

**AN ARGUMENT FOR A PAID AND REGULATED LIVING-UNRELATED KIDNEY
DONATION SYSTEM IN SOUTH AFRICA**

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ABSTRACT

One of the biggest challenges that global healthcare is experiencing is the shortage of kidney organ donors. Globally, the demand for organs is far greater than the supply and as a result, people who are on waiting lists will not get a chance to receive a kidney. Those who are waiting for transplants will require ongoing dialysis to survive (Nath & Fervenza, 2018). Dialysis is extremely costly and burdens the healthcare systems.

Given the enormous gaps between supply and demand, this report seeks to answer the question: "Should South Africa follow the model of a paid and regulated living-unrelated kidney donation system?" I begin with an analysis of South Africa's current structure, the effects of this system and ultimately seeing the need for a different solution. I analyzed the various models globally in kidney donation, including the only country that allows for a paid system and the objections thereto.

Currently, the sale of organs is prohibited in South Africa. My view is that our current South African model is lacking in solutions to the shortage of organ donors, particularly kidneys. There is a need for a better solution as the current system is failing to meet the needs of patients.

In this paper, I use the principlism framework consisting of the four bioethical principles namely, autonomy, beneficence, non-maleficence and justice, to highlight the constitutional conflicts and the ethical dilemmas when considering a paid donation system. As I am arguing for a paid system in South Africa, I have included the ubuntu theory to show why objections to a paid and regulated system would fail.

In conclusion, a paid and regulated living-unrelated kidney donation system is argued to be the most ethically and practically appropriate system in South Africa, to improve kidney donation rates and the livelihoods of the people.

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To my young children, with this report I wish to impart to you what my parents imparted to me, the thirst for knowledge and continual questioning. Never stop learning.

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LIST OF ABBREVIATIONS/ACRONYMS

DAPTA - Dialysis and Transplant Patients Association

ESRD - End-stage Renal Disease

HTA - Human Tissue Act

IRODaT - International Registry in Organ Donation and Transplantation

IMKT - Iranian Model of Kidney Transplantation

IPKP - Iranian Patients Kidney Foundation

LRD - Living Related Donor

LURD - Living Unrelated Donor

NHA - National Health Act

ODF - Organ Donor Foundation

PMP - Per Million Population

WHO - World Health Organization

CHAPTER 1: INTRODUCTION

1.1 Background

One of the biggest challenges that global healthcare is experiencing is the shortage of kidney organ donors. Globally there are many patients on transplant waiting lists, some of whom will not have the chance to receive an organ. Each year the waiting lists become longer as the donor list decreases; this results in increased waiting times for patients which results in some patients who were originally eligible candidates at the time of listing, not being able to receive the transplant by the time an organ was made available, as their condition had seriously deteriorated during this time. The treatment of choice for patients suffering from end-stage renal disease (ESRD) is a kidney transplant, of which there is a greater demand than supply. Those who are waiting for transplants will require ongoing dialysis to survive (Nath & Fervenza, 2018). Dialysis is extremely costly and burdens the healthcare systems. Ahmad, Ahmed, Taylor and Koffman (2008) found that there was truly little difference in results with a living related donor (LRD) versus a living unrelated donor (LURD). Therefore, LURD needs to be explored to reduce waiting lists.

For clarity's sake, I speak about "organ donation" which pertains to an individual voluntarily giving their kidney to another individual. As I am arguing for a "paid" system this "organ donation" will be of the individual's free will but will not be done for free. Therefore, when I talk about paid organ donation, this will be referred to as organ procurement.

At the moment South Africa and the majority of the world do not allow the selling of kidneys. Instead, they rely on people being altruistic and to donate of their own free will. However, this has not led to a decrease in the waiting lists. Instead, people are suffering while waiting for a transplant; that is if they receive one. One can see that we need another solution for kidney donation. There are many arguments against being allowed to sell organs and these rely heavily on the debate about dignity and exploitation of the poor, for the benefit of the wealthy. These arguments hold that "rich, well-resourced people who need organs will buy them from poor people; thus, exploiting their indigence" (Kleinsmidt & Moosa, 2017: p.318). This argument is based on the premise that people's decisions to sell their organs is not truly autonomous but is made purely because they are in a desperate financial situation.

Regarding the various systems, in August 2017, the International Registry in Organ Donation and Transplantation (IRODaT) released donation rates whereby the top countries with the highest rates of donation were all countries with an opt-out policy, therefore not requiring routine consent. Countries such as Israel where the policy is that of presumed refusal and other countries utilizing the opt-in approach have lower donation rates (IRODaT, 2017). Currently, there is only one country globally that allows for monetary compensation for kidney organ donation and that is Iran. By 1999 Iran's waiting list was eliminated (Ghods & Savaj, 2006).

In South Africa, the removal and the transplanting of organs is strictly regulated by Chapter 8 of the National Health Act (NHA). Previously, the removal and the transplanting of organs was regulated in the Human Tissue Act 65 of 1983 (HTA). In both Acts, the sale of organs is prohibited. For the sake of my research, I will only refer to limitations in the Acts which pertain to living donations. The one difference with the NHA is that it allows for reimbursement of "reasonable costs associated incurred to the donor, to provide the donation" (Labuschagne, 2013). However, the issue on 'reimbursement' is not clearly defined in the NHA and as such, has left room for 'self' interpretation. As stated, above the sale of organs is prohibited in South Africa, however, in 2003 it was found that 109 illegal live kidney transplants had taken place between 2001-2003. This involved mainly Brazilians getting paid to donate kidneys to Israeli citizens in South Africa. (Slabbert & Oosthuizen, 2011) One can see that the HTA which was in place at that time failed to stop the sale of kidneys.

According to Shimazono (2007) in the bulletin of the World Health Organization (WHO) 'Transplant tourism' "refers to overseas transplantation when a patient obtains an organ through the organ trade or other means that contravene the regulatory frameworks of their countries of origin". (Shimazono, 2007 p:956) 'Transplant tourism' takes place because of various reasons or factors, for example, where a developed country has long waiting lists; and secondly, when underdeveloped countries have lax prohibitory systems in place and people's lack of income results in them resorting to selling their organs to survive (Broumand & Saidi, 2017). In 2004, in light of this 'transplant tourism' the WHO called upon member states to take action to protect the poor and the vulnerable. This resulted in the signing of the Declaration of Istanbul whereby all countries, who are parties to the declaration need a professional legal framework governing organ donation and transplant activities. Each country should

strive to meet the needs of its people in terms of organ transplants (Delmonico, 2008). 'Transplant tourism' undermines the efforts of countries in providing transplants to non-residents, and therefore the ability to serve their population.

This happened here, as mentioned above, and if 109 illegal transplants managed to take place over three years, will the NHA be enough to stop this 'transplant tourism', especially when one refers to the Act which states that one can get reimbursement for 'reasonable costs'. My view is that our current South African model is lacking in solutions to the shortage of organ donors, particularly kidneys. There is a need for a better solution as the current system is failing to meet the needs of the patients. In the Bill of Rights contained in Chapter 2 of the South African Constitution we see that everyone has 'rights to dignity, life, bodily integrity and access to healthcare'.

Slabbert and Oosthuizen (2007), argued and claimed that for financial remuneration for kidneys in South Africa: "The proposed way of regulating the trade in organs is through 'futures contracts'". Oxford dictionary defines future contracts as 'a contract for assets bought at agreed prices but delivered and paid for later'. A question highlighted by Slabbert and Oosthuizen (2007), is whether property rights in human organs exist, that is, are body parts legal property and can one trade their organs just like any other commodity one owns. Although not legislated in South Africa, Slabbert and Oosthuizen (2007) argued that there are property rights in human body parts (Slabbert & Oosthuizen, 2007). See also M. Slabbert (2009), who specifically addresses the property rights issues, and says, "This is my kidney I can do what I want with it."

We are in desperate need to come up with a solution to alleviate the burden that ESRD is causing both to the patient's quality of life, and financially to the healthcare system overall. This solution lies in amending our current legislation to allow for the inclusion of a model of a paid and regulated living-unrelated kidney donation system whereby waiting lists are eliminated, people's quality of life improves, and the health care system does suffer financial burdens due to patients on dialysis who are endlessly waiting for a transplant.

1.2 Research Question

This report considers the various systems of organ donation to answer the question, 'Should South Africa follow the model of a paid and regulated living-unrelated kidney donation system?'

1.3 Rationale for the Study

Most of the literature has been focused on kidney donations on an altruistic basis; there is little literature on whether a paid system would work better as an alternative to increasing the availability of kidneys for transplanting. The questions that do not seem to have been asked are: what about the numerous people on waiting lists who may never get the chance to have a transplant as well as a better quality of life? Has their human dignity not been taken away from them? The value in this study is to propose a more viable solution and offer an alternative which would potentially increase the donor pool and decrease waiting lists.

1.4 Thesis Statement, Research Aim and Objectives

The research aim is to articulate and defend a thesis that South Africa should follow a model of a paid and regulated living unrelated kidney donation system. I argue that this system is the most practical and ethically justified system for South Africa.

1.5 Study Objectives

- To evaluate the effects of the current structure and the laws in South Africa pertaining to organ donation and to argue why a change in the system is needed.
- To argue, utilizing the theories of principlism and ubuntu, that amongst the various systems for kidney donations, a paid and regulated living-unrelated donor system is best for South Africa.
- To articulate and systematically defend the objections to a paid and regulated living-unrelated kidney donation system.

1.6 Argument Outline

The ethical evaluations of consent systems in kidney donation lend themselves to a normative study, as philosophical theories are used to draw conclusions. I employ the typical research methods and standards applicable to philosophical research. The research question is answered by critically analysing and interpreting the most important literature relevant to the question. The critical analysis includes definitions and clarification of concepts. It also includes the analysis and the evaluation of theoretical frameworks and the identification and the criticisms of assumptions. The sources of literature include and are not limited to research articles, books, online databases, and academic search engines.

For clarity's sake, I speak about 'organ donation' which pertains to an individual voluntarily giving their kidney to another individual. As I am arguing for a 'paid' system, this 'organ donation' will be made of the individual's free will but will not be done for free. I am arguing for a paid donation system; therefore, I talk about organ procurement.

