilini & Sanyal, 2015). They characterize the main camps in this debate as permissive, restrictive and conservative. There are contributors who hold that the "most permissive positions have no objections to a wide range of enhancements," some of which "…are not merely permissible but even morally obligatory" (Giubilini & Sanyal, 2015). On the opposing side are the objections, in principle, to any kind of biomedical enhancement, motivated by a range of arguments, including the alleged inviolability of "human nature" as a (again, allegedly) "moral desideratum".

On this same issue, Savulescu and Bostrom, in their edited volume *Human Enhancement*, propose that a pro-enhancement position can be supported by highlighting the continuity between the "new controversial enhancement methods and the old accepted ways of enhancing human capacities" (Savulescu & Bostrom, 2009). In this argument, all of "…technology can be viewed as an enhancement of human capacities" (Ibid.). Education and training could fall into the same category. Their view is opposed by Leon R. Kass who warns "…that biotechnology may eventually be used as a substitute for virtue, hard work, study, or love" (Kass, 2003). "His concerns about biotechnology stem from what he calls 'the technological disposition' which transforms the meaning and character of human life by believing that all aspects of life can be rationally mastered through technique" (Kass, 2003).

This argument is strongly reminiscent of the opinions of Michael Sandel, who argues that biomedical enhancements entrench the idea that we are supposed to be "masters of nature" and "perfect" in every respect. Sandel's views have recently been comprehensively challenged by Van Niekerk in the *South African Journal of Philosophy*, and this has given rise to a robust debate in that journal (van Niekerk, 2016). Of significant concern is Sandel's position on "the gifted character of human powers and achievements" (Sandel, 2007, p. 26) a view that he believes should constrain us from using everything, including our talents, in the world as "we may desire and devise" (Sandel, 2007, p. 27). In responding to Sandel's notion of the giftedness of life, Van Niekerk argues that although they are not yet engaged in selecting the genetic traits of their offspring, parents engage in what essentially are forms of enhancement:

> …go out of our way to train, educate, instruct and guide them in certain directions. These later activities are, without doubt, efforts to enhance those children, i.e. to make people out of them that they are not yet and that we as the parents regard to be preferable to what they might become without our consistent prompting (van Niekerk, 2014, p. 161).

Although I will, in a later chapter, discuss in further detail the idea of naturalistic arguments against genetic therapies, I must state at this stage that the gifted nature of life and reality,

though quite sensible, is not necessary a valid premise for arguing against human effort in seeking to improve specific aspects of life and reality. To use the giftedness of life as an argument against genetic therapy or enhancement would be to negate all modern technological and medical advancements that make human life both bearable and pleasurable. Although Penrose defends Sandel's position on the basis of certain philosophical technicalities, he admits the inevitability of enhancement gradually becoming "entrenched in first-world societies" (Penrose, 2016, p. 162).[5] This inevitability is a key factor that partly motivates this research, though not with regard to enhancement but with regard to the relevance of genetic therapies. In other words, the future of human solutions to genetic diseases lies in genetic therapies and human enhancement, and we had better begin to get ready, morally, for that future.

Apart from issues about human dignity that are also normally associated with the debate about human enhancement, the other important issue that this thesis will have to address is the implications of possible genetic interventions in HIV-AIDS treatment for the question of social, distributive justice. For instance, if the technology turns out (as is expected) to be very expensive, and if it is only available on a limited basis, then only an especially privileged economic class of a country's citizens would presumably be able to benefit and gain protection from disease. The application of the technology could result in the rich becoming physically stronger and mentally smarter because they would no longer be prone to HIV-AIDS. As Heller and Peterson explain,

> The gap would significantly widen between those who could afford enhancements and those who couldn't, and the threat of creating a permanent un-enhanced underclass would be real. There is the further threat that those that control all the resources, the enhanced class, would feel increasingly disconnected from the underclass, and as a result would not want to engage in politics of economic redistribution, trapping the poor in their position (Heller & Peterson, 2018).

They would possibly regard themselves as superior and only promote their own interests. The net result very easily could be an exacerbation of the already stark divide between rich and poor in society, as well as the (further) violation of human dignity in a society where poverty is consistently eroding relevant claims to such dignity.

[5] Van Niekerk's article *A Response to Penrose's "Sandel on Enhancement: A Response to Van Niekerk"* gives an elaborate reply, essentially summarized in the statement, 'It strikes me that Sandel creates the impression that whenever the possibility of acts that could amount to "taking our evolution in our own hands" or "re-engineering our nature" present themselves, the (almost knee-jerk) reaction is necessarily negative' (van Niekerk, 2016, p. 168). In other words, it is not always necessary to have an adversarial response and "see red flags flickering" every time genetic technology moves towards "genetically influencing human progeny." This idea forms part of my discussion in Chapter 7 of this dissertation.

1.7. RESEARCH METHODOLOGY

1.7.1. Research Goal: This research aims at developing a philosophical-ethical framework in which the challenge of the obstinate disease of HIV-AIDS can be resolved within the context of a utilitarian ethics theory. It proposes models and possibilities that may help in the changing policy framework for the health benefit of the vulnerable and the dependent members of the Kenyan and African society.

1.7.2. Assumptions:

1.7.2.1. It is assumed that genetic therapies are still in their developmental stages, and are not yet an open practice in medical science. However, it is also assumed that the scientific and medical research will continue and seek to make it available for general use in healthcare in future.

1.7.2.2. It is assumed that genetic therapy will endeavour to use some, or all, of the human enhancement techniques that will be developed, for the benefit of healthcare clients.

1.7.2.3. It is assumed that good health is a basic human right which must be sought after and protected in all bioethics engagements.

1.7.3. Research Questions:

The research questions that this dissertation seeks to address are: Should African countries in general, and Kenya in particular, pursue the possibilities of genetically based biomedical therapies for prevention and cure for the rampant HIV-AIDS pandemic in their midst? Should these countries seek to advance such research in their own midst, or should possibly more fruitful models of co-operation with researchers in the developed world be sought and explored? If the latter option is preferred, how can benefit sharing for African communities be optimised? What is the value of a utilitarian approach to moral decision-making for this enterprise, and why is this approach to be preferred? Does a utilitarian ethic provide moral justification for the use of genetic therapies as solutions to the obstinate malady of HIV-AIDS? How can the issues of distributive justice provoked by both the HIV-AIDS pandemic and the possibility of genetic therapies be fairly addressed in the African context, with special reference to Kenya?

1.7.4. Research Design and Methods

In view of the nature of this research in philosophy and applied ethics, especially in bioethics, the methods used involve a careful study of relevant literature, which includes philosophical works, the voluminous literature on ethical issues related to HIV-AIDS research in Africa, empirical scientific studies that focus on the nature, scope and impact of the HIV-

AIDS pandemic, as well as scientific journal articles on the progress made in the research in genetic therapies. In addition, the study involves philosophical reflections on genetic therapies in the context of a utilitarian appreciation of the disease burden in Africa. Apart from such a comprehensive literature study, the method involves regular consultations with my Supervisor.

A third pivotal aspect of this method of research, is independent reflection, as is required from a philosophy and/or ethics student. This reflection entails not only a preparation for careful conceptual analyses, but indeed the construction of thought experiments that could underlie the development of relevant and even novel ideas about the problematic. What is notable about this approach to ethics reflection in this study, is the use that I make of utilitarianism as my prominent approach to moral decision-making in this area. In the context of this dissertation, genetic therapies are examined through the lens of utilitarianism as an ethics theory whose application is not only a philosophical-ethical framework and reflection, but also a method of interpretation and a criterion of assessment. I now proceed to say more about the relevance of utilitarianism for approaching this problem.

1.8. THE CHOICE OF UTILITARIANISM

The study is dominated by the question as to how beneficial the envisioned research into the genetic enhancement therapies for HIV-AIDS would be for the people in Africa generally, and in Kenya specifically. In other words, we seek to find out if the benefits outweigh any presumed challenges related to costs or to other scientific, political or moral concerns. Africa has long suffered from inadequate health provision and services. It carries, as has been pointed out, an inordinate burden of the HIV-AIDS scourge. Although one takes cognisance of a variety of approaches to moral decision-making procedures, and although their legitimacy could in principle often be affirmed, it is the conviction of this candidate that the question of whether genetically based biomedical therapies for HIV-AIDS should and ought to be pursued in the African context, is fundamentally determined by the question as to whether or not such a practice will be accompanied by justifiable benefit-sharing for the peoples of the continent generally, and for Kenyans in particular.

When the issue of benefit sharing is so prominent in an ethics study, it seems inevitable to utilise utilitarianism as the most appropriate ethical approach and method of ethical reflection for this research. African states have often been accused of wasteful mismanagement of resources, including corruption, even as they continue to depend on Western nations for the funding of essential services, including health care. With possible improvements in resource management and allocation, perhaps funds may be available to support research on human

enhancement for preventing and treating HIV-AIDS. But, even with this in view, there is an urgent need to be fairly certain that the research will be of benefit to the majority of peoples. This dilemma calls for the use of utilitarianism as a philosophical-ethical theory that most effectively and convincingly provides moral justification for such undertakings as being beneficial, and with minimum negative consequences.

Utilitarianism has been described as "an altruistic approach" because in a society where the majority of people receive greater happiness, one has an obligation to honour that society's decisions, even if it is not to one's own advantage (Wilkens, 2011). We can see that utilitarianism acknowledges that happiness cannot be achieved in every situation for everyone. Where there may be conflicts in people's interests, some people may have to compromise their own happiness for the sake of the greater good for other people.

This research will examine the matter of genetic therapies through the lens of utilitarianism as developed by Jeremy Bentham (1748-1832) and John Stuart Mill (1806-1973). In Bentham's utilitarianism, what matters is how much happiness can be derived from an action, and for how many people in a given context (Bentham, 1781 (2010)). If we end up listing the benefits and harms of genetic therapies on opposite sides of a page, we will have engaged in what philosophers call "Bentham's hedonistic calculus". Bentham said, "A thing is said to be for the interest of an individual, when it tends to add to the sum total of his pleasures; or what comes to the same thing, to diminish the sum total of his pains" (Bentham, 1781 (2010)). In our case of genetic enhancement therapies, we will evaluate whether they add to comfort and happiness among African peoples, while at the same time diminishing their pain and suffering. Mill, however, taught that the *quality* of happiness is also important; not just the *quantity*. He viewed reason and intellect as higher desires, while biological needs were lower desires.

The choice of utilitarianism for this research is a deliberate one made in the context of the variety of ethical theories that are available for ethical issues related to bioethics in general and health care in particular. The other alternatives are deontology and virtue ethics, which are primarily Kantian and Aristotelian in style, respectively. Without attempting to indicate any preference, Brown gives a summarised comparison of the three ethical theories, and points out that virtue ethics (Aristotelianism) provides a model of practical reasoning in which the main questions to ask oneself are: what habits should I develop; and what is the best kind of person to be? In this model, the will and reason have to combine with desires and character traits to form personal identity. What is good is whatever results from the actions of good people (Brown, 2001).

Deontology (Kantianism) differs and asks, instead: how does one determine what is rational? In this model, will and reason are sufficient for determining what is good, when it is conclusive that there are neither inconsistencies nor self-contradiction in policies. The primary object of evaluation is the act, which is what determines one's moral duty. From these two, utilitarianism differs and defines the good in terms of the results that the act is likely to bring out. In other words, the main question is: how do I achieve what is ultimately good? Action is a means for achieving an end, and not an end in itself. In this context, the right actions are actions that maximise the good. Deontology places the emphasis on adhering to ethical principles or duties and fulfilling obligations. But exactly how these duties are defined may be a point of contention and debate. Moral absolutes make best sense because there is an objective in view which makes the action moral, regardless of circumstances. There are no rules whose purpose is purely to achieve nothing. In the context of ordinary human life, laws exist to achieve some purpose: for instance, prohibition against murder ensures security and continuity of human life; laws that recognise human rights propagate respect and peaceful coexistence; and obeying God is good because it results in objectivity of divine imperatives.

It is easy to associate morality with human character and the need to only engage in acts that are good. Hence virtue ethics is attractive to us. We find it desirable to live with good people, that is, people who are honest, generous, kind, courageous, loyal, fair, and dependable. It is in this context that I agree with Rachels & Rachels in their definition of a moral virtue as "a trait of character, manifested in habitual action that is good for anyone to have" (Rachels & Rachels, 2012, p. 159). They are qualities that are worth having because they are good in themselves; not because of their potential results or because certain rules demand that they be part of our lives. As Aristotle states, "moral qualities are so constituted as to be destroyed by excess and by deficiency" (Aristotle, 1996, p. 35).[6] In other words, "…virtues are the midpoints between extremes" (Rachels & Rachels, 2012, p. 160). When one looks carefully at virtue ethics, there are certain difficulties in identifying what is the "virtuous" action to take in all circumstances, and how to define a virtue. As Thiessen explains, a system of virtue theory "… is only intelligible if it includes an account of the purpose of human life, or in popular language, the meaning of life" (Thiessen, 2011). It seems possible that, in some way, the end has to be brought into perspective for a virtue to be affirmed by an action. Aristotle may have had this in mind when he stated, "In fact pleasures and pains are the things with which moral virtue is

[6] Aristotle explains at length the ethics theory of virtue ethics and the need to keep balance in order to achieve goodness. Suitable quantities have to be maintained if goodness is to be preserved.

concerned" (Aristotle, 1996, p. 36). Aristotle further explained, "Again, if the virtues have to do with actions and feelings, and every feeling and every action is attended with pleasure or pain, this too shows that virtue has to do with pleasure and pain" (Aristotle, 1996, p. 36). As Rachels & Rachels summarise, "…virtues are important because the virtuous person will fare better in life" (Rachels & Rachels, 2012, p. 165). Although the virtuous person may not necessarily be a richer person than others in the same context, every person needs virtues to thrive or flourish. However, one of the most serious weaknesses of virtue ethics is its inability to specify exactly when the virtues apply. For example, "…to be kind is to look out for someone's best interest", yet virtue ethics does not specify "what someone's best interests are" (Rachels & Rachels, 2012, p. 171). In addition, where there may be a conflict between the virtues, there is need to look elsewhere for solution. It is reasonable to say with certainty that, although virtue ethics are truly important, it is not a suitable theory for assessing the relevance of genetic therapies for HIV-AIDS, especially since it will not tell us what the good action is, unless we reach beyond and begin to think about the potential effect those actions will have on the people.

Given the arguments above, the rightness or wrongness of research into genetic therapies cannot be determined by a rule of any kind prior to the research. Research, by itself, cannot be judged to be a virtuous engagement, without first predicting its intended purpose, which in turn must be predictably good. It seems more reasonable to judge the morality of such research by the results it is likely to bear in relation to human health needs. Since utilitarianism teaches that people should maximise human welfare or well-being, including health needs, it seems ideal to employ this theory in this research in which medical research is seeking to find a solution to a human problem that negatively affects a significant population of Africa. Of course, this choice is not ignoring the fact that utilitarianism has challenges when applied wholesale to all ethical issues that may arise. For instance, we cannot always ignore the needs of the minority merely because the needs of the majority are in focus. But in a situation where the likely results will turn misery into good health, happiness, and human dignity, there is need for a form of results-based ethics, which is utilitarianism. In later chapters of the dissertation, the matter of making this deliberate choice of utilitarianism will receive adequate attention.

Since utilitarianism views happiness as the only thing that is intrinsically good, and pain as intrinsically evil, this research will evaluate the disease burden described in the context of Africa in relation to this understanding. In addition, since an action should only be judged on the basis of its consequences, the research will evaluate how genetic therapies can lead to happiness in the context of good health, and whether on this basis these therapies should be

pursued. Finally, the research will evaluate whether genetic therapies will lead to happiness for the greatest number of people in Africa who have remained vulnerable to disease burden. It is, in addition, possible that African governments will benefit significantly from a stronger human resource capacity when the disease burden is alleviated, thereby potentially contributing to economic growth. Stronger economies presumably strengthen citizens who, in turn, become more proactive about their own health issues, and rely less on government.

1.9. OVERVIEW OF CHAPTERS

In order to address the problem under study, the dissertation will be apportioned into eight chapters as outlined below:

Chapter 1: Background information about the impact of infectious disease generally, and HIV-AIDS in particular, on African societies, as well as stating the problem that the dissertation addresses, as explained above. It also outlines the methodology used in the research and how utilitarianism is applied.

Chapter 2: The Health Crisis in Kenya. This chapter examines the challenge of HIV-AIDS in Africa in general, and Kenya in particular, including some ongoing research.

Chapter 3: Genetic therapies and their potential to curb the pandemic: a literature survey.

Chapter 4: Utilitarianism. This chapter gives a comprehensive motivation and justification for the choice of utilitarianism as a philosophical-ethical approach in this research, while giving due recognition of the existence of alternative ethical systems. This is followed by a review of the ethical theory of utilitarianism as stipulated primarily by Jeremy Bentham and John Stuart Mill, as well as contemporary philosophers. The focus is the application of utilitarianism to bioethics, especially the new genetic enhancement therapies available for resolving human disease burdens.

Chapter 5: Arguments against Pursuing Genetic Therapies in Kenya. Based on philosophical reflection on utilitarianism, this chapter focuses on the possible ethical reasons as to why genetic enhancement therapies should not be pursued, and whether alternative remedies may be preferable. It establishes if the application of such therapies may be more harmful than beneficial to societies.

Chapter 6: Arguments in Favour of Pursuing Genetic Therapies in Kenya. With a comprehensive understanding of utilitarianism, this chapter endeavours to establish the desirability and ethical appropriateness of using genetic therapies. It seeks to establish the benefits of such therapies.

Chapter 7: Evaluation. The chapter is an evaluation of the relevance and the ethical implications of the arguments against and in favour of genetic enhancement therapies on the health situation in Kenya.

Chapter 8: Conclusion

1.10. CONCLUSION

In this chapter I have given background information on the disease, HIV-AIDS and the effect it has had on the continent of Africa, taking important note of the fact that Africa continues to bear the greatest burden of the illness and its related consequences. The review of the problem helps prepare the stage for the need for a more effective solution than is currently available. The chapter has also provided information on the infectious disease burden in Africa, thereby showing that HIV-AIDS is not the only serious challenge facing the continent, but is one that aggravates an already bad health situation. In the remainder of the chapter I have outlined the structure and methodology on which the dissertation is based.

CHAPTER 2: THE HEALTH CRISIS IN KENYA

2.1. INTRODUCTION

Having reviewed the prevalence and impact of infectious diseases in general and HIV-AIDS in particular on African societies or countries in the first chapter, this chapter examines the challenge of HIV-AIDS in Kenya in particular as a key component of the health crisis in the country. The term crisis is used here in its broad sense, taking cognisance of the more specific recent health crisis in Kenya's health sector caused by the doctors' strike that literally paralysed medical services in all public hospitals and health centres for slightly over 100 days between 5th December 2016 and 14th March 2017.[7] Although research is yet to be either carried out or concluded, it is reasonable to remark that HIV-AIDS patients, most of whom depend on the public healthcare system for the provision of antiretroviral treatment and follow-up, underwent much suffering during and after the doctors' strike. This chapter examines the challenge of HIV-AIDS in Kenya in particular, including some ongoing research related to the scourge.

2.2. RATIONALE FOR THE FOCUS ON KENYA

In terms of policy in Kenya, the National AIDS Control Council (NACC) has focused on programming the prevention and control of HIV and AIDS in the country since the establishment of NACC in 1999. From 2009 to 2013 the agency sought to provide "…a coordinated, comprehensive, high quality combination prevention, treatment and care services" (NACC, 2019, p. para 5). The current framework continues to build on the previous themes "…through universal access to comprehensive HIV Prevention, treatment and care" hoping for "a Kenya free of HIV infections, stigma and AIDS related deaths" (NACC, 2019, p. para 6). Under NACC, specific strategies and policies have been developed, including "the Youth Communication Strategy, Condom Policy and Strategy, Male Circumcision Policy, HIV and AIDS policy at the workplace, HIV and AIDS Prevention and Control ACT, NACC and Stakeholder's Code of Conduct and guidance notes…" (NACC, 2019, p. para 7). From the foregoing, it is clear that NACC remains focused on public education on prevention of HIV-AIDS, as well as treatment and care, without engaging in any research at all. In regard to human

[7] On 5th December 2016 all doctors and dentists under government service went on strike under their the Kenya Medical Practitioners and Dentists Union (KMPDU) complaining about the government's perceived refusal to implement a 2013 Comprehensive Bargain Agreement (CBA) that had been signed between the Ministry of Health and KMPDU for the improvement of salaries, allowances, and working conditions. The strike ended on Tuesday 14th March 2017 after KMPDU, the Council of Governors, and the Ministry of Health signed a new CBA which is enforceable by the High Court in case the government defaults again. I followed the related events both from personal observation as a healthcare-conscious adult citizen of Kenya and through the local media reports.

rights and the resolution of violations, the HIV and AIDS Tribunal of Kenya was established in 2006 under the HIV Prevention and Control Act. It seeks to "advance the human rights of people living with and affected by HIV in Kenya, notably through addressing barriers to access to justice, swift ruling, and purposeful application of the law" (Eba, 2015, p. 169). However, its mandate is purely legal, and does not extend into research. The Kenya HIV Research Agenda is under NACC, mainly as a coordination function handling such matters as "ethics review committees, outlines capacity development options for research, reviews and data analysis and embraces the use of technology to facilitate availability of research findings to programmers, policy makers, students, implementers and communities" (NACC, 2019, p. para 1a). Its objectives remain limited to items like "define HIV research priorities for the next five years; provide a national framework to guide HIV research; facilitate coordination of HIV and AIDS research among stakeholders; and serve as a tool for resource mobilization and allocation for HIV research" (NACC, 2019, p. para 3a). In all the policies, frameworks, and research that goes on in Kenya, there is no thinking yet on the possibility of any research in genetic therapies as possible solutions to the HIV-AIDS pandemic. There is also, apart from research at the University of Nairobi and KEMRI, no national policy that seeks collaboration with institutions in other countries in genetic research. And since collaboration is not part of the agenda, growth in genetic science is slow and lacks attention. The only provisions made in concerning research are guidelines that provide for the protection of research participants through such laws as "No person shall undertake HIV or AIDS related human biomedical research on another person, or on any tissue or blood removed from such person unless such research conforms to the requirements under the Science and Technology Act (Cap. 250) or any other written law for the time in force" (Laws of Kenya, 2012, p. 21). However, although the protection of participants is important, the country would do much better in moving the agenda forward by beginning to look beyond routine research that only looks into distribution of drugs, the number of recipients under treatment, how many people are infected, the economic impact of HIV-AIDS, and the efficacy of ARVs. There is now need for policies and guidelines for the next level of research, especially genetic therapies and collaboration arrangements on the same.

2.3. BASIC FACTS ABOUT KENYA AND HER HEALTHCARE SYSTEM

Kenya is a politically independent republic in the East African region, and is composed of 47 semi-autonomous county governments. The population of Kenya is 47,564,296 people, according to the 2019 official population census (Kenya National Bureau of Statistics, 2019, p. 7). Out of that figure, 24,014,716 are female, 23,548,056 are male, and 1,524 are intersex.

With an estimated annual growth of one million people, by 2020 the population will be likely over 50 million. Based on the Constitution of Kenya 2010, the government is composed of one national government with a legislature, an executive and a judiciary, as well as 47 counties, each of which has a semi-autonomous government.

In order to serve the health care needs of the aforementioned population, the government organises its health institutions from the national level to the location levels. At the county level, there are hospitals that used to be classified as provincial hospitals under the old constitution (1963-2010). Some counties did not inherit any such facility. But there are county-level hospitals, and sub-county hospitals ranking right below. Progressively, there are health centres and dispensaries in wards[8], although not every ward has such facilities, thereby causing much hardship for the residents. In addition to the public health system, the private sector provides private hospitals, nursing homes, and clinics. These come at very high costs, mostly only affordable to the middle class and the rich.

Dispensaries are the smallest unit in the healthcare system in Kenya, and treatment is usually done by nurses. Dispensaries provide simple outpatient services for such sicknesses as common cold, uncomplicated malaria, and simple skin conditions. Health centres provide comprehensive primary care, and are managed by a clinical officer who oversees a team that would normally include "…a clinical officer, nurses, a health administration officer, a medical laboratory technologist, a health information officer, a nutritionist, a driver, a housekeeper, and supporting staff" (Muga, et al., 2004). A sub-county hospital functions as a coordinating and referral centre for the smaller units, and are managed by a medical superintendent. Normally they would provide comprehensive medical services and surgeries. Each of the 47 counties in Kenya has a county hospital. These should normally be equipped to provide minimum specialised care, including intensive care. Kenya as a whole has three national hospitals namely Kenyatta National Hospital, the National Spinal Injury and Referral Hospital, and Moi Teaching and Referral Hospital.[9] Kenyatta National Hospital provides referral services for Kenya and a number of countries in East and Central Africa. "The equivalent private referral hospitals are the Nairobi Hospital, the Aga Khan Hospital Nairobi" (Muga, et al., 2004), and the Karen Hospital which is a recent addition. The Kenya Healthcare Sector report states that "…there are a total of 9,696 health facilities in the country. About 4,616 of these facilities are owned by the public sector, 3,696 falls under ownership of the commercial private sector and

[8] A ward is an administrative unit under the devolved county government under the Constitution of Kenya 2010.
[9] This statement is made from general knowledge as a citizen of Kenya who has general awareness of the country's health system and institutions.

1,384 are owned by FBOs[10], NGOs[11] or Community Based Organisations (CBOs)" (Kenya Healthcare Federation, 2016). The 2017 GIZ-DE Report says that

> The 2010 constitution grants Kenyans access to affordable high quality health care. Currently, however, much remains to be done to realise this right in practice. The quality of basic health services is often poor and, despite strong economic growth in recent years, many Kenyans face financial barriers to accessing care. Only 20 per cent of Kenya's 48 million inhabitants have health insurance, and most of them are employed in the formal sector (GIZ, 2017).

According to the 2018 Economic Survey by the Kenya National Bureau of Statistics, the four leading causes of registered deaths in Kenya in 2017 are pneumonia, malaria, cancer, and HIV-AIDS. The report indicates that 21,584 people died of pneumonia in 2017, another 17,553 succumbed to malaria, while deaths caused by cancer stood at 16,953. Tuberculosis was the fourth leading cause of death at 9,081 followed by HIV-AIDS at 8,758 (Kenya National Bureau of Statistics, 2018). It is noteworthy that a combination of TB and HIV-AIDS would make the combination second only to pneumonia.

With regard to the allocation of resources such as equipment and healthcare personnel, "Kenya health sector has inadequate crucial health staff like doctors, nurses, and diagnostic scientists" with an establishment of 8,092 doctors for both public and private sector health facilities, out of whom only about 5,000 work in the government sector (Ministry of Health, 2014). The document further elaborates:

> Inadequate staffing levels, lack of appropriate skills, poor staff attitude, low morale, and weak supervision undermine the quality of public health services provided, especially at the rural health facilities. The shortage of health workers compromises service delivery and eventual health and development of a nation… In addition, there are regional disparities in the distribution of the existing health workers and the hard-to-reach get disadvantaged with less staff (Ministry of Health, 2014).

Against the recommendation of the World Health Organisation (WHO) of "…at least 23 doctors, nurses and midwives per 10,000 people, Kenya has one doctor, 12 nurses and midwives per 10,000 people" (Ministry of Health, 2014). According to Kenya Healthcare Sector report, the Kenya government's healthcare cadres are dominated by men. For instance, there are 110 male dentists against 103 females, 307 male pharmacists against 203 females, and 332 medical specialists of various kinds against 87 females. The only female-dominated cadre is nursing and midwifery with 15,428 nurses and midwives against 4,943 males (Kenya Healthcare Federation, 2016). These are figures of personnel serving in the government healthcare system. It is also worth noting that "…75% of all medical doctors and 66% of all nurses and clinical officers work in the private sector because the regulatory board allows

[10] FBOs are Faith Based Organisations, such as churches and organised religious systems in other religions.
[11] NGOs are Non-Governmental Organisations.

health workers to work in both public and private sectors at the same time" (Kenya Healthcare Federation, 2016). Those who do so give preference to the private clinics because they earn much more than they get in the public institutions. This means there is a big shortage of qualified health workers in the public sector.

The health sector human resources face a number of challenges that compromise service delivery. At a conference of health experts in 2015, Dr. Ouma Oluga of the Kenya Medical Practitioners and Dentists Union (KMPDU) pointed out the challenges which included limited training opportunities and career progression, poor working environment, and skewed distribution of doctors. With the devolution of health services in 2013, the problems seem to have compounded:

> With devolution, the HRH problems compounded many times, and are characterised by tribalism and nepotism, deployment of staff with low capacity; staff harassment, threats and political interferences especially by the County Assemblies and community members rejecting members of staff, retarded career progression and; lack of horizontal and vertical transfers. There have been reported hostilities between County Health Managers and Health Workers, too many workers' strikes, and mass exodus of the Human Resource... (Health Rights Advocacy Forum, 2015).

The same challenges were cited by Purity Matu of the Kenya National Union of Nurses, who added to her list the lack of pharmaceutical supplies, insecurity at work places, and lack of political good will.

The basic facts, as discussed above, reveal an over-stretched healthcare system managed by a physically exhausted workforce whose main preoccupation is to try to make a living, a situation that leads to frequent strikes. The situation should cause concern, as healthcare personnel continue to seek migratory opportunities, thereby leaving the country's healthcare in the hands of fewer and less-motivated service providers. Development agencies may need to view this situation as one that provides great opportunities for them to contribute to capacity building for strengthening the public healthcare systems.

2.4. THE CHALLENGE OF HIV-AIDS IN KENYA

In relation to HIV testing and counselling, "…more than half (53%) of the 1.6 million people living with HIV in Kenya are unaware of their HIV status. There are an estimated 260,000 couples in HIV sero-discordant couples, where one partner is HIV positive and the other one is negative" (Kenya National AIDS Control Council, 2014). The report says these couples significantly contribute to new infections. This phenomenon makes HIV testing and counselling an important aspect of the control programme. Apart from "…targeted community-based HIV testing and door-to-door testing campaigns, in 2015, Kenya announced plans to introduce self-test kits and began evaluating distributors" (AVERT, 2017). In recent years,

there has been a great increase in the numbers of people going for testing. It is reported that "…in 2008, about 860,000 people were being tested annually for HIV. By 2013, this had increased to 6.4 million" (Kenya National AIDS Control Council, 2014). The Kenya National AIDS Control Council places emphasis on prevention and reduction strategies, as evidenced by its four objectives set out in the KASF 2014/15-2018/19 policy document over its lifespan of five years: reducing "new HIV infections by 75%, AIDS-related mortality by 25%, HIV-related stigma and discrimination by 50%, and increasing domestic financing of the HIV response to 50%" (Kenya National AIDS Control Council, 2014). A UNAIDS report points out that in 2015,

> …government representatives from Kenya, Zimbabwe and South Africa met to plan the development of a regional roadmap to increase the use of combination HIV prevention services in each country. Combination prevention mixes behavioural, medical and structural interventions and is widely regarded as the most effective approach to preventing new infections (UNAIDS, 2016).

In 2016, Kenya issued a "…full regulatory approval of pre-exposure prophylaxis (PrEP), which uses antiretroviral drugs to protect HIV-negative people from HIV before potential exposure to the virus" (UNAIDS, 2016). Kenya was "the second country in Africa to do so," after South Africa. Currently in the country, there is an on-going "research into the uptake and impact of PrEP, specifically among young women and girls in high-incidence areas" (Ibid.).

Addressing the challenge of TB and HIV co-infection, the Kenya National AIDS Control Council reports that in Kenya, "…up to 38% of people with tuberculosis (TB) are co-infected with HIV" (Kenya National AIDS Control Council, 2014). It is also reported (Ibid.) that "83% of people with a co-infection are being treated for both illnesses" (Ibid.). Although this figure may show commitment to tackling both diseases as a public health concern, the untreated 17% reveals a probable weakness in following up and counselling co-infected patients; small numbers are not necessarily insignificant.

The problem of stigma and discrimination against infected persons remains high, despite the general perception that HIV-AIDS awareness is high. It is reported that "…many people living with HIV face high levels of stigma and discrimination" an experience that "…deters many people living with HIV - particularly vulnerable groups - from seeking vital HIV services" (Kenya National AIDS Control Council, 2014). Stigma affects patient care when a relative declines to take care of an HIV-infected relative; it affects small-scale business when potential customers decline to buy fresh fish or vegetables from an HIV-infected vendor; and it affects careers when parents refuse to allow an HIV-infected teacher to teach their children. Stigma and discrimination have, until recently, found legal backing in a discriminatory law

which required infected persons to disclose their HIV status. "In 2015, the High Court of Kenya declared that law unconstitutional, thus making Kenya the first country in the world to take such a stance, seen by many as a breakthrough for the rights of people living with HIV" (AVERT, 2017). Despite such a milestone, the Kenya National AIDS Control Council reports that HIV-infected people still face stigma, discrimination, and violence, sometimes through denial of essential services, arbitrary arrests and beatings (Kenya National AIDS Control Council, 2014).

It may be stated with a measure of certainty that funding for the HIV response in Kenya is at risk, given reports that "…approximately 68% of Kenya's national HIV response is externally funded. The remaining 30% is funded by the Kenyan government (17%) and private individuals (13%)" (Kenya National AIDS Control Council, 2014). The same report further notes that "…dwindling funds from international donors pose a challenge for the sustainability of Kenya's HIV response." The allocation of these funds is of interest here as "…HIV treatment and care accounted for the majority of HIV expenditure (52%) between 2009 and 2013. Prevention, which includes the provision of HIV testing services, accounted for 21%" (Ibid.). Assuming that the status has not changed positively, it is clear, then, that there are no funds allocated formally for any on-going research in HIV-AIDS in the country. Any research carried out by institutions has to be separately funded by agencies that provide funds for academic research purposes, in addition to the work that international and national organisations carry out in terms of empirical data collection and analysis.

