

OVERCOMING RELIGIOUS AND CULTURAL OBSTACLES TO ORGAN DONATION: A RIGHTS-BASED APPROACH

Tracy Sheila Namirembe Muwanga

u 28017006

Thesis submitted in partial fulfilment of the requirements for the degree

Doctor Legum

(Public Law)

in the

FACULTY OF LAW

UNIVERSITY OF PRETORIA

October 2018

Supervisor: Professor A G Nienaber

Co-supervisor: Professor P A Carstens

DECLARATION OF ORIGINALITY

UNIVERSITY OF PRETORIA

The Department of Public Law places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

Full names of student: **Tracy Sheila Namirembe Muwanga**

Student number: **u28017006**

Topic of work: **'Overcoming religious and cultural obstacles to organ donation: A rights-based approach'**

DECLARATION

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this thesis is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

.....

TRACY SHEILA NAMIREMBE MUWANGA

OCTOBER 2018

ABSTRACT

The transplantation of human tissue, cells and organs has saved and improved the lives of hundreds of thousands of individuals who suffer from organ failure. Advancements in organ transplant technologies have resulted in an increased demand for viable organs for transplantation - a demand which South Africa is unable to meet. Religious beliefs, cultural practices and the system for organ procurement currently used in South Africa are some of the obstacles to donation. The thesis debunks religious and cultural misconceptions about organ donation and transplantation, basing its arguments in a human rights-based approach. Ways in which human rights norms may be used in the promotion of organ donation, whilst still respecting the cultural and religious beliefs of the individuals involved, are interrogated. It is concluded that religious and cultural norms, in fact, support organ donation. The introduction in South Africa of a mandated choice-system as an alternative for the procurement and allocation of organs is recommended by the thesis.

Key words: organ transplantation; obstacles to organ transplantation; human rights-based approach; culture; religion; mandated-choice procurement system

ACKNOWLEDGEMENTS

First and above all, I would like to thank God, the Almighty, for providing me with this opportunity and granting me the capability to succeed.

I extend my profound gratitude and appreciation also to my supervisor, Prof Annelize Nienaber and co-supervisor, Prof Pieter Carstens, for their extensive review of my drafts and for providing the motivation I needed in order to complete the thesis. I also extend my sincere gratitude to Prof Magda Slabbert whose advice has been extremely beneficial and pertinent to the completion of this thesis.

I further extend my sincere appreciation to my family – my brothers and my parents - for their financial and emotional support and encouragement during the duration of my studies.

Lastly, I would like to acknowledge my peers and friends who in some way or another contributed to the success of this academic sojourn.

LIST OF ACRONYMS

CA	Capability approach
CDT	Cadaveric organ transplantation
THP	Traditional Health Practitioners
HOTA	Human Organ Transplant Act
HPCSA	Health Professions Council of South Africa
HRBA	Human rights-based approach
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
LDT	Living donor transplant
MTERA	Medical (Therapy, Education and Research)
NHS	National health system
NHA	National Health Act
NOTA	National Organ Transplant Act
NOTC	National Organ, tissue and cell transplantation
NTC	National Transplantation Council
NTTC	National Transplantation Technical Committee
NTU	National Transplant Unit
OHCHR	Office of the High Commissioner for Human Rights
ONT	Organizacion Nacional de Trasplantes
OPTN	Organ Procurement Transplant Network
TC	Transplant coordinator
UDHR	Universal Declaration of Human Rights

UK	United Kingdom
USA	United States of America
UNOS	United Network for Organ Sharing
UN	United Nations
WHO	World Health Organisation

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION	1
1.1. Introduction	1
1.2. Background	2
1.2.1. A brief history of organ transplantation	3
1.3. Definitions	4
1.3.1. Organ transplantation	4
1.3.2. Human rights law	6
1.3.3. Regional human rights systems	7
1.3.4. Ethics surrounding organ transplantation	7
1.4. Problem statement	9
1.5. Research questions	9
1.6. Research objectives	11
1.7. Research methodology	11
1.8. Potential contribution of the study	13
1.9. Literature review	13
1.9.1. Religion, culture and organ donations	13
1.9.2. Living and deceased organ donations	16
1.9.3. Legislation to be reviewed	23
1.10. Chapter Outline	26
1.10.1. Chapter One	26
1.10.2. Chapter Two	26
1.10.3. Chapter Three	27
1.10.4. Chapter Four	27
1.10.5. Chapter Five	27
1.10.6. Chapter Six	27
CHAPTER TWO: LEGAL AND ETHICAL PRINCIPLES SURROUNDING ORGAN DONATION AND/OR TRANSPLANTATIONS IN SOUTH AFRICA	29
2.1. Introduction	29