I employ the theory of principlism developed from the ethical theory of Beauchamp and Childress (2013), as the basis of the argumentative strategy. This is primarily because principlism is purported to offer a practical method of dealing with real-world ethical dilemmas in health care. This theory was developed by Beauchamp and Childress first in 1979 and has since been revised in subsequent editions. Their idea is that there are four basic principles which we should adhere to when deciding what the right moral decision is to take. These moral principles are, "autonomy (making an informed decision about one's medical treatment, that is emphasizing informed consent), non-maleficence (avoiding intentional harm and mitigating risks associated), beneficence (acting in the best interests of others) and justice (the fair distribution of medical treatment, including limited resources)." (Beauchamp & Childress, 2013. p:12).

Utilizing this framework, I argue for a paid and regulated living-unrelated kidney donation system in the South African context. With South Africa's current structure and laws pertaining to organ donation, the results are long waiting lists, with people on the lists having a poor quality of life, including those who could have done well had they received a transplant and who are now unable to do so as they are now too sick. People on these waiting lists are suffering. Therefore, one can see that non-maleficence is not being achieved. Dialysis comes at a huge cost which affects the state and the private sector. The wealthy benefit and thus justice is not served. Families often feel pressured or obliged to donate. Despite education on organ donation, organ donors are not increasing, therefore beneficence is not being met. People on waiting lists are suffering and they become desperate. The result of this is 'transplant tourism'. The current legislative structure impedes people's ability to fully exercise their autonomy. This current system is an opt-in system, which many countries worldwide adopt. This system relies on the altruistic behaviour of people and has resulted in the demand for organs exceeding supply. Currently, there is only one country globally that allows for monetary compensation for kidney organ donation and that is Iran. By 1999 Iran's waiting list was eliminated (Ghods & Savaj, 2006) and has continually remained so (Bastani, 2019).

In South Africa, the removal and the transplanting of organs is strictly regulated in Chapter 8 of the National Health Act (NHA). Previously the removal and the transplanting of organs were regulated in the Human Tissue Act 65/1983 (HTA). In both Acts the sale of organs is prohibited. For the sake of my research, I only refer to limitations in the acts which pertain to living donations.

“The one difference with the NHA is the allowance for reimbursement of ‘reasonable costs’ incurred to the donor to provide the donation” (Labuschagne, 2013 p:41). However, the issue on ‘reimbursement’ was not clearly defined in the NHA and as such, has left room for ‘self’ interpretation. Badly regulated systems can have severe adverse effects whereby people take the law into their own hands. As stated above, the sale of organs is prohibited in South Africa. However, in 2003 it was found that 109 illegal live kidney transplants had taken place between 2001-2003. This involved mainly Brazilians getting paid to donate kidneys to Israeli citizens in South Africa; so, one can clearly see that the HTA which was in place at that time failed to stop this ‘transplant tourism’.

“Transplant tourism involves not only the purchase and sales of organs, but also other elements relating to the commercialization of organ transplantation. The international movement of potential recipients is often arranged or facilitated by intermediaries and health-care providers who arrange the travel and recruit donors. The Internet has often been used to attract foreign patients. Several web sites offer all-inclusive transplant packages – the price of a renal transplant package ranges from US\$ 70 000 to 160 000” (Shimazono, 2007 p:956) ‘Transplant tourism’ takes place because of two situations, one whereby a developed country has long waiting lists and secondly, when underdeveloped countries have lax prohibitory systems in place, and people's lack of income results in resorting to selling their organs to survive (Broumand & Saidi, 2017).

In 2004 in light of this ‘transplant tourism’, the WHO called upon member states to take action to protect the poor and the vulnerable. This resulted in the signing of the Declaration of Istanbul, whereby all countries need a professional, legal framework governing organ donation and transplant activities. Each country should strive to meet the needs of its own people in terms of organ transplants (Delmonico, 2008). ‘Transplant tourism’ undermines the efforts of countries by providing transplants to non-residents, thereby undermining their ability to service their own population. This happened in South Africa and as mentioned above 109 illegal transplants took place

over three years. Will the NHA be enough to stop this 'transplant tourism'; especially when one refers to the Act which states that one can get reimbursement for 'reasonable costs'.

As my argument is in the South African context, I utilize the theory of ubuntu as proposed by Metz (2011). Metz (2011) constructed a moral theory embedded in Southern African views, which shows a different view of human dignity. According to his conception, "typical human beings have dignity by virtue of their community capacity, understood as the combination of identifying with others and exhibiting solidarity with them, where human rights violations are egregious degradations of this capacity" (Metz, 2011 p:532). He argued that this view of human rights abuse explains many different elements within South Africa's Bill of Rights and can ultimately lead to ways of resolving moral predicaments in South Africa. He argued that his interpretation of ubuntu would help provide an understanding and help find a solution to current disputes about justice and human rights. I argue, based on this moral theory, that 'ubuntu' can ground public morality in terms of a financial reward for living unrelated kidney donations in South Africa.

Various systems exist worldwide, I discuss these, and I argue whether a financial rewards-based system is appropriate and best for South Africa. One such system is the opt-out system which countries such as Wales, Scotland and Spain have adopted. From 20 May 2020, the United Kingdom will be following this too (NHS, 2020). The key to this system is a good education. Without education, its people are poorly informed and as a result, lose their autonomy in decision making. Global literature sees a move away from the opt-in organ donation system towards the opt-out system, otherwise referred to as presumed consent. This is seen in many papers most recently by Bird and Harris (2010), and Gill (2004). Another system which is adopted by Israel prioritizes registered donors. Lavee and Brock (2012) described this as: "once again, this system requires good education and without it, as seen above, people lose their autonomy". This system also discriminates on religious grounds and therefore justice, which equates to fairness that is not being met.

Globally, there are different systems in place, of which there is only one system which has managed to eliminate their waiting lists; being the Iranian model which is a paid and regulated living-unrelated system. According to Ghods and Savaj (2006), this regulated system ensures that both donors and recipients receive optimum medical

treatment, which is ongoing. These regulations also ensure that the poor are not being exploited, and therefore beneficence is being met and justice served. There will be objections raised to a paid and regulated living-unrelated system where the rich will benefit and the poor will be exploited. In the Iranian model, all candidates receive a transplant. The poor receive a government donated kidney and medical care thereafter. Therefore, neither the poor nor the rich are exploited. Another objection that could be raised is that this system will reduce the number of deceased donors donating. In the Iranian model, this has been disproved and numbers are steadily increasing (Ghods, 2009).

In the South African context, there is a great divide between the rich and poor and therefore, bribery and corruption exists. Utilizing an external regulatory body such as in Iran, who oversees the donor-recipient match, will eliminate the potential for bias and corruption. An independent regulatory body can ensure that each potential candidate will be screened, assessed, and issued with a consent form, consequently ensuring that the donor is acting autonomously and will bridge the gap between the private and the public sectors and minimize, if not eliminate bias in South Africa, where resources are scarce, and the majority of the population has limited income. Our country has an ethical responsibility to alleviate harm, and to help where it can, in an effort to ensure a more just society. The model of a paid and regulated living-unrelated donor system can resolve these issues, in terms of improving beneficence and non-maleficence and more notably, do a better job than the current system does.

I begin my argument in Chapter 2 describing the effects of South Africa's current system on organ donation, including aspects such as legislation, education, culture and religion; all of which play a part in organ donation and the effects thereof; thereby leading to an understanding of why critical change is needed. I argue that the negative effects of our current opt-in system, includes those who wish to have their organs donated but have not documented it and as such these organs are 'lost'.

These mistaken non-donations are just as unethical as mistaken donations, i.e., when families think the wishes of the family member was to donate but in fact was not. (Gill, 2004). This is made worse by the fact that most South Africans are willing to donate but families are left to make these decisions in times of heightened emotional stress (Etheredge, Turner & Khan, 2014). Following the analysis of our current law, in Chapter 3 I critically evaluate current organ procurement systems globally and show why a paid

and regulated system such as the Iranian model is suitable for South Africa. In Chapter 4 I show what objections can be raised against this system and why these objections fail to utilize the principlism and ubuntu theories.

In Chapter 5, I conclude with my key findings of this report, including recommendations for implementation, namely, education, government commitment, infrastructure improvement and sufficient time for the public to understand.

CHAPTER 2: THE CONDITIONS UNDER WHICH ORGAN DONATION IN SOUTH AFRICA MAY TAKE PLACE

This chapter discusses the conditions under which organ donation may take place in South Africa and highlights the problems with the legislative framework, in enabling an environment where sufficient kidneys can be procured, and hence become available for transplanting. From this evaluation, I will show what the effects of this policy are in South Africa and why there is a need for a change, to alleviate the current waiting list problems. The system which South Africa follows is otherwise referred to as the opt-in system (otherwise known as expressed consent). This has been the only system that South Africa has ever followed. Opt-in systems assume that you do not wish to donate your organs unless you or your family members consent to it.

2.1 South Africa's Legal Framework

In South Africa, organ donation is governed by regulations in terms of Chapter 8 of the NHA. This came into effect in March 2012 when the HTA (which previously governed organ donation) was repealed, and provisions were made in Chapter 8 of the NHA, dealing with the control and the use of blood, blood products and gametes. "This includes provisions for consent for organ donation, deceased donations, next-of-kin involvement, prohibition on the sale of such organs and persons and institutions permitted to handle donor organs. These regulations also require full informed consent of the person donating, this includes health status ... diagnostic procedures and treatment options ... benefits, risks, costs and consequences generally associated with each option ... the right to refuse ... implications, risks, and obligations of such refusal" (McQuoid-Mason, 2012 p:734).

Provisions within the NHA are laid out in Chapter 8 for organ donation and fall under the following sections. Section 55 states: "Removal of tissue, blood, blood products or gametes from living persons ... a person may not remove tissue, blood, a blood product or gametes from the body of another living person for the purpose referred to in Section 56 unless it is done with the written consent of the person from whom the tissue ... is removed."

Section 56 refers to: "Use of tissue, blood, blood products or gametes removed or withdrawn from living persons." This pertains to who may use these products and states that it needs to be in the prescribed manner, such as for medical or dental procedures.

Section 60 refers to: “Payment in connection with the importation, acquisition or supply of tissue, blood, blood products or gametes”. This explicitly states that payment to acquire organs is prohibited. However, payment to cover the costs involved in the importation of organs is allowed. “The amount of payment contemplated in subsection (1) may not exceed an amount which is reasonably required to cover the costs of importation ... product in question”. This allows for medical professions and institutions to receive payment, but payment may not be made to the donor. As seen in this section, South Africa’s current legislation prohibits any sale of organs whatsoever.