The future, in regard to HIV-AIDS in Kenya officially lies in the Kenya HIV Prevention Revolution Road Map that was published by the Ministry of Health in 2014. The official policy guideline therein "outlines a new approach to drastically reduce new HIV infections that is evidence-informed, rights-based and gender sensitive." Its goal is to bring HIV infections to 'near zero' by 2030" (Ministry of Health, 2014). The roadmap "…commits to combination interventions, targeted towards the different needs of key populations and geographical locations. If implemented successfully, the government projects that it will avert 1,149,000 new HIV infections and 761,000 AIDS related deaths by 2030" (Ibid.). Although the objectives of the roadmap are apparently quite noble, the previously discussed imbalance in funding is likely to frustrate the plans, since the plan seeks to rely heavily on funds from external sources. There is need for Kenya to deliberately budget for prevention, treatment, and research, possibly in equal measure. There is need to progressively decrease donor-dependence, while at the same time increase internal sourcing of funds for HIV-AIDS.

2.5. THE IMPACT OF HIV-AIDS ON KENYA

A review of previous studies carried out reveals various ways in which HIV-AIDS has impacted the people of Kenya in various sectors. Bollinger, Stover and Nalo observe that the household impacts of HIV-AIDS "begin as soon as a member of the household starts to suffer from HIV-related illnesses," as indicated by "loss of income of the patient who is frequently the main breadwinner" (Bollinger, et al., 1999, p. 4). In addition, "…household expenditures for medical expenses may increase substantially… other members of the household, usually daughters and wives, may miss school or work less in order to care for the sick person" (Ibid.). When death occurs, the reality of lost income is reflected in "…less labour on the farm or from lower remittances; funeral and mourning costs; and the removal of children from school in order to save on educational expenses and increase household labour, resulting in a severe loss of future earning potential" (Ibid.). There are cases where children who are withdrawn from school are sent away to live with relatives, thereby further compromising their chances for education. Bollinger, Stover and Nalo have observed that

> In some instances, due to poverty, many communities have found it extremely difficult to cope with the rising number of orphans, forcing some orphans to drop out of school and start engaging in child labour. With high dropout rates of orphans, the quality of future labour force will be compromised …most parents do not arrange for other homes for their children before they die; instead, more and more households are being headed by children, particularly in the rural areas. Schooling becomes a luxury, and agricultural production is negatively affected, as the children are less capable than were the adults (Bollinger, et al., 1999, p. 4).

As the impact of HIV-AIDS is experienced in the households, a heavier burden seems to fall on the children who have to either get scattered among relatives for care or take up adult roles for which they have no prior preparation or training. In the process, they have to forego their real future potential.

There have also been discussions around the various ways in which HIV-AIDS affects education among children and communities. A study reports that

> As parents, guardians and members of communities increasingly become infected by HIV-AIDS and eventually succumb to diseases, children are increasingly lacking basic needs such as food, clothing, shelter, health and even education. Children are now becoming subject to many psycho-socio impacts of HIV-AIDS such as stigma, fear, worry, depression and hopelessness. All these impact negatively on their learning and development (Akunga, et al., 2000).

It is further revealed that "…pupils themselves are getting infected and some of them infect others, attendance and performance in schools is affected, pupils drop out of school, and some even die due to suspected HIV-AIDS-related illnesses" (Akunga, et al., 2000). The situation is worsened by the effect of HIV-AIDS on the teaching workforce as well. It may also be reasonable to conclude that, due to the death of parents and guardians, children would easily give in to child labour in order to gain livelihood; and child labour further deprives children of

any meaningful access to education. Bruhns also makes a similar observation that "…surviving children divide their time between working and learning" (Bruhns, 2006), with learning losing out in cases of conflict of schedule between the two. Bruhns speculates that "…if there had been no epidemic, parents would have had more and better-educated children, whose hypothetical income and lives involve losses which need to be taken into account when measuring the effects of HIV-AIDS" (Bruhns, 2006). This can be generalised into other aspects of life in society: funds spent on prevention efforts, treatment and care would be spent on other important economic ventures; labour dynamics would be positively different for the general well-being of the economy; social life would be more cohesive; and societies would be happier, perhaps.

The study previously referred to from Bollinger, Stover and Nalo shows that "…AIDS will have adverse effects on agriculture, including loss of labour supply and remittance income" (Bollinger, et al., 1999, p. 4). The effect is likely to be felt at household levels as well as on a wider scope, as Bollinger, Stover and Nalo argue:

> The loss of a few workers at the crucial periods of planting and harvesting can significantly reduce the size of the harvest. ...where food security has been a continuous issue because of drought, any declines in household production can have serious consequences. Additionally, a loss of agricultural labour is likely to cause farmers to switch to less-labour-intensive crops. In many cases this may mean switching from export crops to food crops. Thus, AIDS could affect the production of cash crops as well as food crops (Bollinger, et al., 1999, p. 4).

With the general knowledge that a larger percentage of the population works in agriculture and related sectors, agriculture is likely to be the most significant recipient of negative impact of HIV-AIDS. This is likely to set off a difficult situation in which declining agricultural output leads to additional expenditure on food and other essential agricultural products, thereby denying other sectors much-needed funds for growth and development.

Other studies have revealed the negative and damaging impact of HIV-AIDS in Kenya on "fertility patterns" (Magadi & Agwanda, 2010), "among caregivers of persons living with HIV-AIDS" (Musangali, et al., 2016), and "among maternity care providers" (Turan, et al., 2008).

2.6. PAST AND CURRENT REMEDIES FOR HIV-AIDS IN KENYA

Responses to the challenge of HIV-AIDS are varied in both form and magnitude. The use of condoms as a preventive measure against HIV-AIDS infection has been promoted by the government only since 2001. Before then, condoms were only promoted by non-governmental organisations (NGOs). According to the International Business Times (2013), in 2013, "…around 180 million free condoms were distributed although this fell far below

demand." There were also reports of wrong usage in parts of the country. "One report from rural northern Kenya found men reusing condoms or using plastic bags and cloth rags due to shortages and difficulties accessing free supplies at government health facilities" (IRIN, 2011). That was in situations where people experienced scarcity of condoms. But, even where they are available, their use is not guaranteed. The Kenya Demographic and Health Survey of 2014 reported that "…only 40% of women and 43% of men who had two or more partners in the previous 12 months reported using a condom the last time they had sex" (Kenya National Bureau of Statistics, 2015). This raises questions with regard to both efficiency and efficacy of condoms as a preventive measure against HIV-AIDS, although it is generally commonly known that, with proper use, they are mostly effective.

Kenya's strategies towards the possibility of eliminating mother-to-child transmission of HIV include "…efforts to increase knowledge of PMTCT[12], greater male involvement, universal attendance of pregnant women at antenatal clinics, universal uptake of HIV testing among pregnant women and the provision of antiretroviral drugs for those who test positive" (Kenya National AIDS Control Council, 2014). The same report further states that

> The number of women in need of PMTCT over the last 10 years is estimated at an annual average of 80,000. However, this annual need for PMTCT decreased slightly from about 98,000 in 2004 to 79,000 in 2013. This data underscores the need to address epidemic in order reduce the number of infants exposed to HIV infection (Kenya National AIDS Control Council, 2014).

According to UNAIDS, "…in 2015, 59,000 women were offered PMTCT services, out of an estimated 79,000 who were eligible, reflecting 74% coverage" (UNAIDS, 2016). KNACC noted that this was "lower than the 2010 coverage rate of 86%" but argued that the shortfall was "mainly due to the increased demand for PMTCT services" (Kenya National AIDS Control Council, 2014). On a positive side, UNAIDS reported that "…the number of children (0-14 years) newly infected with HIV fell from 12,000 in 2010 to 6600 in 2015, due in large part to PMTCT services" (UNAIDS, 2016).

When voluntary medical male circumcision (VMMC) was identified by the government and implemented as a method for HIV prevention in 2008, priority was given to regions of the country that had the highest HIV prevalence among uncircumcised men (CDC, 2012). Going by the UNAIDS report, "…by 2015, the programme had circumcised 860,000 males (aged 15-49) and met its universal coverage target of 80%. Kenya was one of only three countries in sub-Saharan Africa to increase VMMC in 2015 (the other two having been Ethiopia and Tanzania). There has been a worrying decline in this intervention throughout the rest of the

[12] PMTCT is Preventing Mother-to-Child Transmission of HIV.

region" (UNAIDS, 2016). One would hope that the increment of numbers in those seeking this service were not a reflection of any probable misconception that VMMC in isolation might prevent HIV infection among males, and that the service were accompanied with clear counselling on the need for the integration of other known measures of prevention. Counselling support is called for before and after the circumcision, just as is the normal practice in HIV testing and counselling.

In order to promote HIV education and awareness, education policy was revised in 2013 to enhance "care and support for school pupils as well as education personnel such as teachers," with sensitivity to women and girls because they are "disproportionately affected by the epidemic" (Education Sector Policy, 2013). Since 2003, the national school curriculum in Kenya has integrated HIV and AIDS. However, the Kenya Demographic and Health Survey found that "only 54% of young women and 64% of young men (aged 15-24) had comprehensive knowledge about HIV prevention" (Kenya National Bureau of Statistics, 2015). A research study carried out by Mwamwenda found "…HIV knowledge to be significantly higher among university students" (Mwamwenda, 2014). Controversy continues among Kenyans with regard to HIV and sexual health education. For instance, "the Kenya Demographic and Health Survey 2014 found around 60% of both men and women to be in favour of educating young people about condoms, with the remaining 40% against it. Many cited fear of encouraging young people to have sex as a reason for being against the promotion of condoms" (Kenya National Bureau of Statistics, 2015). There may be need to review curriculum content for the HIV and sexual education to address the society's reservations against the promotion of condom use among youth.

Perhaps the last means of intervention in the HIV-AIDS epidemic in Kenya, as in other sub-Saharan countries, is antiretroviral treatment (ART). In 2015 when Kenya began to implement the recommendations of the World Health Organisation for immediate ARV treatment for people diagnosed with HIV, "…around 826,000 adults and 71,500 children were accessing antiretroviral treatment (ART). This equates to 58% of adults who are in need of treatment receiving it, and 73% of children" (UNAIDS, 2016). There is need for empirical research to establish what leads the left-out percentage to miss out on the available ART treatment, as well as how to integrate them into the treatment programme.

2.7. CURRENT TRENDS IN HIV-AIDS RESEARCH IN KENYA

Much research that goes on in Kenya on HIV-AIDS is basic empirical economics research that examines the extent, distribution, and causes of the epidemic in the country, as

well as the efficacy of the various programmes put in place for prevention and treatment. A review of available literature, as carried out in the chapters above, reveal a cycle of repeated evaluation research showing statistics on the infected population, medical care expenditure, costs on the economy, and whether there is a decline or an increment. It seems only a small percentage of the research is scientifically biomedical in focus, and there is yet to be seen any policy document that places priority on the scientific research. Both the Kenya Medical Research Institute (KEMRI) and the Kenya AIDS Vaccine Initiative Institute of Clinical Research (KAVI-ICR) are generally known to be carrying out scientific research on HIV-AIDS, but with funding coming from overseas partners; not from the Kenya government.

The KAVI-ICR is a research hub at the College of Health Sciences at the University of Nairobi, and has been conducting basic research in HIV and epidemiology, as well as eight vaccine trials. The website of KAVI-ICR shows that their research focus has diversified beyond HIV-AIDS and now extends to non-communicable diseases including "…cancers such as breast, colon, prostate cancers as well as the diseases of the cardiovascular, respiratory, and endocrine systems" (Kenya AIDS Vaccine Initiative, 2014), while retaining the communicable diseases section which focuses on "…HIV-AIDS, along with research on tuberculosis, zoonoses, and childhood respiratory and gastrointestinal diseases" (Kenya AIDS Vaccine Initiative, 2014). One would hope that the institution has not digressed into peripheral diseases, which are also critical in their own right, to the possible neglect of the original core mandate of HIV-AIDS. A research carried out at KAVI-ICR explained that a VRC HIV-1 rAd5 vaccine is one that is delivered by needle and syringe intramuscularly to research volunteers who are healthy people without any HIV infection prior to the vaccination.[13] In that study, "…the VRC HIV-1 rAd5 vaccine was generally well-tolerated when given alone or as boost following the VRC HIV-1 DNA vaccine to healthy, HIV-seronegative African adults at low risk for HIV infection" (Jaoko, et al., 2010). "At the end of the study, most vaccine recipients tested positive on at least one commercial HIV antibody kit without being HIV-infected" (Jaoko, et al., 2010). The study concluded that

> The effect of pre-existing immunity to these vectors on the immunogenicity of rAd vectored vaccines remains to be seen. In addition, enormous efforts are being made to develop HIV vaccines capable of inducing neutralizing HIV antibodies and to design replicating viral vectors.

[13] According to KAVI-ICR website, "the volunteers who participated in the studies were individuals living in UK, Kenya, Uganda and Switzerland. Anybody could participate in these trials regardless of race, ethnicity or gender provided they met the study entry criteria. The volunteers were healthy men and women at low risk of acquiring HIV who are interested in helping ensure that a preventive HIV vaccine is developed as soon as possible. The number of injections one receives varies between 2 and 8. The injections can be given into the skin, just below the skin or into the muscle of the upper arm. The injections are alternated between left and right arms" (Kenya AIDS Vaccine Initiative, 2014).

> While basic discovery and applied research are crucial for the development of a safe and efficacious HIV vaccine, it is important to continue to perform focused human clinical trials of different vaccine strategies to develop a highly effective and safe preventive HIV vaccine. New functional T cell assays that allow determination of correlates of protection and/or predict vaccine efficacy are also urgently needed (Jaoko, et al., 2010).

The programmes at KAVI-ICR are funded by foreign partners from the developed world, including the Canadian Institute of Health Research, Centres for Disease Control and Prevention (CDC), USAID, and universities abroad.

Other research is carried out at the Kenya Medical Research Institute (KEMRI) where "…laboratory research focus has been on understanding B cell biology in HIV infection, specifically describing phenotypes, function and potential mechanism by which viral antigens affect this compartment" (KEMRI, n.d.). Funding here, too, is from overseas institutions. In 1999 the Military HIV Research Programme (MHRP) of the US government launched an HIV vaccine programme in partnership with KEMRI to offer support in prevention, care, and treatment through the provision of ART. According to MHRP, the main highlights of the programme include conducting "the first HIV vaccine study outside of Nairobi and the largest to date in Kenya," establishing "Kenya's first and only College of American Pathologist (CAP)-accredited laboratory," participating in "a study that found starting antiretroviral therapy (ART) soon after beginning tuberculosis treatment could significantly reduce the onset of new AIDS-defining illness and death in those with advanced HIV (the results were published in NEJM in 2011)," and participating in "the OCTANE Study, which was published in the NEJM in 2010 and influenced revision of WHO guidelines for treating some HIV-infected women" (US Military, 2017). In October 2016 the MHRP started a new research in Kenya in collaboration with the Kenya Defence Forces (KDF) focusing on the prevalence of HIV-1, HIV/TB co-infection, and malaria among the Kenyan soldiers. Earlier on in August 2015, MHRP has conducted a study that indicated an increase in the HIV subtypes in Kenya, which "could complicate the picture for HIV vaccine researchers" (US Military, 2017).

It has recently been reported that the CDC is "working on a HIV vaccine that could see an end to new HIV infections in Kenya" (Bulterys, 2019). According to the CDC officials, "…the vaccine - HPTN-081 - is an antibody-mediated prevention that involves giving antibodies to individuals to protect them from HIV infections" (Bulterys, 2019). Given that the report came through a celebration speech rather than through a scientific journal, this could be something that is still a long way away, and may take years to become a reality and become useable in the prevention of HIV infections. And if, as the report stated, the focus will be on women, the vaccine, even if it were successful, will be problematic due to the obvious

discrimination in its intended application to women while leaving out the men for unstated reasons. Also, while prevention through a vaccine will be helpful, there will still be need for treatment for the people who are already sick.

As can be concluded from the foregoing review, research in HIV-AIDS in Kenya is currently focused on reviewing what is going on, how to improve prevention, how best to provide care, and how to implement treatment plans. The research is yet to scale up to start making any attempts at any modification or enhancement of genes as a way of providing therapy to the people.

2.8. CONCLUSION

I have provided a review of the challenge of HIV-AIDS in Kenya and highlighted the health crisis in the country. This helps explain the context in which special reference is made with regard to the need for genetic therapies. In examining the challenge of HIV-AIDS in Kenya, some ongoing research related to the scourge has also been highlighted.

CHAPTER 3: UNDERSTANDING GENETIC THERAPIES

3.1. INTRODUCTION

In this chapter I provide a review of contemporary genetic therapies and their potential to curb the HIV-AIDS pandemic. The review begins with an explanation on what makes it necessary to consider genetic therapies and what these therapies really are. It also explains the life cycle of the HIV, especially how the virus gets into the human body and how it survives there. The intention here is to develop an appreciation of the necessity of genetic therapies. The chapter discusses the various types of genetic therapies that have been developed so far, ending up with a more detailed discourse on CRISPR/Cas9 which, so far, is the most suitable proposed genetic therapy. The chapter develops an understanding of genetic therapies, a necessary goal, before their relevance is evaluated.

3.2. THE NECESSITY AND MEANING OF GENETIC THERAPY

The continued lack of a cure for the infectious HIV, despite much research undertaking over the years in various countries, makes it necessary for scientific research to persist in seeking to find a definitive cure. So far, the use of Highly Active Antiviral Treatment (HAART) for suppression of viral multiplication is the best available treatment option in which one is advised to take a dose at least once a day for the rest of his or her life. Of the HIV-infected number people globally, some are well into their second decade of treatment with these antiretroviral drugs. It is conclusive, then, that the survival rates and the quality of life for HIV-AIDS patients have been significantly improved by the intervention currently available. However, despite the benefits of having supressed viral load on an individual taking these drugs, missing the pills for a number of days unleashes a rapid viral replication. Additionally, some patients experience adverse effects which may interfere with their usual daily activities or lifestyles, leading to poor adherence for some, thereby posing risks of treatment failure of the drugs in use. In other words, with continued treatment interruptions, resistance to these drugs may occur. It is also common that the cost of the HAART drugs is way beyond the capacity of the ordinary patient to afford. In countries such as Kenya and South Africa, where the government provides free HAART to the patients, the cost of transport and other hidden costs still make it expensive for the poor, especially the rural poor, to access treatment. A research done in South Africa showed how transport costs, loss of income on the day of visiting the clinic, and the purchase of food were a hindrance for the rural poor, and were contributing

factors to lack of access to treatment (Rosen, et al., 2007). In Kenya, recent research revealed that, although the average costs had significantly lowered per patient, it was still a major issue:

> The median economic unit cost1 per patient-year was $248.91 (2011 U.S. dollars [USD]) for established adult ART patients; or $120.72 when the cost of ARVs is excluded. The median cost per patient-year was $116.71 for pre-ART patients. Costs were higher for established pediatric patients ($292.60) compared to established adult patients. Newly initiating ART patients were also associated with higher costs than established ART patients at $274.95 for adults and $318.73 for pediatric patients. ARVs, the largest single cost component, cost a median of $123.03 per year for ART patients (CDC & Kenya Ministry of Health, 2013).

Another issue that came out was that WHO had recommended that the use of Stavudine[14] be stopped due to its "long-term, irreversible side effects," and it be replaced with either Zidovudine or Tenofovir which are "less toxic and equally effective." However, Kenya has continued to use Stavudine because it is relatively low-cost (CDC & Kenya Ministry of Health, 2013). The dilemma for the country is to either continue with the low cost Stavudine with full awareness of the long-term side effects of the drug on the patients, or to turn over to the newer drugs recommended by WHO, and pay higher costs per patient. It is theoretically estimated that, if all Stavudine were to be replaced with Zidovudine, "the median per ART patient among 29 sites will increase from $240.33 to $292.71" (CDC & Kenya Ministry of Health, 2013). An ethics question related to this is whether the public health system fully informs the patients of both the short-term and the long-term side effects that are known. The patients, even if they were fully made aware, however, do not seem to have any alternative that they can afford without government assistance. Also, like in South Africa, patients in Kenya spent on transport and lost income whenever they had to visit clinics.

According to Richman, *et al*, apart from adverse effects, "there is some growing concern about the increasing rates of heart disease, diabetes mellitus, liver disease and various forms of cancer in ageing HIV-infected patients" getting antiretroviral treatment (Richman, et al., 2009). It is still unclear whether the rise of these illnesses is related to antiretroviral drugs or to being HIV infected or due to the combined effects. It seems clear that eradicating the lethal infection of HIV-AIDS remains a mirage, unless gene therapy is developed as a viable option. Gene therapy promises to offer an alternative treatment option that, if successful, may

[14] "Stavudine is used along with other medications to treat human immunodeficiency virus (HIV) infection. Stavudine is in a class of medications called nucleoside reverse transcriptase inhibitors (NRTIs). It works by decreasing the amount of HIV in the blood. Although Stavudine does not cure HIV, it may decrease your chance of developing acquired immunodeficiency syndrome (AIDS) and HIV-related illnesses such as serious infections or cancer... Stavudine may cause serious or life-threatening lactic acidosis (build-up of acid in the blood) that will probably need to be treated in the hospital. The risk that you will develop lactic acidosis is higher if you are a woman, if you are overweight, and if you have been treated with medications for human immunodeficiency virus (HIV) for a long time. The risk may also be higher if you are pregnant and you are taking Stavudine along with Didanosine (Videx)" (Medline Plus, 2018).

have less adverse effects. In the last 25 years "AIDS has turned from an untreatable, rapidly lethal syndrome into a chronically manageable, tolerable disease compatible with a long life-span… and …anti-HIV-AIDS gene therapy is one of the most promising strategies, although challenging, to eradicate HIV infection" (Richman, et al., 2009). Other scientists have observed that

> Although successful treatments with highly active antiretroviral therapies have made a major impact on survival, there still remains no vaccine for prevention and the available therapies do not cure the disease. As a result, AIDS has been transformed into a chronic, lifelong disease which requires continuous antiretroviral drug treatment together with on-going treatment of the associated systemic medical complications. It appears that as survival improves, the prevalence of chronic central nervous system involvement may be increasing (Paul, et al., 2009).

This context in which HIV-AIDS is not adequately treatable raises a number of questions, on genetic therapies, which should lead into an exploration: What are genetic therapies? In what forms have they been developed, so far? How do they work? Is there any hope in their efficacy? Are they relevant to African needs, especially with regard to the treatment of HIV-AIDS?

Genetic therapy may be one of the most welcomed preventive and/or treatment advancements in medicine. The use of the phrase gene therapy initially surfaced when there was a need to differentiate it from the Orwellian meaning of "human genetic engineering" which evolved from "the term genetic engineering first used at the Sixth International Congress of Genetics hosted in 1932" (Wolff & Lederberg, 1994). According to Wolff and Lederberg, "genetic therapy" has evolved through the decades with the transfer of genes into bacteria having been founded around the 1960s. To transfer a gene into a human body, a technique which included using "either a viral vector and or genetically modified cultured cells" was utilized (Wolff & Lederberg, 1994). Although there was an inadequate trustworthy method of gene transfer, scientists and researchers continued to persist resulting in establishment "of retroviral vectors in the 1980s" which brought about a possible "efficient gene transfer into mammalian cells" (Ibid), with the intent of gene therapy which has now become widely accepted, although not used as a preferred method of treatment for a variety of diseases in many countries.

Before delving deeper into gene therapy, it is essential to understand the concept of gene therapy in order to correctly discuss its relevance in the treatment of HIV-AIDS. The Genetics Home Reference (GHR) of the US National Library of Medicine explains "gene therapy" as "…an experimental technique that uses genes to treat or prevent disease" (National Library of Medicine (US), 2017). Ongsimei states the same definition, adding that "the goal of gene therapy is to treat a genetic disease by repairing the damaged gene responsible for the

disease. It involves introducing a normal copy of the gene into cells containing the damaged version" (Ongsimei, 2016). Gene therapy has also been defined as "the introduction of nucleic acids into cells for the purpose of altering the course of a medical condition or disease" (Kay, et al., 1997). Mandal defines it as "a form of therapy that involves inserting one or more corrective genes that have been designed in the laboratory into the genetic material of a patient's cells to cure a genetic disease" (Mandal, 2014). The "Your Genome" website is the only one that specifically includes the deoxyribonucleic acid (DNA) in the definition: "Gene therapy is when DNA is introduced into a patient to treat a genetic disease. The new DNA usually contains a functioning gene to correct the effects of a disease-causing mutation." This means genetic therapy actually causes the modification of the genes or DNA of a patient. The same idea has been summarised that

> Gene therapy is a medical intervention consisting in the introduction of genetic material into cells to cure a disease. Although somatic gene therapy was developed with the primary intention to correct genetic diseases, it was soon recognized that *ex vivo* or *in vivo* genetic modification could be applied as well to cancer, cardiovascular, and infectious diseases (Bovolenta, et al., 2012).

A futuristic perspective says "In future, this technique may allow doctors to treat disorder by inserting a gene into a patient's cells instead of using drugs or surgery" (National Library of Medicine (US), 2017). This means that, firstly, the technique is still in research stages, and conclusions are not yet drawn as to the efficacy of this type of therapy. Secondly, the use of the technique is not yet available for doctors to use on patients, but there is hope that it will be available in the future, whether distant or near. Research is on-going on various approaches to gene therapy that may become possible in future, including "replacing a mutated gene that causes disease with a healthy copy of the gene; inactivating or knocking out a mutated gene that is functioning improperly; and introducing a new gene into the body to help fight a disease"(Ibid).

3.3. PATHOGENS AND THE LIFE CYCLE OF HIV

In order to carry forward a discussion on gene therapy as a possible solution for HIV-AIDS, it seems necessary to seek basic understanding of how the virus enters and establishes itself in the human body. The HIV is transmitted into the human body through contact with various bodily secretions from a person with HIV. Such body fluids include blood, semen, pre-seminal fluid, vaginal fluids, rectal fluids, and breast milk. Upon entry into the human body, the infection process takes place in stages, namely "Acute Infection Stage, Chronic Infection

Stage, and Acquired Immune Deficiency Syndrome (AIDS)"[15] (US Department of Health, 2017). Upon entry into human body, the HIV life cycle begins by the virus attaching itself to "CD4 cell receptor and one of the two co-receptors, *CCR5* or *CXCR4* receptors" located on the surface of the "CD4+ T-lymphocyte[16]" (Ibid.). In this attachment the virus gets into a union with the host cell where it releases its genetic material, that is, the RNA [Ribonucleic Acid], which is single stranded. The single-stranded genetic material is, in turn, transformed into DNA (Deoxyribonucleic Acid) by an enzyme called "reverse transcriptase". The DNA is double stranded and it stores the genetic material of the human immunodeficiency virus. This DNA accesses the host cell nucleus via an enzyme referred to as *the integrase*. Through this integration of the HIV DNA into that of a host, the viral DNA is in other words hidden inside the host nucleus as a "provirus which may remain dormant for a number of years, produce few or no new copies of the virus" (Ibid). It is an intricate process in which the HIV tricks the human immune system. When the host cell receives a message prompting it to become active, the host's "RNA polymerase enzyme" is used by the HIV genetic material (viral DNA) to multiply, thereby unleashing enormous copies of the virus within the human body cells. As the new viral copies are formed, they push out of the infected cell taking along with them part of the outer cell envelope, which is used as the virus' cover that later combines with the HIV glycoprotein to invade and infect other cells.

To enable one to have some clarity on how the virus may look like, the following image is taken from the website of AIDS Info (2017) to depict the HIV structure and its contents which are essential for its attachment and survival in a host cell:

[15] AIDS stands for Acquired Immune Deficiency Syndrome: Acquired means you can get infected with it; Immune Deficiency means a weakness in the body's system that fights diseases. Syndrome means a group of health problems that make up a disease. *www.aidsinfonet.org/fact_sheets/view/101*

[16] "T-lymphocyte cells are divided into antigen-naïve and antigen-experienced memory cells." The antigen-experienced memory is further sub-divided into "central memory cells and effector memory cells" (Grossman, Meier-Schellersheim, Paul & Picker, 2006). The effector T memory cells are the type of cells targeted by the HIV which are laden with the co-receptors.

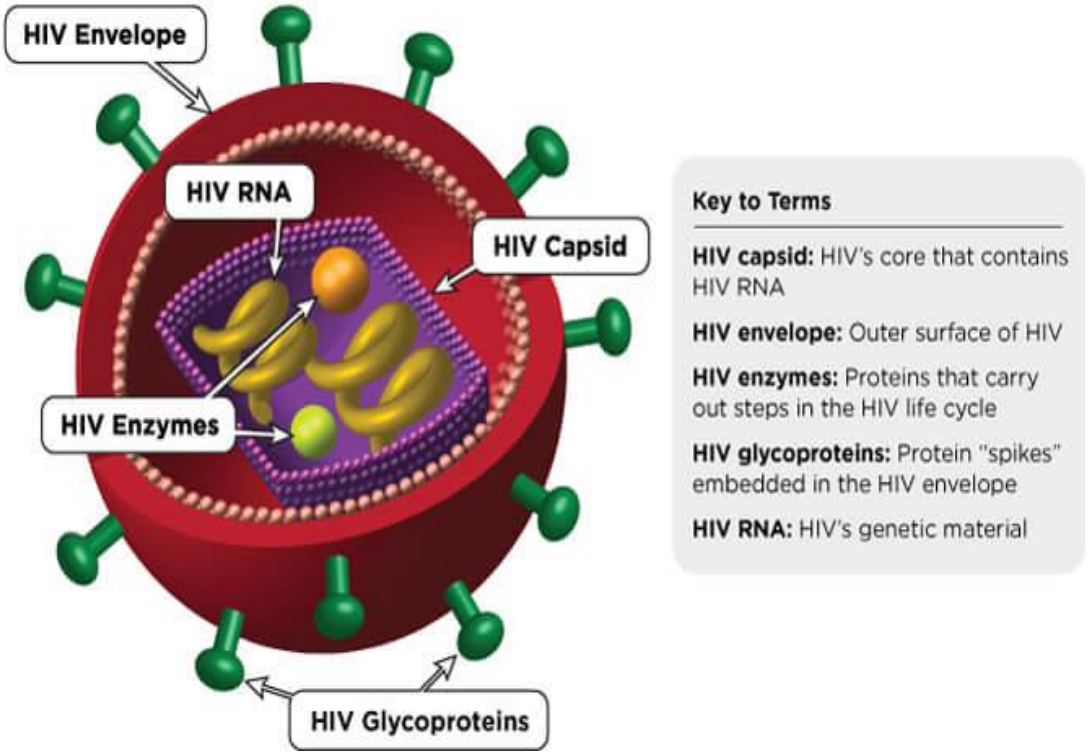

Figure 1: The Structure and Content of HIV[17]

Consequently, at each of the seven stages in the HIV life cycle, the HIV attacks a CD4[18] cell and uses the machinery of the cell to multiply. The behaviour of the HIV in the body is vividly illustrated in the following image, which is also from AIDS Info (Ibid.):

[17] Figure 1 is adopted from http://aidsinfo.nih.gov.
[18] CD4 cells are a type of white blood cell that plays a major role in protecting the body from infection.

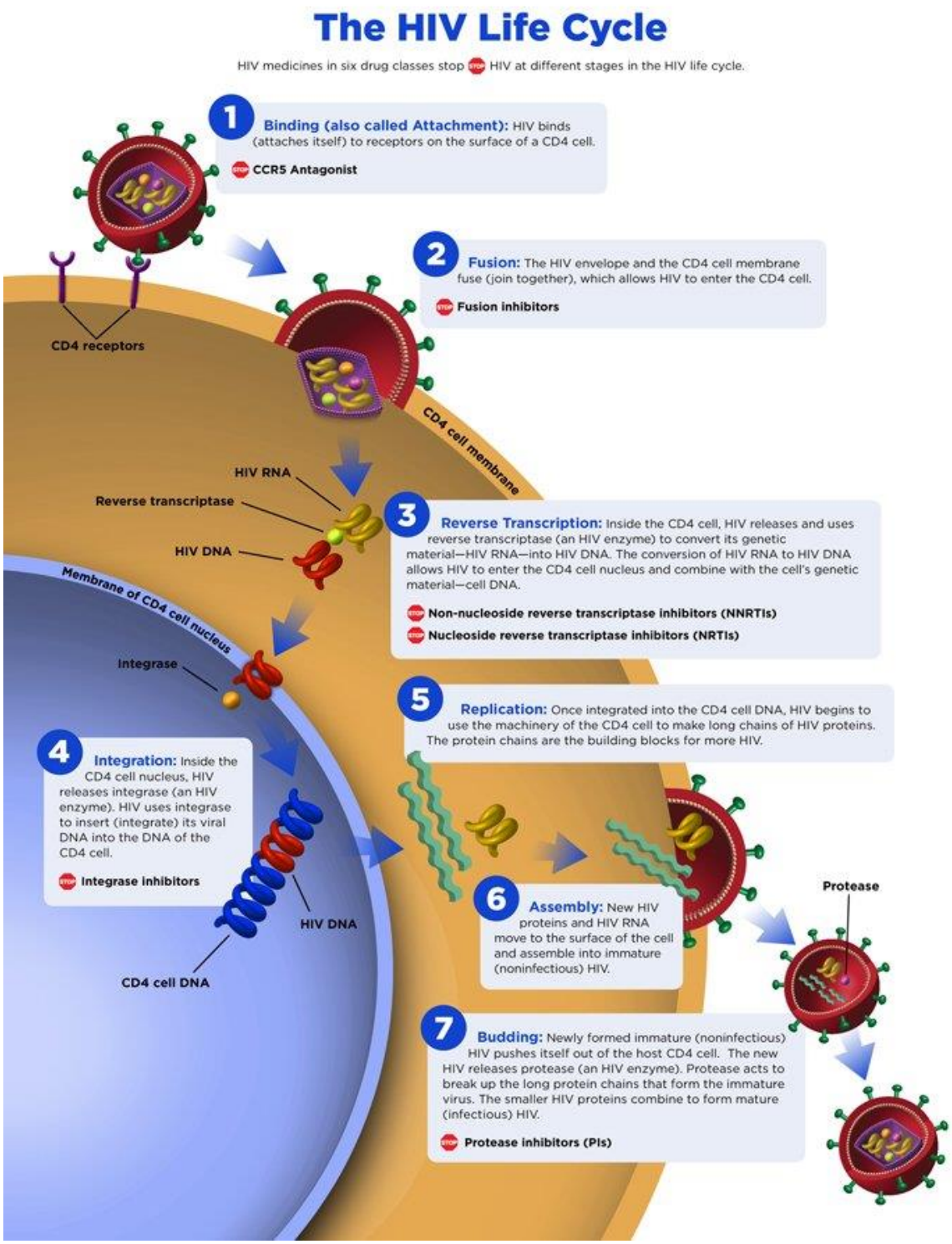

Figure 2: The Life Cycle of HIV[19]

The image shows how the HIV virus mutates in the body and modifies the genetic structure and function of the human genetic make-up, thereby effectively insulating itself from any attempts at treatment, thereby necessitating genetic therapy.