2.2. Principles of biomedical ethics	31
2.2.1. Respect for autonomy	32
2.2.2. Beneficence and non-maleficence	41
2.2.3. Justice	47
2.2.4. Difficulties in aligning ethical principles to the systems of organ donation and/or transplantation	50
2.3. Law governing organ donation and/or transplantations	62
2.3.1. Legislative enactments surrounding organ donation and transplantation	62
2.3.2. Living organ donations (LDT)	65
2.3.3. Cadaveric organ donation and/or transplantation	70
2.4. Conclusion	78
CHAPTER THREE: RELIGION, CULTURE AND ORGAN DONATION	81
3.1. Introduction	81
3.2. Religious belief and organ donation – can they be reconciled?	84
3.2.1. Christianity and organ donation	84
3.2.2. Islam and organ donation	90
3.2.3. Judaism and organ donation	95
3.2.4. Hinduism and early transplantation	102
3.2.5. Buddhism and the Buddhist Canon	105
3.2.6. African cultural beliefs	108
3.3. The concept of <i>ubuntu</i>, traditional healing, Western medicine and organ donation	110
3.3.1. The Traditional Health Practitioners Act	116
3.4. Cadaveric donation, the moment of death and their reconciliation in religion and culture	119
3.4.1. Determining the incorporation of an opting-out system of organ donation in the South African legal dispensation	122
3.5. Conclusion	124
CHAPTER FOUR: A HUMAN RIGHTS-BASED APPROACH TO ORGAN DONATION AND/OR TRANSPLANTATION	126
4.1. Introduction	126

4.2. Sen’s capability approach and organ failure	131
4.3. Capabilities, human rights and organ failure	134
4.3.1. Right to human dignity	137
4.3.2. Right to life	143
4.3.3. Right to an adequate standard of living	146
4.3.4. Right to health and access to healthcare services	148
4.3.5. The right to bodily integrity	155
4.3.6. The right to privacy	157
4.3.7. Equality and non-discrimination	161
4.4. Main features of a HRBA to organ failure	164
4.4.1. Empowerment and participation	164
4.4.2. Recognition of national and international human rights frameworks	168
4.4.3. Accountability	169
4.4.4. Progressive realisation	170
4.5. Contribution of a system of mandated choice to a HRBA to donation	172
4.5.1. Content of a system of mandated choice for organ donation	173
4.5.2. Incorporating a mandated choice system with a HRBA	175
4.6. Conclusion	177
4.6.1. Human rights and the capability approach	177
4.6.2. Main features of a HRBA to organ failure in the implementation of the capability approach	179
4.6.3. Concluding remarks	181
CHAPTER FIVE: A COMPARATIVE EVALUATION OF ORGAN DONATION PROCEDURES – LESSONS FOR SOUTH AFRICA	182
5.1. Introduction	182
5.2. Organ procurement systems	183
5.2.1. South Africa	183
5.2.2. Singapore	184
5.2.3. Spain	187
5.2.4. Malaysia	191
5.3. Lessons learnt to aid, and implications for, a human rights-based approach (HRBA) to organ donation and/or transplantation in South Africa	194
5.4. Allocation and distribution of organs	196

5.4.1. South Africa	197
5.4.2. Singapore	202
5.4.3. Spain	203
5.4.4. United States of America	205
5.4.5. Lessons learnt to aid a human rights-based approach to organ donation and/or transplantation and the implications of them for such a system	207
5.5. Conclusion	209
CHAPTER SIX: CONCLUSION	211
6.1. Introduction	211
6.2. Biomedical ethics and donation	211
6.3. Law and organ donation and transplantation	214
6.4. Religion, culture and organ donation and transplantation	217
6.4.1. Organ donation and Christianity	218
6.4.2. Organ donation and Islam	218
6.4.3. Organ donation and Judaism	219
6.4.4. Organ donation and Hinduism	221
6.4.5. Organ donation and Buddhism	221
6.4.6. Organ donation and African cultural beliefs	222
6.4.7. Moment of death in religion and culture	223
6.4.8. Incorporation of a presumed consent model for donation	224
6.5. A human rights-based approach to organ donation and/or transplantation	224
6.6. A system of mandated choice in a HRBA	229
6.7. Comparative analysis of donation systems	230
6.8. The need for new legislation – national and international standards	232
6.8.1. The World Health Organisation – international inclusion	233
6.9. Concluding remarks	234
BIBLIOGRAPHY	236

CHAPTER ONE

Introduction

1.1. Introduction

The transplantation of human tissue, cells and organs has saved and improved the lives of hundreds of thousands of human beings.¹ As medical technology advances, the demand for viable organs and tissues for transplantation increases.² Currently there is a shortage of much-needed organs for transplantation to individuals experiencing organ failure. South Africa is reported to have over 5 000 patients suffering from kidney failure, and more than 2 500 of these are awaiting viable kidneys for transplantation.³ In the United States of America (USA) it is documented that about 21 people, on average, die each day while waiting for an organ to become available.⁴ A new name is added to waiting lists for organs every 10 minutes or so in that country.⁵