As stated previously, these next few sections in the NHA provisions are related to my argument to see the broader picture of South African legislation, but as my report is on ‘living kidney donations’, they hold less value. However, the importance of them is to understand that our current system does not need a complete overhaul. It just requires a modification to allow for the choice of financial remuneration, specifically for kidneys, while still allowing for deceased donations.

Section 54 states that: “The minister may by notice, in the gazette, designate any institution other than an institution contemplated in Section 63 as an authorised institution”. This pertains to acquiring and using of the body and/or tissues of a deceased person and supplying thereof. Institutions are however not listed per se in the NHA.

Section 58 states that: “a person may not remove tissue from a living person for transplantation in another living person or carry out the transplantation of such tissue except in a hospital ... or an authorised institution ... on written authority of the medical practitioner in charge of clinical services ...” This clearly states that transplantation may only take place in an authorised institution and by an authorised person.

Section 61 deals with the allocation of human organs, with particular reference to deceased persons. “Human organs obtained from deceased persons for the purposes of transplantation or treatment or medical or dental training or research, may only be used in the prescribed manner”. It further clarifies that, “no organ may be transplanted into a person who is not a South African citizen or a permanent resident”. This provision in the law is to stop what happened in 2003, when Israeli citizens came to South Africa to receive kidney transplants from alleged Brazilian relatives; ultimately trying to prevent accusations of ‘transplant tourism’.

Section 62 and Section 63 deals with the donation of deceased human bodies and tissues. Under these regulations persons competent to make a will **that is, persons over 16 of age**, in the presence of two competent witnesses, may choose to donate their body and or their tissue. What needs to be included is naming the intended donee or institution. However, this does not apply to organs donated for transplant purposes, provided that it is done in the prescribed manner and that what is done is done according to the correct criteria. These sections also confirm who may consent on behalf of the donor. Partners or spouses take precedence over all other family members and other family members may not overrule their decisions without a court application. In terms of a donation for transplanting, one needs to determine 'brain death'. While there are no set criteria, there have to be two medical doctors not linked to the transplant team, who have over five years' experience, who are then able to sign it off.

Section 64 deals with the purposes of donating tissue, blood products etc., of deceased persons. In these regulations it states that this donation may only be used for training, research, advancement of health science and for therapeutic purposes in terms of transplantation into living persons.

Section 65 pertains to revocation by the donor. This may take place in the same manner as it was made. Donors may change their minds at any time prior to the transplant. This includes people who are legally allowed to make decisions on behalf of the donor. However, these submissions for revocation must be made in a medically acceptable time span, that is not when the recipient is on the operating table waiting for a transplant.

For a more comprehensive discussion on how the law influences organ donation, one can refer to the article by Slabbert, M (2018) "The law as an obstacle in solid organ donations and transplantations".

The legislation that governs organ transplanting forms a minute part of the NHA, in total, fifteen out of ninety-four sections. According to Slabbert and Venter (2015) the countries that are excelling in organ donation have an entirely separate act on its own, which governs this activity. The overarching law in South Africa was founded in the **Constitution of the Republic of South-Africa, 1996**, The Bill of Rights (Chapter 2) provides the guiding values on which these laws are built. These laws are binding on

the state and the legislature. In terms of section 172 of the Constitution, “If any legislation does not comply with the Bill of Rights, it must be declared invalid”.

Labuschagne and Carstens (2014) are of the opinion that the state has failed in organ procurement, according to Section 27 of the Bill of Rights, which states that: “The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights”. Labuschagne and Carstens (2014) are of the opinion that the NHA does not meet “the standard of a reasonable legislative measure with regard to organ transplantation law, as required by Section 27(2) p.241”. They believe that it is “the state’s duty to find alternative options if a specific resource has been limited for a number of years” (Labuschagne and Carstens, 2014 p:241) and therefore, according to them, our current system of opt-in does not uphold **the Constitution of the Republic of South Africa, 1996**, as potentially other systems would.

In opt-in systems individuals must give their expressed informed consent, usually by signing up, in a register, committing to donate their organs after death. Thus, the system assumes that a person is not a donor unless they sign up to be one. In South Africa, this needs to be expressed in a will or signed document and at time of death family members will still have the final say whether they wish to have their relatives’ organs donated or not (NHA 2003, Chapter 8, 55(1)). South Africa and various other countries such as Australia, Canada, Denmark, New-Zealand, and the United States of America utilize the opt-in system (Arshad, Anderson & Sharif, 2019: p.1454).

In terms of kidney donations, there can be a live donation. As shown above, in South Africa, only relatives can opt to donate to relatives with consent, as regulated in the NHA (2003, Chapter 8, 55). If there are no relatives who wish to donate or who are a match, reliance is then placed on finding a non-living donor. This is where the majority of people in need of kidneys find themselves and dialysis is then their only option to prolong life. Success of the opt-in system relies on the altruism of people’s pro-activeness to make one’s intentions clear and then also on the existence of sound public awareness and educational input about organ donation being provided.

Gill (2004) was of the view that the majority of people do not donate their organs as they see no value for themselves. My view is that this is part of the reason for the lack of donations but not all of it. Prior to 2020, the United Kingdom (UK) had an opt in

system. What was shown was that “when seventy percent of the population were surveyed, they stated that they would be willing to donate their organs and yet there were in fact only twenty percent of the population who carried an organ donor card.”

Thus, many potential life-saving organs are lost due to procrastination, and the requirement that one **must take active steps to make one’s intention known to donate one’s organs.** (English & Somerville, 2003). This shows that this system does not encourage people to donate, and the result is a lack of donors.

In South Africa, studies suggest that” “a significant number of potential donors were not referred to transplant coordinators for discussion with the family” (Muller, 2013). This shows that the problem lies in a lack of education or communication with hospital staff etc. Doctors are placed in incredibly stressful and highly emotional situations when a family member is about to die, and they have to bring up the subject of organ donation. They should not have this burden placed on them and one way of counteracting this would be to have an overseeing governing body. Therefore, we can see that this system results in many non-donations which results in the situation where demand exceeds supply.

I claim that the only pro of this system is that it is strongly grounded in the notion of respect for autonomy, because potential donors must be clear about their wishes and must make their decisions known. However, in South Africa, these wishes can be overridden by family members, therefore limiting the donor’s autonomy. This system relies heavily on altruistic behaviour of people and as such, is promoting doing good, thereby adhering to the principle of beneficence. However, globally, this system has not been shown to increase donor numbers. Consequently, **I claim** that it is failing the people (affected and non-affected people) and therefore doing more harm than good. People are suffering while sitting on endless waiting lists. Others who could donate and would donate if there was a reward of sorts do not, as this is not available as an option. Therefore, **I claim** it is not adhering to the principle of non-maleficence.

As mentioned previously, this system also relies on people being proactive about making their intentions regarding organ donation known. In my view, most people are uncomfortable with doing this and they delay making that decision until it is too late. People can also be very apathetic and while they may have good intentions to donate, they never get around to registering to become a donor or making their intentions clear.

Kidneys can be procured from a living donor's family members being suitable matches who are considered first-line donors. These donors often feel pressurized into donating, as they know that the waiting lists **are** long and that their family member may possibly never receive a kidney if they do not donate. In my view, this is unethical and can be viewed as emotional blackmail. Once again, opt-in does not promote non-maleficence. **I submit** that this is doing more harm to the families, due to the emotional pressure of feeling the need to donate.

This system also has the potential to lend itself to 'transplant tourism' as the demand for organs exceeds supply. People become desperate and those who have the ability and the means to do so will seek out countries that have lax controls, in order to save themselves. These countries with lax controls are usually poorer countries where people are desperate for financial relief. This 'transplant tourism' has taken place in South Africa; however, it is now prohibited by our NHA. The Declaration of Istanbul was established so that all countries could have a professional, legal framework which governs organ donation and transplant activities.

Though exact numbers on kidney waiting lists are hard to determine, we do know that the only country to have eliminated this is Iran using a regulated compensated system (to be discussed later). Therefore, we can surmise that all other systems are failing to do good, causing more harm than good, which can be said to be unjust to the majority.

2.2 The Effects of the Current System on Kidney Donation

Having seen what our current law is concerning organ donation, I will now analyse the effects of the NHA in South Africa.

South Africa is emerging from an unequal past, due to apartheid oppression. This has resulted in a massive divide between those who can afford private healthcare (sixteen percent), versus those who need to seek public health care (eighty-four percent) (Moosa, 2019). The distribution of kidneys between state and private citizens or institutions is unequal, and thus it provides unequal benefit to those who can afford private healthcare, as opposed to those who cannot. A study published by Moosa (2019: p.235) showed that over the last twenty-five years, 7 191 kidney transplants were performed in South Africa.

“The overall kidney transplant rate was 6.4 per million population (PMP), averaging 4.8 PMP in the public sector and 15.2 PMP in the private sector. However, between these two sectors there was a steady increase in the private sector and a decline in the public sector.” (Moosa, 2019 p:235) From 2009, the private sector has consistently exceeded the public sector. Between 1994 and 2015, the number of dialysis units in private hospitals increased from five to two hundred and twenty-eight, to cope with the demand for people with ESRD who were unable to receive a transplant. However, in the same period, the public sector merely increased from twenty-six to thirty (Moosa, 2019).

In 2012 the private sector transplant rate was sevenfold higher than in the public sector. This in itself is alarming as it places an already burdened state healthcare system under further pressure for renal dialysis units. The result is that these centres are overwhelmed, and they struggle to meet the needs of the patients.

According to the Organ Donor Foundation (ODF)¹, the number of solid organ transplants has declined from three hundred and seventy-six in 2009 to three hundred and sixty-one in 2016. Furthermore, the total number of South Africans on waiting lists has increased from three and a half thousand in 2009 to four thousand three hundred in 2016. Labuschagne and Carstens (2014) claim that as many as fifteen thousand South Africans need a kidney transplant. However, as there is no national waiting list on the numbers attending dialysis, it is hard to quantify. What can be seen is that the current system is not meeting demands and is unsuccessful in procuring enough organs for its people.