[19] Figure *2* is adopted from http://aidsinfo.nih.gov.

According to an article in the Gene Therapy Net, "…all cells in the human body contain genes, making them potential targets for gene therapy. However, these cells can be divided into two major categories: somatic cells (most cells of the body) or cells of the germ-line (eggs or sperm)" (Gene Therapy Net, 2018). In theory, either somatic cells or germ cells can be transformed. Gene therapy that focuses on germ-line cells produces "permanent changes that are passed down to subsequent generations." The article further explains that

> If done early in embryologic development, such as during pre-implantation diagnosis and in vitro fertilization, the gene transfer could also occur in all cells of the developing embryo. The appeal of germ line gene therapy is its potential for offering a permanent therapeutic effect for all who inherit the target gene. Successful germ line therapies introduce the possibility of eliminating some diseases from a particular family, and ultimately from the population, forever (Gene Therapy Net, 2018).

The perceived impact, especially the possibility of eliminating a debilitating disease, such as HIV-AIDS, from the human population makes germ-line gene therapy an attractive mode of potential treatment. As Ongsimei explains, "Germ-line gene therapy involves the reproductive cells. In germ-line gene therapy, the germ cells (sperms and eggs) are modified by the introduction of functional genes into their genomes" (Ongsimei, 2016). The article further explains the two main ways in which germ-line gene therapy will be used:

> …the use of *in vitro* fertilization technique to treat a pre-embryo that carries serious genetic defects before implantation into the mother; and the application of some expertise to remove the defective genes from the germ cells of the afflicted adults to avoid the defects to pass on to the subsequent generations (Ongsimei, 2016).

In other words, germ-line gene therapy has the potential to benefit both the unborn and the grown-up adult members of the human population, in terms of eliminating deadly diseases. However, there are likely to be ethical concerns that make germ-line gene therapy controversial. For instance, although a family may be helped to avoid passing on a genetic disorder to future generations, no one presently knows what long-term negative impact the treatment may cause in the unborn. In addition, it is worthy of consideration that consent is impossible to obtain from the individuals to be affected by germ-line gene therapy simply because they are not yet born and cannot choose whether they would have the treatment or not.

Somatic cells, however, are non-reproductive, and "it affects only the targeted cells in the patient, and is not passed on to future generations… In other words, the therapeutic effect ends with the individual who receives the therapy" (Gene Therapy Net, 2018). Certain challenges have been noted with this type of gene therapy:

> Often the effects of somatic cell therapy are short-lived. Because the cells of most tissues ultimately die and are replaced by new cells, repeated treatments over the course of the individual's life span are required to maintain the therapeutic effect. Transporting the gene to the target cells or tissue is also problematic (Gene Therapy Net, 2018).

In a few countries in the developed world, such as the US and parts of Europe, this type of therapy is already accepted to the treatment of such disorders as "cystic fibrosis, muscular dystrophy, cancer, and certain infectious diseases. Clinicians can even perform this therapy *in utero,* potentially correcting or treating a life-threatening disorder that may significantly impair a baby's health or development if not treated before birth" (Ibid). In broad understanding, somatic gene therapy can be divided into two categories:

> *Ex vivo*, which means exterior (where cells are modified outside the body and then transplanted back in again). In some gene therapy clinical trials, cells from the patient's blood or bone marrow are removed and grown in the laboratory. The cells are exposed to the virus that is carrying the desired gene. The virus enters the cells and inserts the desired gene into the cells' DNA. The cells grow in the laboratory and are then returned to the patient by injection into a vein. This type of gene therapy is called *ex vivo* because the cells are treated outside the body. *In vivo*, which means interior (where genes are changed in cells still in the body). This form of gene therapy is called *in vivo*, because the gene is transferred to cells inside the patient's body (Gene Therapy Net, 2018).

Additional explanations may be useful for a deeper understanding of *ex vivo* somatic gene therapy. Ongsimei shows how *ex vivo* gene therapy corrects disorders by using viral vectors to alter cells and transplanting them back to the body of the patient.

> *Ex vivo* gene therapy modifies the cells outside the body and transplanted back after selection and amplification. *Ex vivo* gene therapy normally targets on bone marrow stem cells, liver cells, blood vessel smooth muscle cells, and tumour-infiltrating lymphocytes for cancer treatment (Ongsimei, 2016).

Ex vivo gene therapy is quite specific in its target and is able to avoid rejection, since in the first place the cells are collected from the patient. However, "host cells must be capable of dividing, thus certain post-mitotic cell populations such as neurons cannot be targets of transduction for *ex vivo* gene therapy" (Ongsimei, 2016).

In vivo gene therapy, on the other hand, involves "the direct introduction of the genetic materials into the human body."

> Physical methods applied for *in vivo* gene delivery are based on making transient penetration in cell membrane by mechanical, electrical, ultrasonic, hydrodynamic, or laser-based energy so that DNA entrance into the targeted cells is facilitated. The target tissues of this technique include skin, lung, colon, muscle, pancreases, liver, bone marrow, spleen and brain (Ibid).

In vivo gene therapy is simple and repeatable, and is achieved by a "single step of direct vector injection into the desired target organ to correct the disorders" (Ibid). Some disadvantages have been pointed out, such as the possibility that "different cell types can be infected when *in vivo* vectors are injected… including neurons, glia, and vascular cells. Besides, this technique might cause toxicity. Some *in vivo* vectors are toxic to host cells and elicit immune responses" (Ibid). This explains why much research is still on-going in this regard in order to ascertain safety and reliability.

It is important to understand the primary concept of genetic therapy, which is "…to introduce a gene with the capacity to cure or prevent the progression of a disease. Gene therapy introduces a normal, functional copy of a gene into a cell in which that gene is defective," say Bowen, *et al*, who further explain that

> Cells, tissue, or even whole individuals (when germ-line cell therapy becomes available) modified by gene therapy are considered to be transgenic or genetically modified. Gene therapy could eventually target the correction of genetic defects, eliminate cancerous cells, prevent cardiovascular diseases, block neurological disorders, and even eliminate infectious pathogens (Bowen, et al., 2003).

The point Bowen, *et al*, are making is that genetic therapy has the potential of resolving much of humanity's struggle against disease and disability. They also point out that gene therapy "should be distinguished from the use of genomics to discover new drugs and diagnosis techniques, although the two are related in some respects" (Ibid.).

It is considerably important to understand how gene therapy works in order to appreciate its potential use in the treatment of HIV-AIDS. In gene therapy, genetic material is introduced into cells to either "compensate for abnormal genes or to make a beneficial protein" (National Library of Medicine (US), 2017). It is explained that "…if a mutated gene causes a necessary protein to be faulty or missing, gene therapy may be able to introduce a normal copy of the gene to restore the function of the protein" (Ibid.). The article further explains that

> A gene that is inserted directly into a cell usually does not function. Instead, a carrier called a vector is genetically engineered to deliver the gene. Certain viruses are often used as vectors because they can deliver the new gene by infecting the cell. The viruses are modified so they can't cause disease when used in people. Some types of virus, such as retroviruses, integrate their genetic material (including the new gene) into a chromosome in the human cell. Other viruses, such as adenoviruses, introduce their DNA into the nucleus of the cell, but the DNA is not integrated into a chromosome. The vector can be injected or given intravenously (by IV) directly into a specific tissue in the body, where it is taken up by individual cells. Alternately, a sample of the patient's cells can be removed and exposed to the vector in a laboratory setting. The cells containing the vector are then returned to the patient. If the treatment is successful, the new gene delivered by the vector will make a functioning protein (Ibid.).

The foregoing explanation, therefore, calls on research scientists to develop reliable and efficient ways by which genes can be targeted to specific cells and also bring the new genes under the control of the body before genetic therapy is made available for practical treatment of diseases. Serious risks, including toxicity and inflammation, have to be eliminated by researchers, research institutions, and agencies responsible for regulation.

3.4. VARIOUS TYPES OF GENETIC THERAPIES

There are various types of genetic therapies for which a degree of understanding is necessary as an integral aspect of this research. Changqing Su discusses the concept of adenovirus-based gene therapy in relation to cancer and defines as "a biomedical technology

to treat diseases with functional genes or therapeutic genes by transferring these genes into cells" (Su, 2011). But what are adenoviruses? Benaroch defines adenoviruses as "a group of common viruses that infect the lining of your eyes, airways and lungs, intestines, urinary tract, and nervous system. They're common causes of fever, coughs, sore throats, diarrhoea, and pink eye" (Benaroch, 2016). He observes that adenoviral infections "happen in children more often than in adults, but anyone can get them. Most kids will have at least one type of adenovirus infection by the time they are 10" (Ibid). Su points out that most of the gene therapy treatments for cancer on clinical trials are using adenovirus as the vector, and explains the superiority of oncolytic adenoviruses which can be "…genetically modified to target, infect and replicate in cancer cells causing them to lyse with an improved, superior efficacy compared to non-replicating adenoviral vector" (Su, 2011). The viruses do not replicate in normal cells, but do so in cancer cells in tumours. He further explains that, whereas the "…traditional strategies for cancer treatment, including surgery, chemotherapy and radiation, are difficult to eradicate the root of various cancers, the gene therapy absolutely searches for the roots cause of carcinogenesis, and corrects the genetic defects in transformed cells" (Ibid.). In other words, it will be possible to avoid the currently prevailing means of cancer treatment in preference for the yet-to-be-perfected adenovirus genetic therapy. It implies that, with further research, maybe eventually HIV-AIDS too can be treated through this method.

There have been reports of much progress in the development of treatment of HIV-1 through gene transfer. Scientists have worked from previous failures to improve their understanding of such associated factors as "the HIV-1 replicative cycle, host factors involved in HIV-1 infection, vector biology and application, transgene technology, animal models, and clinical study design…" (Strayer, et al., 2005). The improved understanding will, in turn, help in the development of strategies for genetic treatment of HIV-AIDS, thereby giving hope to patients. This should encourage scientific research in this area to continue. However,

> …the success of highly active antiretroviral therapy (HAART) has brought into question the need for continued research in AIDS gene therapy. Why study expensive, risky, and potentially impractical treatments if safe pharmacologic approaches produce durable remissions? (Strayer, et al., 2005).

The response lies in the fact that HAART remain non-curative, they are expensive, and they are still significantly toxic. It has been observed that

> Drug-resistant HIV-1 is increasingly frequent, even in lymph nodes of patients receiving HAART with undetectable HIV-1 in the blood. Studies of structured treatment interruptions, designed to provide respite from HAART's burdensome toxicities, complexity, and cost, show that HAART cannot be effectively suspended, even briefly (Ibid.).

It seems reasonable that science should pursue research into other approaches, including genetic therapies, which will complement rather than replace. Strayer, *et al*, explain the four goals of anti-HIV-1 gene therapy as

> …to deliver transgenes: (a) to hematopoietic progenitor cells (HSC) to protect their differentiated progeny from HIV-1; (b) directly to HIV-1-susceptible cells, to render them resistant to HIV-1 infection or inhibit HIV-1 replication in them; (c) to immunize against HIV-1 antigens; and (d) to inhibit HIV-1 in discrete organ target sites e.g., central nervous system (Ibid.).

Although gene therapy focused on HIV-1 has not achieved any of the above objectives, it is reasonable to believe that it may be of significant value or contribution to the treatment of HIV-AIDS in future.

Another type of genetic therapy is the kind that is used for restoring muscle strength and functioning that have been lost due to either disease or age factors. When athletes use this technology to enhance muscle performance, it is called gene doping. The World Anti-Doping Agency (WADA) defines gene doping as "the non-therapeutic use of cells, genes, genetic elements, or of the modulation of gene expression, having the capacity to improve athletic performance" (Gene Therapy Net, 2018). This matter becomes a subject of debate in ethics, as it borders types of human enhancement in which "the recreational use of gene therapies is intended to treat muscle waste disorders" (Ibid). An example is erythropoietin which athletes are already abusing to form red blood cells. Concern over gene doping in sport circles may be deduced from the following description:

> In 2003, WADA decided to include a prohibition of gene doping within their World Anti-Doping Code, which is formalized in its 2004 World Anti-Doping Code. In 2004, the Netherlands Centre for Doping Affairs (NeCeDo) and the WADA have organized a "Gene Doping" workshop. In addition, NeCeDo has published a report on gene doping as an inventory of the possible applications and risks of genetic manipulation in sports. Although there have been no documented cases of gene doping, the science of gene therapy and interest in the techniques by the sports community has risen to a level that makes gene doping inevitable (Ibid).

Scientists have already been asked by WADA to find ways of preventing gene therapy from becoming a doping mechanism is sports (Ibid.). In other words, in the world of sports, there is already express fear that gene therapy may introduce negative dimensions in athletics, not just in human competition, but in horse racing as well. It has been reported that in Germany, a blood test kit has been developed that can detect gene doping "even after 56 days" using ordinary blood samples (Ibid).

The science of gene editing technology has seen the development of transcription activator-like effector nuclease (TALEN) which is becoming a prominent tool. Its use is described as follows:

> By combining such an engineered TALEN with a DNA cleavage domain (which cuts DNA strands), one can engineer restriction enzymes that will specifically cut any desired DNA sequence. When these restriction enzymes are introduced into cells, they can be used for gene editing or for genome editing in situ, a technique known as genome editing with engineered nucleases (Gene Therapy Net, 2018).

This technology has already been applied efficiently to solve a number of problems such as "…to efficiently engineer stably modified human embryonic stem cell and induced pluripotent stem cell (IPSC) clones and human erythroid cell lines; to correct the genetic errors that underlie disease; to correct the genetic defects that cause disorders such as sickle cell disease, xeroderma pigmentosum, and epidermolysis bullosa" (Ibid.). It can also, potentially, be used as a tool to harness the immune system to fight cancers. The lack of an efficient mechanism of delivery limits its use, although the technology can be easily combined with other genome engineering tools for better performance, as illustrated by the following report:

> In 2015, Physicians at the Great Ormond Street Hospital announced the first clinical use of TALEN-based genome editing. An 11-month old baby suffering from CD19+ acute lymphoblastic leukaemia[20] was treated with modified donor T cells that had been engineered to attack leukaemia cells, to be resistant to Alemtuzumab, and to evade detection by the host immune system after introduction. A few weeks after therapy, the patient's condition improved; though physicians are cautious, the patient has been in remission for several months following treatment (Ibid).

The impressive factor in this technology is its capacity for combination with others as well as its proven efficacy in the treatment of leukaemia, a blood disease whose treatment has been a challenge for ages, thereby, by implication, giving hope that other serious challenges, such as HIV-AIDS may receive solutions related to this.

There are also the zinc finger nucleases (ZFNs), which are "artificial restriction enzymes generated by fusing a zinc finger DNA-binding domain to a DNA-cleavage domain" (Ibid.). The relevance of this technology is that it has been used "…in a clinical trial of CD4+ human T-cells with the CCR5 gene disrupted by zinc finger nucleases to be safe as a potential treatment for HIV-AIDS" (Ibid). In other words, there is a high likelihood of this technology emerging as an effective treatment for HIV-AIDS, once research eliminates any potential risks.

3.5. TREATMENT-ENHANCEMENT DISTINCTION

There is need for clarity in the understanding, distinction, and usage of the terms treatment and enhancement in this dissertation, especially in view of the moral significance of the distinction between the two. Treatment refers to an intervention that aims at the cure or

[20]"Childhood acute lymphoblastic leukaemia (ALL) is a type of cancer in which the bone marrow makes too many immature lymphocytes (a type of white blood cell). Leukaemia may affect red blood cells, white blood cells, and platelets." Source: https://www.cancer.gov/types/leukemia/patient/child-all-treatment-pdq

prevention of a disease, or even to only reduce its effects on a human being. The term disease, then, is "an adverse departure from species-typical normal functioning" (Holtug, 2011, p. 137). Enhancements have a completely different, though related, aim from treatment: enhancements aim "to affect various non-disease related factors that have a genetic component, including intelligence, talent, strength and height" (Holtug, 2011, p. 137). In other words, whereas treatments of disease and disability either restore or preserve normal functioning, enhancements seek to compensate nature's victims of insufficiency in desired aspects of life. This matter has been given attention by Norman Daniels who explains that

> The treatment-enhancement distinction draws a line between services or interventions meant to prevent or cure (or otherwise ameliorate) conditions that we view as diseases or disabilities and interventions that improve a condition that we view as a normal function or feature of members of our species. The line drawn here is widely appealed to in medical practice and medical insurance contexts, as well as in our everyday thinking about the medical services we do and should assist people in obtaining (Daniels, 2000, p. 309).

In Daniels' discussion of the treatment-enhancement distinction, he draws a close relation to the concept of "medical necessity" in which "medically necessary services are those that effectively treat physical or mental disease and disability or ameliorate conditions deriving from them" (Daniels, 2000, p. 309). He argues that, although some medical services may be of benefit to certain people, they do not count as medically necessary. He gives two examples from insurance practice to illustrate his point:

> For example, insurance coverage is provided by public and private schemes for growth hormone treatment for children projected to be very short, provided that there is an underlying disease condition, e.g., some diagnosable growth hormone deficiency. Insurers do not cover the treatment for children whose parents simply want them to be taller, regardless of how short they will be, if there is no underlying disease condition. Similarly, insurers will generally reimburse reconstructive breast surgery following mastectomy or trauma. But they do not reimburse "cosmetic" surgery, however strongly a woman may feel that her life will be improved if her breasts are made larger or smaller (Daniels, 2000, p. 310).

Hormone deficiency is understood to be a condition that denies normal functioning to a child, whereas ordinary shortness does not interfere with normal functioning. Seeking to resolve the former falls under treatment, while seeking to resolve the latter falls under enhancement. A similar argument suffices for the breast surgery example. This is what Daniels calls the "normal functioning model." This dissertation proposes that HIV-AIDS should be classified as a condition that threatens, interrupts, or stops normal functioning in human beings, hence one that needs treatment through somatic genetic therapies. However, HIV-AIDS is a complex disease that gets transmitted to one's children as well, and such children need capacity for immunity as may be best achieved through germline genetic enhancement of well-being. In this regard, the state should have an obligation to promote and provide somatic genetic

therapies for HIV-AIDS patients, while germline genetic therapies should be permissible as well to those who would prefer and afford them.

3.6. THE POTENTIAL OF CRISPR/CAS9 TO CURB HIV-AIDS

Since 2014 much scientific research has focused on CRISPR/Cas9[21], which is "an adaptation of an elegant, naturally occurring gene splicing mechanism" (Kirtley, 2016). CRISPR/Cas9 is "a unique technology that enables geneticists and medical researchers to edit parts of the genome by removing, adding or altering sections of the DNA sequence" (Your Genome, 2016). It is a new technology that is faster, cheaper and more accurate than previous techniques of editing DNA and has a wide range of potential applications. It is further known that

> …depending on whether the goal is to obliterate gene function or introduce specific changes in the DNA sequence, different modifications of the CRISPR/Cas9 system are used. The system has worked in almost every organism tested, including organisms previously resistant to more traditional forms of DNA manipulation (Kirtley, 2016).

The usage of this technology and its potential for solving a number of human problems is significant. For example, already the producers of yoghurt are testing its use in the protection of yoghurt-making bacteria "from infections that can ruin large batches of yogurt" (Ibid.). Agribusiness establishments need it "to create genetically modified livestock and crops" (Ibid.). There has been some reasonable progress in the potential that lies in the technology to produce herbicide-resistant crops, through genome editing, without introducing a foreign DNA into the modified plant. In 2014, "…scientists used CRISPR to precisely target two genes in cynomolgus monkeys (a variety of macaque), the first time researchers were able to selectively disrupt genes in primates" (Niu, et al., 2014). Through additional research, scientists have shown that "…a mutation associated with tyrosinemia, a human metabolic disease, could be corrected in an adult mouse using CRISPR/Cas9 to fix the mutation" (Yin, et al., 2014). In other words, there is now hope that viral diseases that remain devastating due to the mutation of the virus in the human body, such as HIV-AIDS, may soon be tackled through similar approaches.

There is on-going research on the possibility of using CRISPR/Cas9 to create gene-drives with which "…scientists could eradicate vector-borne diseases such as yellow fever, malaria or Zika by engineering disease-free mosquitoes specially designed to take over the entire mosquito population in a few generations" (Kirtley, 2016). Such a development "could

[21]CRISPR stands for "Clustered Regularly Interspaced Short Palindromic Repeats," while Cas9 stands for "CRISPR-associated" and the number 9 is the protein enzyme's serial number in the scientific research series. There are a number of Cas enzymes, but the best known is Cas9, which comes from Streptococcus pyogenes.

have an enormous public health benefit" (Ibid). However, there is need to proceed with great caution, "…since the release of these organisms could have unintended ecological consequences as there is no way to control the genetic drift of the engineered mosquitoes once released into the wild." But suppose scientific research would develop means for such control for genetically engineered mosquitoes; the world would be a much better residence for humans, with such devastating diseases completely eradicated. There may also be a possibility that the envisaged genetically modified mosquitoes may cause a positive ecological impact.

The most significant area of interest is the potential for CRISPR/Cas9 emerging as an effective means of treating HIV-AIDS. Kirtley explains how "…the CRISPR/Cas9 system has generated so much enthusiasm is its potential for use in human gene therapy protocols" especially since it can be used "to correct mutations in human adult stem cells or induced pluripotent stem (iPS) cells."[22] He further explains that

> These edited cells could then be transplanted back into the patient to treat diseases. In basic laboratory experiments, scientists have already used CRISPR/Cas9 to excise HIV from the DNA of human cells and to correct a mutation that causes a blood disorder called Fanconi's anaemia in iPS cells that are then differentiated into hematopoietic (blood) stem cells. Although this has not yet been tested in human patients, these now-healthy stem cells could in theory be transplanted back into a human patient to reconstitute a healthy blood cell population. Researchers are exploring a similar technique to re-engineer patients' blood cells to become HIV-resistant (Kirtley, 2016).

This is where research into genetic therapy for HIV-AIDS begins to give much hope to humanity on the possibility of a permanent solution to the pandemic. The moment it becomes possible to re-engineer the blood cells so that people become HIV-resistant, humanity will become free from one of the most dehumanising diseases ever known to human societies. It will be a solution to the desperation often expressed across the world through voices represented by the statement that

> AIDS is a global scourge that has killed millions, has brought heartache and suffering to millions more, and is likely to continue its grim lethal crescendo for the foreseeable future. The success of HAART in controlling HIV-1 offers hope, but the difficulties of this therapy and the ability of HIV-1 to mutate into drug-resistant variants necessitate continuous development of new therapies. The sobering results of clinical gene therapy trials for AIDS are cause, not for despair, but for reflection. Gene delivery may yet have a role to play in the fight against AIDS: continuing work in tissue culture and animal models encourages cautious optimism (Strayer, et al., 2005).

As the preceding review reveals, scientific research on genetic therapies for HIV-AIDS have been largely fragmented and uncoordinated among the various institutions involved. In order

[22] Induced Pluripotent Stem Cells (iPS) are derived from skin or blood cells that have been reprogrammed back into an embryonic-like pluripotent state that enables the development of an unlimited source of any type of human cell needed for therapeutic purposes. For example, iPS cells can be prodded into becoming beta islet cells to treat diabetes, blood cells to create new blood free of cancer cells for a leukaemia patient, or neurons to treat neurological disorders. Source: https://stemcell.ucla.edu/induced-pluripotent-stem-cells

to develop an effective solution, there is need for coordination and linkage among investigators and institutions.

Discussions on CRISPR indicate that it may offer a solution sooner than the other attempts, although it may be too early to judge at this point. In April 2015, a research group reported results of their research on "…an attempt to alter the DNA of non-viable human embryos using CRISPR to correct a mutation that causes *beta thalassemia*, a lethal heritable disorder. The experiments resulted in changing only some of the genes, and had off-target effects on other genes" (Liang, et al., 2015). From this statement, CRISPR is yet to reach the optimum level where it can be applied as a reproductive technology or for gene editing in embryos. The Chinese scientists summarised their findings as follows:

> Repair template of HDR can be either the endogenous homologous gene or exogenous DNA sequence. This competition between exogenous and endogenous sequence complicates the analysis of possible gene editing outcomes make it difficult to predict the consequence of gene editing. Furthermore, mosaicism and mutations at non-target sites are apparent in the edited embryos. Taken together, our data underscore the need to more comprehensively understand the mechanisms of CRISPR/Cas9-mediated genome editing in human cells, and support the notion that clinical applications of the CRISPR/Cas9 system may be premature at this stage (Liang, et al., 2015).

Granted that clinical applications of this technology are still considered premature by experts as outlined above, there seems to be likelihood of a more thorough development after further research and tests. Such research may produce solutions to various threats, including HIV-AIDS.

While notable strides have been made with regard to the gene editing research, significant security concerns have been raised which may either slow down on-going research or refocus it positively. In the United States, the National Intelligence has recently included gene editing among weapons of mass destruction because of its ease of use and access. James R. Clapper, the Director of National Intelligence, in his report to the Senate Armed Services Committee on 9th February 2016, wrote:

> Research in genome editing conducted by countries with different regulatory or ethical standards than those of Western countries probably increases the risk of the creation of potentially harmful biological agents or products. Given the broad distribution, low cost, and accelerated pace of development of this dual-use technology, its deliberate or unintentional misuse might lead to far-reaching economic and national security implications. Advances in genome editing in 2015 have compelled groups of high-profile US and European biologists to question unregulated editing of the human germ-line (cells that are relevant for reproduction), which might create inheritable genetic changes. Nevertheless, researchers will probably continue to encounter challenges to achieve the desired outcome of their genome modifications, in part because of the technical limitations that are inherent in available genome editing systems (Clapper, 2016).

Even when Clapper's report does not mention CRISPR directly, the description clearly has this technology in mind as one that the intelligence agencies are concerned about. And, although

they do not discuss financial implications, the report is likely to influence the possibility or otherwise of any further funding and support from the US government and its allies in global politics. There is, therefore, need for the scientific researchers to bring clarity to the US government and other governments as to the potential benefits of genetic technologies, especially with regard to therapies for devastating illnesses, in order that research funds may not be withheld. This is in view of the possibility of the US government, and other governments in the developed world, proverbially throwing out the baby with the bathwater.

In recent research in CRISPR/Cas9, focus has been on seeking to improve its efficacy, especially with regard to HIV. "Given its popularity and availability, CRISPR dominates genome-editing predictions. CRISPR-based systems will continue to improve incrementally…" (Tachibana, 2019). It appears that the practice of using CRISPR to correct disease-causing mutations is growing, and this is where it gives hope to sufferers of a constantly mutating virus such as the HIV. Already trials are going on for inherited blindness in humans. Recently, for the first time, doctors in the US used the gene-editing technique CRISPR to try to treat a patient with a genetic disorder that causes sickle cell disease. Victoria Gray, the first patient to be publicly identified as one involved in a study testing the use of CRISPR for a genetic disease, said she had always "hoped that something would be done" and that she was happy over that possibility. "But it probably will take months, if not years, of careful monitoring of Gray and other patients before doctors know whether the treatment is safe and how well it might be helping patients" (Stein, 2019). Reports like this are evidence that the technology will only get better with time, and will eventually apply to such illnesses as HIV-AIDS too.

3.7. CONCLUSION

In this chapter the discourse has focused on the need for clarity of meaning on the concept of "genetic therapy" in order to appreciate what the subject under study is. I have also sought to provide an understanding of the various types of genetic therapies that already exist and how they are used, in order to clarify on the potential benefits and challenges posed by the new genetic technologies. The chapter ends with a discussion on the potential of genetic therapies to curb HIV-AIDS, which is the focus of this dissertation. The main idea in the chapter is that, despite the challenges that are posed by genetic therapies in their current state of research, trials and development, they remain possibly the best remedies for devastating diseases if the challenges are eliminated through further research. Therefore, research into genetic therapies, especially with a sharp focus on finding treatment for HIV-AIDS, should be

encouraged through adequate funding and enhancing collaboration among scientists, institutions, and governments.

CHAPTER 4: UTILITARIANISM

4.1. INTRODUCTION

In this chapter I give a comprehensive motivation and justification for the choice of utilitarianism as a philosophical-ethical approach in this research, as I also recognise the existence of alternative ethical systems. I follow this with a review of the ethical theory of utilitarianism as stipulated primarily by Jeremy Bentham and John Stuart Mill, as well as contemporary philosophers. The focus is the application of utilitarianism to bioethics, especially the new genetic enhancement therapies available for resolving human disease burdens, especially HIV-AIDS. The ethics theory of utilitarianism is the framework within which reflections are done on genetic therapies, while it is, at the same time, also a criterion for evaluation.

4.2. MEANING AND MOTIVATION FOR THE CHOICE OF UTILITARIANISM

In the first chapter of this dissertation, the ethics theory of utilitarianism was introduced as the most appropriate theory for assessing genetic therapies for the problem of HIV-AIDS in Africa. The question of how the perceived benefits of research into genetic therapies would benefit the people of Africa dominates the study. Despite the availability of various approaches to ethical decision-making, the question of benefit-sharing for the majority of the people is fundamental. It is the point of benefit sharing, with minimum negative consequences, that makes utilitarianism the most suitable ethical approach and method of ethical discourse. The theory of utilitarianism as developed by Jeremy Bentham (1748-1832) and John Stuart Mill (1806-1973) will be the lens through which the relevance of genetic therapies will be examined.

In order to proceed with clarity, it is necessary to understand what the term ‘utilitarianism’ means. As Van Niekerk explains,

> Utilitarianism refers to an ethics theory that, strictly speaking, forms a sub-category of a group of theories known as *consequentialism*. Consequentialism as an approach to moral theorizing simply means that the consequences of actions are to be taken, and taken exclusively, as the only concern in terms of which the moral status (i.e. the moral rightness or wrongness) of an action is to be decided (Van Niekerk, 2017).

He cites the classic example of the manner in which the Second World War was brought to an end through “…the explosion of two atomic bombs in the cities of Hiroshima and Nagasaki in Japan in August 1945…” (Ibid.). The argument here is that, although death and suffering was inflicted on the immediate victims, worse consequences were effectively prevented by the immediate surrender of Japan upon the bombing of the two cities. The matter of the strengths and weaknesses of the ethics theory of utilitarianism will be discussed in a subsequent section

of this chapter. For the time being, further reflections on the meaning of utilitarianism will be sought.

According to Blackburn, utilitarianism is an ethics theory that teaches the maximising of utility or happiness through life and action. He also says it is "the view of life presupposed in most modern political and economic planning, when it is supposed that happiness is measured in economic terms," and quotes from J. S. Mill the statement that "actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness" (Blackburn, 2008). Merriam-Webster defines utilitarianism as "a doctrine that the useful is the good and that the determining consideration of right conduct should be the usefulness of its consequences; specifically a theory that the aim of action should be the largest possible balance of pleasure over pain or the greatest happiness of the greatest number" (Merriam-Webster, 2019). The same idea is defined as "the doctrine that the morally correct course of action consists in seeking and attaining the greatest good for the greatest number, that is, in maximizing the total benefit resulting, without regard to the distribution of benefits and burdens" (Collins English Dictionary, 2012) and further explained as "…a system of ethics according to which the rightness or wrongness of an action should be judged by its consequences. The goal of utilitarian ethics is to promote the greatest happiness for the greatest number" (Ibid.). The same line of thought is carried by Business Dictionary which defines utilitarianism as

> …an ethical philosophy in which the happiness of the greatest number of people in the society is considered the greatest good. According to this philosophy, an action is morally right if its consequences lead to happiness (absence of pain), and wrong if it ends in unhappiness (pain). Since the link between actions and their happy or unhappy outcomes depends on the circumstances, no moral principle is absolute or necessary in itself under utilitarianism (Business Dictionary, 2017).

The definitions provided place emphasis on happiness, as a result of an action, being a criterion for deciding that a course of action is either good or bad, and right or wrong. It is also important that the envisaged happiness be beneficial to the greatest number possible in a given context. In the assumption that actions that promote good health also, at the same time, promote happiness, a deliberate choice is made to apply utilitarianism in assessing the relevance of genetic therapies for HIV-AIDS in Africa.

There are other ethics theories, such as virtue ethics and deontology, which can be applied in the assessment of genetic therapies. From previous discussions in the first chapter of this dissertation, virtue ethics places emphasis on the character of the moral agent in order to form personal identity which, in turn, leads to judgement of the agent's action in the principle that good actions are results of the actions of good people. In other words, a good person has

good habits which guarantee good results. But one may argue that virtue ethics creates a situation in which one has to consider results in order to judge an action virtuous. In this sense, then the practical value of virtue ethics is in its link with utilitarianism. Similarly, there is deontology as an ethics theory which is based on the agent's moral duty, and where the right actions are those that maximise the good, based on commitment to duty as the means of judging any action. But rules and duties are always intended to achieve certain outcomes, which are viewed to be good, hence the link with utilitarianism.