The shortage of organs available for transplantation is partly the result of obstacles to organ donation created by different religious beliefs and cultural practices. Rodriguez mentions religion as a factor contributing to the lack of organ donors in the United States of America.⁶ She states that there is a belief among many people that their religion is against organ donations and also that there is a widespread distrust 'of the medical establishment in certain racial and cultural groups'.⁷ Williams discusses certain 'cultural taboos' which are so deep-seated that the idea of organ procurement is impossible to justify to those who adhere to them.⁸ He mentions, for instance, that there are certain 'Buddhist and cultural traditions that forbid the removal of organs because of a belief that

¹ World Health Organisation Guiding Principles on Human Cell, Tissue and Organ Transplantation – As endorsed by the sixty-third World Health Assembly in May 2010, in Resolution WHA63.22. - <http://www.who.int/transplantation/Guiding_PrinciplesTransplantation_WHA63.22en.pdf> (accessed on 23/05/2018).

² As above.

³ E Muller 'Organ donation and transplantation in South Africa – an update' (2013) 31 *Continuing Medical Education Journal* 221.

⁴ US Department of Health and Human Services- 'The need is real: data' <<http://www.organdonor.gov/about/data.html>> (accessed 09/02/2015).

⁵ As above.

⁶ S Rodriguez 'No means no, but silence means yes? The policy and constitutionality of the recent state proposals for opt-out organ donation laws' (2011) 7 *Florida International University Law Review* 175.

⁷ S Rodriguez (n 6 above) 176.

⁸ C Williams 'Combating the problems of human rights abuses and inadequate organ supply through presumed donative consent' (1994) 26 *Case W Res Journal of Int'l Law* 331.

the corpse must be buried intact'.⁹ Slabbert *et al* discuss a number of religious objections to organ donations, such as the Japanese religion 'Shinto', which they state contains a doctrine that is directly against organ transplantation.¹⁰ Contrary to the view expressed by Williams above, Slabbert and her co-authors remark that Buddhism has not taken a stand on the issue of organ donation.¹¹

Wong refers to culture, religion, and negative attitudes in Southeast Asian communities and mentions that these factors contribute to a lack of organs available for donation.¹² In addition to this, Bhengu explores the Zulu culture in South Africa in relation to organ transplantation.¹³ He describes the hesitation of Zulu people in that they believe they have no authority to donate their organs, or bodies, which are from the 'Creator', or from God.¹⁴

Considering the obstacles outlined above, the thesis investigates whether a human rights-based approach may succeed in overcoming some of the restrictions (or the perceptions of restrictions) imposed by culture and religion on the donation of organs for transplantation. Consequent upon such a human-rights-based approach, legislation that respects the religious and cultural beliefs of individuals may be adopted and this may potentially increase the donor pool. The study focuses on the shortage of organs as opposed to that of tissue, although in some contexts these terms (organs and tissue) are used interchangeably.

1.2. Background

As stated above, advances in medical technology have been accompanied by an increase in the need for organs for transplantation. The current situation is dire, and all nations face similar difficulties.

⁹ C Williams (n 8 above) 332.

¹⁰ M Slabbert, FD Mnyongani & N Goolam 'Law, religion and organ transplants' (2011) 76 (2) *Koers* 272.

¹¹ M Slabbert, FD Mnyongani & N Goolam (n 10 above) 271.

¹² LP Wong 'Factors limiting deceased donation: focus groups' perspectives from culturally diverse community' (2010) 42 *Transplantation Proceedings* 1439.

¹³ BR Bhengu 'Organ donation and transplantation within the Zulu culture' (2004) 27 *Curationis* 25.

¹⁴ As above.

1.2.1. A brief history of organ transplantation

The beginnings of organ transplantation go back to mythology.¹⁵ In Chinese mythology Pien Ch'iao, a physician, is said to have replaced the heart of Kung He with that of Ch'I Ying who had a strong spirit but a weak will.¹⁶ In the real world, Indians and Egyptians practised the transplantation of skin to replace noses which had been damaged by syphilis more than 5 000 years ago.¹⁷

More recently, the first kidney transplant was done in 1951 in Boston, USA, by Dr David Hume.¹⁸ The transplant involved the use of a kidney from a cadaver and was unsuccessful, although this did not hold Hume back from attempting ten further kidney transplants.¹⁹ The first successful kidney transplant occurred in 1954 when a living donor donated one of his kidneys to his twin brother who went on to live for a further eight years before dying from a heart attack.²⁰ These successes gave rise to further transplantations: 1967 saw the world's first open-heart surgery performed by Prof Christiaan Barnard at Groote Schuur Hospital in Cape Town, South Africa.²¹ Although the patient survived for only 18 days after the surgery, the transplant was seen as a triumph and the surgery was performed again two weeks later.²² That patient survived for 18 months.²³

Continued advances in the success of organ transplantations have led to a situation where the supply of organs no longer meets the demand for organs.