Our overarching law lies in the Bill of Rights in our Constitution which states that: “everyone is equal before the law and has the right to equal protection and benefit of the law” (Constitution, Chapter 2, Bill of Rights, 9 (1) 1996). As much as our legislation makes provisions for organ procurement, this legislation does not help in trying to provide enough organs to meet the demand, and thus is not satisfying the requirements of equal protection and benefit, as set out in Section 9(1). Our current system is not achieving equality and therefore is in direct violation of our Bill of Rights (Labuschagne & Carstens, 2014). This inequality shows that those who can afford private healthcare have better access to facilities involved in the transplant process.

¹ The national umbrella body for the promotion of organ and tissue donation.

Our organ donation system is not coping with meeting the demand for organs and people are sitting on endless waiting lists, while their quality of life is reduced and therein lies another violation of our Bill of Rights. The Bill of Rights pronounces that: “everyone has inherent dignity and the right to have their dignity respected and protected” (Bill of Rights, 1996). Labuschagne and Carstens (2014) link human dignity to ‘right to life’ and this right to human dignity not only offers a personal benefit but also a communal one. Their argument lies in their interpretation that: “the rights to life and human dignity are intertwined and dependent on one another”. (Labuschagne and Carstens, 2014 p:224)

“Without life, there cannot be dignity. However, without dignity, the quality of human life can be compromised.” (Labuschagne and Carstens, 2014 p:224) Our current system is failing and once again not meeting our Constitution therefore denying us these rights. In terms of ‘the right to life’ as seen in our Constitution, this ‘right to life’ is not just about life and death but protecting the ‘right to life’. Our current system is not protecting our right to life as it is denying individuals a chance to continue living (Labuschagne & Carstens, 2014). Thus, once again, our current model is failing in upholding our constitutional rights. I think that this right to life is imperative for people with ESRD, as by denying them a second chance with a transplant they sit on endless waiting lists suffering with lifelong dialysis.

In Section 27 of our Constitution, it states that, “everyone has the right to have access to healthcare services” and that: “the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights”. As mentioned previously, Labuschagne and Carstens, 2014 stated that they feel that it is the state’s duty to adopt alternative measures if a specific resource has been unavailable for a number of years and therefore according to them, our current system of opt-in does not uphold these rights, as potentially other systems would. Our current system was not changed, nor has it been reviewed since the NHA came into effect.

Labuschagne and Carstens (2014) averred that the state must find alternative measures to alleviate the ever-increasing organ shortage and thus it must change the current system. They stated that Section 7(2) in the Constitution of the Republic of South-Africa, 1996, is applicable to all rights and places a duty on the state to protect these rights. In terms of my report on kidney procurement, this would mean that it is

the state's duty to allow people to exercise their rights, prevent others with other vested interests from infringing on these rights and establish a legislative framework that allows for progressive realization of these rights. They claimed that "human dignity should have the biggest influence on the choice of a suitable method of organ procurement. The determination of whether a method of organ procurement would be constitutionally acceptable or not would include an investigation into what constitutes 'reasonable' legislative and other measures, within [the State's] available resources, to achieve the progressive realization of; chiefly the right to life" (Labuschagne & Carstens, 2014 p:243). They feel that as the state has not provided a legislative framework to relieve organ shortage; therefore, it has failed to uphold people's constitutional rights.

The logistics of South-Africa's organ donation system is overseen by transplant coordinators who have the extremely important task of handling the organ donation process from handling donors and families to harvesting the organs for transplanting. In April 2015, it was reported that there were only twenty-two coordinators, of which eight represented the state and fourteen represented private interests. Some providers do not even have co-ordinators (Muller, 2013). This is a shocking statistic considering that we have a population of approximately fifty-two million. There is also no central body regulating these co-ordinators in terms of education, standards, performance, and the effectiveness of the donation system as a whole (Muller, Thomson & McCurdie, 2015). This is an area which reveals that our organ donation rates have been severely limited.

This is certainly an area which needs massive change. I submit that this would come in the form of a regulatory body. McQuoid-Mason (2012) discussed this need for establishing a central regulatory body, similar to the UK Human Tissue Authority. This regulatory body needs to be independent but funded by the government. This is further seen in the success of the Iranian model (to be discussed in Chapter 3) whereby kidney donation is regulated by an external regulatory body (Ghods & Savaj, 2006). This is further clarified by Bastani (2019) who claimed that this was one of the factors contributing to making the Iranian model successful.

The ODF is the national body for matters related to organ donations. They help increase awareness and educate the public and families at large on organ donation. They do not however, have a central organ donor registry which can be accessed and

utilized nationally. This is key as without it, one is unable to match potential donors with potential recipients efficiently. There is also a need to have a database where further research can be recorded in terms of making the system effective. This is largely due to the lack of accessible infrastructure which is needed to monitor overall donation and transplanting statistics, as well as running an education programme for hospital staff, and form standardized organ procurement methods (required referrals etc.), (Muller, et al., 2015). McQuoid-Mason (2012) suggested that there should be a central body in South Africa comprising government officials, medical persons', as well as ordinary people.

The **imbalance** in transplantation in South Africa - specifically in transplant rates between those that are able to have medical aid and those that are not, show how South Africa is failing to employ distributive justice, which in terms of ethics is the fair distribution of resources (Dhai & Mcquoid-Mason, 2011). These resources not only pertain to organs but in addition to others such as transplant coordinators and institutions should show the inequalities that exist between the public and the private sectors.

In 2011, a study by Steyn showed that sixty-three percent of transplants were performed in the private sector on funded patients (Steyn, 2011). This showed how critical it is that change should happen regarding how South Africa procures organs. The national government needs to take responsibility to uphold the legislation, as set out in **the Constitution of the Republic of South Africa, 1996**; and accordingly find a solution to alleviate the critical shortage of kidneys and the situation whereby people suffer as a result of being on endless waiting lists.

In the following section, I will focus on the shortcomings of the policy which in turn will help to highlight the need for a solution.

2.3 Understanding the Need for a Solution

The South African organ procurement and transplant system has not been revisited. As mentioned, the result is that people are suffering, waiting lists are increasing, individuals are enduring costly treatments and families are suffering from emotional anxiety and financial stress. The state also feels the impact of the endless costs associated with the treatment of ESRD. Cotter (2011) showed that the associated costs of treating ESRD are far greater when organ transplanting is not used. This has

a domino effect in that the money spent could have been used elsewhere for the good of others. Seeing this severe shortage of organ donation, one assumes that the general population does not want to donate organs.

However, Etheredge, et al.'s (2014) report showed in its empirical findings that seventy to ninety-one percent of the South African population appeared willing to donate their organs. So, if the majority of the population is willing to donate, why then do we still have such a shortage of donors? In my view this is critical, South Africa has people who are willing to donate so why are they not doing so? This could be due to education, the lack of a donor list, a lack of infrastructure, religious and or cultural reasons or simply due to the lack of an incentive such as financial gain. I think that if the willingness to donate is there, then by making a change in our current policy as a start to kickstarting kidney donations especially living donations, the numbers of donations will increase.

In South Africa, the shortage of kidney donations is not the only inadequate resource. One also needs to consider the lack of trained health care professionals and the lack of infrastructure, transplant coordinators and transplant hospitals (Steyn, 2011). My view is that by creating an external regulatory body utilizing structures such as the current ODF and having one body to regulate kidney transplants would be the first step towards establishing an altogether better system.

To increase kidney donation there needs to be a supportive regulatory body overseeing the process, which ensures that autonomy is respected; by educating individuals and allowing them the choice of whether to donate or not and allowing them the chance of financial gain if they do. Relying on altruistic behaviour has not resulted in people donating in high numbers. Rather, it is clearly a system that is failing in South Africa and does not stand up to the principle of autonomy.

Varelius (2006) described autonomy; thus: "Personal autonomy is, at minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice." Beauchamp and Childress (2013, p. 186) claimed that even in cases when paternalism is justified, "this should not substantially restrict one's autonomy". I believe that our current legislation is failing to allow us the freedom to decide whether we wish to be rewarded for donations. Is this not a case for people who wish to donate ova and sperm whereby

donors receive an honorarium for donating? Autonomy is closely related to the right to human dignity, which forms one of the cornerstones of our Constitution (Labuschagne & Carstens, 2014). Why should the choice of donating a kidney for financial gain be taken away from individuals? Is autonomy not our human right?

The principle of non-maleficence places an obligation on the state not to cause undue harm to its people. This is underpinned in our Constitution in Chapter 2 of the Bill of Rights, right to human dignity (10) and again in Section 27. (1). “Everyone has the right to have access to health care services. (2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.” While one might argue that the state is providing dialysis as there is a lack of kidney supply, it is not doing so without causing harm. Some people may never receive a transplant and will ultimately remain on dialysis for the rest of their lives.

Labuschagne and Carstens (2014, p. 225) stated that: “A lack of access to transplantable organs could result in denying individuals the right to dignity and compromising their right to life.” South Africa’s current opt-in system is failing to meet the healthcare needs of the people, by not providing sufficient kidneys and thus these individuals will suffer from continued illness, a poor quality of life and stress associated with the thought of losing their lives as well as the financial pressures of possibly not being able to work, and increased costs of treatment. Not only is it the individual and their families who are affected, but the state as well. The state will have to cover the costs of treating ESRD which are much higher when a transplant is not used (Cotter, 2011). Thus, the system is undermining the principle of non-maleficence.

The principle of beneficence refers to doing good (Moodley, 2017). Beneficence encompasses all forms of action intended to do good or to benefit others. As our system essentially is relying on the altruistic behaviour of people, it means that they are relying on people donating organs free of any self-interest and the only benefit to them is the knowledge that their organs will go to a stranger who is in need. The fact that our government has such a policy in place **I believe**, is perhaps a start but it is not good enough as the policy is simply not doing enough to reduce the waiting lists and ultimately improve people’s quality of life. The system is not allowing beneficence to thrive as there are not enough organs to meet patients’ needs.

The principle of justice pertains to a just and fair distribution of that which is good and that which is bad i.e., **resources** and burdens (Dhai & McQuoid-Mason, 2011) The most obvious limited resource here is kidneys. As mentioned previously this is not the only inadequate resource as there is also a shortage of transplant centres, coordinators etc. The vast majority of South Africans use government funded public health care. Logically this should mean that the distribution should be favoured towards the public sector, but this is not the case. Steyn (2011) reported that in 2011, sixty-three percent of all transplants were done in the private sector; thus, showing the inadequate distribution of vital resources. The state simply did not have the resources to allow for more transplants. The system is unjust because there is an inadequate dispersal of vital resources, in terms of organ donation and transplanting.