My argument is that before the research is carried out and concluded, genetic therapies cannot be judged to be either good or bad speculatively. Similarly, rules cannot be set for or against the genetic therapies without already knowing with absolute certainty the consequences of these therapies. It is reasonable to use conclusive scientific evidence of their goodness or badness to, in turn, make rules on their use. In other words, the purpose and efficacy of the therapy must be potentially good for human health. Given the disease burden of HIV-AIDS as described in the first chapter, and in the assumption that the resultant pain is intrinsically evil, a utilitarian assessment is proposed to be the most reasonable approach. In any case, it is also reasonable to assume that any effective and efficient relief from the burden of HIV-AIDS is intrinsically good for Africa in general and Kenya in particular.

4.3. ALTERNATIVE APPROACHES TO MORAL REASONING

There are a number of alternative ethics theories and systems by which the relevance of genetic therapies for the treatment of HIV-AIDS in Africa may be assessed, and it is worth the effort to seek to understand at least some of them, even if not all. Time and space do not allow for the consideration of all the ethics systems available, hence my preference to review only the Aristotelian and the Kantian theories. I shall begin with Aristotle's virtue ethics.

Aristotle (c.384–c.322) views the ultimate purpose of human life, which is happiness, as the goal of ethics. For him, all other goods are temporal; only happiness is ultimate. So the main question for any human being is how to attain happiness. For Aristotle, both pleasure and honour fail the test of ultimately attaining happiness because, while pleasure reduces human beings to the level of animals, honour "places too much emphasis on the praise of others." He concludes that the true means to happiness is virtue, which involves both habit and choice. Based on our choices in the past, we develop a virtuous character by which we make current choices. Indeed for Aristotle, "the virtuous choice was the mean between two extremes: excess and defect. For example, between profligacy and insensibility there lies self-discipline; between obsequiousness and coldness there lies friendliness" (Spark Notes, 2017).

We may then ask, what is virtue? Cambridge dictionary defines virtue as "…a good moral quality in a person, or the general quality of being morally good" (Cambridge Dictionary, 2017). Blackburn defines virtue as "a trait of character that is to be admired; one rendering its possessor better, either morally, or intellectually, or in the conduct of specific affairs" (Blackburn, 2008). For Aristotle, a virtue is "a trait of character that enables a person to flourish."[23] Hume goes a little further and says, "…a virtue is a trait of character with the power of producing love or esteem of others, or pride in oneself, by being useful or agreeable to its possessors and those affected by them" (Ibid). For Kant, however, "…virtue is purely a trait that can act as a handmaiden to the doing of duty, having no independent ethical value…" (Ibid.). Virtue ethics takes the notion of virtue as the foundational factor in morality. Rather than look at action as the producer of good, or at duty to provide rules for human action, virtue ethics views the qualities of moral goodness as the producers of human happiness.

It is useful, at this point, to turn to Beauchamp and Childress for an application argument with regard to health professionals. They argue against replacing virtuous judgements of health care professionals with rules, codes, or procedures. Their opinion is that

> Rather than relying on institutional rules and government regulations to protect human research subjects, for example, the most reliable protection is the presence of an "informed, conscientious, compassionate, responsible researcher." The claim is that character is more important than conformity to rules and that a premium should be placed in inculcating and cultivating the virtues through educational interactions and guidance by role models. Persons who are respectful, benevolent, and just reliably perform right actions: The respectful person respects others; benevolent persons act beneficently; and just persons conform their behaviour to the rules of justice. Even if a virtuous person makes a mistake in judgement, leading to a morally questionable act, he or she is less blameworthy than a habitual offender who performed the same act (Beauchamp & Childress, 2013).

From the above reasoning by Beauchamp and Childress, the great value of virtue ethics is in the transformation of the character of the health care practitioner. It seems, then, that virtue ethics can be applied as a motivational theory with which to educate researchers on the right virtues or values to inculcate in themselves as they proceed with human subjects in biomedical research, including genetic therapies. In addition, virtue ethics enhances human relationships as a fundamental reason for getting involved in solving human problems, rather than doing so only on the basis of commitment to duty. However, there is much limitation in attempting to

[23] In *Nicomachean Ethics* II 6, Aristotle points out virtue as the mean in the various situations. For example: "…with respect to acting in the face of danger, *courage* is a mean between the excess of *rashness* and the deficiency of *cowardice*; with respect to the enjoyment of pleasures, *temperance* is a mean between the excess of *intemperance* and the deficiency of *insensibility*; with respect to spending money, *generosity* is a mean between the excess of *wastefulness* and the deficiency of *stinginess*; with respect to relations with strangers, *being friendly* is a mean between the excess of *being ingratiating* and the deficiency of *being surly*; and with respect to self-esteem, *magnanimity* is a mean between the excess of *vanity* and the deficiency of *pusillanimity*." Source: http://www.philosophypages.com/hy/2s.htm

use virtue ethics alone to justify why research into genetic therapies is necessary, and why African governments should prioritise it in budgeting and resource allocation. One such limitation is the apparent need to relate the required expenditure in research with potential outcomes, which cannot be done on the basis of virtue ethics; at least not exclusively and comprehensively.

It is worthy of note that other thinkers also point out to a link between virtue ethics and the practice of medicine. Walker explains that

> An affinity between medicine and virtue ethics can be traced to ancient Greek philosophers: Plato, who praised Hippocrates' method for understanding the body as a model for efforts to understand the soul and Aristotle, who compared the goal of medicine as health with the goal of virtue as human happiness or flourishing. Aristotle criticized the idea that the physician's aim was health as an abstract idea, but rather emphasized that the goal was *human* health, and more specifically the health of the physician's individual patients (Walker, 2010).

There is a clear emphasis on the care of the patient as an individual through the exercise of practical wisdom based on the character of the physician.

In discussing Kantian ethics, Sjöstedt-H presents a popular saying among philosophers, "You can philosophise with Kant, or philosophise against him, but you cannot philosophise without him" (Sjöstedt-H, 2007). Immanuel Kant (1724-1804) can be classified as one of the most influential of all philosophers, perhaps equal in influence to Socrates, Plato and Aristotle. Kant argues that morality is deontological, which means moral acts are done because they are good in themselves, and not because they cause good consequences. For instance, when both necessity and opportunity direct one to steal food to feed a hungry family, we hold and uphold the duty to avoid theft, "…not because we may end up in prison, nor because we may feel regret or remorse, but because it is a wrong thing to do *per se* (in itself)." Whereas in utilitarianism we would assess the action based on the pleasure it would cause and the pain it would reduce or alleviate, in moral deontology we are bound to abide by duty. Kant teaches that "humans have reason above instinct, and this means that our motivations go beyond mere pleasure." In this regard, the function of reason is not pleasure or happiness, but "to produce a will that is good in itself (not good for something else, such as happiness)" (Sjöstedt-H, 2007). Kant argues for the following of the Categorical Imperative as not doing so would mean that one acted for one's own pleasure. This would mean that one is misusing reason – being irrational. The Categorical Imperative of Kant teaches two maxims: the first one is '*I ought never to act except in such a way that I can also will that my maxim should become a universal law'* (Kant, 1956), while the second one is '*Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end'* (Kant, 1956). The first maxim requires us to treat others as we

ourselves would like to be treated, while the second one requires us to treat people as ends in themselves, and not as means to achieving other objectives for ourselves. In the context of this research, Kantian ethics is applicable to the ethics of research in genetic therapies in so far as affirming human dignity goes. However, as a theory for assessing their relevance, the theory would have minimal applicability into the discourse, because it does not address any potential or perceived impact.

4.4. A REVIEW OF THE THEORY OF UTILITARIANISM

A general understanding of utilitarianism is that morality is primarily concerned with maximising happiness and minimising pain and misery. This means that an action is judged to be right when it affirms this principle, and wrong when it negates the same principle. Of course, when it does neither, then it is judged to be neutral. There are various notions of utilitarianism worthy of looking into in order to appreciate the theory in so far as it relates to genetic therapies. One of the notions is hedonistic utilitarianism which generally views pleasure as the only good to be cherished and enhanced, and pain as the only evil to be fought or prevented. Good, in this context, is defined as "that for which people feel approval" (Ewing, 1948). On the basis of an empirical argument, Ewing points out the weakness of defining "good" only on the account of people's approval. He says, "…it may well be the case that people only feel approval for the kinds of action and qualities of character which will in general bring pleasure to someone; but it is certainly not true that the approval is proportionate to the amount either of actual or of anticipated pleasure"[24] (Ibid). In other words, the level of actual pleasure may be quite far off from the mere fact of pleasure hence people's approval may not be a valid measure of validating what is good.

So, one may ask, what is the nature of utilitarianism? What are its basic concepts? Henry R. West, in discussing this concept, explains that utilitarianism is an effort to provide an answer to the practical question "What ought a person to do?" to which the answer is that "a person ought to act so as to produce the best consequences possible" (West, 2015). West continues to say,

[24] Ewing (1948:101) argues "Suppose, in the first place, I were offered as alternatives thirty years more of life as pleasant as the most pleasant week I have ever experienced on condition that I went mad or could only enjoy the pleasures of a pig and twenty-nine years of life equally pleasant with the pleasures of a good and reasonably cultivated human being. Would it not be rational and right to choose the second alternative rather than the first even though the pleasure was exhypothesis less and even if my choice neither increased nor diminished the pleasures of others?" He further gives an example: "…suppose two men who are deriving at the moment equal pleasure, one from enjoying the company of friends he loves and the other from torturing enemies he hates (West, 2015). In both examples, there is a clear difference between pleasure as an end and pleasure as a means to an end.

> In the notion of consequences the utilitarian includes all of the good and bad produced by the act, whether arising after the act has been performed or during its performance. If the difference in the consequences of alternative acts is not great, some utilitarians do not regard the choice between them as a moral issue. According to Mill, acts should be classified as morally right or wrong only if the consequences are of such significance that a person would wish to see the agent compelled, not merely persuaded and exhorted, to act in the preferred manner (West, 2015).

Both Bentham and Mill were hedonists who sought to establish an understanding of happiness as a balance of pleasure over pain, and that these two feelings alone are of intrinsic value. Utilitarianism argues for the possibility of comparing "…the intrinsic values produced by two alternative actions and to estimate which would have better consequences" (Ibid). Bentham believed in a hedonic calculus by which a moralist "…could sum up the units of pleasure and the units of pain for everyone likely to be affected, immediately and in the future, and could take the balance as a measure of the overall good or evil tendency of an action" (Ibid). In other words, whenever one has to compare values that derive from alternative acts, it becomes necessary to apply Bentham's hedonistic calculus in order to arrive at what is good.

As a consequentialist ethics theory, utilitarianism takes seriously the potential or actual outcome of every action, whether such a consequence is observable during the action or at the end of it. There has to be a clearly discernible difference between the consequences of acting in a certain way and acting differently, for it is that difference that determines whether the act is moral or amoral. In this regard, according to Mill, "…acts should be classified as morally right or wrong only if the consequences are of such significance that a person would wish to see the agent compelled, not merely persuaded and exhorted, to act in the preferred manner" (West, 2015). This means that, if an act is to be judged to be good, it has to be so good that legislation would probably compel such action from those responsible for it. Conversely, if an act is to be judged to be bad, legislation would prohibit it.

It is still necessary to seek a deeper understanding of the concept of happiness and unhappiness in utilitarianism since it is the epicentre of this theory. Hodder endeavours to explain:

> By happiness, therefore, is intended pleasure and absence of pain; meaning to imply by this that not only those acts cause happiness which give someone pleasure, or which actually free him from pain, but those also which lessen his unhappiness. By unhappiness is intended pain, including every irksome and uncomfortable state of mind whatsoever, and implying that not only those acts cause unhappiness which actually give(s) one pain, but those also which curtail his happiness (Hodder, 1892).

In other words, it matters that an act leading to happiness has the dual consequences of causing pleasure and freeing one from pain or harm. It also matters that an act leading to unhappiness be identified as one that causes pain and discomfort in either the body or the mind, or both. The

friend to be embraced is happiness that leads to pleasure and freedom from pain; the enemy to be fought is unhappiness that causes pain and discomfort. But what do utilitarians mean when they talk of the word 'pain'? They have to use quantitative words like 'bigger' or 'more' to create a comparison with the desired opposite. So the pain could be 'bigger' than a certain pleasure; or that an act brings about 'more' pain than pleasure.

In discussing the historical development of utilitarianism[25] Bertrand Russell records of Bentham's use of the words 'pleasure' and 'happiness' synonymously, and held them as good, while holding 'pain' as bad. He says, "Therefore one state of affairs is better than another if it involves a greater balance of pleasure over pain, or a smaller balance of pain over pleasure. Of all possible states of affairs, that one is best which involves the greatest balance of pleasure over pain" (Russell, 1948, p. 802). From a calculus of pleasures and pains, Bentham developed a strong belief in equality, which caused him "to advocate equal division of a man's property among his children" (Ibid). This idea is supported by Nathanson who explains that

> Utilitarians believe that the purpose of morality is to make life better by increasing the amount of good things (such as pleasure and happiness) in the world and decreasing the amount of bad things (such as pain and unhappiness). They reject moral codes or systems that consist of commands or taboos that are based on customs, traditions, or orders given by leaders or supernatural beings. Instead, utilitarians think that what makes a morality be true or justifiable is its positive contribution to human (and perhaps non-human) beings (Nathanson, 2017).

Nathanson proceeds to explain the necessity of knowing three things that are important for a reasonable understanding of the theory of utilitarianism: "what things are good and bad; whose good (i.e. which individuals or groups) we should aim to maximize; and whether actions, policies, etc. are made right or wrong by their actual consequences (the results that our actions actually produce) or by their foreseeable consequences (the results that we predict will occur based on the evidence that we have)" (Nathanson, 2017). This is necessary because, although utilitarianism appears simple due to its only one evaluative principle, it has various nuances to it, such as act utilitarianism and rule utilitarianism, which may make it complicated.

What is good may not be limited only to happiness, but may extend to include other aspects of life such as health, freedom, friendships, food, knowledge, wealth, and a few more, all of which may fit into what Nathanson refers to as 'well-being'.[26] A lack of these items, then, diminishes well-being. On the concern over whose good should be maximised, utilitarians think of individuals, specific groups, and those who are affected by the subject of moral

[25] According to Russell, utilitarianism was initially advocated by Hutcheson in 1725, long before Bentham whose main contribution in the development of the theory was in "his various application to various practical problems" (Russell, 1948, pp. 802-3).

[26] The nature of well-being is discussed in great detail in chapters 1-4 of Russ Shafer-Landau, The Fundamentals of Ethics, 2nd Edition, Oxford University Press, 2012 (Shafer-Landau, 2012).

reasoning. At the individual level, one only needs to consider what would enhance one's well-being, like in ethical egoism.[27] For instance, an individual in a restaurant may opt to eat either a pizza or a hamburger, and has no obligation to consider the preference of any other person; he or she simply chooses what is likeable and most suitable for his or her well-being. But if the same consideration has to made by a group, then there may arise a situation in which probably eight out of ten persons select to eat pizza, and only two prefer hamburgers. If only one type of food is to be prepared and served for the entire group, then the serving of pizza to the entire group will bring the greatest fulfilment to the greatest number in the group. In overriding the preferences of the two who would want hamburgers, the justification would be that at least they have something good to eat, and they have not been left to go hungry, which would have diminished their well-being. At the furthest end, in considering all affected persons, it would be important to focus on the fact that there are people who are hungry and need food to eat. Providing food for them would be the beneficial action to take, over against denying them food. Similarly, if certain people are sick of a disease for which treatment is available, it is a morally good act to provide the necessary treatment to them, rather than deny them the same. In relation to the subject of this research, the relevance of genetic therapies should be assessed in the context of the needs of affected people, rather than at group or individual levels. I will return to this aspect in greater detail at a later stage.

Deciding whether moral judgements should be "based on the actual consequences of actions or their foreseeable consequences" is a cause for differences among utilitarians. Nathanson refers to J. J. C. Smart who explains this difference by imagining the action of a person who, in 1938, saves someone from drowning:

> While we generally regard saving a drowning person as the right thing to do and praise people for such actions, in Smart's imagined example, the person saved from drowning turns out to be Adolph Hitler. Had Hitler drowned, millions of other people might have been saved from suffering and death between 1938 and 1945. If utilitarianism evaluates the rescuer's action based on its actual consequences, then the rescuer did the wrong thing. If, however, utilitarians judge the rescuer's action by its foreseeable consequences (i.e. the ones the rescuer could reasonably predict), then the rescuer—who could not predict the negative effects of saving the person from drowning—did the right thing (Nathanson, 2017).

In the story narrated above, the rescuer could not possibly foresee the future bad consequences of saving the drowning man, and it would not be fair to judge the rescuer of acting wrongly. What was foreseeable was that the rescue may allow someone to live who would otherwise drown.

[27] "Ethical egoism claims that it is necessary and sufficient for an action to be morally right that it maximizes one's self-interest" (Shaver, 2015).

Although utilitarians unanimously focus on producing the best overall result, they disagree on how to make that possible. They are divided into act utilitarians and rule utilitarians. For act utilitarians, the focus is on the greatest net utility resulting for an action. The right action is that which will cause more well-being than other actions would. For rule utilitarians, a specific action should be in conformity with a specific rule, and that specific rule is justified because it leads to greater well-being. As Nathanson further affirms,

> The key difference between act and rule utilitarianism is that act utilitarians apply the utilitarian principle directly to the evaluation of individual actions while rule utilitarians apply the utilitarian principle directly to the evaluation of rules and then evaluate individual actions by seeing if they obey or disobey those rules whose acceptance will produce the most utility (Nathanson, 2017).

This distinction is important for the creation of a balance in moral decision-making that is based on a utilitarian theory. On the one hand, act utilitarianism delivers moral agents from dry rule-based moralities and making moral judgements more objective. On the other hand, while rule utilitarianism tends to maximise utility, it ends up dissolving into act utilitarianism because, in the end, it is the action taken that actually matters.

There is need to develop further the aspects of utilitarianism that attract criticism and the counter-arguments advanced in its favour. The broad theory of consequentialism is the view that "the value of an action derives from the value of its consequences" (Blackburn, 2008). It runs in contrast to virtue ethics which places emphasis on the character of the moral actor, and deontology which focuses on the intrinsic value of an action. The most prominent version of consequentialism is utilitarianism, which "…was first formulated by the English philosopher Jeremy Bentham (1748-1832) towards the end of the eighteenth century and refined by his successor John Stuart Mill (1806-1873) in the nineteenth century." Christopher Falzon explains the foundation of utilitarianism as follows:

> Human beings, for utilitarianism, are primarily creatures that feel; creatures that seek to maximize pleasure and avoid pain. The role of reason is now to calculate what we can do to best bring about pleasure and avoid pain. And morality is now a matter of the consequences of our acts, of doing whatever will maximize the amount of pleasure, of happiness, in the world (Falzon, 2002).

In consequentialism, of which utilitarianism is only part, the rightness or wrongness of a moral act is judged by the kind of consequences it produces. Only consequences matter and are to be considered when weighing moral acts. In utilitarianism, right acts are discerned only on the basis of the good results they bring about. No consideration is made of either the character of the person who does the act or the motive behind the act. Certain questions may be raised with regard to the morality of an act, questions on whether the individual recipients of the act are treated within the realms of equality, justice, and fairness, whether their rights

are violated or respected, and whether they are treated as means for achieving other ends. Such questions are ignored in utilitarianism and considered irrelevant. What matters is that the results of the act should maximize happiness. Furthermore, in strict impartiality utilitarian acts include every affected person, such that not even the moral agent's happiness would receive special attention. In other words, in utilitarianism, three features stand out as fundamental: only happiness matters, only consequences matter, and moral acts must be applied impartially on all.

The features of utilitarianism discussed in the above paragraph are the prominent ones which are strongly criticised by opposing philosophers. Rachels and Rachels give strong criticism of these characteristics of utilitarianism as reasons for rejecting the theory. First on the line is the notion that happiness is the only factor that matters intrinsically, such that pleasure is the only good, and pain the only bad. Rachels and Rachels argue against hedonism in its false assumption that "things are good and bad only in terms of how they make people feel" (Rachels & Rachels, 2012). They point out that other things, such as artistic creativity and friendship, are also of intrinsic value to us. They cite the example of the loss of hands for a young pianist, and point out that the loss of hands is not bad simply because it makes the pianist unhappy, but rather because of her loss of talent. Similarly, a friend who ridicules one behind one's back is wrong even if one is not aware of the ridicule, and cannot be excused merely because the subject of ridicule was not aware. Through these arguments, Rachels and Rachels portray as mistaken the utilitarian notion that only happiness or unhappiness of the consequences of an action matter. It is worth pointing out that contemporary utilitarianism is no longer strictly confined to hedonistic assumptions, but has streamed in new strands like "preference utilitarianism, where good is whatever individuals prefer, and ideal utilitarianism, where good involves a number of ideals, including friendship, pleasure, and aesthetic enjoyment" (Rachels & Rachels, 2012). This is especially so because quantifying various pleasures and pains is not easy. For instance, the joy of parenthood cannot be equated with the joy of eating something sweet. Peter Singer is an example of a philosopher who once held the preference utilitarian position, and would argue that

> …the consequences to be promoted are those which satisfy the wishes or preferences of the maximum numbers of beings who have preferences. In other words, the more people get what they want, the better, from a moral point of view, the world is. The more people's desires are frustrated, the worse the world is. It is only morally right to frustrate the preferences of others if by so doing we enable more beings to satisfy their preferences. Actions should not be judged on their simple pain-and-pleasure outcomes, but on how they affect the interests, the preferences, of all beings involved (The Tablet, 2019).

It is worth noting that Singer has shifted his position and now aligns closer to the sophisticated hedonistic view of Henry Sidgwick. Singer now believes that "only consciously experienced events matter, although we should construe hedonic experience more broadly than just raw pleasure and pain" (Tomasik, 2016).

The second notion in utilitarianism that receives criticism from Rachels and Rachels is that of consequences as the only thing that matters, which would make utilitarianism seem to ignore matters of justice, individual rights, and moral considerations that look into the past. It is neither fair nor just that an innocent person should not be punished just to stop a race-based riot in a city; the police should not violate a woman's privacy just to make themselves happy; and past events or commitments have a bearing on present moral actions, such that we cannot simply ignore the past. It is practically easier to rely on the past than to predict outcomes and impacts of human actions. The third notion of utilitarianism that Rachels and Rachels challenge is that of strict impartiality which they find too demanding. Equal concern for everyone may require that we change our lifestyles significantly in order to help those who are in need. Besides, the theory's emphasis on happiness for the many seems to ignore the plight of the few. In other words, utilitarianism seems to guarantee nothing for the minority.

Mark Sheskin and Nicolas Baumard have recently criticised utilitarianism, arguing that, "…although people may judge that utility maximization is morally acceptable (in some cases), they do not think it is morally required. Second, people do not think equal utility trade-offs (e.g., sacrificing one life for a different life) are even acceptable" (Sheskin & Baumard, 2016). In other words, in the first statement, what is acceptable is not necessarily required; and in the second one, sacrificing one person's life in order to save another or others is wrong.

The points raised against utilitarianism are worthy of paying attention to, especially the systematic manner in which the issues are raised by Rachels and Rachels. However, there are counter-arguments that not only respond to the points of criticism, but also strengthen a defence of the theory. Firstly, it is not always the case that the most favourable consequences will result when an innocent person is punished, or when an individual's rights are violated, or when one fails to keep a promise. Indeed, a utilitarian argument would propose that treating people justly and keeping promises would normally promote good consequences. But Rachels and Rachels argue that "…once in a while, one can bring about a good result by doing something repugnant to moral common sense" (Rachels & Rachels, 2012). In instances where this is the case, utilitarianism will be "in conflict with common sense" (Rachels & Rachels, 2012). On the other hand, it must be pointed out that the occasional instances are not the norm. Secondly, in order to get over the hurdles of individual moral acts, utilitarianism can be a guide for formulating

rules that can be used to maximise overall happiness. This is what rule utilitarianism is all about. The moral act, in this case, will be one that conforms to the rules, such that the outcome will bring maximum happiness and minimum pain. For instance, the rules that prohibit violation of people's right, the ones that promote justice and fairness, the ones against lying, and the kind in favour of loyalty to friends and family, will also be the rules that result into the greatest happiness. However, although this is tenable, Rachels and Rachels argue that there may be an instance in which "the ideal rules have exceptions," a situation that may arise when "a forbidden act would greatly increase the overall good." Either the utilitarian sticks to the rules, or grant an exception to the rules. Strictly sticking with the rules will move rule utilitarianism into the likeness of another moral theory, other than utilitarianism. It will lead to what J. J. C. Smart (Ibid.) calls "irrational rule worship." Conversely, granting any exception takes rule utilitarianism back to act utilitarianism whose apparent weakness it was intended to resolve. But it must remain clear that the focus of rule utilitarianism is not the rules in themselves, but in the outcomes of actions that conform to those rules. In other words, the utilitarian rules are not an end by themselves but are a means to an end: they are rules that should lead to greater good for the people involved. Rules from which no benefit would accrue are typically not utilitarian rules; they are part of deontological ethics theory.

The arguments presented by Sheskin and Baumard are valid to the extent of the first point they raise that not all that is acceptable is required. But it may be challenged because once an act is found acceptable its usefulness makes it viable for replication in similar contexts. The aspect that needs closer scrutiny is their second point in which they propose that sacrificing one person's life in order to safe another or others is morally wrong. This seems to suit better in a deontological presentation than a utilitarian one. Human experience is full of stories of sacrifice with the intention to save others. This is the stuff of which heroism is composed. A vivid illustration is found in the Christian doctrine of salvation in which Jesus Christ teaches the virtue of love through self-sacrifice in a statement in John 15:13, "Greater love has no one than this; that He lay down His life for His friends." A similar statement is repeated in Romans 5:8, "God demonstrates His own love for us in this: while we were still sinners, Christ died for us." Without getting into the theological arguments related to these statements, the idea that one dies in order to save many is held high as a perfect example for humanity. It blends well with intuitive responses of parents when an offspring is in grave danger: a parent risks drowning in order to safe a drowning child. Similarly, a soldier risks death in war so as to ensure the safety of citizens. Surely, if we say this is wrong, then humanity would behave inhumanly and unnaturally.

A fair evaluation that focuses on all consequences of a moral act, while not dismissing the points of criticism against utilitarianism, will find the theory possessing advantages that make it suitable, especially in dealing with challenges that have severe negative impact on human life and health. It is reasonable to conclude in agreement with Rachels and Rachels that "All values have a utilitarian basis" (Rachels & Rachels, 2012). Although happiness is prominent in utilitarianism, it is not the only value that has intrinsic worth in the theory. Other values such as love, life, freedom, respect, peace, justice, art, and knowledge, also have intrinsic worth that makes them good and beneficial to individuals and societies. The human intuition that harming people is wrong finds a strong anchor in utilitarianism. The theory is easy to apply, as it only requires one to weigh up positive effects of an act against negative ones before making a choice. Additionally, its neutrality on beliefs makes the theory fair and objective to the religious and irreligious alike. And since it seeks to affirm general good instead of individual pursuit, utilitarianism turns out to be democratic in the way it functions for society.

4.5. APPLICATION OF UTILITARIANISM TO NEW GENETIC THERAPIES

The fundamental focus of utilitarianism is to promote actions that can result into the greatest well-being for the greatest number of people. In the context of the scourge of HIV-AIDS in Africa in general and in Kenya in particular, utilitarianism focuses on advocating for such research actions as have the potential of turning around the situation and bringing about desired curative treatment for the disease, thereby relieving individuals, families, communities and nations of devastating burdens. Although no cure is presently ready for clinical testing on human beings, a review of the genetic therapies that are currently undergoing research and development reveals great potential for treatment. I will now endeavour to apply the theory of utilitarianism to the new genetic therapies for HIV-AIDS.

Firstly, there is the magnitude of the problem of HIV-AIDS affecting a huge portion of Africa's population. The infected people are under treatment which only suppresses the symptoms of the disease without actually curing it. Many people still die of HIV-AIDS related complications. A utilitarian approach to this problem looks at whether genetic therapies, if confirmed through research, would bring the greatest well-being to the greatest number. The theory would also seek to confirm if genetic therapies would minimise or even eliminate pain, as far as AIDS-induced suffering is concerned. In this regard, I conclude that a utilitarian approach will enhance the well-being of the infected and the affected people of Africa and the world. The sick individuals will also experience happiness as a result of receiving not only a

cure for their own illness, but also a means for preventing future infections in the respective families.

Secondly, there is the matter of looking into the possibility of foreseeing the potential results, and whether the results will be negative or positive. For example, until scientifically observed or verified, it is not yet known whether any genetic modification of the human genes to make humans resistant to HIV-AIDS infections will in future lead to other forms of genetic abnormalities in humans. For the sake of speculation, suppose in future it is established that all persons whose genes have been modified to make them resistant to HIV infections end up producing one-eyed offspring. Would it be said at that time in future that the implementers of genetic therapies did the wrong action? I would argue that, since such a result cannot be foreseen right now, the implementers should not be judged of wrong action because in the present the focus is on the saving of the millions of human beings whose lives and well-being are severely compromised by the infections. In any case, since research is still on-going, it is possible to eliminate potential extremities in this regard.

I refer here to Albert R. Jonsen for an argument proposing that medical treatment does not focus only on the patient presenting at the clinic but also on the population, and that the population should form the new base for the practice of medicine. And if population is the new base, then it follows that diseases that affect large populations need more serious attention.

> The drift of medicine from a patient base to a population base poses a major challenge to the ethics of medicine, ethics that have grown up around the imperative of competence in patient care. The intrinsic ethical limits to competence, based on undesirability of care from the patient's viewpoint or futility of care from the physician's, are no longer sufficient. Even if a particular patient should judge medical attention to be undesirable, we know that others in the relevant population may be affected by that refusal or need information or therapy that depends on the patient's decision (Jonsen, 1990, p. 35).

If the focus were to remain on only one patient, the medical profession would miss out on the benefits that go to other people. Jonsen argues that even if a particular intervention fails to help a specific patient, it may be of help to another, and cites two examples: "the brain-dead mother perfused for two months to bring her fetus to vitality, or the anencephalic perfused until his heart and liver can be transplanted into another baby." The professional relationship between the doctor and the patient can benefit significantly from the population which should be an integral part of that relationship. This is a new approach that is unfamiliar to both the Hippocratic and Cabotean[28] medicine (Jonsen, 1990, p. 35).

[28] The term "Cabotean medicine" was coined by Jonsen from the name of Dr. Richard Cabot (born 21st May 1868; died 7th May 1939) who served as a member of the Harvard Medical School faculty. Dr. Cabot was the first to emphasize the centrality of clinical competence to the ethics of medicine. For him the professional goodness of a

In application of a utilitarian ethics theory on the relevance of genetic therapies for treating HIV-AIDS, three points seem to emerge: the patient will be cured; the patient's family will be relieved of burdens arising out of having to care for a sick member; the descendants of the patient will be prevented from inheriting the disease; and future societies will be saved from a devastating disease burden. Of course an opponent of utilitarianism may argue that consent will not be obtained from future generations on the modification of their genetic make-up. But such an argument would not stand, given that the change would not lead to their pain, disability, or stigmatisation in any way. Surely, any measure to prevent a future child from inheriting a deadly virus must be in the child's best interests.

4.6. CONCLUSION

Here I have provided a comprehensive motivation and justification for the choice of utilitarianism as a philosophical-ethical approach in this research, while I have also recognised alternative ethical systems such as deontology and virtue ethics. I have reviewed the theory of utilitarianism as postulated by Bentham and Mill. I have attempted to apply the theory of utilitarianism to bioethics, especially the new genetic enhancement therapies available for resolving human disease burdens, especially HIV-AIDS. The ethics theory of utilitarianism is established in this chapter as the framework within which reflections are done on genetic therapies. In the subsequent chapters, I argue in further details on the merits, or otherwise, of the use of genetic therapies through the lens of utilitarianism.

physician consisted of one understanding specific diseases, their causes, signs, symptoms, courses, prognosis, and treatments. This standard of practice is what Jonsen referred to as "Cabotean medicine".

CHAPTER 5: ARGUMENTS AGAINST GENETIC THERAPIES

5.1. INTRODUCTION

The fifth chapter of the dissertation discusses various possible reasons that either have been raised or may be raised against any research and usage of genetic therapies. The goal is to seek to establish if genetic therapies may be more harmful than beneficial if applied in Africa for the treatment of HIV-AIDS, and whether existing remedies may be satisfactory and therefore preferable. The arguments developed are slippery slope, naturalist, distributive justice, lack of consent, and negative theological-ethical arguments. Later on, in Chapter 7 of this dissertation, evaluations and responses are made to these arguments, as well as arguments in support of genetic therapies as discussed in Chapter 6.

5.2. SLIPPERY SLOPE ARGUMENTS

There are arguments known as "Slippery Slope Arguments"[29] that are advanced against genetic therapies on the grounds that such therapies are likely to lead the scientific society into a slippery slope of carrying out other forms of genetic engineering which may be unacceptable to the human society for various reasons. The first argument is that once one level or form of genetic therapy is accepted by the human society scientists will yield to the temptation to move to another level or form. Accepting a second phase of moral action is considered a logical commitment that follows the acceptance of a first phase. For example, there may be fear that using genetic therapy to treat HIV-AIDS may put medical science on a slippery slope in which soon a desire will grow for 'curing' baldness, obesity, poor eyesight, and other kinds of human bodily challenges through genetic therapy. It may lead couples into seeking what has been referred to as "designer babies", a term that generally refers to babies whose physiological, intellectual, psychological characteristics are designed, through genetic manipulation, to meet the exact desires and expectations of parents. Such action may turn out to be actual enhancements of the human population, which may very much be like eugenics and Hitler's idea of a master race. The argument is that accepting genetic therapy for HIV-AIDS logically leads to a commitment to accept genetic solutions to other aspects of human defects. The

[29] The term "Slippery Slope" is commonly used in ethics arguments to refer to situations in which permission to carry on with an act has the potential of leading into morally more precarious acts in the same area or other dangerous acts in other areas but based on similar ethics reasoning. In this chapter, however, I have borrowed the phrase "Slippery Slope Arguments" from McGleenan who discusses the idea in fair detail (McGleenan, 1995). Frederick Schauer defines slippery slope argumentation as one in which "a particular act, seemingly innocent when taken in isolation, may yet lead to a future host of similar but increasingly pernicious events" (Schauer, 1985).

assumption is that there are challenges that humans have which are natural and should be left to continue without interference. I will argue in the next chapter that there is nothing morally wrong with the use of genetic therapies to solve human disadvantages such as the kind mentioned above. Wharam explains that the fear is with reference to "…the development of gene therapy for a valid medical reason, but used for purposes not initially intended" (Wharam, 1999, p. 2). He reports of a discussion that arose at the first Gene Therapy Policy Conference that was sponsored by the Recombinant DNA Advisory committee (RAC) of the National Institutes of Health (NIH) in the United States, where scientists predicted that within two years,

> a researcher will propose a gene-therapy experiment that, although initially aimed at curing disease, could eventually be used to enhance a trait in healthy people (Vogel). One such example has to do with hair loss as a result of chemotherapy. A biotechnology company has developed a means of transferring genes into hair follicles, and is looking for the genes that promote hair growth. The objective is to reverse hair loss due to chemotherapy, which seems to be a worthy cause. If the company is successful and develops a protocol to stop hair loss, cancer patients would no longer have to be bald. However, those opposed to gene therapy worry that many naturally balding people will be receiving gene therapy to treat their hair loss (Wharam, 1999, p. 2).

The example cited here may seem frivolous, or simplistic, but it exemplifies of the kind of fear that is in the minds of people who see gene therapy as an attempt to make superior human beings.

The second slippery slope argument is based on fear of the perceived "historical link between eugenics and genetics," a perception that arises out of "…the Nazi experiment and the scientific and technological advancements of the last decade (of the 1990s)" (McGleenan, 1995, p. 350). This argument says, in the case of euthanasia for example, that "if we allow the legislation of mercy killing of individuals in terminal and intractable pain, we will be taking the first step towards the type of genocide perpetrated by the Nazis" (McGleenan, 1995, p. 352). In other words, if we allow 'A' we will end up in a situation where 'B' is also allowed. If we allow genetic therapy for HIV-AIDS we may end up in a situation where genetic solutions are applied to other kinds of problems, including racial and ethnic problems, and this is what some people fear may lead to something similar to eugenics. I will later argue against the danger of throwing away the baby with the bathwater, so to speak. In other words, it may be incorrect to conclude that just because eugenics is morally wrong does not necessarily make genetic therapy also morally wrong. We cannot reject genetic therapy for such a devastating illness like HIV-AIDS merely because fear the return of eugenics. There should be stronger moral reasons for doing so. Besides, realistically, it is not possible to accurately predict, with certainty, that allowing genetic therapy will ultimately lead to a return of Nazi ways of doing

science. It may be possible, but it is unlikely, and no one can accurately predict its future occurrence.

The third slippery slope argument is based on the general fear of any new frontiers in medicine as potentially more harmful than beneficial to humans. With regard to both somatic and germ-line gene therapy, some would accept one form while rejecting the other. In the United Kingdom, for instance, the Clothier Committee decided that a clear line be drawn between somatic gene therapy and germ-line gene therapy. The report mandated scientific research on somatic gene therapy to continue and stated that "…the development and introduction of safe and effective means of gene modification for this purpose is a proper goal for medical science. We, therefore, recommend that the necessary research continues" (Committee on the Ethics of Gene Therapy, 1992). The Clothier Committee decided to allow and regulate research on somatic gene therapy. However, they declined doing the same for germ-line gene therapy due to insufficient knowledge on possible risks at the time:

> The purpose of gene modification of sperm or ova or cells which produce them would be to prevent the transmission of defective genes to subsequent generations. Gene modification at an early stage of embryonic development, before differentiation of the germ line, might be a way of correcting gene defects in both the germ line and somatic cells. However, we share the view therefore that there is at present insufficient knowledge to evaluate the risks to future generations… We recommend, therefore, that gene modification of the germ line should not yet be attempted (Committee on the Ethics of Gene Therapy, 1992).

The argument here is that, if a mistake is made on germ-line therapy, it will be passed on to future generations; and depending on the magnitude of the mistake, thousands of people may be affected. In case any germ-line gene therapy goes wrong, in this case, terrifying mutations could result, with the possibility of a completely new species of genetically modified humans. This argument seems valid at this stage in the research of gene therapy, which is why, ironically, it may also be reasonable to argue the research should continue in order to not only ascertain the efficacy of the therapy but also take care of all known safety concerns. Of course, the argument also assumes that the regulatory framework on genetic therapy will, for the most part, be either extremely weak or absent altogether, an assumption which is unjustifiable given that regulatory frameworks have previously existed and worked. The question then is, do the potential benefits of germ-line gene therapy outweigh the potential risks that may arise? In the foregoing argument, the answer is in the negative because the effects of gene therapy are too unpredictable at present. Even if genetic therapy successfully cures the disease for which it is designed, other mutations may potentially be introduced into the genetic makeup of the individual. The resulting fear is that, since germ-line gene therapy targets the reproductive cells, any additional mutations that are introduced into the body will be passed on to the next

generation. Theoretically germ-line gene therapy could be used to select for particular physical characteristics regardless of whether they are important for the health of the individual. On a large scale, germ-line gene therapy could result in the selection of characteristics to "improve" the genetics of a population, thereby alienating sections of the human population that are yet to benefit from similar therapy. In the end, the widespread use of germ-line gene therapy may make society less accepting of people who are different or who have a particular disability or genetic condition.

Slippery slope arguments against genetic therapies are worthy of attention in order to address the concerns raised. But, as I will argue later in the next chapter, they are weak and flawed in logic. As I will argue in the evaluation chapter from a utilitarian ethics theory perspective, they are not sufficient to lead to a prohibition of both somatic and germ-line genetic therapies. I must now look at another type of argument raised against genetic therapies, namely naturalist arguments.

5.3. NATURALIST ARGUMENTS

The set of arguments that I herein refer to as naturalist arguments are those that seek to preserve and defend the natural state of human beings, an endeavour in which genetic engineering in general and genetic therapy in particular are perceived as enemies that need to be kept at bay. These arguments are closely related to (but not necessarily based on) the philosophy of naturalism which refers to "the theory that everything in the world and life is based on natural causes and laws, and not on spiritual or supernatural ones" (Hornby, 2010, p. 983). That which is natural is what exists in nature without having been made or caused by humans. A naturalist proposes that something is good because it is natural. In this context specifically, the human body is good as it is, without being re-made, or modified, or materially altered in any way. On the contrary, an act may be judged morally wrong because it is not natural. An argument that states preference of the natural over the unnatural is a naturalist argument.

The first naturalist argument in this category is the one that says genetic therapies are not natural. But what is natural? What sort of idea does the term 'natural' convey? To be natural is to be usual and normal; it is to be ordinary and accepted; it is to be in a state that society is familiar with. One may then ask, is natural good or bad? Is it right to be natural or is it wrong? In what physical, spiritual, emotional, psychological, intellectual, social, or economic state would a human being be considered natural? As far as the physical part goes, it is natural to be tall or dark-haired. But is it natural to take a shower before going to bed in the evening after a

football match, or is the shower a good act that society socialises me to consider as a requirement? Being a worshipper of some supernatural or natural being may be natural; but being a Christian may not be natural. One consciously decides to become a Christian, or a Muslim, or an atheist. Further on, is the process of decision making natural, or is it dependent on socialisation by one's immediate family or society? To be uneducated or unschooled is the natural state of most regular humans. Getting an education, becoming a technician, or becoming a university professor are forms of improvement of the human state. It seems education, for the most part, produces improved human beings, at least intellectually. Similarly, the human body is susceptible to disease and death, which are enemies of human well-being. One of the ways human beings improve eye sight is through the use of spectacles and optic lenses, and one may wonder whether the wearing of such devices is unnatural. It seems plausible that most corrective methods and devices that human beings use in dealing with diseases and defects are not necessarily natural. They are methods, procedures, and devices that have been scientifically developed to alleviate specific human challenges. We ask ourselves, in this context, whether contracting a disease and allowing it to cause death is more natural than seeking treatment against the disease, or if the contrary is true. Of course, genetic therapies are not natural. But this can be ascribed to almost all therapies, save for a few herbal drinks that some people prefer for certain minor ailments. The question is, is it morally wrong to prescribe and make use of unnatural remedies? It seems the argument that genetic therapies are not natural is an argument that may not stand close scrutiny. It seems to need a backup from another argument in order to credibly draw philosophical attention.

The second naturalist argument, closely related to the foregoing one, says that genetic therapies interfere with how humans are constituted. In other words, it is sometimes perceived that genetic therapies are an affront on what I call 'genetic authenticity', a term by which I refer to the presumed genuineness of the human genetic makeup as naturally constituted, a trait that presumably needs to be preserved at all costs. Any development, change, or manipulation that causes the genes to function differently in response to disease or harm is perceived to be a form of interference. The assumption is that interference of any sort is wrong and should be outlawed. This argument is upheld by world bodies such as UNESCO which declares the importance of preserving "the human genome as a common heritage of humanity" (UNESCO, 2005). Some thinkers fear that genetic therapies will enable human beings to "replace natural selection with deliberate selection, Darwinian evolution with 'enhancement evolution'" (Anderson & Tollefsen, 2008, p. 79). The argument develops into two sub-themes. One sub-theme holds that we have the right to unique genetic identity as human beings. In this case,

genetic editing, even for the purpose of treating an illness, is thought to have the potential to interfere with this presumed uniqueness. Empirically, this allegation remains unproven, as long as research into genetic therapies has not been concluded and treatment formally launched. The other sub-theme holds that human nature is something that we need to sustain. But what is the nature of the human being for which preservation and protection is sought? Anderson and Tollefsen propose that this nature be understood in two parts namely descriptive and normative. In seeking to understand the descriptive aspect of the nature of the human being, "…human persons must be shown to be human animals -- bodily organisms of the species *homo sapiens*…" while the normative aspect in "…a reflective critical account of the practical horizons of human wellbeing, an account that grounds an understanding of human benefits, harms, and moral obligations" (Anderson & Tollefsen, 2008, p. 79). But this way of understanding the nature of the human being seems to be inadequate in considering how genetic therapies are an interference with human nature. The mere fact of humans belonging to a certain species in the animal kingdom does not necessarily give direction as to whether interfering with that nature is right or wrong. There have been improvements made in certain animals with fundamental positive changes in the bodily functioning of those animals in response to certain adversities such as disease, and this should apply to humans as well. This is an argument I will develop further in the succeeding chapter.

The third naturalist argument points to the genetic complexity of human beings as another reason against genetic therapies. That human beings are genetically complex is not in doubt. Indeed, the human genome has only been known in science since 2003, and much is yet to be known. Even what is known is yet to be adequately known and described. The human genetic code "…consists of three billion letters (or base pairs), which is equivalent to 500 million words, and subsequently equivalent to about 8,000 books" (Kilner, 2018, p. 5). The argument goes that, given the magnitude of what remains unknown on the human genetic code and exactly how each gene functions in relation to the others, there is a likelihood of any changes, or modification, or improvements, even when providing therapy against a specific disease like HIV-AIDS, to lead to some unknown negative effect on other genes, a state that may not be known until many generations later. The argument raises fear of the unknown. In other words, it is medically risky to carry out genetic therapies on the complex human genome, especially because human knowledge about it is currently limited. Costley argues that

> The danger objection points out that a few recent attempts at gene therapy in clinical trials have made headlines because of the tragic deaths of some of the people participating in the trials. It is not fully known to what extent this was due to the gene therapy itself, as opposed to pre-existing conditions or improper research techniques, but in the light of such events some critics

> have called for a stop to gene therapy until more is known. We just do not know enough about how gene therapy works and what could go wrong (Costley, 2018, p. 4).

Based on currently inadequate knowledge on genetic therapy as well as genetic enhancement, naturalist arguments further raise four scientific concerns:

> …the vectors may deliver the DNA to cells other than the target cells, with unforeseen results; viruses as vectors may not be as innocuous as assumed and may cause disease adding new genes to a nucleus does not guarantee they will go where desired, with potentially disastrous results if they insert in the wrong place; if the changes are not integrated with other DNA already in the nucleus, the changes may not carry over to new cells and the person may have to undergo more therapy later; (and) changing reproductive cells may cause events not seen until years later, and undesirable effects may have already been passed on to the patient's children (Costley, 2018, p. 4).

The concerns raised in this argument are strong and worthy of serious note, especially in the context of further research to ensure that sufficient precautions are established in order to ensure safety. However, the major weakness with this argument is its assumption that the limited human knowledge on the human genome is a permanent and unchangeable condition. But knowledge is a dynamic reality in which change and growth are a regular experience. Today we may not know much; but we may discover and know tomorrow what we do not know today.

The fourth naturalist argument against genetic therapies says there is no moral obligation to genetically modify human beings. For an act on the human body to be morally obligatory, it has to necessarily possess two qualities: one, it should introduce a solution to a problem that is causing or supporting a harmful phenomenon (treatment of disease); and two, it should help the body to develop capacity to prevent harm (prevention of disease). Susan Hall in explaining the difference between therapy and enhancement says, "…therapy aims to achieve, in a particular individual, the level of functioning that would have pertained for that individual …in the absence of disease or disability" (Hall, 2012, p. 94). She argues that, although enhancement seeks to introduce capacities that make the individual function at a higher level than the individual's contemporaries, there is a basic similarity between treatment and enhancement:

> This similarity lies in the fact that both treatment and enhancement are directed towards bringing about a change in the physical condition of a particular individual that is better for that individual than their previous condition. In other words, both treatment and enhancement are desirable, from the perspective of the affected individual, because they contribute towards an increased level of well-being (Hall, 2012, p. 98).

Mark Costley, however, insists on a dichotomy between the two ideas: "We use the term 'gene therapy' for efforts to bring people up to normalcy and 'genetic engineering' or 'enhancement genetic engineering' for efforts to enhance people's capabilities beyond normalcy" (Costley,

2018, p. 2). It appears to be the case that any interventions that are not yet understood and accepted to be within the 'natural' are to be avoided because there is no moral obligation to apply to them. However, an alternative analysis may support the argument that, actually, we are morally obligated to provide therapy, especially when we closely examine the idea of vaccination which is a form of enhancement. Indeed, this argument will be developed in the next chapter in support of genetic therapies.

Another argument of the naturalist kind is that there is a good side of bodily weakness, so humans must not be overly determined to eradicate disease and bodily faults. This is an extension of the previous argument, especially since it seeks to have the human body retained naturally, with its strengths and weaknesses, without any perceived interference. Bodily weakness has its good side, especially in reminding the human race of its frailty, finitude, and limitation. It is a trait that causes us to be careful for own wellbeing and caring for fellow humans at the same time. The argument here is that if human weakness is genetically removed from human characteristics, humans may never know the true value of strength and health, since human weakness will have disappeared.

The last argument I want to discuss in this section focuses on procreation which is supposed to be a natural process. Genetic therapy is seen as an interference with this natural process since genes are engineered to become resistant to one, or many, disease(s). Reproduction will no longer be simply a result of human gametes meeting and getting fertilised; it will now involve an additional procedure to ensure a scientific elimination of vulnerability to certain diseases. The question is whether this would be morally wrong. Already doctors monitor pregnancies for any vulnerability to any diseases for early diagnosis, decision making, and possible treatment. I doubt if genetic therapy will function differently in this specific scenario. Already, as has been argued earlier, vaccinations are in use to help prevent diseases that would otherwise be truly deadly and devastating to human populations.

I will review each of the preceding arguments from a utilitarian perspective and point out strengths and weaknesses thereof. Meanwhile, in the next section of the current chapter, I will proceed to a new set of arguments against genetic therapies, namely, distributive justice arguments.

5.4. DISTRIBUTIVE JUSTICE ARGUMENTS

Some arguments advanced against genetic therapies belong to the category generally classified as distributive justice arguments. They are arguments that focus on the distributive challenges in relation to what should be prioritised in the context of on-going scientific research

in genetic therapies. From the start, I point out that these arguments may appeal to governments in Africa, including Kenya which receives special focus in this dissertation. The first argument in this category is an intra-health argument which appeals to better use of available resources. The argument presents the lower, common, and cheaper categories of health needs as worthier of government support than the heavier, rare, and expensive illnesses. Simply stated, the enormous resources that are currently being invested in research on genetic therapies (especially in the developed world), and the potential investment of the meagre resources (especially in Africa), can be used in improving general healthcare. In expressing concern about general healthcare needs, reference is made to the fact that numerous deaths are caused by malaria, TB, and water-borne diseases. These are largely preventable and curable, except that resources are not sufficient to meet treatment needs and preventive public health campaigns. Afrobarometer Policy Paper Number 31 points out that, although healthcare access has improved over the last decade, the reality of people's experience points to a wide gap that still needs serious attention in several areas:

> In many areas, a continued absence of basic health-care facilities; Shortages of needed medical care experienced by almost half of all Africans; Widespread difficulties encountered in obtaining care, sometimes compelling patients to pay bribes; (and) Poor government performance, according to citizen ratings, in improving basic health services (Armah-Attoh, et al., 2016, p. 1).

Research in genetic therapy is, of course, both expensive and intensive, consuming huge amounts of resources as well as time. In resource-scarce regions such as Africa, such research is viewed as "luxuries" which should not be promoted at the expense of supposedly "real" healthcare. This view is supported by a survey in nine sub-Saharan countries which found out that people were deeply concerned about such basic issues as "improving hospitals, preventing and treating HIV-AIDS (through ARVs), …fighting hunger, quality drinking water, infectious diseases, prenatal care, and childhood immunizations…" (Simmons, 2015). As long as healthcare in Africa is still held down with the basics, like the ones mentioned here, genetic therapy is still not even part of a dream. If any money becomes available, the governments would rather use it to take care of the basic levels of health needs than to invest it in research in genetic therapies.

The second distributive justice argument, which is closely related to the first, although slightly wider in scope, is a matter of choice between the developmental and educational needs of all the citizens on the one hand, and the healthcare needs of the sick "minority" in the population. It is easily understood that public funds should be used to construct and maintain roads, schools, power generation plants, and other infrastructural establishments. The argument

is that economic and infrastructural development and educational institutions and systems benefit everyone in a country. Research, on the other hand, especially the kind carried out on genetic therapies, seems to benefit only a small segment of the population. The question that follows is, does Africa need more development than research, or does it need more research than development? It appears both are needed in equal measure, since research and development have a symbiotic relationship that makes them interdependent. To advocate for one without the other is to kill both. Elina Christoforou, the Coordinator of the doctoral programmes at the multi-campus UNICAF University, says that African countries should do more. She is quoted to have said,

> African countries face many challenges, which hinder the growth of research and sustainable development. Postgraduate education remains underdeveloped, access to it is still limited and, as a result, contribution to research is equally small. In spite of the fact that 15 percent of the global population comes from Africa, the continent only contributes a mere 2 percent of the world's scientific knowledge. African countries have significantly increased investments in science in the last few years, but most of them still invest less than 0.5 percent of their GDP in research (Walker, 2018).

If Africa, and indeed the rest of the world, is going to place emphasis on development, it has to, at the same time, place emphasis on research, including research in areas that currently seem to be of less priority, and especially research on possible genetic solutions for deadly diseases such as HIV-AIDS. Greater economic justice will be served better to the people in this way than with a narrow focus on infrastructural and educational aspects of development.

The third distributive justice argument says that genetic therapies are likely to encourage class differences among human populations. This is likely to show itself in at least two ways: economic power for accessing genetic treatment on the one hand, and discrimination based on treatment received or not received on the other hand. On the first count, it may be argued that only economically well-endowed people will have access to these genetic treatments because they are expensive. If this became a reality, genetic therapy will work against ideas of equality and justice in society. Any scientific development that either causes or enhances inequality and injustice in society is a harmful development which should be discouraged and discontinued. This is a strong argument against genetic therapies, given that they are extremely expensive to develop and to produce. In April 2018 it was reported[30] that it had become possible to clinically treat blindness through genetic therapies, but that "…many people with rare diseases that could be treated in this way may never benefit from these therapies because they are too expensive for drug companies to develop, or too costly for the

[30] The report was made by Sterghios Moschos who is an associate professor in cellular and molecular sciences at Northumbria University, Newcastle.

patient or health service to afford," with the cost standing at "$425,000 (£302,000) per eye" (Moschos, 2018). That is what middle-level professionals in African countries, outside South Africa and Egypt, would earn in their entire employment life. The poor majority would not earn that even in an entire lifetime. Definitely it would be out of question for governments to take over the costs of such treatment. Moschos describes a situation in which there was much hope when genetically engineered stem cells restored the damaged skin of a young boy.

> Genetically engineered skin stem cells restored around 80 per cent of the skin of a seven-year-old who had suffered from blisters and open wounds from birth due to a genetic disorder. Two drug companies received approval for ground breaking gene therapies for childhood leukaemia (Moschos, 2018).

She continues the description saying there had recently been a development of a gene therapy for an inherited form of blindness, and that it was now possible to edit the genome of an adult human being to correct genetic disorders. "The cost of these treatments, though, ranges from about $500,000 to $1.5m. And over a lifetime, drugs like nusinersen[31] can be even more expensive: $750,000 in the first year followed by $375,000 a year after that – for life" (Moschos, 2018). This price range is the same for most genetic therapies so far successful and available, such as

> Kymriah, the recently-approved treatment that delivers an engineered immune system protein in gene therapy wrapping, is a one-time treatment for a form of leukaemia, costing $475,000. Yescarta, for a different blood cancer, is similarly priced. The seven-figure cap may come from experience with Glybera, the first gene therapy approved in Europe. Despite decades in development, the drug was yanked after only two patients got it, the $1 million-plus cost deemed excessive. The second gene therapy approved in Europe, Strimvelis, to treat an inherited immune deficiency, costs $665,000 (Lewis, 2017).

From these prices, it is clear that, after years of designing a genetic drug and getting it approved by the relevant authorities, getting it to the market for physicians and patients is extremely expensive. In the end, the costs will be too high for patients to afford, resulting into extremely few patients. Consequently, it will not be profitable for pharmaceutical companies to manufacture and sell such medicines. The question, then, is how much genetic treatment should cost, and how such costs should be taken care of, and whether insurance companies will be interested in giving cover for them. One may agree with Bill Gates in his statement that

> Gene editing is generating a ton of optimism for treating and curing diseases, including some that our foundation works on (though we fund work on altering crops and insects, not humans). But the technology could make inequity worse, especially if it is available only for wealthy people (Gates, 2018).

[31] Nusinersen is a genetic therapeutic "prescription medicine used to treat spinal muscular atrophy (SMA) in paediatric and adult patients" (Spinraza, 2018).

Gates, although quite optimistic on the prospects of finding cures for certain devastating illnesses, points out that it will be problematic if the genetic therapies would become available only to rich people, and not to all who will need it.

It seems clear that, whether individuals pay for them or insurance companies provide cover, genetic therapies are an expensive affair that only the super-rich in societies will be able to afford. But it may well be asked, is it morally wrong to manufacture treatment that only rich people in society can afford? The answer to this question depends on a few factors. In an ideal world in which the large majority are rich and able to afford anything they decide to have, the manufacture of such treatment would be beneficial to the majority. In other words, such action would bring maximum happiness to the greatest number of people. In such a case, producing such treatment would be morally right, at least in a utilitarian sense. But even if rich people were an absolute rarity, making treatment available that only rich people can afford would be the virtuous act to carry out. It is already the way medical treatments are done all over the world anyway. There are certain levels of treatment that are highly expensive and only accessible to the rich. As a matter of fact, society is not obliged to ensure that every critically ill patient gain access to a highly specialized hospital. It is simply a fact of life that certain things are only accessible to the rich, although certain basics are made available to everyone. But I will develop this argument further in the next chapter.

On the second count of the third distributive injustice argument is closely linked to the first count, and points to genetic discrimination which is likely to emerge and grow based on treatment received. In other words, it is likely that those who will be able to afford genetic therapies will be the only ones able to insulate themselves and their descendants from experiencing certain diseases and their devastating impact. This will make them a preferred class of people within the insurance industry and also among employers. Conversely, people who will not afford genetic therapies will face forms of discrimination based on their genetic inability to prevent the occurrence of disease in themselves. In the United States where people fear genetic tests because of the likelihood of discrimination, the Department of Health and Human Services has explained the occurrence of defined genetic discrimination saying, “Genetic discrimination occurs when people are treated differently by their employer or insurance company because they have a gene mutation that causes or increases the risk of an inherited disorder” (US National Library of Medicine, 2019). As a result, the US federal government as well as various state governments have enacted laws that prohibit insurance companies from deciding on any individual’s eligibility for cover solely on the basis of that person’s genetic information. The laws also declare it illegal for employers to make decisions

on people's suitability for employment or promotion based on genetic information. The discrimination is not just on people who have certain genetic conditions that make them prone to certain diseases; it will in future also extend to those who will not be able to genetically secure themselves and insulate themselves from disease. The discrimination objection to genetic therapies also includes people whose genetic makeup has caused them to be impaired physically, mentally, or emotionally.

> Such impairment can result in disablement in our society. People with disabilities are often discriminated against by having fewer opportunities than other people. By removing genetic disorders, and resulting impairment, it is true that gene therapy could contribute to removing one of the sources of discrimination and inequality in society. But the implicit assumption being made, the objection claims, is that people impaired through genetic factors need to be treated and made normal. The objection sees gene therapy as a form of discrimination against impaired people and persons with disabilities (Costley, 2018, p. 4).

Such people will no longer appear "normal" in a society where genetic therapy, including germ-line therapy, will have become "the new normal." In other words, in an ideal society in which genetic therapies will be accessed by a large majority, such therapies will become regular, ordinary, or typical, and those who will not have treated themselves with the therapies will be sort of "abnormal" in the eyes of the many. It is such situations that the "abnormal" will experience discrimination in employment, in healthcare insurance, and in social life.

5.5. ARGUMENTS FROM LACK OF CONSENT

An argument may be advanced that the people directly and indirectly affected by germ-line gene therapy, such as children and future descendants, had neither agreed to nor given any consent to the treatment. And it could not be assumed that such agreement or consent could have been given on their behalf by their parents since proxy consent can only be given on behalf of existing persons for treatments that are actual and necessary. In other words, it is only normal for consent to be present and current. Consent cannot be effectual if it is only hypothetical. The morally problematic matter is that the individual who has a problem for which there is need for a solution is the existing person suffering from, say, HIV-AIDS. The treatment sought, however, is not only a solution to the current disease but is also providing the protection of a possible future person through genetic modification. The presently existing person assumes that the potential future person would also like to have their genetic material modified. But that is something that is only presumed. No one has the capacity to know for sure what will be the preferred method of treatment for a yet-to-be-conceived person. The germ-line therapy gives such descendants capacities which they simply inherit rather than choose, even though treatment method is a choice someone needs to make freely and

consciously. There are various ways of understanding the consent argument in this context: consent as right, consent as permission, and consent as agreement.

Rights are civic liberties that are guaranteed to individuals and societies because they belong to an organised system of modern governance, such as a state or a nation, as citizens. Such civil liberties are normally defined and protected by the constitution of the country. Existence is a prerequisite for the guarantee and enjoyment of civil liberties or rights. For example, the Constitution of Kenya states that every person in Kenya has the right of access to health care (Constitution of Kenya, 2010, p. 24). The Constitution here assumes that the person on whom the right is conferred actually exists and is personally able to choose whether and how to enjoy this right. For a person to enjoy treatment, they have to have the capacity to give consent to forms of treatment that they understand and prefer. A presumed future person does not exist in reality, and does not enjoy such a right to health care as prescribed in the Constitution because the prescription is for present people. A future person cannot give consent for a present procedure because the future person is only presumed to possibly come into being in future. How about parental consent given on behalf of a minor? The fact is that parental consent is given on behalf of, and in the best interests of, an existing minor who is either actually physically undergoing treatment or has treatment plans being made on their behalf. Future persons do not exist, so they do not have rights to give consent on treatment. The question then is, if non-existing persons cannot make treatment decisions in the present, why should existing persons have the right to give consent on behalf of the non-existent ones? There is a close relationship between consent and rights, and consent "…can create rights as well as turn what would otherwise be a wrongful act into an act that is right. It can, for example, give another person a right to do something that would otherwise be wrong" (Gunderson, 2008, p. 87). Consent can also be a means by which a right can be waived, or a way of leading a patient not to stand up for a right. In this sense, consent is a sort of "double-edged sword."

There is also the idea of consent as permission as an argument that challenges the use of genetic therapies. In giving consent, one gives authorisation for the treatment to be applied to the body, such that a physician is absolved from liability that would otherwise be applicable if the patient had not given such consent. The patient gives a "go-ahead", or approval, or endorsement, to be treated in the manner prescribed by the doctor. One analyst explains that "…consent functions as way of allowing another to do what would otherwise be morally or legally impermissible. Consent functions to facilitate, or at least not prevent, an action" (Gunderson, 2008, p. 87). A future person cannot be personally present to understand the treatment as described and actually approve of it. The responsibility falls on the present adult

parent or legal guardian to give such permission. A complication arises with the reality that there are no legal provisions for existing persons to sign legally enforceable documents of consent one behalf of persons who are yet to be even conceived in the first place. In other words, it is not clear how a non-existent person can grant permission for any form of treatment. Therefore, any decision made should be considered arbitrary. Yet a counter-argument will respond that life is packed with arbitrary decisions, including contraception, pre-natal treatments, and vaccination, which are all permitted and carried out on behalf of potential as well as actual living persons. As such there should be no exception with regard to germ-line genetic therapies.

Finally, there is a sense in which consent is an agreement between the patient and the physician. It is a form of a contract or treaty which should be binding on both parties, with guarantees, and should be legally enforceable. For instance, in the event that a progeny of a genetically treated individual gets infected with HIV-AIDS after birth, they should be able to sue for damages. That necessitates that appropriate legal framework be put in place across international boundaries to take care of the nature of agreements, treatments, and any resulting litigation. In the context of treatment, there is no right not to receive medical treatment and care. For example, it is never considered wrong to provide treatment to a sick child, or to a mentally disabled person, or to an elderly person, even when it may not be possible to obtain their consent because they are not able to give it. The argument advanced by Holm is worthy of note:

> …it is quite usual to make decisions that have far reaching effects on one's descendants (e.g., deciding what country to live in). If these decisions are not problematic, why should we regard germ-line engineering as a problem? …lack of consent would have to be equally problematic even if future generations were benefited (Holm, 2002, p. 88).

Consent from persons unable to give it seems unnecessary even in cases where the potential benefits of an act are clear and non-controversial. As Gunderson points out, "…it would be absurd to refuse to engage in germ-line genetic engineering to prevent a person from being born with a devastating genetic disease such as Tay Sachs on the grounds that the future persons would not have consented" (Gunderson, 2008). If we have to have consent for every good action that we need to take, there would be very few solutions procured for either children or the unborn.

5.6. NEGATIVE THEOLOGICAL-ETHICAL ARGUMENTS

In this section I introduce a discussion on theological-ethical arguments which I treat as necessary due to the dominant influence that religion holds in the lives of the majority of

Africans in general, and Kenyans in particular. The World Factbook gives a breakdown on the religious diversity of Kenyans, based on the last official population census carried out in 2009: "Christian 83% (Protestant 47.7%, Catholic 23.4%, other Christian 11.9%), Muslim 11.2%, Traditionalists 1.7%, other 1.6%, none 2.4%, and unspecified at 0.2% of the population" (Kenya Population, 2019). These figures are supported by official records of the Kenya National Bureau of Statistics which place Catholics at 9,010,684, Protestants 18,307,466, Other Christian 4,559,584, Muslims 4,304,798, Hindu 53,393, Traditionalists 635,352, Other Religions 557,450, no religion 922,128, and those who do not know 61,233 (Kenya National Bureau of Statistics, 2013). With variations on inclinations, the religious commitment in Kenya is reflective of other countries in Africa. Some of the earlier mistakes made in response to HIV-AIDS in the 1990s were based on faulty theological persuasions, which in turn informed ethics. An example was the false idea that AIDS was a form of punishment from God, an idea that was later and gradually corrected by theologians and moral philosophers. Based on the prevalent influence of religion, it is, therefore, important to discuss theological-ethical arguments that may be raised against genetic therapies.

Arguments that appeal to the authority and sovereignty of God in relation to morality are classified as theological-ethical arguments, regardless of the religious persuasion in focus. Theological ethics are ethics that are primarily founded on religious or theological doctrines or principles. It is important to understand these arguments especially because religion is a dominant facet of human life throughout the world. Belief systems are strongly influential in matters of life and health, and frequently form the basis for either accepting or rejecting new approaches to medicine. The connection between Christianity and Western philosophy has been discussed in fair depth by Vincent Brümmer who argues that there are four facets of which Western philosophy consists, and each has its own basic theme with which it is identified.

> Christian philosophy is dominated by the biblical motive of creation, fall and redemption; Greek thought by the motive of form and matter; humanistic thought since the Renaissance by the motive of nature and freedom; and scholastic thought (that is an attempt at accommodating the Christian motive to one of the other motives) by the motive of nature and grace (Brümmer, 2006, p. 41).