2.4 Conclusion

In this chapter, I sought to describe South Africa's current system on organ procurement. I have shown that this system is unsuccessful as it is unable to meet the healthcare needs of the people. There is an insufficient supply of kidneys. However, more than fifty percent of South Africa's population is willing to donate organs, including kidneys (Etheridge et al., 2014).

There is a mismatch between the state and private citizens in terms of the lack of resources. There is no central governing body managing organ donation and transplanting on a national level; therefore, **I submit** that the system needs to be replaced or amended. Only once one understands how the current system works can one evaluate which system is better and what the way forward should be. In the next chapter, I will describe the various other organ procurement systems used globally and evaluate them to see if they could offer a more suitable option for South Africa.

CHAPTER 3: ORGAN PROCUREMENT SYSTEMS WORLDWIDE

Around the world, organ donation policies vary greatly, but essentially, they can be classified as one of the following general approaches, namely, Opt-in, Opt-out and Incentivised models. South Africa utilises the opt-in system and since this system was already considered in Chapter 2, I will focus this chapter on critically evaluating alternative systems, utilizing the principlism framework that is used to procure organs, specifically kidneys, for transplanting, in order to assess their suitability for South Africa. This chapter is divided into two sections namely, presumed consent systems, under which the opt-in and the opt-out systems fall and incentive systems under which priority models and paid and regulated models fall.

3.1 Opt-out System (Presumed Consent System)

In opt-out systems, organ donation occurs automatically unless there is specific mandate made before death by an individual who chooses to be removed from the organ donor list (Griffith & Tengnah, 2009).

This system presumes one to be a donor unless otherwise stated, that is a person has given consent to opt-out of being a donor. This system has been challenged by many ethicists, on the basis that there is no explicit consent but rather presumed consent. Presumed consent requires that the people need to have been properly educated as to what donation entails. Without education one can question whether the person has been truly informed and therefore is it right to assume their consent. Explicit consent on the other hand, is when a person has stated either way what their wishes are. No assumption is made. A point to note regarding this system is that it still allows a person to consciously object to the donation of his or her organs and consequently it is respectful of freedom of choice and one's autonomy.

Autonomy is seen as one of the main guiding principles in biomedical ethics. However, Beauchamp and Childress (2013: p.14) maintained that the principle "has only prima facie standing and thus it can be overridden by competing moral considerations". Limiting a person's autonomy is accepted in many countries in terms of decisions such as taxation and vaccinations, that is limiting a person's autonomy is justified if it produces a greater good for the community. This system is therefore not unreasonable when it comes to limiting a person's autonomy, as it is doing a greater good for people. It is indirectly saving lives. It is also not purely limiting, as persons' have the autonomy

and the ability to object to donating their organs by removing themselves from the donor list.

No country can make a move to an opt-out system unless there has been sufficient education and that it is widely understood what the consequences are if no action is taken, that is if a person does not wish to donate one's organs' they need to remove themselves from the register. This is of vital importance as a lack of education can cause levels of distrust and therefore reduce organ donation rates. Distrust comes into play when people have not been fully educated on the process of organ donation, on what 'brain dead' means. It is important to reassure people that their organs will not be removed before they are clinically dead. This distrust and fear was seen in Brazil when they made the change from opt-in to opt-out (Griffith & Tengnah, 2009). In 2010-2011 following the change in policy from opt-in to opt-out Brazil saw a twenty-nine percent decline in donations (Dominguez & Rojas, 2013). Therefore, without optimizing education, harm could be done when implementing this system.

To the contrary, a benefit of this system is that it results in families not being able to override a person's wishes. A person who might not have wanted to donate in an opt-in system might not necessarily be able to donate if their family doesn't agree but will be able to donate in an opt-out system even if their family disagrees. This system is not reliant on altruistic behaviour, as one is presumed to be a donor unless otherwise expressed. In terms of organ donation, I believe that if one only looks at beneficence in terms of altruism one is only looking at the donor. However, one needs to look at promoting a suitable environment that promotes the best interests of others which includes all involved, that is healthcare professionals, families, donors, and recipients.

Therefore, I believe that the opt-out system is better as people's wishes are being honoured, lives are being saved and organs that would have been lost in an opt-in system whereby organs from a person under the opt-in system may not have made their wishes known to the family would now be available; therefore, more organs become available (Gill, 2004).

However, an opt-out system may result in decreased rates of donation because of a lack of trust as was seen when Brazil implemented the system. Appropriate education can be used to counter this risk (Griffith & Tengnah, 2009). In 1986 when Denmark moved from presumed med consent to expressed donation rates fell by 50 percent

(Gundle, 2005). However, Rockloff and Hanley (2014) maintained that positively framing organ donation changes people's attitudes and improves donation rates.

I believe that in South Africa's current state, this system would be impractical and probably impossible to implement. The key drivers in this system are good education and sufficient resources to be able to do the transplants. Currently, South Africa is not in a position to accomplish either of those aims and therefore the system would fail. It would be unethical to attempt to implement an opt-out system right now.

The next system I will discuss is known as Incentivised Organ Donation, in other words people are incentivised to donate. I will discuss two variations of this namely the priority model which Israel uses and a paid model which Iran uses.

3.2 Incentivised Organ Donation Systems

Incentivised organ donation systems are premised on the belief that people will not inherently donate unless they are motivated or incentivised to do so. As seen with previous models which rely on altruism this, does not increase donors. There are variations of these systems worldwide of which the two that I will discuss are the priority model utilised in Israel and a paid and regulated system that is utilised in Iran.

3.2.1 Priority System (The Israeli Model)

This system is unique in that Israel is the only country that utilises it, but it is still successful. It is otherwise known as the priority system. People are rewarded by being prioritised on the organ donation list if they meet certain criteria. These criteria come in the form of signing a donor card, making a nonspecific organ donation, or by way of an immediate relative who has signed a donor card or consented to the donation of their organs after death. (Berzon, 2008)

There is some reward for living donors in terms of reimbursement for costs incurred by the donation and this compensation is overseen by an ethics committee (Slabbert & Venter, 2015: p.45). This system functions on the premise that justice demands that if one is willing to receive an organ one must be willing to donate. It differs from the opt-in and opt-out systems in that people are incentivised to donate by means of priority on the donor list. For those who are living donors this report focusses on receiving financial reward. Opt-in and opt-out do not prioritise nor do they offer any financial reward. Opt-in relies on altruism and opt-out relies on people remaining on the donor

list and therefore there will automatically be more donors. According to Slabbert and Venter (2015: p. 46) “this system reflects a communitarian model where everyone stands to benefit from co-operation, whereas the purely opting-in system without any rewards is founded on personal autonomy”.

This system came into effect in 2008 as a response to increased demand versus the supply of organs. This is currently the only system worldwide that uses non-medical criteria to assess for organ donations. Other systems used globally all assess recipients on a medical basis for transplant. You need to fulfil certain medical criteria in order to receive a transplant if one is made available. Since Israel implemented this system improvements have been seen in living donor rates and also there has been a reduction in unethical practices such as transplant tourism. However, it is still not sufficient to satisfy the demands for organs.

Prior to the 2008 system insurance companies were re-imbursing patients for transplants they had received abroad, regardless of whether the donors or the procedures were legal or not (Slabbert & Venter, 2015: p. 46). Between 2000 and 2007, approximately 150 transplants were done outside Israel. In those years, this amounted to fifty percent of the total kidney transplants performed on Israelis. In 2010, this number was reduced to forty and then thirty-five percent in 2011. During this time, kidney transplant waiting lists rose from five hundred and eighteen in January 2007 to seven hundred and thirty-three in January 2011 (Boas, Moz & Michowitz, 2015: p. 1078).

In terms of the new Israeli law, one may not receive financial rewards for a living or for a deceased donation (Jotkowitz, 2008). However, the law does state that you may be re-imbursed for financial losses accrued due to the donation. This includes up to forty days of lost earnings and medical expenses for up to five years. The law also allows for rewarding a person who agrees to donate the deceased persons organs (Slabbert & Venter, 2015: p. 45).

This Israeli law rewards individuals with prioritised access to organs. These include those who have registered as donors or have family members who have donated, on condition that they participate in procurement efforts and have been registered for at least three years, prior to their organ listing. Candidates who have previously donated an organ (kidney, liver lobe or lung lobe) are granted top priority in the allocation of

these organs. Points are then awarded and added to the individual's organs recipient profile (Berzon, 2018).

The success of the system lies in 'reciprocal altruism' and 'collective participation'. I consider reciprocal altruism to be consistent with fair justice, that is if you are willing to receive you must be willing to donate. This system serves justice as it is rewarding the 'givers' and not the 'takers' as it prioritizes those who are willing to donate. Robertson (2007) refers to this priority allocation as a 'cooperative system'. He believes that this system is a matter of justice by allowing non-donors or 'free riders' equal access completely violates the principle of justice. This model can be controversial as not having sufficient awareness of it can lead to people who would have signed up as organ donors to do not do so, due to a lack of awareness. In terms of collective participation, Berzon (2018) argued that: "Although organs are a scarce medical resource, they are not a typical good - their provision rests on the willingness of individuals to give their body parts to others. In this sense, the success of the entire transplant enterprise depends on collective participation."

While some might refer to this as a just system, others claim it is punishing the non-altruistic and rewarding the altruistic. Barilan (2014) felt that punishing people who do not donate is explicitly contravening their freedom of conscience and ultimately not allowing for human dignity and therefore is completely unjust. Berzon (2018) also claimed that the system was unjust because it favoured those who have family members who then also have to donate, therefore those families who have a lot of members are given an advantage. This is discriminatory and is therefore unjust. Another argument against this system is that scarce medical resources should be allocated in accordance with medical criteria.

From seeing the pros and the cons of the Israeli model I believe that it would be impractical to implement this system in its entirety, in South Africa. South Africa does not have a national database of either organ donors or those in need. However, according to Slabbert and Venter (2015) South Africa could take a few pointers to improve its system, particularly prioritizing organ donation. Israel has an entire act dedicated just to organ donation, as opposed to South Africa which is incorporated into our NHA. Within Israel's Act makes provision for such a database to be held at a central transplant centre which contains all the details nationally of those who need donations and those who are willing to donate.