In Vincent Brümmer's argument, although the latter three motives are different from that of Christian thought, there is a pivotal place for Christian philosophical thought that cannot be ignored because religion underlies much of philosophical and scientific thought. It is important, then, where religious thought is prevalent, to delve into theological-ethical reflection. The peoples of Africa, the context of focus for this dissertation, are pertinently described by John

Mbiti[32] in his statement, "Africans are notoriously religious" (Mbiti, 1969, p. 1). These words of Mbiti remain as true today as they were 30 years ago when he wrote his classic work *African Religions and Philosophy*, in description of the dominance of religion in the life of the indigenous African. For the African, reality is primarily interpreted in religious terms. It is, therefore, highly likely that the acceptance or rejection of genetic therapies for HIV-AIDS in Africa will be, to a great extent, based on religious or theological perception of the new phenomenon, hence the importance of developing an understanding of certain theological arguments against genetic therapies in this section.

The first theological-ethical argument is what is referred to in theological thought as the Creator-creature distinction. This is in reference to the doctrinal dichotomy between God as the Creator on the one hand, and human beings and the rest of the universe as creatures on the other hand. "The distinction between God as the Creator and everything else (the creation; the heavens and earth) is a fundamental Christian belief…" (Sigler, 2014), a belief that Christianity shares with Judaism and Islam. God is the creator of all that exists, and remains distinctly different from what He has created, including human beings. As humans we owe our existence to God who alone has neither beginning nor end. There should never be confusion between the Creator and His creation. Caneday explains how humans relate to God through "five primary analogical relationships" namely "(1) king and subject; (2) judge and defendant/litigant; (3) husband and wife; (4) father and child; and (5) master and slave" (Caneday, 2003, p. 163). The idea is that, although God reveals Himself to humans in human terms, God remains incomparable to humans. We must maintain the perception that humans are able to create because humans are like God and are created by God in God's own image and likeness. "God is the original; we are the organic image, the living copy" (Caneday, 2003, p. 163). This idea of creator-creature distinction has serious moral implications, especially in relation to the subject of genetic therapies. Firstly, it is the idea that should lead human beings into acknowledging finitude in all endeavours, including scientific research and medical practice. In other words, human beings should humbly acknowledge that God created human beings with a complex genome which should not be subject to human editing or modification of any kind for any reason. Secondly, it should bar humans from venturing into doing things that only God can do, the idea commonly referred to as "playing God" in ethics discourse. In

[32] Professor John Samuel Mbiti (born on 30th November 1931; died on 6th October 2019) was a Kenyan-born, Cambridge-educated, Christian religious philosopher and writer. Between 1977 and 2005, Mbiti was a Professor of Philosophy of Religion at the University of Bern, Director of the Ecumenical Institute of the World Council of Churches, and an ordained Anglican parish minister to the town of Burgdorf, Switzerland. This academic and religious background is intended to affirm the intellectual depth of Mbiti's statement.

essence, humans must not venture into areas in which only God reserves knowledge and authority, and this includes genetic engineering. Any science that modifies human genes and the way these genes function is an affront onto the majesty and authority of God, as it blurs the creator-creature distinction.

A second theological-ethical argument focuses on the given-ness of life, in which case the term "given-ness" implies that God is the giver of life. Both the Bible and the Quran teach that life comes to us from God as a gift. The first book of the Bible, Genesis Chapter 1, tells of how the Spirit of God (the Holy Spirit) hovered over the face of the waters and that the earth was formless, empty and dark (Genesis 1:2). When God miraculously spoke with His almighty Word and power, everything immediately came into being, including the light; the atmosphere; the land, water and plant life; the sun, moon and stars; the birds of the air and the fish of the seas; and finally, every land animal and human life. In a later book, the Bible presents a character named Job who, in his extreme suffering, spent time thinking more about life than most people would do in similar situations.

> His day seemed to pass quicker than a "weaver's shuttle" (Job 7:6), or a single breath (Job 7:7). His days appeared to rush by like a courier with an urgent message (Job 9:25), as a "swift ship," or like an "eagle who hastens to the prey" (Job 9:26). He saw man's days as "few." He was rather like a flower that blossoms and then quickly dies, or as a rapidly passing shadow (Job 14:1-2).

The prophet Jeremiah quotes God, "Before I formed you in the womb, I knew you; before you were born, I set you apart" (Jeremiah 1:5a). The Psalmists addresses God saying,

> For You created my inmost being; You knit me together in my mother's womb. I praise You because I am fearfully and wonderfully made; Your works are wonderful; I know that full well. My frame was not hidden from You when I was made in the secret place. When I was woven together in the depths of the earth, Your eyes saw my unformed body. All the days ordained for me were written in Your book before one of them came to be. (Psalm 139:13-16)

Saint Paul was once invited to speak before the philosophers of Athens, his limited opportunity forced him to focus on the origin of life. He confidently affirmed that it is the true God who "gives to all life, and breath, and all things" (Acts 17:25). Later, in a letter to a young student of his, St. Paul reminds Timothy that the Creator is the one who "gives life to all things" (1 Timothy 6:13). The Quran says that there are great blessings for those "who, when a misfortune overtakes them, say, 'Surely, we belong to God and to Him shall we return'" (Surat Al-Baqara, 2016). As Suzy Ismail says in one lecture at Princeton, "Life's fragility should remind us of the greatness of God, and the goodness of God's creation should inspire us to respect life" (Ismail, October 6th, 2014).

Other writings also carry the same idea. Tolstoi, in his book Anna Karenina, brings out the idea of the given-ness of life through the character, Anna, whose concerns and comments

before death reveal dependence on God for life itself: "'Where am I? What am I doing? Why?' She wanted to rise, to throw herself back, but something huge and implacable pushed at her head and dragged over her. 'Lord, forgive me for everything!' she said, feeling the struggle to be in vain'" (Tolstoi, 1886, p. 725). At the end of her life, Anna turns to God in expression of deeply genuine regret and repentance. In this case we may join Andrews in her lament, "It can be a helpless and terrifying feeling to think that one does not have the power in himself to change, improve, or fill his own life with meaning. What is the purpose of our lives if everything that eventually comes to us is a gift and is not a result of our own efforts?" (Andrews, 2017). She continues into a different perspective, saying,

> "But maybe that's the wrong question. Maybe it needs to be turned on its head. If life itself is a gift– if our being is the gift– what if its purpose is the business of the giver and not of the gifted? If the changes that take place in me are a gift, then I am filled with all the more gratitude for my … productive energy" (Andrews, 2017).

All of life, including suffering moments, is given to us from the Creator. Of course, we are responsible for our own failures in the things we are supposed to carry out. But ultimately life is not of our own making. It is a gift from the Creator who has its finer details that we are not aware of, and who brings it to an end at His will. This argument, though in support of human medical effort to treat diseases and assure physical comfort, views scientific effort to alter or modify human genetic functioning as an extremity that seeks to either introduce permanence of life or somehow defeat God's decision to end it. This is viewed as morally wrong because human beings are raising their intellectual and creative capacity beyond what humans were really created to be.

The notion of the giftedness of life is given attention by Sandel who, while discussing the topic of enhancement, criticises "the drive to mastery" among humans who approach live as "a kind of hyperagency – a Promethean[33] aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires… And what the drive to mastery misses and may even destroy is an appreciation of the gifted character of human powers and achievements" (Sandel, 2004, p. 5). Sandel says

> To acknowledge the giftedness of life is to recognize that our talents and powers are not wholly our own doing, despite the effort we expend to develop and to exercise them. It is also to recognize that not everything in the world is open to whatever use we may desire or devise. Appreciating the gifted quality of life constrains the Promethean project and conduces to a certain humility. It is in part a religious sensibility. But its resonance reaches beyond religion (Sandel, 2004, p. 5).

[33] The term Promethean describes a characteristic of "being rebelliously creative and innovative" like the ancient Greek demigod Prometheus who, in Greek mythology, "modeled humans from clay and taught them agriculture and all the arts of civilization. He also stole fire from the gods and gave it to the humans" (Merriam-Webster, 2019).

The idea that Sandel brings out is relevant to the matter of human enhancement, especially with regard to sports performance, height increment for children, and memory capacity, beauty, and other not-so-necessary aspects of enhancement. However, if we reflect upon it in connection with genetic therapy for devastating illnesses, then it is not fair to attribute the human struggle to defeat disease to "the drive to mastery". Human beings who strive to defeat danger are not just seeking heroic achievements, but are naturally affirming self-preservation.

A third theological-ethical argument is based on an evaluation of the human bodily endowment as given by God. The human body and the way it functions has been described by some as "God's masterpiece" (Paturi, 1998). It is a precise and efficient machine, so to speak. Paturi marvels at the wonder that the human body is:

> The body has a chemical plant far more intricate than any plant that man has ever built. This plant changes the food we eat into living tissue. It causes the growth of flesh, blood, bones and teeth. It even repairs the body when parts are damaged by accident or disease. Power, for work and play, comes from the food we eat (Paturi, 1998).

The human body, as made by God, has its God-given mechanisms for dealing with infiltration and disease, whose treatment should be as natural as possible. The natural way the human body responds to disease is through the immune system which is absolutely indispensable for human survival, especially "…in a world full of potentially dangerous microbes, and serious impairment of even one arm of this system can predispose to severe, even life-threatening, infections" (The College of Physicians of Philadelphia, 2019). The cells of which the immune system consists are found in the blood and in some internal organs of the body. God is understood to be the maker of this complex system for the protection of humans. From this perspective, treatment should only aid the body's capacity to fight disease without any genetic engineering taking place. Genetic therapy is seen to be tampering with bodily mechanisms established by God. This argument gets weaker under close scrutiny when other human experiences are brought to the fore. For example, humans have invented and used vaccinations for decades in order to prevent disease without waiting for natural bodily responses.

The last argument in this section is based on the idea that I have chosen to call "eschatological perfection" because of its focus on the future end times as taught in the Judaism, Christianity, and Islam, though in varying details. The key though is that the world and all of reality, as presently constituted, will come to an end and will be replaced by an eternal bliss in which human being will experience no more sickness, pain, or death. In his article 'Eschatology and Christian Perfection,' CJ Barker explains that eschatology is concerned with "ineradicable aspirations of mankind," in relation to time and eternity, setting forth the idea that although this life is full of strife and tension, God will usher in a final time of incomparable

peace and perfection (Barker, 1944, p. 8). “It is a commonplace of the language of piety to contrast the temporal with the eternal” (Ibid.). The Kingdom of God is expected to usher in an end to all human suffering, an idea that should comfort the believer to persevere when contemporary solutions fail to yield expected remedies for disease and pain. Does that mean human beings should stop all efforts at finding treatments for harmful diseases? Of course not. But the endeavour to find solutions must be in the context of, at the same time, appreciating human limitations which frustrate final solutions, and will continue to do so, until God brings in a new dispensation of peace, security, and justice. The value and urgency of this eschatological perfection is propelled by the anonymity of the dates and times when this final bliss in heaven will become a reality, as stated in several portions of the Bible (Matthew 24:36-44, 1 Thessalonians 5:1-3, 2 Peter 3:10, Revelation 3:3), as well as in the Quran (Surah 20:15 and Surah 30:63).

Admittedly, theological arguments against genetic therapies turn out to be the weakest from a purely philosophical point of view. Ironically, on the ground, especially on a continent like Africa in general, and in Kenya in particular where there are “more than 4,000 registered churches,” mainly Catholics and evangelicals, (Information Cradle, 2018), the same theological arguments turn out to be also the strongest arguments against genetic therapies. These arguments make sense to many people in various contexts that are influenced by religious and theological ethics.

As stated earlier at the beginning of this section, the value of these theological-ethical arguments is in developing the idea that religion is held high in the lives of the majority of Kenyans, who happen to reflect upon issues with a religious or theological perception. The theological-ethical arguments discussed above are not necessarily entirely agreeable. Firstly, the view that there is a distinction between creatures and the Creator does not annul human scientific developments intended to solve human problems such as disease. Secondly, the notion of the given-ness of life does not prevent humans as “receivers” from creativity and development, especially if consistency is to be maintained together with the notion that humans are made in the “image and likeness” of God. Such creativity, in consistency with being in the “image and likeness” of God, may include genetic therapies for deadly diseases such as HIV-AIDS. Thirdly, the complexity with which God is viewed to have made humans – a point used in supporting the idea of letting the human genome stay as it has always been – has never prevented humans from catching killer diseases. Indeed, such an argument would go against the science of medicine, a tendency that would be really absurd! Lastly, eschatological expectations belong to a realm that is far from reality for most people. In any case,

eschatological perfection is likely to benefit only those who believe, which is why Rabbi Abbahu said, "The day of rain is of more importance than the day of resurrection; for on the latter day only the righteous will arise from the dead, but rain falls for all alike, righteous and wicked" (Jewish Virtual Library, 2019). In other words, eschatological expectations will not necessarily be beneficial to all. We might as well consider the day of genetic therapies to be the day of rain in this context. In the third section of Chapter 7, I respond in some detail to the theological-ethical arguments.

5.7. CONCLUSION

I have discussed various possible reasons that either have been raised or may be raised against any research and usage of genetic therapies. I have used these arguments to establish that although genetic therapies may be perceived to be harmful beneficial if applied in Africa for the treatment of HIV-AIDS, the perceived harm should be carefully evaluated with a view to seeking solutions, especially since existing remedies are not a permanent solution. I have presented and developed arguments such as slippery slope, naturalist, distributive justice, lack of consent, and negative theological-ethical arguments. These arguments are challenged by the arguments in support of genetic therapies as discussed in Chapter 6 hereafter.

CHAPTER 6: ARGUMENTS IN FAVOUR OF GENETIC THERAPIES

6.1. INTRODUCTION

In this sixth chapter I endeavour to establish the desirability and ethical appropriateness of using genetic therapies. In seeking to establish the benefits of such therapies, I argue in support of their development and application in the treatment of HIV-AIDS in Africa. In the sections I present arguments from the nature of human genes, the potential of genetic therapies, communitarianism, theological ethics, justice, cost-based arguments, current limitations of treatments through ARVs and HAARTs, affirmation of good parenthood, unfounded hostility towards genetic therapies, and current headways in the development of genetic therapies.

6.2. ARGUMENTS FROM THE NATURE OF HUMAN GENES

In this chapter, I discuss arguments in favour of genetic therapies for diseases in general, and for HIV-AIDS in particular. And this first section begins with two arguments from the nature of human genes. The first of these arguments is that the human DNA is mostly shared with other forms of life that exist on the planet earth, such that it is quite accurate to say that there is nothing special or unique about the human DNA. Curchoe summarises the idea in her statement that

> We share 98% of our DNA with chimpanzees, and over 50% with chickens, fruit flies, and bananas… some regions of our genomes are ultra-conserved and not a single letter is different from primitive bacteria. All of us alive today share one unbroken genetic lineage with our single cell ancestors from billions of years ago (Curchoe, 2018).

This scientific statement seeks to affirm the inter-relatedness of life while at the same time postulating the idea that difference is a natural aspect of that shared nature of existence. Research has also revealed "…99.9 percent of the genetic information in DNA is common to all human beings. The remaining 0.01 percent is responsible for differences in hair, eye and skin colour, height and propensity to certain diseases" (Deziel, 2018). If it is true that humans share their DNA with other forms of life, especially animals, then it should follow that scientific or genetic tests carried out on animals such as mice, or rabbits, should have the potential of relatively transferable effects. In other words, the special status of human beings should not be over-exaggerated as to perceive any research on the human DNA as an affront that must be prevented at all costs. On the contrary, any beneficial genetic tests found to be successful on animals should be subjected to further development in order to become suitable for human beings. This argument is especially relevant in response to a generally prevalent idea that genetic tests and treatment can be effected on animals and plants, but not on human beings because the human DNA is special and should not be interfered with, thereby causing extreme

delays, or prohibition altogether, in the development of genetic therapies for devastating diseases, including HIV-AIDS. The argument is not against any control in the scientific development and testing of genetic therapies. No. There is great value in the regulatory frameworks established by countries such as the United Kingdom and the United States to prevent potential misuse of genetic therapies to select desired human characteristics for non-medical purposes, besides ensuring that potentially harmful outcomes are avoided.[34] Internationally, UNESCO plays a general advisory and regulatory role through the establishment of global declarations and treaties, such as the Universal Declaration on the Human Genome and Human Rights, 1997. Indeed UNESCO also carries out general monitoring and sends out cautions from time to time, like it did on 29th November 2018 after a Chinese scientist, He Jiankui, had just announced success in producing two genetically edited babies (UNESCO, 2018). Yet in all their noble tasks and roles, these bodies must not view human genetic makeup as forms that must be protected from science without regard to other potentialities that may emerge out of rigorous scientific work.

The second and closely-related argument is in recognition of the fact that human genetic makeup mutates in response to the environment in which one lives. In other words, as UNESCO notes in its Article 3 of the Universal Declaration on the Human Genome and Human Rights,

> The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment, including the individual's state of health, living conditions, nutrition and education (UNESCO, 1997).

In real life, this means if someone has ever had common cold, or chickenpox, or flu, the virus modified that person's genome. Similarly, the DNA of a child can be detected throughout the birth-mother's body. As Curchoe briefly states it, "…a static, unchanging genome is not part of human nature" (Curchoe, 2018). Ellen Matloff, the President and CEO of My Gene Counsel, says

> Most people are born with at least 15-20 gene mutations. Some of the mutations are for very minor things, but some of them may be life threatening, especially those related to hereditary cancer. These mutations may range from things such as high blood pressure, hypercholesterolemia, hereditary heart conditions, to clotting disorders, and various cancers -- it runs the gamut (Hurst, 2015).

[34] In the UK, the Gene Therapy Advisory Committee (GTAC) regulates the use of gene therapy, and its Research Ethics Committee (REC) must evaluate and approve all requests to carry out genetic therapy on humans. In the US National Human Genome Research Institute (NHGRI) is responsible for identifying ethical and legal issues in genetic research.

This idea points out that no human being is static in so far as their genetic characteristics are concerned. So much change takes place in a human being's DNA, including disease-causing changes, that it is no longer reasonable to attempt to protect the DNA through prohibitive policy framework. It would be reasonable to have a genetic diagnosis on one's proneness to a genetic disease, although such a diagnosis would only force a patient into anxiety as they confront mortality. It would be more helpful if such diagnosis would possibly be followed by careful explanation of genetic treatments available. Granted that genetic therapies may be more aggressive in terms of the magnitude of change they may achieve in the human DNA. But even without these therapies, the DNA will mutate anyway; only that it will do so in a natural way without human influence. Therefore, genetic therapies should be perceived as a collaborative process between what the human body does on its own and what science does to creatively and efficiently manage the same or similar processes for the benefit of the human body. These therapies should be accepted in the same way vaccines have been accepted for strengthening the body's capacity to deal with certain potentially debilitating illnesses. I suggest that, once the efficacy of genetic therapies is ascertained and applied on certain diseases, research should push further for the possibility of eliminating even the presumed small sicknesses.

6.3. ARGUMENTS FROM THE POTENTIAL OF GENETIC THERAPIES

In this section I present arguments which are based on the potential of genetic therapies in the provision of solutions facing humanity, especially disease and related factors. From the arguments presented, it will be possible to assess whether the potential benefits outweigh potential risks. The first argument is that genetic therapy could provide cure for genetic diseases through the correction of disease-causing genes which are normally transmitted from one generation to another. Genetic therapies could lead to the saving of future generations from suffering, thereby leading healthy lives. Presently, diseases like cystic fibrosis, thalassaemia, Alzheimer's disease, HIV-AIDS, Parkinson's disease, Diabetes, Multiple sclerosis, Lupus, Asthma, Schizophrenia, and Cancer have no known effective cure, and genetic therapy would provide a viable solution. Some who oppose genetic therapies may suggest "…the selection of healthy embryos or foetuses…" as a preferable approach to genetic therapy, to which Savulescu responds,

> But such genetic tests require abortion or embryo destruction, which is also objectionable to some people. What's more, genetic selection doesn't benefit patients - it's not a cure. It merely brings a different person, who is free from disease, into existence. Future people would be grateful if their disease is cured, rather than being replaced by a different healthier or non-disabled person (Savulescu, 2015).

A common trait in human societies is the endeavour to protect future generations from experiencing similar problems as the present generations. The present generation is instinctively duty-bound to make their best effort at finding solutions so that offspring do not experience the same. Ancient communities who experienced drought found ways of digging wells or boreholes for their use and the benefit of their descendants. Others discovered treatments for certain killer-diseases and passed on the knowledge to the next generations. As Hurst advises with regard to genetic testing,

> Your life is not your own, especially when you are a parent. You owe it to yourself, to your children, and to the rest of your family to know whether or not you have a hereditary cancer syndrome. Besides, you may be saving many other lives besides your own by alerting them to the possibility that they may be carriers, too (Hurst, 2015).

That idea also applies to genetic therapies, had they already been made available and functioning. It is not natural for a human being to experience or discover a problem, yet not seek a solution for that specific problem, a solution that the founder ends up passing on as valuable knowledge. In genetic therapies research, science seeks to provide treatments to the present sufferer as well as protection to the future offspring, especially of deadly diseases that have troubled humanity for millennia. Diseases in which many genes combine to cause ill health are complex and would be likely reduced, or even eliminated, through genetic therapy. A disease-free life would be a worthy gift to bequeath the future generations of humanity.

A second argument is that, since genetic editing has been proven to delay ageing in mice, it can be inferred that genetic therapies may eliminate age-related illnesses such as heart disease or cancer. “Gene editing might offer the prospect of humans living twice as long or perhaps even hundreds of years, without loss of memory, frailty or impotence” (Savulescu, 2015). In other words, there is a link between ageing and certain illnesses, including HIV-AIDS. The speed of ageing is faster in situations of poverty and disease. When genetic therapies reduce or eliminate such diseases, ageing will also be slowed down considerably, leading to longer, happier, and more fulfilling lives. There is nothing, morally or otherwise, beneficial from the early death of anyone. Rather, a longer life enables one to contribute to the development of society in a way that only that one person can.

The third argument is that genetic therapies are likely to benefit the most disadvantaged members of the human society, as part of the health care. Although an earlier argument against genetic therapies in the immediate previous chapter postulated that such therapies are likely to benefit only the wealthy members of society, a public health funding approach could make the treatments available for all who need them. This is the same way vaccines are availed to many in most countries, and no one is disadvantaged. A similar approach has worked with regard to

the use of ARVs among disadvantaged populations. Savulescu uses a similar argument to point out that "the biological lottery – nature – has no mind to fairness" (Savulescu, 2015). He reminds us that, while some people are born gifted and talented, others are born with either "short painful lives or severe disabilities." As a result, interventions such as diet, education, and specialised care are attempts to rectify inequalities caused by nature. In the case of the potential use of genetic therapies for HIV-AIDS, the most disadvantaged and the most vulnerable populations are likely to benefit, thus reducing inequalities rather than increasing them. If the use of germline genetic therapies were to be scientifically validated, their safety guaranteed, and their availability widespread, certain genetic conditions could be eliminated from the population altogether. Conditions like HIV-AIDS could become diseases of the past, in the same way that global vaccination programmes have eradicated diseases like polio. Such benefits far outweigh any monetary expenditure or human capital investment that governments and research institutions may use in research.

6.4. ARGUMENTS FROM COMMUNALISM

There are arguments that emanate from the idea of communalism in order to promote common good. These arguments view genetic therapies as potentially resourceful solutions to universal communal problems, including HIV-AIDS. The first argument here is that no human being is an island on his or her own. Each person is involved in the life of another person. Life is a corporate phenomenon that gives us the obligation to live justly in the world. In the Christian faith, this shared nature of life is what makes us the "communion of saints" with a worldwide network. It causes us to acknowledge our dependence on others as it also reminds us of our obligation to support others, especially in situations of need. Because of the communal nature of human life, the individual choices we make affect other people in diverse ways, although those affected may have no opportunity to express their preferences, especially if they are not presently involved in our lives in any active and interactive way. We choose who to marry, and what career to follow; yet the future children born in our marriage and the future employers have no prior say to these choices we make. We are simply seeking satisfaction in life as it really is. Therefore, it is important that there be a global effort put in place for a potentially beneficial solution for HIV-AIDS and other diseases, for the survival of all.

The second argument is that any harm to one is harm to all. From a communal perspective, the domination of HIV-AIDS on the African continent is a form of harm to the whole world. A potential solution to a major cause of harm in one continent is also a potential

solution for a major cause of harm in the global community. Even at individual levels, parents have a duty to seek to prevent harm from affecting their children.

> Your life is not your own, especially when you are a parent. You owe it to yourself, to your children, and to the rest of your family to know whether, or not, you have a hereditary cancer syndrome. Besides, you may be saving many other lives besides your own by alerting them to the possibility that they may be carriers, too (Hurst, 2015).

From the argument presented by Hurst, genetic testing is an obligation for parents who necessarily need to alert their offspring who may be potential carriers of genetic diseases. Yet, we may ask, of what value is it for a parent to make an offspring aware of a particular genetic condition? Surely, it would be more beneficial to the offspring if such a parent would pass on a solution, rather than mere information. Unborn children, whether conceived naturally or artificially through IVF and germline gene therapy, are unable to make any choices about their genetics; they cannot decide whether they are born with or without particular conditions. It is better for the current generation to bequeath a solution, rather than a continuity of harm through disease and suffering. When genetic therapies become efficient and available for treating HIV-AIDS in Africa, it will be of great benefit to the whole world. It is also, in this regard, important to note that a solution for a disease that is prevalent in Africa is not merely a favour for African peoples; it is a solution to a global problem. The global community will enjoy some peace and improved health when assured those future generations will have nothing to worry about, as far as HIV-AIDS is concerned. For this reason, the on-going scientific research should be encouraged and funded through global collaboration, in the same way other concerns have been addressed.

The third argument is that we have an obligation to help our neighbours when their situations are dire and need our positive intervention, regardless of whether the sufferers are nearby or far away. Peter Singer argues this principle out in a 1972 article, "Famine, Affluence, and Morality", after the catastrophic cyclone in Bangladesh in 1971. Singer rejects the common pre-philosophical assumption that physical proximity is a relevant factor in determining one's moral obligations to others. In discussing the matter of whether people living in wealthy nations should be more obliged to help those near them than to contribute to famine relief in distant places, Singer writes: "It makes no moral difference whether the person I can help is a neighbour's child ten yards from me or a Bengali whose name I shall never know, ten thousand miles away" (Singer, 1972, p. 229). For him the only consideration should be "whether the evil that may be prevented by one's contribution outweighs whatever inconvenience or hardship may be involved in contributing, and for the large majority of people in affluent societies, the answer is clearly yes." In other words, as he explains,

> The fact that a person is physically near to us, so that we have personal contact with him, may make it more likely that we *shall* assist him, but this does not show that we *ought* to help him rather than another who happens to be further away. If we accept any principle of impartiality, universalizability, equality, or whatever, we cannot discriminate against someone merely because he is far away from us (or we are far away from him). Admittedly, it is possible that we are in a better position to judge what needs to be done to help a person near to us than one far away, and perhaps also to provide the assistance we judge to be necessary. If this were the case, it would be a reason for helping those near to us first. This may once have been a justification for being more concerned with the poor in one's town than with famine victims in India. Unfortunately for those who like to keep their moral responsibilities limited, instant communication and swift transportation have changed the situation. From the moral point of view, the development of the world into a "global village" has made an important, though still unrecognized, difference to our moral situation (Singer, 1972, p. 230).

Singer applies the time-honoured utilitarian argument that any action becomes a duty if it will prevent more pain than it causes or cause more happiness than it prevents. More significantly in this argument is the idea of communitarian utilitarianism by which the affluent countries should find it justifiable to support research in genetic therapies in order to alleviate suffering among patients of HIV-AIDS, the majority of whom are in Africa.

6.5. POSITIVE THEOLOGICAL-ETHICAL ARGUMENTS

In this section, I intend to explain four theological arguments, very much from a Christian perspective, in support of genetic therapies for HIV-AIDS, while responding to the theological-ethical arguments that I had raised earlier in Chapter 5. These arguments are premised on the general understanding that Africans are very religious and tend to respond to issues of disease and suffering with religious viewpoints, whether justifiably or not. The first of these arguments focuses on the concept of the image of God in humanity. It is a fundamental belief in Christianity, Judaism and Islam that the human being is created in the image of God, the *imago Dei*. Without engaging in theological depth, the image of God in humanity involves creativity and innovation in solving human problems, among other qualities. A few examples may be relevant to illustrate this. God created human beings and left them to think, design and develop houses, clothing, shoes, vehicles, medicine, working tools, weapons, and communication gadgets, among other life AIDS. Each of these life AIDS gets remarkably improved in successive generations. Understandably, the advent of every new development comes with a measure of surprise and resistance before people accept and learn to make good use of it. Of course, any new development that is proved useless or dangerous is discarded in the process, but the good and the useful are retained, polished up, and improved with time. The scientific efforts at developing genetic therapies for various diseases, including HIV-AIDS, should be appreciated as an extension of the functions of the *imago Dei*, and not as a way of "playing God", as some would argue. Indeed, save for occasional divine interventions in the

form of miracles, God normally lets humans discover for themselves what may cure diseases and wisely make use of such discoveries. It is a gift from God; not a sign of rebellious competition with the divine.

The second argument is that God only tolerates defects and disease. He never embraces them; instead, He seeks to overcome and remove them. In biblical narratives, for example, God does not allow people with defects to serve as priests, prophets, or kings. He also does not allow animals with defects as offerings. Instead God always seeks to heal the blind, the lame, the crippled, and the demon-possessed. This should tell us that God prefers a life of completeness and wholesomeness for human beings. It follows that humans should desire completeness and wholesomeness, rather than tolerate defects, including genetic defects, in life. If there may be any way of correcting a defect or curing an illness, including the possible successful use of genetic therapy, it should be understood to be the will of God. Healing from illness is the perfect desire of God for every person. There is no theological justification at all for either preventing or rejecting genetic therapies.

The third argument is one that I have inferred from the concept of salvation in order to develop the idea that God's purpose for human beings is to move them towards perfection. God plans to move each human being from the worst to the best; from sin to justification (conversion); from justification into a process of sanctification (purification); and finally from the process of sanctification into a final state of glorification (perfection) in eternity. This divine process shows that humans are in God's scheme of things when they engage in efforts that seek perfection. Human experiences through education, healthcare, enculturation, mentorship, religion, business, professionalism, sports, travels, and other engagements, are means by which humans grow and improve, reinforcing efforts towards perfection. It is not normal among humans to desire to remain poor, or sick, or vulnerable, or ignorant, or uncultured, or pagan, or primitive, or any such related states. Even in the present availability of ARVs for reversing some of the effects of HIV-AIDS, it remains clear that there is still no cure for HIV-AIDS. Our desire for the perfect should drive us into seeking a viable solution, such as the use of genetic therapies. Of course, that same desire for perfection should drive us into making great effort at ensuring the safety of these therapies, as well as eliminating faults and undesirable consequences on life and health. However, we must never shy away from the journey towards perfection. That move towards perfection may include not only treatment and prevention of diseases, but also genetic capacity-building so that humans may become actually incapable of contracting certain illnesses or even becoming ill at all.

The fourth argument is that the creation of solutions to disease is not a challenge to God, but a complement to God's work. God is portrayed as compassionate and merciful towards those in need, including the sick and the disabled, and consistently seeks to deliver the victims from such life experiences. God's use of, or collaboration with, human agents to resolve human problems, is consistent with the fundamental creationist view that God created humans in His image and likeness. Similarly, the involvement of human beings in resolving human miseries, including illnesses, is one of the highest virtues in collaboration with the divine. Genetic therapies, if put to use to treat HIV-AIDS, are developments that God would approve, rather than detest, because it is not competition with the divine.

6.6. JUSTICE ARGUMENTS

In this section I will discuss two arguments in support of genetic therapies from the perspective of justice. The first of these arguments focuses on the idea of equity in the development and use of these therapies in view of the economic inequalities among the various nations of the world. Both equity and equality can be used to create fairness in a society. Sometimes it is thought that equal treatment automatically results into fairness, but that is not necessarily the case. There is need for clarity on the difference between equity and equality. "Equity is giving everyone what they need to be successful. Equality is treating everyone the same" (Sun, 2014). Although the objective of equality is to promote fairness, "it can only work if everyone starts from the same place and needs the same help. Equity appears unfair, but actively moves everyone closer to success by levelling the playing field" (Sun, 2014). Yet, in many aspects of life, people do not get to start from the same place, and they do not all have the same needs. The difference between the two concepts can be clarified a little further. For instance, whereas equity identifies the differences and attempts to narrow the gap between various groups, equality does not regard the differences between the groups. Through equity people get what they need, while through equality everyone gets what others within the group gets, even if that is not their need.

Equity is realistically achievable; equality is not, and remains a pipe dream for all human societies. The fear that genetic therapies may create inequality in societies is unfounded. Inequality is already a real human phenomenon to which no society is a stranger. It is an experience humans have through education, income levels, economic strength, bodily strength or beauty, intellectual ability, family size, spiritual experience, and professional life. Experiences vary as much as outcomes of these common life ventures. While some people attain the highest levels and quality of education in the highest-ranked institutions, others only

manage the lowest levels available. In contemporary healthcare, while some people afford available cancer treatment options, others die of undiagnosed cancers. Similarly, when genetic therapies will become available, some people will find them affordable, while others will not afford them. The idea of affordability for everyone should not be a key factor influencing whether the therapies should be researched and developed or not. As the potentially high cost of a new highly efficient model of a car or a plane does not necessarily prevent the development of the new model, so the possible high cost of potentially highly effective genetic therapies should not be a reason to prohibit the research and development of those therapies. No one ever stopped the development of either the Mercedes Benz or the Rolls Royce for the reason that only a few people would drive it. Instead, with regard to genetic therapies, modalities of equitable distribution should be discussed, agreed upon, and implemented after the therapies will have been successfully developed. The rich may become generous in donating funding for the universal treatment of everyone; governments may take up the responsibility of implementation among citizens; religious organisations may engage in charitable support to the effort; world organisations may mobilise for a unified global approach; insurance agencies may develop affordable schemes for these therapies; researchers may end up developing affordable genetic therapies in the long run; and other options may just turn up. The concept of distributive justice becomes relevant and applicable only once something good has been developed and availed. For instance, once genetic therapies will have been fully developed, tested, and availed, then discussions about distribution and matters of equity will arise. How do we know or not know if, when genetic therapies become standardized, the presumed wealthy nations will not assist the poor in the developing world in order to make the treatment available and affordable? Besides, the fact that genetic therapies will be expensive does not necessarily dictate that poor people will never have access to them. When ARVs were first developed, they were, and still are, expensive. But governments and world organisations developed creative ways of ensuring distribution and treatment access. In any case, we should not stop the development of a good thing only because we fear it may be expensive. We cannot reasonably instruct a child to stop studying hard in school merely because we think the parents may not afford subsequent university fees, for what if the child wins a generous scholarship? The point here is that equitable access should be the focus, rather than seeking equal access for everyone. In the end, what everyone needs is a fair chance of accessing the genetic therapies once they become reliably available.

Questions may arise, such as: What if the poor are not able to afford genetic therapies? What if they are hindered in some way from accessing the treatment? What sort of social

conditions cause poverty among people? And what actions are necessary to alleviate these conditions? It is very much possible that the poor, who are also the worst affected by HIV-AIDS, may not afford genetic therapies when those therapies become available for patients. Empirical research has led to conclusions that certain social and economic conditions make people poor and complicate their access to healthcare, and this should be of concern in relation to a possible lack of access to genetic therapies as well. Loignon, et al, in a study carried out in Canada, report that

> Persons living in poverty (PLPs) are at greater risk for deterioration in health status, chronic illnesses, and premature death than are affluent persons. Yet there is a growing body of evidence indicating that PLPs receive the least amount of healthcare (known as the inverse care law). PLPs are less likely to have a family physician and to obtain preventive and secondary care, and more likely to report negative experiences of care (Loignon, et al., 2015, p. 2).

Poverty causes people to either avoid or cease the use of various health services because the poor perceive that healthcare service providers "do not listen to them or are rude, judgmental, or controlling" (Loignon, et al., 2015, p. 3). The poor also believe "their poverty affects the quality of care they receive and that they are mistreated, marginalized, and discriminated against because of their financial situation" (Ibid.). Given that Canada, where the study was carried out, is a developed country with fairly advanced healthcare systems, the situation can only be worse in African countries such as Kenya. A similar research in Nigeria and Uganda revealed that poverty-stricken women were unable "to prioritize accessing fistula treatment over household expenditures" and recommended "innovative approaches to financial assistance, transport, information of the available repair centres, rehabilitation, and reintegration in overcoming cost barriers" (Keya, et al., 2018). It is, therefore, necessary to address poverty if HIV-AIDS patients – and indeed other patients – are to gain access to healthcare, especially when genetic therapies become a reality. Loignon, et al, propose a five-point approach to changing how healthcare should be provided among the poor:

> "…compensation models for health equity practices (which) should be tested, implemented, and evaluated for effectiveness before being scaled up; …more resources to support interdisciplinary healthcare teams in underserved areas and to modify primary care practice guidelines to incorporate social and economic factors; …the need to develop effective training that integrates evidence on the social inequalities of health and poverty to provide the knowledge and tools required to help healthcare professionals avoid stigmatizing and developing negative attitudes towards the poor; …the need to close the equity gap in healthcare systems by better addressing the social determinants of health, such as poverty, poor housing, and food insecurity; (and) …the need to alter the law that mandates physicians to determine whether or not patients are fit for work, hence determining the amount of social assistance they receive and consequently the living conditions that impact their health and healthcare" (Loignon, et al., 2015, p. 9).

Income levels are generally inadequate in low-income countries in Africa, including Kenya, and wages cannot be relied on for keeping good health, let alone provision of housing and food.

Priority will need to be given to factors that make poverty such a prevalent experience in many households in Africa. Governments will need to initiate policy changes so as to remove barriers to healthcare access, especially for the poor. The concern about poverty and healthcare grows deeper as far as HIV-AIDS is concerned:

> There are strong bi-directional linkages between HIV-AIDS and poverty in resource-poor settings. HIV-AIDS is both a manifestation of poverty conditions that exist, taking hold where livelihoods are unsustainable, and the result of the unmitigated impact of the epidemic on social and economic conditions. HIV-AIDS is at the same time a cause and an outcome of poverty, and poverty is both a cause and an outcome of HIV-AIDS (ILO AIDS, 2005).

In other words, as AIDS impoverishes people, it also slows down economic growth and enables poverty to, in turn, expose more people to HIV-AIDS, thereby sustaining the deadly cycle of cause and effect. Strengthening economic performance at both national and household levels will have to be a top priority of the Kenya government if the citizens have to benefit from the emerging genetic therapies. The ten main causes of poverty in Kenya, as in many parts of Africa, are inadequate access to clean water and nutritious food, little or no access to livelihoods or jobs, conflict, inequality, poor education, climate change, lack of infrastructure, limited capacity of the government, lack of reserves, and mismanagement of public resources through corruption. These are the issues to be addressed by the government, if poverty is to be effectively alleviated, especially as it affects healthcare.

The second argument is that the geographical location of the scientific base of the development of genetic therapies should not necessarily affect distribution and access. This argument responds to such fears as the possibility of the developed world producing the therapies by themselves and for their own people, leaving out the majority sufferers of HIV-AIDS who live in Africa. Going by previous experience, medical products developed and produced in developed nations are distributed all over the world, including Africa and other developing areas of the globe. If genetic therapy will be first successful in the developed world, there is nothing morally wrong with that. Development must practically begin from somewhere, before it spreads or benefits the rest of the world. Airplanes are still manufactured in the developed world, yet Africans buy them and use them for transport. What needs to be encouraged is a network of collaborative approach to the research so that, rather than individual scientists from various institutions in diverse jurisdictions carrying out individualised research on genetic therapies, there should be deliberate inclusion of scientists from Africa too, as well as formalised collaboration with research universities in the continent. The point here is that there should be no fear that, just because much of the on-going research into genetic therapies is based in the developed nations, distribution of the final product will be skewed against Africa

and other developing nations. Since other scientific products have been previously developed and distributed from the developed world before, there is no sound basis for any fear that things will be different when it comes to genetic therapies.

For research collaboration[35] to turn out well it will need to be structured or restructured to involve scientists and institutions in the developed countries like the United States, China, the United Kingdom, and Australia, where significant strides have been made in genetic research, on the one hand, and countries in Africa, especially Kenya, South Africa, Nigeria, and other African countries, where HIV-AIDS continues to infect and affect large populations. Such partnerships will require input in terms of resources, finances, and personnel, for them to fully fledge out. Western research institutions have a long-standing tradition of scientific engagement that has resulted in the developments currently being reported in genetic therapies research. In contrast, with the exception of only a few top universities in South Africa, the continent of Africa lacks research capacity, generally arising from a serious lack of research funding for universities. Consequently, Africa will not successfully engage in meaningful genetic research on its own due to the lack of sufficient resources to dedicate to the process. But the West, and China, will also not go far enough in genetic research, especially in relation to HIV-AIDS, without collaborating with Africa where the disease has had the most impact. Africa-based scientists may be faced with strong impediments such as prejudice against Africa generally by well-endowed western-based researchers, together with the prevalent economic hardships in which Africa-based scientists operate. But these should not be barriers against collaboration. South African research universities such as University of Cape Town and University of Stellenbosch have spearheaded scientific and technological research in certain areas, including in more recent times, the first successful penile transplant[36] done at the University of Stellenbosch on 11th December 2014, besides previous success in nuclear science and other technological developments. Such achievements by a research university in Africa should be positively viewed as clear signs of strong capacity to engage in new frontiers such as genetic therapies, and should encourage collaboration. Kenya is not too far behind with its leading role in technological advancement, especially in money transfer systems, which has been borrowed by other settings, including western countries. Although it is not directly

[35] The exact details of how such collaboration may be initiated and how it may work are beyond the scope of this dissertation, and should be the subject of a research that focuses on a topic like, say, "Potential Collaboration between Africa and the West in Research in Genetic Therapies for Prominent African Diseases."
[36] The details of the transplant are at https://www.sun.ac.za/english/Lists/news/DispForm.aspx?ID=4898

relevant to medical science, the country holds much potential for growth in research in such serious laboratories as the Kenya Medical Research Institute (KEMRI).

6.7. COST-BASED ARGUMENTS

There is a cluster of arguments that I generally refer to as cost-based arguments because they present the matter of costs either against or in support of genetic therapies. In a previous presentation of an argument against genetic therapies, there was an argument that genetic therapies will be extremely expensive and unaffordable to the poor majority who are also the sufferers of HIV-AIDS, particularly in Africa. However, in this section, I present a contrary argument. If successfully developed, and if all risks are identified and resolved, germline therapy has the potential to remove HIV-AIDS completely from the population. This will, in turn, reduce or even remove the long term healthcare costs of treating the disease. Consequently, the costs of providing genetic therapies for HIV-AIDS patients will now be a cheaper option than the combined future costs of providing a lifetime of conventional treatment for the same patients and their descendants. If governments can consider this option, if approved, overall spending on healthcare will be slashed significantly. This possibility should justify making genetic therapies available through public funding in each country.

6.8. THE PRESENT LIMITATIONS OF ARV AND HAART

Patients of HIV-AIDS the world over have had their lives extended and their mortality reduced through the use of contemporary treatment using highly active antiretroviral therapy (HAART). At times, and in some contexts, this may have led to a misconception that HIV-AIDS has a cure, a misconception that is quite unhelpful in the fight against the HIV-AIDS pandemic.

> …in fact, as soon as the therapy is interrupted viral load inevitably resumes from cellular and anatomical reservoirs and CD4+ T cells level declines again. Thus life-long administration of the drugs, which requires a complex and cumbersome dosing regimens, is needed to contain viral rebounds after drug interruption. Unfortunately HAART is costly and leads to cardio-metabolic complications, cumulative toxicities and development of viral-escape mutants. Therefore, the unavoidable therapy failure and the side effects outbreak make necessary sooner or later treatment interruption and multiple changes of different cocktail regimens over the life-span of an AIDS subject (Bovolenta, et al., 2013).

A cure for HIV-AIDS remains a medical mirage. Experts have known for a while that antiretroviral treatment is not curative.

> Despite the tremendous advances in antiretroviral combination therapy over the last decade, eradication of HIV from the infected organism is still an elusive goal. Lifelong therapy is associated with potential long-term toxicity, adherence problems, and development of drug resistance. Thus, gene therapy approaches targeting viral eradication are still attractive (van Lunzen, et al., 2011, p. 78).

Furthermore, "…despite the progress in medical and behavioural approaches to control HIV infection, a cure for AIDS is far from being available because eradication of cryptic cellular reservoirs is not achievable with existing therapies" (Bovolenta, et al., 2013). It is clear that HAART treatments are only partial, as it has been observed that "…viral load rapidly rebounds after HAART cessation since there are inadequate HIV-specific immune responses generated by classical HIV drug therapy regardless of the drug combination used" (van Lunzen, et al., 2011, p. 78). In other words, the availability of ARVs or HAART has not provided a cure for HIV-AIDS, despite alleviation of much physical suffering and extension of life. These current treatments are severely limited in terms of providing a cure. The statement is not judgmental on the HAART, since they were not developed as a cure in the first place. My argument here is that the availability of ARVs and HAART should not lead to complacency against the search for a cure. It is in this context that genetic therapies are proposed as a potentially viable alternative approach for the treatment of AIDS. A study published in 2012 showed that

> Highly active antiretroviral therapy dramatically improves survival in HIV-infected patients. However, persistence of HIV in reservoirs has necessitated lifelong treatment that can be complicated by cumulative toxicities, incomplete immune restoration, and the emergence of drug-resistant escape mutants. Cell and gene therapies offer the promise of preventing progressive HIV infection by interfering with HIV replication in the absence of chronic antiviral therapy (Hoxie & June, 2012, p. 1).

Recent studies revealed that babies born to mothers with HIV face higher risks even though they had been born HIV negative. "HIV-uninfected children born to mothers with HIV are prone to infections that are more severe, are at almost two times greater risk of dying before their first birthday, and are more likely to be born prematurely than children born to mothers without HIV" (Slogrove, et al., 2018). Mortality persists among HIV-exposed infants, "even with maternal antiretroviral therapy." This is confirmed among mothers who are on ARVs before and during pregnancy, and after the birth of the children. It affirms that, rather than providing protection against HIV-AIDS, these treatments leave the new-borns more vulnerable to other infections. This situation calls for not just somatic treatment of HIV-AIDS, but also for germline gene therapies which will effectively prevent babies from inheriting the devastating illness from their mothers. Even if all other arguments were to be rendered unworthy, this is the one argument for genetic therapies that should receive serious attention. It is agonising for a mother to pass on a serious illness to her child, in full knowledge that nothing can be done to reverse the baby's condition permanently for the baby's sake. Conversely, it gives much satisfaction for parents and medics to know that they can bring HIV-negative children into the world, regardless of the status of the parents.

6.9. AFFIRMATION OF GOOD PARENTHOOD

The argument in this section is developed from Janet Malek who, taking note of objections to genetic technologies on the grounds that such technologies are not supportive of "the unconditional acceptance that lies at the heart of praiseworthy parental attitudes," argues that "it is possible for a parent to exhibit unconditional acceptance of the child herself without accepting each of that child's traits" (Malik, 2013, p. 59). Given that it is now possible for parents to become aware of the risks of a genetic disease to which their future children may be at risk, medical science employs genetic diagnosis to help parents avoid the birth of a child with such a genetic illness. The idea that Malik argues against is summarised as follows:

> Some scholars have argued that potential parents who use RGTs to reduce the likelihood that their future child will have a disabling genetic condition demonstrate an inappropriate attitude toward parenthood. More specifically, they claim that this choice reflects conditional acceptance of the child, an attitude that is antithetical to what it is to be a good parent (Malik, 2013, p. 59).

It is assumed that good parenting involves taking care of a child as received at birth, inclusive of any defects, disabilities, without turning the child into what they are not, thereby focusing on the parent-child relationship rather than the child's traits. The idea is that a potential parent should simply welcome the child, and not spend time evaluating a child's suitability based on potential for disability and illness. This is the idea that Malik objects to as she points out the fact that cultural variations in the concept of good parenting makes it impossible for people to agree on what really constitutes good parenting. She argues that parental love does not mean neglecting to correct deficiencies which could be corrected before the birth of a child. She further argues that "…the idea that parents should do what they can to make their future children better off is not part of the obligation of unconditional love but rather is a distinct duty" (Malik, 2013, p. 61). An important point is raised to give clarity to the necessary distinction between a person and a person's traits, with the emphasis that "…if a person were identical to his traits, any change in that person's traits would bring about a change in that person's identity" (Ibid.).

> If a future child is not identical to his traits or characteristics, it is possible for a potential parent to accept one and not the other. That is, a parent can show an attitude of unconditional acceptance for the child himself, but not take that same attitude toward each of the child's traits. When a potential parent's attitudes toward the future child are distinguished from her attitudes toward the future child's traits, it becomes clear that a potential parent can use RGTs[37] with the intention of determining the traits of her future child in a way that is not inconsistent with praiseworthy parental attitudes (Ibid.).

[37] RGTs are reproductive genetic technologies (RGTs) over which there arise some ethical concerns. In the context of this research similar consideration is accorded them as genetic therapies.

Malik's idea makes much sense in logic, for the reason that accepting a child as a gift is not the same as accepting the disease that troubles the child. Accepting, tolerating, and sustaining debilitating defects would be irresponsible of a parent if a solution may be within reach. The validity of this argument is in the idea that a normal parent should possess the capacity to give good things to their offspring. Parents who desire good traits, including good health, for their children are affirmed as good parents. Conversely any parent who knows an offspring's potential to be born with a correctable defect, and knowingly avoids correcting the defect should lay no claim to good parenthood. A parent whose child has a disability of any kind is a good parent if she seeks to help the child live better despite the challenges. Although they unconditionally accept, love and appreciate their children, good parents exemplify proper parenting by working to improve the lives of those children. A parent who has HIV-AIDS should normally make effort to deflect the disease from her offspring, as people generally do through the use of ARVs. In a context where genetic therapies will provide a permanent solution for HIV-AIDS, future children will have benefited from the wise choices made by their parents for their sake. As such, these therapies should be accepted as an affirmation of good parenthood. And good parenthood among the majority sufferers of HIV in Africa will be good for humanity globally.

6.10. UNFOUNDED HOSTILITY TOWARDS GENETIC ENGINEERING

There appears to be a generally prevalent hostility towards genetic engineering, especially in relation to either genetic therapies or human enhancement, or both. This hostility is propagated by regulatory bodies and civil organisations whose mandate is to safeguard human interests in relation to scientific research and medical progress. For the most part, the hostility comes out of genuine concerns for human safety and a suspicion that rogue scientists could take advantage of any available loophole to push forward a scientific agenda without due regard to human safety and ethical concerns. In many instances there is a clash of perception between policy-makers and medical scientists, each side claiming a measure of control over the other. As Curchoe points out,

> Policy-makers the world over typically do not have a background in medical sciences, genetics, or medical ethics but they are tasked with making the policy that governs these concerns. Often, science moves more quickly than policy and it is up to the scientific societies to display a modicum of self-governance, as with the voluntary, worldwide moratorium first on transgenic organisms, then later on human cloning (Curchoe, 2018).

In many cases, the hostility emerges from within scientific professionals, either out of valid scientific concerns or perhaps out of what appears to be professional rivalry. An example is cited from July 2012 when the European Medicine Agency (EMA) recommended Glybera®

(alipogene tiparvovec) for "…approval for the treatment of lipoprotein lipase deficiency (LPLD). Patients with this disorder of triglyceride metabolism experience severe acute pancreatitis attacks that can be fatal" (Boudes, 2014, p. 33). This led to the European Commission approval in November 2012, and Glybera® became the first gene therapy approved in the Western world, and gene therapy became a reality. What is not commonly known is that the approval had been preceded by a lengthy process after the original submission had been made in January 2010, but had been turned down by the EMA, and a re-examination was only done when the sponsor, Amsterdam Molecular Therapeutics, repeatedly requested it. Between October 2011 and November 2012 there were tests, repeated tests, a falling out of the sponsor leading to a takeover by a new sponsor, additional analysis, re-examinations, and numerous committee reviews (Boudes, 2014, p. 34). On the one hand, this process can be acclaimed as a mark of thoroughness, leaving nothing to chance, which is absolutely commendable. On the other hand, one can perceive underlying hostility towards genetic therapies in this case, leading even bodies that normally would depend on the judgment of EMA to also demand independent scientific verification procedures before making further recommendations. The common legal doctrine in criminal justice that "a crime suspect is innocent until proven guilty in a court of law" may be applied in reverse: genetic therapies are guilty until proven innocent in an extremely rigorous scientific verification process. I perceive this to be a form of unfounded hostility towards genetic therapies.

In March 2019 a group of specialists called for "a global moratorium on all clinical uses of human germline editing". They asked governments to commit themselves to not approving any germline editing unless certain conditions are met. The time would allow for the establishment of an international framework before further research is done on human germline editing (Lander, et al., 2019). The call for a moratorium was specifically with regard to "all clinical uses of human germline editing — that is, changing heritable DNA (in sperm, eggs or embryos) to make genetically modified children."

> By 'global moratorium', we do not mean a permanent ban. Rather, we call for the establishment of an international framework in which nations, while retaining the right to make their own decisions, voluntarily commit to not approve any use of clinical germline editing unless certain conditions are met (Lander, et al., 2019).

This call was made after a Chinese biophysicist He Jiankui reportedly edited embryos to create two babies, and it was suspected that a number of scientists had been apparently aware of this work but had not made any attempts to stop it. This was in the context of perceived "growing interest in proposals for genetic enhancement of humans" (Lander, et al., 2019, p. 165). One would have expected that such a serious call from respected scientists would have brought out

new ethical dimensions as foundational to the call. But in the end the reasons were the same old ones, quite similar to the kind already discussed in Chapter 5 of this dissertation. The reasons advanced include the need for broad societal consensus, the fear that the results may backfire, the fear of potential stigmatization, the possibility of commercialisation of enhancement, the possibility of psychologically negative experiences of children, the fear that humans may fundamentally become different from who they really are, unequal access to the technology, and the possibility of genetic harm to other species (Lander, et al., 2019, p. 167). This is another sign of unfounded hostility towards genetic therapies. Recently, Chinese state-run news agency *Xinhua* reported that "He Jiankui, the researcher responsible for creating the world's first gene-edited babies, had been sentenced to three years in prison on the charge of illegally practicing medicine" (Houser, 2019, p. para 1). Earlier, China had condemned He's research soon after the birth of the twin babies out of his experiment. The same news agency also reported that, in addition to the two babies announced earlier, "a third gene-edited baby has officially been born" (Houser, 2019, p. para 3). It appears that the severe opposition to He's research is fired up by what Scherz calls "the issue of enhancement or making people better than well" (Scherz, 2019, p. 28). Scherz argues that "…the He case was especially worrisome since his goal was not to cure a genetic illness in a person with a specific mutation, but to protect against HIV by introducing a mutation" (Scherz, 2019, p. 28). This argument against He does not provide any moral difference between curing an illness in a patient and protecting a healthy person from contracting a deadly disease. It would appear that, for Scherz, it would be morally right – perhaps even obligatory – to use a genetic therapy to cure a patient of HIV, but absolutely wrong to use the same therapy to prevent a healthy person from contracting HIV. But such an argument would be invalid because protection from harm is just as important as cure from a harmful disease. Otherwise, if Scherz's argument were to stand, then medical science would concentrate on treating the sick while totally ignoring vaccinations and public health education and regulations whose aim is to protect the healthy. A careful reading of the report reveals a general attitude of fear and hostility towards genetic research as the more obvious basis for the severe punishment accorded to Jiankui, whereas it would be prudent, at this stage, for the scientific community to seek to appreciate efforts made, correct any mistakes – real or imagined – in the research protocols, and develop new and useful guidelines for further research.

The argument against unfounded hostility towards genetic therapies is not intended to discard regulatory oversight over new and emerging genetic technologies. Indeed, research "…must ensure the rights of human subjects, and all medical products and techniques should

be ensured to be safe and effective" (Hughes, 2019, p. 112). In addition, there is need for regulatory agencies "to enforce cultural norms, protect against hypothetical social harms, or ensure that the human genome remains unchanged" (Hughes, 2019, p. 112). However, regulation is not the same concept as prohibition. Regulation should provide for rational guidelines, as in the case of the Nuffield Council on Bioethics which, while taking note of the prevailing illegality of genetic therapies in Britain, "…cautions against a rush to ban such therapies without extensive public debate, and urges research on their safety and efficacy" (Hughes, 2019, p. 112). Their advice is that there be a careful assessment of the risks of adverse results, after which the genetic therapies should be approved for clinical use.

The argument that I am developing here is that there has been unfounded hostility towards genetic engineering in general and genetic therapies in particular. Such hostility is not based on any grounded philosophical foundations. Instead, they are based on fear-mongering and die-hard comfort with *status quo* science. Yet if humans had been fearful of making attempts at treating disease, death would have probably wiped out the human race through the previous plagues. Human beings must remain in a forward match towards liberation from disease, indignity, and pain, and must remain unhindered by those whose desire is to remain within familiar science territories. People who are generally hostile towards genetic therapies must not prevent scientific work whose intention is to bring an end to human suffering and pain through such illnesses at HIV-AIDS. Instead, the points of concern need to be raised with a view to seeking proper solutions in the overall context of assurance of safety in health care.

6.11. CURRENT HEADWAYS IN GENETIC THERAPIES

This last section presents arguments based on the phenomenal headways that are being achieved in research in genetic therapies a factor that has not received attention from those who oppose these therapies and any related research. The argument is that when a new development emerges that seeks to solve a human problem, then, although it may show signs of being problematic in some ways, the society needs to find ways of resolving its problematic aspects and then move forward with its implementation, rather than merely reject the new approaches in whole. A substantial amount of work has been done, and new developments have emerged in the last three years or so, including successful clinical trials. These new developments cannot be ignored by rational human beings who seek solutions to such challenges as HIV-AIDS, cancer, diabetes, and TB.

In March 2019 a patient in Britain was cured of the HIV infection "after he received a bone marrow transplant from an HIV resistant donor" (Reuters, 2019). This report revived hope

that a cure for AIDS will successfully be developed soon, in agreement with the comment from Anton Pozniak, the President of the International AIDS Society: "Although this is not a viable large-scale strategy for a cure, it does represent a critical moment. The hope is that this will eventually lead to a safe, cost-effective and easy strategy… using gene technology or antibody techniques" (Reuters, 2019). In June 2019, reports emerged that a gel had been developed in Kenya "that can kill the AIDS-causing virus" (Nation Media Group, 2019). "If the human trials are successful, Kenya could be the first country in the world to put an effective anti-HIV microbicide[38] in the market." If this were to become a reality soon, it would bring significant progress in the search for a cure for HIV. In July 2019 researchers published a report saying they had gotten closer to finding cure for HIV after they had used CRISPR technology to eliminate disease in live mice for the first time (Dash, et al., 2019). The scientists, based at Temple University and the University of Nebraska, had used a combination of CRSPR gene-editing technology and a therapeutic treatment called LASER ART, and succeeded in erasing HIV DNA from the genes of the mice. Dr. Kamel Khalili[39] who co-authored the study commented, "We think this study is a major breakthrough because it for the first time demonstrates after 40 years of the AIDS epidemic that the HIV disease is a curable disease" (Turner, 2019). Of course, not all that works well in mice necessarily works well in humans. And, of course, the absolute safety and efficiency of the procedure has to be ascertained. But the study gives hope that genetic therapies have capacity to cure patients of HIV-AIDS in the near future.

The argument here is that, with so much progress already made in scientific research, with strong indications of possible success, save for necessary improvements and appropriate further tests, it is more prudent to proceed with the development of genetic therapies than to create hurdles and push backwards. There seems to be too much positive progress to allow for a reversal of the efforts made in recent times. If ever the invested funds were to go to waste, it would be better to "waste" the funds making progress towards perfecting these milestones than to waste the same by a halt of any activities due to the fear of the unknown. The current headways in genetic therapies provide much hope on the perhaps imminent development of genetic therapies against HIV-AIDS, especially for Africa which bears the greatest burden of the disease.

[38] "A microbicide, according to the World Health Organisation, is a substance applied inside the vagina or rectum to reduce the transmission of sexually transmitted infections, including HIV… It works by lowering and stabilising the environment at levels that are too acidic for HIV to survive" (Nation Media Group, 2019).
[39] Dr. Kamel Khalili is the chair of the Department of Neuroscience and Director of the Center for Neurovirology and the Comprehensive NeuroAIDS Center at Temple University.

6.12. CONCLUSION

I have established the desirability and ethical appropriateness of the proposed use of genetic therapies. To establish the benefits of such therapies, I have argued in support of the necessity to develop and apply them in the treatment of HIV-AIDS in Africa. I have presented arguments from the nature of human genes, the potential of genetic therapies, communitarianism, theological ethics, justice, cost-based arguments, current limitations of treatments through ARVs and HAARTs, affirmation of good parenthood, unfounded hostility towards genetic therapies, and current headways in the development of genetic therapies, all to explain the necessity of these therapies.

CHAPTER 7: EVALUATION AND RECOMMENDATIONS

7.1. INTRODUCTION

In this final chapter I provide an evaluation of the arguments against and in favour of genetic enhancement therapies in order to determine their relevance and their ethical implications on the health situation in Kenya. As part of the discourse, I evaluate the magnitude of HIV-AIDS in Africa, especially Kenya, as well as the necessity and suitability of genetic therapies as solutions to the problem. I also give a utilitarian assessment of the challenges of genetic therapies and an appraisal of the same therapies for HIV-AIDS, before making recommendations.

7.2. MAGNITUDE OF HIV-AIDS IN AFRICA, ESPECIALLY IN KENYA

The extent to which HIV-AIDS has impacted Africa in general, and Kenya in particular, is the subject under discussion in Chapter 1 of this dissertation, although a brief recollection may be useful here. While the population of Kenya in 2016 was 48.46 million, the estimated prevalence of HIV among people of ages 15 to 49 was 6.9%, resulting into about 31,000 deaths and 840,000 orphans from AIDS in the same year. It was also reported that about 940,000 people were receiving antiretroviral therapy (ART) (CDC, 2019). By 2018 it was estimated that there were 1,493,382 Kenyans living with HIV, with new infections standing at 52,767, and deaths at 28,214 in that year (Oketch & Kilonzo, 2018). The rest of the world has not done any better. "In 2017 an estimated 36.9 million people were living with HIV (including 1.8 million children) – with a global HIV prevalence of 0.8% among adults. Around 25% of these same people do not know that they have the virus." It was reported that the vast majority of people living with HIV are "...located in low- and middle- income countries, with an estimated 66% living in sub-Saharan Africa. Among this group 19.6 million are living in East and Southern Africa which saw 800,000 new HIV infections in 2017" (Sidibé, 2018). These statistics continue to confirm that Africa bears a large and disproportionate burden of the HIV-AIDS scourge. All cadres are directly or indirectly affected by the disease. It remains of concern that in sub-Saharan Africa, "...three in four new infections are among girls aged 15–19 years and young women aged 15–24 years are twice as likely to be living with HIV than men" (Sidibé, 2018).

Whether one is studying the general situation in Africa of the specific situation in Kenya, the likely observation is that HIV-AIDS remains a formidable health challenge in both contexts. Africa continues to carry the greatest burden of the challenges brought about by HIV-

AIDS. It continues to kill millions who leave destitute dependants behind. It also continues to affect the economic capacity of the population to produce and engage in development. Kenya is, specifically, of concern because, together with Mozambique and Uganda, it shares the position of being the fourth largest bearer of the HIV-AIDS epidemic burden in the world. The human resource capacity in Kenya, and further on in Africa, continues to suffer from the impact of HIV-AIDS. The illness is an issue that cannot be simply wished away. It is also quite clear that ARVs or HAART are only a temporal means for quelling the illness while leaving the problem alive and unhindered. In reality, therefore, there is no cure for HIV-AIDS.

The situation is getting worse, rather than better, with recent reports indicating that "an alarming surge in resistance to crucial HIV drugs" had been observed.

> Surveys by the World Health Organization (WHO) reveal that, in the past 4 years, 12 countries in Africa, Asia and the Americas have surpassed acceptable levels of drug resistance against two drugs that constitute the backbone of HIV treatment: efavirenz and nevirapine. People living with HIV are routinely treated with a cocktail of drugs, known as antiretroviral therapy, but the virus can mutate into a resistant form (Mega, 2019).

The WHO carried out the surveys from 2014 to 2018 in selected clinics in 18 countries, and concluded that "…more than 10% of adults with the virus have developed resistance to these drugs in 12 nations" (Mega, 2019). The organisation now says it is "not considered safe to prescribe the same HIV medicines to the rest of the population, because resistance could increase" (Mega, 2019). In those surveys, sub-Saharan Africa showed the highest level of resistance in infants with HIV. This report reinforces the notion that the magnitude of the HIV-AIDS scourge remains alarming and in need of a more effective solution than currently available.

It is clear that the magnitude of the HIV scourge is devastating, especially in the context of drugs that neither cure nor remove the disease from the human community. In this situation, what kind of solutions should scientific medical research endeavour to provide for Africa? It is imperative for governments in Africa to prioritise the problem of HIV-AIDS and seek solutions in the same way European nations had to put plans in place in fighting against Black Death and other plagues, actions that led to the saving of European populations at the time. There is renewed need to remind Sub-Saharan governments that millions of the population are sick with HIV-AIDS, for which there is actually no cure. In addition, workers are incapacitated and many die; economic challenges affect families and cause poverty; the cost of doing business increases and affects the economy; poverty and hunger continues to ravage the continent; child and maternal mortality in relation to HIV-AIDS continues; AIDS continues to infect the most economically active segment of the population in the ages between 18 and 35;

and the economies of African nations, including Kenya, continue to experience the effects of the disease. It is not possible to talk about health among African populations without reflecting on HIV-AIDS. The magnitude of the problem is huge, and cannot be ignored. It cannot be assumed any more that ARVs and HAARTs will solve the problem, or that the problem will somehow simply go away. With Africa carrying 70% of the HIV-AIDS burden, and with Kenya being among the leading countries with infected and affected populations, the country needs to take serious note of the problem and put plans in place to not just reduce the infections but actually eliminate the disease.

An understanding of the magnitude of the disease should lead to the conclusion that a continuation of the disease in infecting the people is a serious form of harm. Furthermore, it is also important to consider if the use of ARVs and HAART, which help patients to manage their lives and enable them to live active lives, but without actually providing a cure, is also a form of harm. If both are a form of harm, then there is need to deal with HIV-AIDS beyond the provision of ARVs and HAART. In the first instance, HIV-AIDS is harmful to the people in many ways, as already previously discussed. I hasten to add that additional harm occurs as governments simply express satisfaction with providing ARTs to the people, and no longer seek to eliminate the disease. Although the government is not responsible for causing the initial harm, since the government does not promote infection, and although the government acts benevolently by providing ARTs and HAART to the sick, failure to draft any plans for the elimination of such a highly devastating illness is a serious form of harm to the citizens. Furthermore, a good idea always gets overtaken by a better idea that emerges, especially where the magnitude of the problem clearly calls for a better idea.