The next point we can take from the system is that of provision for financial reimbursement of the donor and the recipient. **I believe** that if legislation is written comprehensively that it states exactly where the re-imbursements go, that this would assist in the interpretation of our current act which could be considered vague, (NHA Chapter 8 60 (4) (a)). “It is an offence for a person who has donated tissue ... to receive any form of financial or other reward for such donation, except for the reimbursement of reasonable costs incurred by him or her to provide such donation.” If one adopts Israel’s policy and has a fully comprehensive act this would eliminate the vagueness.

I have described three different systems which are used globally. I have shown where they are successful and where they need improvements. Considering all their positives and their negatives, all three systems are failing to meet the demand for donations and the demand continues to exceed the supply.

The next model I will speak about is also an incentivized system but one offering a purely financial reward and it is the only model worldwide which has eliminated its kidney donation list (as this report pertains to kidney donations). Following the discussion on models, I will conclude that a paid and regulated living-unrelated donation system with a few changes made to the Iranian model is ethically and practically suited for the South African context.

3.2.2 A paid and regulated living-unrelated kidney donation system (The Iranian Model)

Currently, there is only one country globally that allows for monetary compensation for organ donation and that is Iran. By 1999 their waiting list was eliminated (Ghods & Savaj, 2006). Iran has over thirty years of experience with this model, which involves active roles from the government and the charity foundations. Irrespective of socioeconomic status the current Iranian model has enabled most of the Iranian kidney transplant candidates to have the ability to have a kidney transplant (Mahdavi-Mazdeh, 2012). The Iranian Model of Kidney Transplantation (IMKT) is a model of a functioning organ compensation system. This is a highly regulated system that is run by a charity known as the Iranian Patients Kidney Foundation (IPKP). This charity regulates the kidney procurement process, from matching donors to recipients, to writing contracts and all else that is involved in the compensation system. Information on donors and recipients as well as all statistics are entered into a database to find matches. The

IPKF then introduces the candidates who agree on an acceptable price to be paid from the recipient of the kidney to the kidney donor (Fry-Revere, 2014).

To ensure that strict protocols remain in place regarding transplants, all transplants are performed in university hospitals under the supervision of the Ministry of Health and Medical Education. To prevent potential exploitation and 'transplant tourism' the Iranian compensation programme is only open to Iranian citizens. However, if a recipient does not have the finances to pay for the transplant, charitable organizations step in to help with the costs.

Therefore, regardless of socio-economic class, everyone is helped. "50% of kidneys from paid donors were transplanted into patients from poor socioeconomic class. This finding is a clue against commercialism in the Iranian model renal transplant program". (Ghods & Savaj, 2006 p:1140). After the transplant has taken place an organization known as the Charity Foundation for Special Diseases further rewards the donor with monetary compensation, as well as providing a year's free medical insurance (Aramesh, 2014). What cannot be overstated is the function of the charities involved and the IPKF working with other charities such as the Dialysis and Transplant Patients Association (DATPA). This arrangement ensures that there are no conflicts of interest which lessens the chances for exploitation and corruption. It also eliminates middlemen and brokers (Larijani, Zahedi & Taheri, 2004).

The success of this model is the complete elimination of waiting lists. (no other model has achieved this). Together with this comes lower rates of ESRD and less need for costly dialysis. As long as one can pay for kidneys, this model works. However, what is noted in Iran is that because of the high supply of kidneys the price is kept low; but in addition, charitable organizations do step in to help those who are unable to afford the costs themselves (Ghods & Savaj, 2006). Where other models have failed this model is succeeding. Another example of this is the eradication of 'transplant tourism' or organ trafficking. The IPKF takes over all procurement and contract details, so there are no brokers or agencies etc., thereby eliminating organ trafficking. As no foreigners are allowed to receive kidneys from Iranians, this has essentially stopped 'transplant tourism'.

The Iranian model succeeds on many ethical levels. it is promoting autonomy by allowing participants to have a choice and control over their bodies. This system also

promotes justice, waiting lists have been eliminated, and organ trafficking is non-existent, transplant tourism has been eradicated and there is financial assistance for the poor. The Iranian government refers to the compensation as a 'gift for altruism' (Aramesh, 2014) this system is therefore promoting beneficence. According to Potter (2015), this model can address notions of commercialization and exploitation. In a study with over five hundred renal transplant recipients, "50% of kidneys from paid donors were transplanted into patients from poor socioeconomic class. This finding is a clue against commercialism in the Iranian model renal transplant program". (Ghods & Savaj, 2006 p:1140).

Another point to note according to Ghods and Savaj (2006) is that this model did not reduce the number of deceased organ donors who donated but instead this number has increased steadily. This model has also helped to alleviate family pressure to donate, as in some cases in countries without legalization of buying a kidney, relatives were emotionally coerced into being 'altruistic' when in fact they would rather have not donated their organs. "It may be more ethical to perform a paid renal transplantation from a volunteer living-unrelated donor than from an LRD or a spouse who is under some degree of family pressure or emotional coercion" (Ghods & Savaj, 2006). Therefore, this system is promoting non-maleficence.

According to the World Health Organization (WHO, 2007), there is a global estimate of two hundred thousand people on the waiting list for kidney transplants and hundreds of thousands more needing other organs. Surely, it is time to look at a compensated system for live kidney donations. I believe that if one sees that 'purchasing organs' is inherently different to financial incentives, then this system can be proposed as preferable to our current altruistic one. There will be objections to this system which I will discuss and refute in the next chapter.

3.3 Conclusion

Following the critical evaluation of the various models of organ donation globally, I have shown why these models are not favourable. In Chapter 4 I argue why a compensated regulated system for living unrelated kidney donation is a suitable amendment for South Africa 's current policies and why the objections to such a system will fail in the South African context.

CHAPTER 4: OBJECTIONS TO A PAID AND REGULATED LIVING-UNRELATED DONATION SYSTEM

A paid and regulated model does not come without disadvantages and with these disadvantages, objections are raised. The first issue is that of commodification. Human organs are commodified as two monetary processes are involved. The first is a direct negotiation on payment between the donor and the recipient and the second monetary transaction is from the nongovernmental organization the Charity Foundation for Special Diseases. The state refers to this monetary compensation to the donor as a 'gift of altruism' (Aramesh, 2014). Technically, it is not altruistic as one is being paid for it. So, this act of beneficence comes under the guise of a financial reward which in itself could be seen as a perverse incentive. Marino, Wight and Wigmore (2002) felt that it is unethical to commodify the body as it goes against human dignity and should never be subject to trade.

The arguments against being allowed to sell organs rely heavily on the debate about dignity and exploitation of the poor for the benefit of the wealthy. This argument states that: "rich, well-resourced people who need organs will buy them from poor people, thus exploiting their indigence" (Moodley, 2017). This argument is based on the fact that the decision to sell their organs is not truly autonomous but purely because they are in a desperate financial situation.

Marino et al. (2002) argued that this system would exploit the poor as the wealthy would have no reason to sell their organs. They feel that transplantation rates will go up and people will benefit indiscriminately but ultimately these contributions will be coming from the poor. They argue that the human body should never be a subject of trade as it undermines human dignity, even if it is governed by the state. Their view is that the focus should be aimed at increasing investments into transplant education programs for cadaveric and living donations. Marino et al. (2002) claims that by allowing payment organs will ultimately lead to a decrease in cadaveric donations. Marino et al. (2002) feels that allowing the sale of organs will also lead to increased 'transplant tourism' as different countries will have different approaches and models and people will naturally seek out the cheapest option and once again prejudice the poor as they will be the ones who are ultimately donating.

Another possible disadvantage is where the majority of the objections lie and that is that the rich will benefit and that the success of this system relies on the poorer

populations. Studies have shown that the majority of recipients are from poorer populations, however, a greater number of donations are from the poor Iranians (Ghods & Savaj, 2006). This is expected as financial incentives will always appeal more to the poorer populations. This skewed decision making makes one question, is this decision truly voluntary (Aramesh, 2014). One can also question the lack of non-financial incentives, as it only incorporates a one-year free medical insurance for donors and thereafter they are on their own. This is a true drawback as these donors will need lifelong health support (Pajouhi, Farzaneh, Zeinab & Bagher, 2014).

Objections to this model would also include the suppression of altruistic donations as people will not feel the need to do good and help others as there is a model in place which allows financial rewards (Aramesh, 2014). It will also cause stigmatization of donors to such a degree that they become isolated from people from their own country as many people view donating a kidney for compensation as inhumane or an improper thing to do (Koplin, 2014).

I believe that the benefits and the advantages of a paid and regulated system outweigh the disadvantages and that within South Africa, using this model with a few revisions will answer our problem of kidney shortages. Even though some of the fundamental problems such as commodification and exploitation will always remain, **I believe** that these can be overcome by addressing them and ultimately taking us to a better place in terms of kidney donations and peoples' livelihoods.

4.1 Why these Objections Fail in the South African Context Utilizing the Principlism and Ubuntu Theories

South Africa is not dissimilar to other developing countries which include a great amount of poverty and high unemployment rates. However, it has its uniqueness when it comes to its people and that is where the term 'ubuntu' comes in. The term itself is derived from the prefix ubu- meaning "a collection or a group" and the suffix, -ntu, meaning "human" (van Binsbergen 2001: p. 53). Therefore, meaning the collection of people.

The impact and the significance of 'ubuntu' has a far greater impact and from an ethical point of view implies relationships with and between people. "I am because we are" and how we should be conducting these relationships, but its significance is far greater than that. *Ubuntu* in *King III* is defined as follows: "*Ubuntu* means humaneness and the

philosophy of *ubuntu* includes mutual support and respect, interdependence, unity, collective work and responsibility. It involves a common purpose in all human endeavour and is based on service to humanity (servant leadership)" (*King III*, p. 23).

Metz's (2011) moral theory which as mentioned is grounded in Southern African views, suggested a new conception of human dignity. According to his conception, "typical human beings have dignity by virtue of their community capacity, understood as the combination of identifying with others and exhibiting solidarity with them, where human rights violations are egregious degradations of this capacity" (Metz, 2011: p. 541). He feels that his theory will lead to ways to resolve moral dilemmas in South Africa. I agree with his interpretation of *ubuntu* and that it does provide guidance to resolve present-day disputes about justice and human rights. This notion should be utilised when deciding on policy regarding kidney donations.