The other question that needs attention is that of whether the magnitude of HIV-AIDS in Africa in general, and Kenya in particular, is of such significance as to warrant attention in a utilitarian understanding. Granted that not all health problems necessarily affect the majority in a given population, and certainly HIV-AIDS is not affecting everybody in Africa in any direct way. However, a health challenge, especially a devastating illness, draws the attention of a utilitarian philosopher due to the effects of the disease on the people. A solution to the scourge of HIV-AIDS will definitely bring much happiness to the infected people and their families, besides giving them relief from pain, discomfort, and anxiety, while at the same time, causing no additional harm to the people. Indeed, it can be said with certainty that no African nation will be left out of the resultant happiness and fulfilment when a lasting solution will be made available to the problem of HIV-AIDS. A solution to a worldwide disease whose impact

is primarily felt in Africa should be worthy of attention, planning, and investment by African governments. That will be an excellent utilitarian achievement.

7.3. NECESSITY AND SUITABILITY OF A GENETIC THERAPY SOLUTION

For an idea or a thing or an experience to be necessary, it has to be vital for certain events or conditions to continue or to thrive. It is essential, obligatory and basic. An example would be the way life would not continue without food. Hence food is a necessity to life. Water and air belong to the same category, and are necessities. In logic, the term necessity would refer to three ideas: a proposition which, if denied, would lead to a self-contradiction; an inference or an argument whose conclusion cannot be false if its supporting premises are true; and a condition which "must exist if a given event is to occur or a given thing is to exist" (Blackburn, 2008, p. 71). It is in this third sense that I make reference to the term necessity with regard to genetic therapies as solutions to the HIV-AIDS pandemic in Africa. I will argue that the development and realisation of genetic therapies is a condition that needs to exist if the world, especially Africa, is to become completely free of HIV-AIDS. For now, it is also necessary to clarify that suitability refers to something deemed appropriate for meeting a need or resolving a problem. It is right and befitting for the purpose for which it is intended; something that is correct and befits the situation. The idea also has the connotation of timeliness and convenience. I will further develop this idea in arguing that genetic therapies are suitable for resolving the HIV-AIDS disease.

It is a necessity for genetic therapies to be brought into reality and functionality in the world in general and in Africa in particular, if HIV-AIDS is to be stamped out and good health is to be realised. In other words, genetic therapies are not merely an idea that people should imagine or wish for; it is not a concept that belongs to the domain of science fiction any more. Rather, it is a necessity. It may have actually become an absolute necessity, without which human life can no longer proceed as we know it. Since Africa is home to 15% of the world's population, it is necessary to pay attention to any health challenges facing the continent. Resolving the HIV-AIDS disease in Africa relieves a significant percentage of humanity of a huge threat to human survival and well-being. And since Africa bears 70% of the world's HIV-AIDS burden, eradicating the disease from Africa relieves the world population of one of the worst health challenges the world has ever faced in modern world. Surely, it makes utilitarian sense for genetic therapies to be applied into ensuring that 70% of those who are infected by HIV-AIDS get cured, and possibly their descendants will never have to get infected. Already significant and elaborate research has been carried out with notable success, especially with

regard to CRISPR, with significant investments in terms of time, money, and human resource capacity. The scientific community cannot be going to such great lengths only for the sake of the 30% sufferers in the rest of the world, although even the suffering of the 30%, for sure, deserves attention. From a utilitarian perspective, the substantial scientific and technological investment in genetic therapies will lead to the greatest happiness for the greatest number of HIV-AIDS patients when it applies to Africa.

Genetic therapies are suitable for resolving the problem of HIV-AIDS in Africa and meeting the health needs of a fairly large segment of the population. The suitability of genetic therapies is strategic in the context of previous and existing attempts at dealing with the problem. Such attempts include the promotion of abstinence from premarital and extramarital sex, the building up of faithfulness as a virtue in marital relationships, the use of condoms to prevent HIV infections, and the use of ARVs to sustain the lives of those already infected with the virus. Yet it has to be noted that if these attempts had been successful in dealing with HIV-AIDS there would have been significant decline in the number of infections. Indeed the problem would have been solved decades ago, especially when ARVs were introduced. Mother-to-child infections should not be happening any more. Abstinence and faithfulness are excellent ideas if self-control were an enduring virtue in all African peoples. But I would be stretching my imaginations too far if I ever claimed that African peoples were paragons of virtue. Therefore, both abstinence and faithfulness can be classified as ideal and suitable but only rarely effective for HIV-AIDS. They cannot be relied on to provide cure. In theory, if abstinence and faithfulness were efficiently practised, it would be possible for all the infected people to die in a given span of time, and leave a population devoid of the illness. But this is an impractical theory that remains largely ineffective. They are not befitting for the purpose for which they are intended, as they do not help the majority. Condoms, too, should be a great solution under the assumption that they are used properly in all sexual engagements. But it has been said that some people even recycle them; and some men even wash them and pass them on to their friends, a clear illustration that the correct use of these items is still far from becoming reality. Where they have been used well, they have helped in the reduction of sexually transmitted diseases as well as unplanned pregnancies. But their use as a prevention against HIV has not resulted into a significant reduction in new infections. To claim that condoms are truly effective would be a stretch of human imagination. The last category of attempted alleviations come from ARVs which boost bodily functioning without providing a cure from the illness, although the general population mostly erroneously thinks ARVs are of curative value.

Although the development of genetic therapies for HIV-AIDS is still far from conclusive reality, the potential for both somatic and germline treatments gives hope that is otherwise lacking in all prevailing attempts at dealing with the disease efficiently and conclusively. Somatic genetic therapies, as discussed in detail earlier, will eliminate HIV-AIDS in the patient, although without insulating the future generations from infections. But even with that comes a clear possibility of actually eliminating the disease from the population. If governments in Africa will join in funding the on-going research, and later engage in supporting the production and distribution of the resulting somatic genetic therapies, it is possible for all the people currently infected with HIV to get cured completely. I must add that germline genetic therapies will only make it better by ensuring that future generations will not get infected because they will have not inherent capacity to get infected. Of course, there are still numerous scientific challenges to be resolved before these therapies can become a medical reality. But for a virus such as HIV which continually mutates and defeats the development of conventional medicines for treatment, genetic therapies are the right and befitting solution which will also be most convenient. And for the sufferers and their families, genetic therapies will also be timely.

7.4. A UTILITARIAN ASSESSMENT OF THE CHALLENGES OF GENETIC THERAPIES

In this section I do not intend to recount or narrate the arguments raised against genetic therapies, a task already carried out in Chapter 5 of this dissertation. Rather, I intend to develop a utilitarian assessment of the challenges in order to make rational conclusions on their validity or otherwise, based on the three basic tenets of utilitarianism: that happiness is the only idea that has intrinsic value; that actions are right when they promote happiness and wrong when they cause pain; and that everyone's happiness counts equally. From this perspective, challenges posed by genetic therapies should be considered valid if they prove that genetic therapies work against these three principles of utilitarianism. If pleasure is to be sought after, pain is to be avoided. Firstly, to say that pleasure is the only thing that has intrinsic value is to say that pleasure is good in itself, and that a world in which pleasure exists is a better world than a world without pleasure. Secondly, to say that right actions are those that lead to happiness and wrong actions are those that cause pain is to place emphasis on consequences of actions. An act that causes greater happiness among a greater number is better than an act that causes happiness in just one person. When the focus is on only one person then the right act is the one that will result in the happiness of the person, while the wrong act is one that will cause

pain in the same person. But it is not only the consequences of an act that counts, but the motives of the agent as well. In this case, generosity motivated by compassion is much better in a utilitarian context than a similar act motivated by desire for popularity for the giver. Thirdly, if everyone's happiness counts in equal measure, the life of one person is not more important than the life of another person. In other words, the life of a king is as important as the life of a peasant. For example, a good utilitarian health policy is the one that will provide for health services to the citizens without regard to social or economic status of anyone involved.

This understanding should lead to the question of whether the challenges posed by genetic therapies cause pain and harm, thereby acting against the pleasure of the many. I will now assess arguments raised against genetic therapies, such as slippery slope arguments, naturalistic arguments, economic justice arguments, arguments from lack of consent, and theological-ethical arguments, all of which are discussed in Chapter 5 of this dissertation. These clusters of arguments postulate on the challenges, real or imagined, of genetic therapies.

Slippery slope arguments hold the idea that accepting a form of genetic therapy will cause temptation to initiate other forms of therapy that are morally much more dubious. If genetic therapies are accepted for the treatment of HIV-AIDS, the same therapies may be sought after to resolve other challenges in human life. Fear is an important tool of trade in slippery slope arguments: the fear of making improved or superior human beings, the fear of re-introducing eugenics, and the fear of opening up new frontiers in medicine. These fear factors need closer examination before a conclusion is reached on the validity of the arguments. Firstly, there is fear that success in treating HIV-AIDS using genetic therapies will lead to attempts to improve human life through, for instance, curing baldness, suppressing obesity, eliminating poor eyesight, improving physical and intellectual performance, and technologically enhancing the human race in other areas. The glaring failure of most slippery slope arguments is in not showing what harm is caused by such envisioned improvements. For example, if genetic therapies will be used to cure poor eyesight, it is extremely difficult for a rational person to explain how such an act could be harmful, against all obvious indications that the act would cause happiness to the recipients of such genetic treatment. Similarly, if the use of genetic therapies were to tempt humans on a slippery slope into improving intellectual capacity, humans would only be happier to develop higher capacity to solve their problems. This, in turn, would cause greater happiness among those who would receive such capacity. It is possible that such benefits could spread out to others progressively, thereby causing

happiness to the entire human race. Secondly, there is the fear of re-introducing eugenics, like in the Nazi days, through genetic science, a fear that has no reliable basis at present.

In Nazi Germany, there was "the frightening series of coerced medical experiments and the severe violations of human rights, not only in relation to Jews, gypsies and 'people of colour', but, particularly, in relation to people living with disabilities... there are alarming signs that old-style eugenics is apparently still looked upon favourably by even some modern-day policy-makers such as those in Singapore, Malaysia and even China" (Van Niekerk, 2018, p. 35). If the utilitarian goal of genetic science is to cause happiness through elimination of suffering and enhancement of positive traits, the same genetic science would not at the same time seek to cause painful human experiences motivated by racism. In any case, given the challenges from past experience, it is now easier to mobilise world governments to legislate to control genetic therapies so that they are not turned into enhancement experiments with racial undertones. Thirdly, there is the general fear of getting into new frontiers in medicine. This is exemplified by the slow acceptance of somatic gene therapy by regulatory committees due to perceived relative safety, while holding off on germline therapy due to perceived greater risk. However, medicine is a discipline that continues to evolve and grow on the basis of new ideas and developments. Indeed, the history of medical science is lined up with encounters of resistance to new advancements that were feared at introduction because very little was known about them. But later, with more knowledge and widespread use, the same medical technologies gained acceptance, and are today taken for granted. Newness is always greeted with hesitation and scepticism. I conclude that slippery slope arguments are mostly speculative and do not give evidence of harm likely to occur if genetic therapies are developed and implemented to cure and eliminate HIV-AIDS. The arguments themselves seem to be more harmful in seeking to prevent the use of genetic therapies to solve a human problem and cause happiness to a significant population.

The next cluster of arguments against genetic therapies is naturalistic arguments which hold to the following key ideas: that genetic therapies are not natural; that genetic therapies interfere with how humans are constituted; that human beings are genetically complex; that there is no moral obligation to genetically modify human beings; that there is a good side to human bodily weakness; and that procreation is supposed to be a natural process. These arguments do not forecast beyond the natural, and may appear to promote the maintenance of the *status quo* with regard to how human beings deal with problems. To argue that genetic therapies are not natural is to put forward assumptions that only the natural is good, and that the natural is always good. But both of these assumptions are false. To allege that only the

natural is good is to assume that nothing good is obtainable from the artificial which is not true, given the numerous artificial machines, vehicles, equipment, and facilities that human beings have become so dependent on for efficient functioning. These artificial developments have caused much happiness in human life. To imagine that the natural is always good is to ignore the devastating turbulence and destruction that natural calamities visit on human beings from time to time. Nature has sometimes been a source of great pain to human beings. An item or an idea does not have to be natural to be of such value or quality as to cause great happiness to human beings.

There are two examples of how nature has previously caused misery, pain, and death to human beings. The first example is the Tuskegee syphilis experiment that was conducted from 1932 to 1972 by the US Public Health Service. It was an observational study of the natural progression of untreated syphilis among Africa-American men while, all along the men were lied to that they were recipients of free treatment from the government (Nix, 2017). Although penicillin was already an available form of treatment for syphilis, nature was left to take its full course in this research as a result of which many participants died while others went blind or insane. The Tuskegee story is a sad one that warns us of the terrifying dangers of a let-nature-take-its-course attitude towards disease. The second example is that of the influenza pandemic – also known as the Spanish flu – that infected about 500 million people around the world between January 1918 and December 1920, killing about 50 million. This was a disease that broke out from unknown quarters and progressed naturally as people made contact with others through sneezes and coughs. The situation was made worse by the on-going world war at the time (CDC, 2019). The Spanish flu was a terrifying disease that wiped out populations without much warning, and exposed the helplessness of humans when confronted with strange debilitating illnesses.

The argument that genetic therapies interfere with how humans are constituted is a valid one in the sense of pointing out a fact. In other words, genetic therapies affect and alter the normal bodily functioning of a human being. This argument goes together well with the subsequent two arguments: first, that human beings are genetically complex and secondly, that there is no moral obligation to genetically modify human beings. It is admissible that any effect on the body that leads to deformation or disability or mental degradation or failure of bodily organs would be wrong. Furthermore, if the genetic therapy would change the formation of what is known as human, it would be wrong too. For instance, if in an extreme case of bodily malfunction someone were to develop an additional eye and a third leg, that sort of genetic science would be wrong because it would be re-creating a new species of humans. However,

in discussing about genetic therapies, the focus is not on changing the way humans look or function. Rather, the focus is on correcting the genetic structure in order to develop capacity to evade certain diseases, such as HIV-AIDS. This is an intention that is likely to cause greater happiness among those who have experienced the devastating impact of incurable life-threatening illnesses quite in the same way as vaccines have helped reduce or eliminate certain diseases. Of course, there is a good side to human bodily weakness; but bodily weakness should never be a desirable state of life. Bodily weakness should be something that catches up with us, rather than something we seek after. Human beings should naturally seek to remain healthy, be able to work, and be able to function in a regular way in order to remain fulfilled and happy. Any scientific procedure that gives an assurance of that should receive requisite approval. It is agreeable that, in an ideal world, procreation is supposed to be a natural process. However, modern medical science has developed fairly adequate technological interventions, such as in vitro fertilisation, artificial insemination, and surrogacy that have resolved human infertility in modern times in unprecedented proportions. As van Niekerk has suggested, although care and responsibility must be taken seriously, it is not proper that "science and technology could or should be stopped in its tracks…" (Van Niekerk, 2018, p. 35). Despite the moral challenges associated with some procedures in some specific contexts, these procedures have largely reduced the pain of childlessness, while at the same time increasing happiness in families. Human beings can no longer consistently argue against artificial interventions in an age in which transport, medicine, education, commerce, agriculture, housing, and numerous other aspects of human life are run by sophisticated technology.

Distributive justice arguments focus on challenges that are likely to come with the introduction of genetic therapies in a Sub-Saharan country like Kenya where there is understandable need to prioritise on less costly but common health needs, rather than the long-term and costly ones. In Kenya, like in other countries in Africa, numerous deaths still occur from malaria, TB, and water-borne diseases. Although these diseases are curable and preventable, resources for treatment and prevention campaigns are not sufficient. Research in genetic therapies is, therefore, viewed as an unaffordable luxury and a dream. Available resources would rather be spent on infrastructural development. However, the government of Kenya and other African governments should view this matter differently in order to cause the greatest happiness possible for the people. Rather than attempt to prioritise the more affordable health concerns at the neglect of research into genetic therapies, it is possible to invest comprehensively in all the concerns, including research in genetic therapies for HIV-AIDS. It seems to be an engagement in futility of sorts if African governments will invest in treating

and preventing the common tropical diseases, only for the same people to continue to suffer from the effects of HIV-AIDS, which would be a case of replacing one form of pain with another. The priority choices should be between comprehensive health policy that includes supporting research in genetic therapies, rather than between affordable health concerns and expensive ones.

A continuation of the challenges related to economic justice will raise the twin points of economic power as a means for gaining genetic treatment on the one hand, and resultant discrimination between treatment recipients and non-recipients on the other hand. As discussed earlier in Chapter 5, genetic therapies are expensive to develop and produce; once made available in the market, they will be expensive to administer too. This means only wealthy people will afford them, which is a form of economic injustice. However, it may be argued that all human life is lived on the basis of affording or not affording certain things. Good things should not be kept away from the market just because some people will not afford them. Governments do not stop constructing roads because some people will not drive on them. Similarly, hospitals are built, equipped, and staffed, even if some people will never fall sick. In any case, the Kenya government should be encouraged to classify the treatments and develop cost-sharing mechanisms. For example, the government can undertake to provide government-funded treatment to everyone who has HIV infection using somatic genetic therapies, but leave germline genetic therapies to individuals who desire them and can afford them. In this way, the choice to eliminate HIV-AIDS from the people will be a government responsibility, while the choice to eliminate the potential of one's children to contract HIV will be the choice of the individuals. Public funding for the somatic treatment can be sourced from taxes, insurance, and donor aid. If the government funds somatic genetic therapies, then there will be no inequality in the access to the treatment, and discrimination will not arise against those who will have not been treated with the same technology. Individuals who will elect to go the extra mile and take up germline therapies will be simply perceived to be seeking something better that they can afford. In this way, the utilitarian calculus will have been fairly applied, and the majority will be happy.

The challenge of lack of consent from future descendants is one that can only be hypothetical and speculative, and does not address reality. It is possible to approximate that what makes existing humans happy will make future generations happy too, if all other life factors will remain the same. Parents may save resources for their unborn children without having to worry that the assets will not please the children. If it is agreeable that disease is a bad thing, and that to get rid of the disease in some way is a good act, then eliminating HIV-

AIDS is a good act whose results should result into great happiness among the future generations. In the present generation, people make choices that lead to the elimination of certain disease-causing traits, and no child complains after birth that they had been denied opportunity to have a bad experience. In any case, it is not right to subject the existing generation to such a serious illness as HIV-AIDS only for the reason of respecting the future generation's supposed right to consent. If for some strange reason, the world were to come to an apocalyptic end before the future generation were born, surely the existing generation should have a happy ending for themselves, such as ending the scourge of HIV-AIDS. The future is planned for by those who exist now; those who are yet to exist are beneficiaries of decisions and developments brought about by those who live now. Surely no one would be counted as reasonable for withdrawing from Law School on the account of lack of assurance in knowing whether it would be in the best interest of future children to be born into a family of practising lawyers. No one really knows for sure what the preferences of future generations will be, so decisions made that affect them are on the basis of the experiences and preferences of the existing parents. It should also be understood that consent is a contract agreement that has to be withdrawable if its terms and conditions are violated by either party involved. If genetic therapy works against the interests of an unborn person, that unborn person should be able to seek legal redress in a valid court of law. If the unborn will not sue on their own, those who sue on their behalf do so in their own interests and not those of the unborn. It is a complication that is realistically unnecessary.

The Creator-creature distinction that forms an integral part of the theological-ethical arguments against genetic therapies is an essential belief in the monotheistic faiths of Judaism, Christianity, and Islam. The emphasis is placed on the incomparable difference between God as the Creator and humans as the creatures. It is a doctrine that subdues humans into finitude in knowledge and science, while at the same time barring humans from attempting to do what only God can allegedly do. Human activity must never undermine the authority of God, and humans must not "play God" in scientific efforts like genetic therapies. As a person who believes in God, I agree with this idea fully. However, it is reasonable to rationally conclude that God has endowed human beings with a creative capacity that is not found in other creatures. The creative capacity in humans is evident in science, architecture, art, music, technology, engineering, education, and medicine. Indeed, human capacity for creativity has caused much development and progress in the modern world. For example, instead of creating roads for us, God gives us engineering and technological capacity – through education and training – to construct roads and highways as we need. Instead of sending angels to sing for us

for entertainment, God enables us to create music and drama for ourselves. And rather than preventing diseases from attacking us, God allows them to attack but also gives us medical knowledge to treat them.

The idea that God seeks the happiness of humans has been linked with utilitarianism in an argument developed by Bentham who thought that the faithful would endorse the utilitarian standpoint if only they viewed God as benevolent" (Rachels & Rachels, 2012, pp. 100-101). Bentham decried the small number of believers who were truly consistent in their belief in God's benevolence, and went further to appeal to the faithful to not only talk about God's benevolent character but to actually emulate the same in their own lives (Rachels & Rachels, 2012, p. 101). John Stuart Mill also said

> If it be a true belief that God desires, above all things, the happiness of his creatures, and that this was his purpose in their creation, utility is not only not a godless doctrine, but more profoundly religious than any other. If it be meant that utilitarianism does not recognize the revealed will of God as the supreme law of morals, I answer that a utilitarian who believes in the perfect goodness and wisdom of God necessarily believes that whatever God has thought fit to reveal on the subject of morals must fulfil the requirements of utility in a supreme degree (Mill, 1979, p. 21).

For Mill, subscribing to utilitarian ethics is not necessarily equivalent to being anti-religion, and utilitarianism should not be a threat to religion. As Rachels & Rachels point out, "…the classical utilitarians did not think they were advocating an atheistic or antireligious philosophy. God, in His benevolence, wants His creatures to be happy, so He acts towards them to promote their happiness. This may mean that those who act in ways that bring happiness to other people act in God's interest. In the context of this dissertation, acting in God's interest would be to develop genetic interventions for HIV-AIDS and make them available for the treatment of patients. Allowing an illness to prevail and cause pain and death under the guise of refraining from "playing God" would be the height of religious hypocrisy. Ending a disease like HIV-AIDS through genetic therapy would not only please human beneficiaries but also please God who created humans and endowed them with knowledge to do so.

7.5. A UTILITARIAN APPRAISAL OF GENETIC THERAPIES FOR HIV-AIDS

In this section I review and give an appraisal of genetic therapies for HIV-AIDS using, as in the previous section, the three foundational principles of utilitarianism: that happiness is the only idea that has intrinsic value; that actions are right when they promote happiness and wrong when they cause pain; and that everyone's happiness counts equally. In this context, arguments in favour of genetic therapies for HIV-AIDS should enable us to appreciate such therapies as having capacity to eliminate pain and bring happiness for everyone.

Firstly, the similarities that exist in the genetic makeup of humans and other living things should assure humans that the safety of new medical technology, once proven on certain living organisms and animals, can be tested for efficacy on humans without extraordinary risk. The role of regulatory bodies is to provide a framework that will lead to proper development of safe genetic therapies and supervised clinical trials in order to assure the human population of the validity and safety of these new technologies. If the objective of the genetic science is to eliminate pain and suffering, and to ensure that more people live long, healthy, and happy lives, that is the greater good and is what governments and regulatory bodies should work to promote. In any case, since the human genome evolves and is subject to mutations, it is not the duty of governments and regulatory committees to protect the DNA, as genetic therapies are only an enhanced version of what the body already does naturally.

Secondly, the possibility is there for genetic therapies to provide cure for illnesses for which there is no known cure, such as HIV-AIDS. While some people may think that stem cell treatments and bone marrow transplants for certain specific illnesses may be the better way to go, there is need to remember that such alternatives are individualised and are beneficial to only singular patients. It should be preferable to develop genetic therapies which have the potential for benefitting the entire country of Kenya, the continent of Africa, and the world at large, by eliminating HIV-AIDS and protecting future generations from it, thus causing longer, happier, and satisfying lives.

Thirdly, genetic therapies for HIV-AIDS have the potential for enhancing the communal nature of human beings. The deadly virus causes harm to individuals, an impact which ends up affecting the community and the world as well. A permanent cure for HIV-AIDS will enhance global peace and good health. Future generations will be disappointed to learn that the present generation were on the verge of developing genetic solutions to the HIV-AIDS complication but fell short of doing so because of fears that were possible to resolve. Therefore, Kenya should collaborate with other countries in funding research and involving its scientists in order to develop, test, and eventually implement genetic solutions.

7.6. RECOMMENDATIONS

This dissertation comes to an end with seven recommendations in which I propose a way forward with regard to the relevance of genetic therapies for HIV-AIDS in Africa:

7.6.1. Developing a Revised View of Facts about HIV-AIDS Treatment

The first recommendation is the need for a revised view of facts about HIV-AIDS treatment. Although it is a scientific fact that ARVs and HAARTs keep the HIV viral load in a

patient's body low enough for the patient to remain strong, the viral load resumes as soon as the patient stops taking medication. This is currently the best available treatment for the disease, and it is admissible that 'the best' is not good enough because it does not provide an actual cure from the virus. Given the reports that any failure to adhere to the treatment regime results into a relapse which sometimes turns fatal, there is need to re-educate the public in general and HIV-AIDS patients in particular about the treatment facts, as well as the risks involved in non-adherence to the medication pattern established. It cannot be assumed that it is the patients who are either careless or undisciplined. Additionally, apart from re-educating patients on following a strict medication regime, there is need to clearly explain to people that ARVs are not a cure for HIV-AIDS, while acknowledging the important role they play in alleviating the symptoms and lengthening life. Such a situation calls for fast-tracking research in genetic therapies which will not only provide cure but also possibly protect future generations from HIV-AIDS.

7.6.2. Propagating a Positive View of Genetic Therapies

The second recommendation is for the governments of the world to propagate a positive view of genetic therapies. Currently, there is general negativity against genetic therapies, apparently and mainly because of the uncertainty and mistakes still prevailing in the science and research. Governments and regulatory bodies should not, at this stage, make conclusive judgements on the efficiency and efficacy of genetic therapies. The mistakes that have occurred so far are developmental mistakes which are bound to happen in any new and progressive technology that is new to human societies. Reports emanating from researchers are progress reports that update the global community on the stages of research. Therefore, the lack of polished and conclusive work should not be a basis for propagating fear of genetic therapies. Regulatory committees should begin to perceive themselves as helpful monitors of progress, rather than as research police whose work is to issue warnings and moratoria. A positive view will help collate much-needed socio-economic support for the on-going research, with the hope of properly concluded studies and tests that end up producing reliable therapeutic procedures. A positive view will inspire hope and confidence in the scientific processes currently going on, and honest mistakes will be corrected as part of a good process.

7.6.3. Call to Continue with Research and Development of Technologies

The third recommendation, closely related to the second one previously discussed, is a call to the scientific community to continue with research as well as the development of technologies that already exist. Continuation of research in technologies such as CRISPR will happen if governments and international organisations, including regulatory bodies, will cause

and enhance a desire for perfecting what has already been developed, while also giving hope to affected populations. Despite the negative branding of scientists who have made efforts at genetic modification of embryos in an attempt to develop genetic therapies for HIV-AIDS, the role of science must remain forward looking in order to discover and develop solutions to devastating illnesses. With valid caution and monitoring from the relevant committees, it is important that research scientists remain focused on the final objective of developing genetic therapies into trustworthy methods of treating HIV-AIDS and other debilitating illnesses. Continuation will require persistence and focus in order to achieve the desired objective of developing a lasting solution for deadly diseases.

7.6.4. Collaboration in Funding and Doing Research

The fourth recommendation is for inter-governmental, multi-sectoral, and international collaboration in funding the research in genetic therapies. Governments in Africa are prone to responding by simply stating that they do not have money for collaborating in such sophisticated and expensive research. But it can be argued that African governments can save significant financial resources by simply minimising corruption and properly managing public finance. Of course, recovered resources from corruption alone may not be enough, but it will be significant enough to demonstrate seriousness in desire to eliminate HIV-AIDS from the peoples of Africa. Such demonstrated effort is likely to attract global attention, resulting in significant if not adequate funding for the research into genetic therapies. Furthermore, I think the funds should go to recognised research universities and institutes with demonstrated history of achievement in pioneer and cutting edge research, both in the West and in Africa, in collaborative arrangements, if genetic therapies are to be made directly focused and relevant for the treatment of HIV-AIDS. The collaboration called for here should not be limited to funding and international aid for research in Africa, but should be extended to include cooperation in research. There is much to be gained in a cooperative approach among scientific researchers, including the acceptance and trust that comes as a result of mutual engagement. International collaboration will also help remove the perception that Africa could only be relevant at the later stage of mass clinical trials.

7.6.5. Inter-Governmental Commitment Treaties

The fifth recommendation is for governments to hold inter-governmental meetings under the guidance of experts in order to discuss and sign agreements committing themselves to use the newly developed genetic therapies for HIV-AIDS in order to bring the pandemic to an end in the world. A commitment to usage agreement will ensure justice and equity in the production, distribution, and application of the therapies once they are approved and made

available. This recommendation is both preparatory and anticipatory. It is preparatory in the sense that inter-governmental discussions and agreements on the usage of the anticipated genetic therapies will prepare the people positively for the results of the on-going research into genetic therapies. It is also anticipatory in the sense that such discussions re-position governments from passive waiting to expectant planners for the use of what research is moving the world into with regard to human health, that is, a new state in which humans will no longer live in fear of contracting HIV-AIDS because genetic therapies will have eliminated the disease. In the same way governments collaborate to deal with diseases like yellow fever and polio through vaccination policies that are implemented across borders, they need to cooperate to use genetic therapies when they are finally developed and availed.

7.6.6. Public Education Campaigns on Genetic Therapies

The sixth recommendation is for governments and non-governmental organisations to get actively involved in public education campaigns in order to help people know about genetic therapies in simple language. In the process, this approach is likely to aid the therapies into gaining acceptance. This can be modelled very much along the same lines as family planning and vaccination campaigns that have gone on for decades through public health educators. Currently, it appears only a few are even aware that research is going on in genetic therapies for certain kinds of diseases. The updates are restricted to academic and scientific journals whose content are best appreciated by scientists and interested philosophers. The regular media rarely reports on the progress and the challenges, hence the general lack of public awareness. It is strategic for governments, non-governmental organisation, universities, communications establishments, and international agencies to develop systems and resources for educating people in appropriate stages regarding the developments going on in the field of genetic therapies. Since the research is currently moving fast, public education needs to begin to prepare people now in manageable doses.

7.6.7. Taking Responsibility in Cases of Failure

The seventh recommendation is to encourage the scientific community, research universities, institutions, and governments, to take responsibility for failure that may arise from the implementation of newly developed genetic therapies for HIV-AIDS. If failure will be noticed, there will be need for clear explanations on what went wrong and how it may be prevented in future. Where appropriate, due compensation needs to be undertaken. This is the stage at which health financing policies will need to be re-drafted to take care of expenses arising from the need for compensation. It may be advisable to engage with insurance companies and other forms of insurance in order to find solutions. Taking responsibility will

help reinforce public confidence in the therapies and will assure people that there are no secret cards hidden under the table. I need to clarify that the final responsibility for the genetic therapies for HIV-AIDS should rest with the governments of each country, separately and corporately. In order to get ready to take such responsibility, it is important that experts and policy makers begin to discuss various aspects of the therapies, not necessarily to arrive at conclusions, which would be premature as of now, but to begin to think and plan for what is coming and how certain aspects may need government intervention and responsibility. In this way, governments begin to prepare citizens for an inevitable future.

CHAPTER 8: CONCLUSION

This research set out to establish the appropriateness of genetic therapies for the treatment of HIV-AIDS and alleviating the burden created by the disease in order to encourage the Kenya government and other African governments, together with their partners from the developed world, to carry out research on these technologies and develop them for the benefit of the majority of Africans. This objective was motivated by the present reality of having no known cure for HIV-AIDS in the whole world. A review of the health crisis in Kenya in Chapter 2 provides clarity on basic facts about the country's healthcare system, especially in relation to the problem of HIV-AIDS, including some on-going research.

In the third chapter there is a comprehensive review of genetic therapies which are necessary because any available treatment for HIV-AIDS is only temporal and does not cure the illness. A distinction is made between somatic and germline genetic therapies as different but potentially effective cures for the illness. Special attention has been given to CRISPR Cas9 because, so far, it is the only technology close to providing real treatment for HIV-AIDS although there is need for caution and further development.

The ethics theory of utilitarianism was chosen for addressing the problem because there was need to evaluate if genetic therapies would have justifiable benefit-sharing for the people, with minimum negative consequences. The motivation behind this choice was the desire by research scientists to turn misery into good health, pain into happiness, and shame into dignity. Given the magnitude of the problem and how it affects a large portion of the African population, and given the potential that the results of any genetic therapies will affect many either positively or negatively, a utilitarian evaluation was taken as the most suitable.

From a utilitarian perspective, when (not if) genetic therapies will be made available for the treatment of HIV-AIDS, three utilitarian benefits will be realized: the patient will be cured; the descendants of the patient will be prevented from inheriting the disease; and future societies will be saved from a devastating disease burden.

Although Chapter 5 enumerates a few arguments advanced against genetic therapies, the succeeding Chapter 6 presents valid arguments in support of the therapies, in addition to later assessments in Chapter 7 which give weight to the necessity of the therapies from a utilitarian perspective. The dissertation argues and concludes that genetic therapies will lead to elimination of misery and pain caused by HIV-AIDS, thereby causing greater happiness in Kenya, in Africa, and in the world. Therefore, there is sufficient justification in investing both technologically and scientifically in the on-going research into genetic therapies.

The dissertation ends with recommendations that call on governments, research universities, research institutions, and regulatory agencies to seek collaborative arrangements in order to support on-going research into genetic therapies, propagate a positive view of the developing genetic therapies, continue with the research to the best possible standards, to enter into agreements supporting the use of the therapies once fully developed, to get involved in educating the public about genetic therapies, and to take final responsibility in case certain aspects of these treatments do not turn out as expected. In view of these recommendations, research into genetic therapies is viewed as the most viable solution to the effects of HIV-AIDS in Africa and beyond.

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