The values of *ubuntu* have influenced how our leaders formulate and implement a strategy in business. Ngouessy-Guibinga and Landry's (2012) analysis showed that leaders of organisations would urge all South African organisations to implement these values, to facilitate stronger economic growth. These leaders have a duty to educate and raise awareness amongst their people and to encourage them to integrate these values with their organisations, thus creating and building a continent comprising of tireless, considerate, sincere, non-discriminatory, and honourable people, which will, in turn, stimulate economic growth and facilitate the fairer distribution of capital in Africa.

What needs to happen now is that these values need to be instilled into our leaders when deciding on a policy, more specifically organ donation. Would it not be to just allow a policy which benefits all its people, would this not be the spirit of *ubuntu*, "I am because we are". This is justice and this is exactly what is required when it comes to organ donation. The poor are being uplifted and the sick are receiving quality of life. This does lead to a major objection, being that this system benefits the rich to the detriment of the poor.

One could argue that this financial incentive coerces the poor and that they are basing their decision on finances rather than on an altruistic one. The question though that seems to be missing from this objection is what these potential donors will do if unable to donate in exchange for a reasonable financial incentive. What would they be doing

to change their desperate financial situation or the emotional burden of trying to help a sick relative? What are the alternatives that are available to them, and at what cost to themselves and to society? If there is a system in place that benefits an individual and society as a whole, surely is this not the answer? "If the alternatives were incarceration, loss of a loved one, stealing, murder, drug trafficking, suicide, or homelessness, then donating a kidney in exchange for a fair financial incentive and saving a life would be a more reasonable and honourable choice, even if the relief is partial or temporary". (Bastani, 2019 p:195).

Is this not what we are facing currently in South Africa, poverty increasing, joblessness increasing, resulting in increased crime. Surely if we can alleviate this in some way, we are ethically bound to help? Matas and Chapman (2008), **their view** dismisses the claim that the poor will be exploited. His view is that everyone is capable of making rational decisions about their lives. This is done on a daily basis anyway. Why take this decision out of their hands if they feel it will uplift their lives? Taking this decision away from the poor is not allowing for autonomy.

With the availability of a living unrelated kidney donation, this also reduces the potential for **emotional** coercion and families feeling under pressure to donate. Another point to note, according to Ghods and Savaj (2006), is that this model did not reduce the number of deceased organ donors, in fact, that number has increased steadily. This model has also helped alleviate family pressure to donate. In some cases, in countries without legalisation of buying a kidney, relatives are emotionally coerced into being 'altruistic' when in fact they would rather not donate. "It may be more ethical to perform a paid renal transplantation from a volunteer living-unrelated donor than from an LRD or a spouse who is under some degree of family pressure or with emotional coercion" (Ghods & Savaj, 2006).

People should not be coerced into donating as they have an individual right to their bodies and informed consent. **I believe** that the Iranian model has overcome this by allowing for paid living-unrelated donors; thereby stopping the need for coercion towards family members. One must also consider the fact that in the Iranian model no one is interfering with the poor to decide to take or not take a relatively high risk that the rich do not have to take. This is similar to the risk that people take when they choose higher-risk jobs such as firefighters and policeman which all carry a great risk to the person but in doing so, they help others. One could say that by denying people

the choice to take such jobs is paternalistic and denies people the ability to improve their economic status (Mahdavi-Mazdeh, 2012).

The next objection which is always raised is that of commodification. As mentioned before Marino et al. (2002) feels that it's unethical to commodify the body as it goes against human dignity and should never be subject to trade.

Kahn and Delmonico (2004) argued against organ selling as they believe that we need to treat each other with respect and not just as a means to an end. We cannot put a price on the human body as this would go against our human dignity. Savulescu (2003) feels that commodifying organs will result in huge ethical and legal problems as to whether a person has property rights to his organs while alive. However, in this argument, it simply ignores the fact that globally people are already compensated for parts of their bodies such as sperm, ova and are also compensated for the loss of body parts (Mata & Chapman, 2008). **I am of the view** that what is important to ask here is why is it morally acceptable to be **reimbursed** for sperm and ova which have the potential to bring about an entirely new human life, whereas to be **reimbursed** for donating a kidney which will save a life is morally unacceptable?

The question that no one seems to be asked is what about the numerous people on waiting lists who may never receive the chance for a transplant and have a good quality of life. Has their human dignity not been taken away from them? Savulescu (2003) stated that: "The argument has also been made that an organ, like other organic matter, has no inherent dignity and has value insofar as it can be a vital source of life". Therefore, **I claim** that the argument that one should not be allowed to sell one's organs fails, as organs are organic matter with no inherent dignity but are useful in helping to save lives and are thereby preserving human dignity. By preserving lives, improving peoples' quality of life, and retaining dignity beneficence and non-maleficence have been achieved.

According to Matas and Chapman (2008), regulated systems respect a person's autonomy, in stark contrast to the current paternalistic ban that assumes that individuals are incapable of making their own decisions. Savulescu's (2003) view was that people should have the right to decide what to do with their bodies. This is respecting one's autonomy. The risks of kidney donation are minimal, and someone else's quality of life is benefited as opposed to the state allowing things such as

smoking where no one benefits, and more harm is done to the person and the public. Globally, there will always be an inequity of wealth and why not give people a choice concerning their bodies if they wish to sell an organ. One is still allowing them their autonomy whilst helping them with some form of compensation.

It is the state's duty to have policies in place which prevent harm to people and as we are humans, we are rational persons which allows us to make rational moral choices as we are owed this respect. Therefore, by being rational human persons who are owed respect can we not assume that we can make our own choices as to whether we want to sell our kidneys or not? Are we not morally deemed to help people who are sitting on long waiting lists who will ultimately die if they do not receive a kidney? Are we not morally obliged to allow persons to decide for themselves whether they want to sell their kidneys? By allowing them compensation one is fulfilling global ethical principles of autonomy, justice, beneficence, and non-maleficence.

The next objection to this system of regulated government incentivized living unrelated kidney donation is that it will result in the disappearance of living related and deceased donor donations. However, the Iranian model has shown that this is not the case. "The paid kidney donation model did not inhibit the establishment of a deceased-donor organ transplantation program. Since April 2000, when legislation that was passed by parliament accepting brain death and deceased-donor organ transplantation, the annual number of cadaveric kidney, liver, and heart transplants has increased steadily in the country. In 2000, only 1.8% of all renal transplants were from deceased donors. This increased to 12% in 2004 and 2005" (Ghods & Savaj, 2006 p:1140).

This follows onto the next widely spoken about objection to a paid system and that is that it will increase 'transplant tourism'. This unwanted scenario would be likely to increase should a market in organs be established in South Africa. "The illegal exploitation of human tissue as a tradeable commodity will continue to occur for as long as there is an enormous gap between supply and demand for human solid organs" (Rens, 2008 p:14). I disagree with this statement as I believe that the only reason why 'transplant tourism' exists is that the demand is greater than the supply and there are many people who live below the breadline. I also think that South Africa can also have the prohibition that only South African citizens may be part of a compensated system.

This is very prevalent in our country with the unemployment rate moving from thirty percent to thirty-eight percent, due to COVID-19. 'Transplant tourism' and organ trafficking exists because South Africa's current policy is that of prohibiting the sale of organs (NHA, 2003) and coupled with the above factors, this is the result. This was mentioned previously regarding the illegal transplants that took place in Durban between 2001 and 2003.

As mentioned in the introduction the Declaration of Istanbul on Organ Trafficking and Transplant Tourism 2008 was put into place to provide guidelines and prevent unethical practices of the donation of unrelated living kidneys. Bastani (2019) reported that there is an increase in transplant tourism and people from first world countries are paying thousands of dollars to black-market brokers to buy kidneys in third world countries. These transplants are often performed in unsafe conditions and there is no post-op follow up. Recipient's risk getting suboptimal kidneys with possible other infections. There is no legal backing and often the donors are cheated by the brokers. Iran has completely eradicated this problem. Is this not fulfilling all the basic principles of medical ethics? Do good, do no harm, allow patients the right to decide and serve all the people with justice. According to Mahdavi-Mazdeh (2012) "poverty cannot interfere with individuals' autonomy. As long as the donation is not coercive, it is the responsibility of the community to respect the dignity of the human as is done for firefighters, soldiers, and policemen who take high-risk jobs to protect others".

Being a developing country with a high rate of unemployment South Africa will always have the lure of corrupt and illegal behaviours. People need to survive and will do what they can to do so. Iran's model is not perfect, but **I believe** it will be a step in the right direction to improving livelihoods for all its people. Is this not what South Africans espouse, the spirit of 'ubuntu', "I am because we are", we need to uplift each other for a better future for us and future generations. Ubuntu's emphasis is on humanity, compassion, and social responsibility. Through this, it has the ability to facilitate solutions and avoid conflicts when the dilemma comes in between individual rights and public health. "The use of ubuntu shifts the moral reasoning and ethics of decision-making from a field of philosophy shaped by the global north to the everyday values, decision-making, and consequent practices of people in much of Africa" (Sambala, Cooper & Manderson, 2020)

As previously discussed, in altruistic models' donors are praised for saving peoples' lives, so why can we not praise an unrelated donor who is not only saving someone from ESRD but also helping to uplift his or her family situation with monetary compensation. The unrelated donor is risking his or her life to save another and is helping his or her family. Surely this should be even more revered and praised.

When one looks as to why the Iranian model of compensated kidney donation is successful (although not a perfect model) the key is to have a regulated system with a regulatory body that oversees the process. As it is a system of incentives, it has to have regulations and oversight to protect both donors and recipients. The law dictates the space by which the obligations between recipients and donors are being met and define how these arrangements are met. Amongst these protections that are met are safety for donors and for recipients, transparency into the risks involved for both and having institutional integrity, that is a healthcare facility which maintains standards for effective transplants and whose patients and healthcare providers are protected. These protections are what morally differentiates a regulated system of incentivised organ donation to the harm that is created by organ trafficking and 'transplant tourism' (Hippen, Ross & Sade, 2009).

When looking at 'compensation' it need not be limited to cash payments. In South Africa where poverty is high and the **majority** has no access to private healthcare, one could offer an incentive of an added comprehensive, lifelong healthcare benefit, or a deposit into a retirement fund, above what the state provides. The list is endless. Is the specific nature of the compensation not less important than having a successful organ donation system which is meeting the demands of the people and having an incentive which does not perpetuate further harm? South African culture is known to be that of collectiveness, that is ubuntu. "In Africa there is a concept known as 'ubuntu'- the profound sense that we are human only through the humanity of others; that if we are to accomplish anything in this world it will be in equal measure due to the work and achievement of others" (Nelson Mandela, 2008).

As mentioned previously, ubuntu's emphasis is on humanity, compassion, and social responsibility. Therefore, through this, **I believe** that it facilitates the dilemma between individual rights and public health. Compensated donation for unrelated living donors requires that there be two parties, one in need of a kidney and one in need of compensation (in whatever form that is) the one party cannot achieve their goal without

the other. Both are needed to satisfy each individual need. As individuals' alone we cannot function but as a collective, we will be successful, once the high cost for dialysis can be utilised for transplants; thus, allowing these people a better quality of life, together with being able to contribute to society. People on dialysis will not be able to work as they spend most of their time on dialysis machines and therefore, they are unable to contribute to the economy. People who are able to get a transplant can go back to work and can therefore contribute to the economy, which South Africa is in desperate need of.

I **claim** that in raising objections to a compensated procurement system in South Africa the point that is being missed is that the current system is failing and ultimately bringing harm to recipients who sit on waiting lists and never get a chance to receive a kidney. Secondly, it brings harm to donors who perhaps would have donated but, due to one of the factors being a socio-economic problem, they do not, as they fear what medical attention they would receive. Thirdly, it is bringing harm to the victims of organ trafficking, as our public policy is failing them, and these are the people who are silently bearing the true cost of this failed system. These are the objections worth noting and this is what our transplant co-ordinators and political leaders need to understand and then change the status quo.

I have addressed the objections to a compensated living donation system, and I have shown how they have failed in South Africa. After addressing these objections, one needs to ask where to from here? What is evident is that our current opt-in system is failing dismally, and what is needed is a practical and ethical way for South Africa to achieve better organ donation rates and in doing so, with a LURD compensated system this will ultimately eliminate the kidney waiting list just as Iran has done.

Society is constantly changing and what was viewed as unacceptable years ago is now acceptable. In vitro-fertilisation, heart, and lung transplants. All of these innovations were met with major ethical problems and are now widely acceptable. Thus, when looking at compensation for LURD for kidneys this is not unforeseeable. The success is in having a regulated system, black markets remain unregulated and that is where the harm is done. No one benefits except maybe the organ vendor. With South Africa's history of change and people becoming more aware than ever of their rights, especially individual autonomy, is it not time that the law changes to allow for one's rational reasoning to accept being able to sell or buy a kidney?

The obvious need for change in South Africa's current organ procurement system has been a long time coming. It brings us to the question of what shortcomings need to be changed and what inefficiencies need to be alleviated for South Africa to have a successful organ procurement system. Slabbert (2012) who argued for financial remuneration of kidneys in South Africa proposed that we have a system whereby there is an agreement between donor and recipient, with an agreed price and a futures' contract for deceased donors. I agree that we do need to look at how we can uplift our people as a nation and this will be through a regulated system with a sound agreement for compensation between donor and recipient, at a price deemed fair by both.

Metz's (2011) moral theory of ubuntu prescribes that self-realization comes through communal relationships. Metz (2011) claims that the focus is on communal relationships rather than self-realization. This is in stark contrast to Western ethics where the dominant force is on self. The moral theory of ubuntu confirms how, when, and why to help others. Metz (2011) stated that: "Lastly, the idea of solidarity with groups whose survival is threatened is morally important but is surely not the whole story about the right action. Helping to protect the lives or ways of life of vulnerable populations is one way to promote shared identity and goodwill, but it is not the only way" (Metz, 2011). Metz (2011) feels that it is more common amongst Africans than Westerners to have a moral obligation with one's people and to support the community's way of life. Ubuntu honours human life, dignity, and community-based value systems.

Onah (2008) speaks about these principles which ground African values. "At the centre of traditional African morality is human life. Africans have a sacred reverence for life, and this is in order to protect and to nurture their lives; all human beings exist within a given community. The promotion of life therefore is the determinant principle of African traditional morality and this promotion is guaranteed only in the community. Living harmoniously within a community is therefore a moral obligation ordained by God for the promotion of life".

Metz's (2011) moral theory and conception of human dignity, is based on the virtue of being part of a community, identifying with the community and exhibiting solidarity with them. This therefore naturally speaks of ways of resolving moral dilemmas in South Africa, particularly when it comes to organ donation. Organ donation cannot take place with one person, it requires a community for it to be successful. By community, I am

not just referring to the donor and to the recipient but to the families on both sides, who need to be supportive, the transplant team doctors, the co-ordinators to conduct the process etc.

Metz (2011) claims that and **I believe** that he is correct in saying, “If I am correct that this jurisprudential interpretation of ubuntu accounts for a wide array of intuitive human rights and provides guidance to resolve present-day disputes about justice, then the three worries about vagueness, collectivism and anachronism should not stop one from thinking that something fairly called 'ubuntu' can ground a public morality” (Metz, 2011). Insofar as treating people with dignity, the system of organ procurement in any country should support this. It is also enshrined in our Bill of Rights as a constitutional right (Bill of Rights, 1996) Implementing a system which promotes such dignity is imperative and it is the duty of our government to uphold it. By placing value on a culture and a community when implementing policies, one immediately creates trust within the community and therefore adherence.

4.2 Conclusion

When seeking change to any system, one needs to understand the culture of the people for the change to be successful. This is paramount as there needs to be buy-in from everyone. South Africa is diverse and has many challenges within this diversity, but one thing which is certain and that is the spirit of ubuntu in everyone. Africans promote life and wellbeing within communities. This is why **I believe** that having an amended regulated compensated system for LURD will be a success. Communities will be uplifted, and peoples' lives will be changed. Changing a country's system of organ donation is not simple or easy. However, it will be more cost-effective in the long run, than treating people without organ transplants (Cotter, 2011). Investment will be needed to build the infrastructure. However, this is needed as it will improve the supply and the demand for available kidneys. **I believe** that this is worth the effort as it cannot result in a worse situation than the one that currently exists.

CHAPTER 5: CONCLUSION

Organ donation is a medical marvel and has come a long way over the years, but with it comes many ethical and practical considerations. It has been shown that transplants are far more cost-effective in the long run, when treating ESRD, on dialysis (Cotter, 2011). Considering these benefits for the state and for individuals it is obvious why kidney transplants remain the treatment of choice. Globally, South Africa is not alone in this battle worldwide, except for Iran where **supply is greater than demand.**

In this report, I sought to propose an amendment to our current policy on organ donation pertaining to kidneys. The rationale behind my report was due to the fact that there is little literature on whether a paid system would work better as an alternative to increasing the availability of kidneys for transplanting. The value of legalising paid donations would be to propose a more viable solution and offer an alternative which would potentially increase the donor pool and decrease waiting lists. I have argued that this system is the most practical and ethically justified system for South Africa.

I considered various organ donation systems worldwide, I have evaluated South Africa's current structure and the laws pertaining to organ donation utilising principlism and ubuntu frameworks and I have argued that South Africa's current system for organ donation has not proven to be effective. It is, in my opinion, failing. Therefore, the policy and legislation need amending. This report specifically is about LURD in kidneys (kidneys being the organ in greatest demand worldwide). I have shown a practical model which is thriving and currently the only model which has ended waiting lists. I have argued that this is the most practical and ethical solution for South Africa to implement.

Although the Iranian model is not perfect, South Africa can use it as a foundation on which to base a new amended model. This model will attract issues from opponents and proponents of a compensated system. However, I have argued that this model favours proponents' arguments in that it has the potential to reduce kidney waiting lists, organ trafficking, and transplant tourism if not eliminate them. It also promotes the global ethical principles of autonomy, beneficence, non-maleficence, and justice, as well as providing financial and health support to those who desperately need it. I have argued that opponents' arguments in exploitation, commodification and associative harms have failed in the South African context.

South Africans are a diverse and a resilient nation. Metz (2011) showed that human dignity is viewed in a different light and it is through communities that South Africa as a nation who can uplift themselves. Therefore, by allowing a compensated LURD system to be employed in South Africa this will address more than just the critical shortage of kidneys, but it will also uplift a nation as a whole.

“Action without vision is only passing time, vision without action is merely daydreaming, but vision with action can change the world” (Nelson Mandela and Joel Barker).

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APPENDIX A: TURNITIN PLAGIARISM REPORT



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APPENDIX B: ETHICS DECLARATION FORM



University of the Witwatersrand Student Ethics Declaration Form

(To be completed during the protocol assessor meeting)

Background

All Research conducted by a University of the Witwatersrand student, with human subjects or animals, requires approval by the Wits Human Research Ethics Committee or Animal Research Ethics Committee, respectively.

If research has been undertaken without the necessary ethics approvals, this is considered an ethics violation. This will be reported to the relevant structures, the data will have to be discarded, and in the case of students, they cannot use the data towards their degree.

To prevent any ethics violations, the ethics requirements for the proposed project will be discussed with you at the protocol assessment.

Declaration

Based on the current protocol assessment (and any proposed changes suggested by the assessor committee), we, the undersigned, understand that the proposed research requires:

- | | | | |
|---|--|---|--|
| 1. Human Research Ethics clearance certificate | <table border="1"><tr><td>Yes</td><td>No</td></tr></table> | Yes | No |
| Yes | No | | |
| a. Covered under existing supervisor ethics | <table border="1"><tr><td>Yes</td><td>No</td></tr></table> | Yes | No |
| Yes | No | | |
| b. Requires a new HREC application | <table border="1"><tr><td>Yes</td><td>No</td></tr></table> | Yes | No |
| Yes | No | | |
| 2. Animal Research Ethics clearance certificate | <table border="1"><tr><td>Yes</td><td>No</td></tr></table> | Yes | No |
| Yes | No | | |
| 3. No Human or Animal Ethics Clearance | <table border="1"><tr><td><input checked="" type="checkbox"/> Yes</td><td>No</td></tr></table> | <input checked="" type="checkbox"/> Yes | No |
| <input checked="" type="checkbox"/> Yes | No | | |
| 4. Unclear, will seek appropriate guidance from the HREC/AREC committees (whichever relevant) | <table border="1"><tr><td>Yes</td><td><input checked="" type="checkbox"/> No</td></tr></table> | Yes | <input checked="" type="checkbox"/> No |
| Yes | <input checked="" type="checkbox"/> No | | |

Signatures

Supervisor/s:

Student:

Date:

7 May 2020

11 March 2019/MP