¹⁵ M Siemionow, A Rampazzo & BB Gharb 'Cultural differences in views on transplantation, including composite tissue allotransplantation' (2011) 66 *Annals of Plastic Surgery* 412.

¹⁶ As above.

¹⁷ JE Dunphy 'The story of organ transplantation' (1969) 21 *The Hastings Law Journal* 67.

¹⁸ M Slabbert, FD Mnyongani & N Goolam (n 10 above) 264.

¹⁹ As above.

²⁰ As above.

²¹ R Hoffenberg 'Christiaan Barnard: his first transplants and their impact on concepts of death' (2001) 323 *British Medical Journal* 1478.

²² As above.

²³ As above.

1.3. Definitions

1.3.1. Organ transplantation

The World Health Organisation (WHO) defines transplantation as the 'transfer (engraftment) of human cells, tissues or organs from a donor to a recipient with the aim of restoring function(s) in the body'.²⁴

An organ is defined by the WHO as a:

Differentiated and vital part of the human body, formed by different tissues, that maintains its structure, vascularisation and capacity to develop physiological functions with an important level of autonomy.²⁵

Organ transplantation can be performed for a single organ, but attempts have also been made to transfer multiple organs at a time.²⁶ This is referred to as 'multi-organ transplantation'.²⁷ It may, therefore, be concluded that transplantation, or in this case organ transplantation, is a form of medical treatment which involves the replacement of an unhealthy - or malfunctioning - organ with a healthy one in order to repair the body's functions.

The term 'graft' is synonymous with that of 'transplantation' as determined by the WHO.²⁸ A distinction may be made between three types of grafts: auto-grafts; allo-grafts; and xeno-grafts.²⁹ These three types are distinguished as follows:

1. Auto-grafts, which originate from the recipients themselves (e.g., in the case of skin or bone transplantation);
2. Allo-grafts, which are transplants between genetically non-identical humans; and
3. Xeno-grafts which are living animal organs or tissue transplanted into humans.³⁰

²⁴ World Health Organization – 'Global glossary of terms and definitions on donation and transplantation' <<http://www.who.int/transplantation/activities/GlobalGlossaryonDonationTransplantation.pdf>> (accessed on 30/07/2014).

²⁵ As above.

²⁶ As above.

²⁷ As above.

²⁸ World Health Organisation – 'Global glossary of terms and definitions on donation and transplantation', as above.

²⁹ S Schicktanz, C Wiesemann & S Wohlke (eds) *Teaching ethics in organ transplantation and tissue donation* (2010) 4.

³⁰ As above.

A distinction is also drawn between living organ transplantations and deceased organ transplantations and/or donations. Living organ transplantations involve the replacement of a malfunctioning organ of a recipient with that of a living donor rather than one received from a cadaver. This form of transplantation is possible for a partial liver, intestine, lung, pancreas, and for a single kidney.³¹

The donation of organs from a living person may also be categorised as 'living related donors' and 'living unrelated donors' or 'non-related donors'.³² When donations are made to direct blood relatives, they are referred to as 'living related donors'.³³ This form of donation is acknowledged worldwide, provided that there is appropriate consent and lack of coercion.³⁴ Living non-related donations or living unrelated donations refer to donations made to individuals who are not related to each other, such as friends, spouses, mere acquaintances or strangers. This form of donation became a possibility as early as 1983, when the first anti-rejection drug was developed.³⁵

The concept of death is also important for the purposes of organ transplantation. Death may be classed as either brain death or cardiac death. Donation after cardiac death, which has also been referred to as 'non-heart beating donation', is determined by the use of 'conventional cardio respiratory' criteria and the 'deceased' individuals are often kept 'alive' by artificial ventilation.³⁶

Donation after cardiac death can further be divided into two different categories, uncontrolled donation after cardiac death and controlled donation after cardiac death.³⁷ Four categories were coined in 1995 during the First International Workshop on Non-

³¹ K Lobas 'Living organ donations: how can society ethically increase the supply of organs' (2006) 30 *Seton Hall Legis. Journal* 484.

³² K Lobas (n 31 above) 487.

³³ As above.

³⁴ As above.

³⁵ As above.

³⁶ P Borry *et al* 'Donation after uncontrolled cardiac death (Udcd): A review of the debate from a European perspective' (2008) 36 *Journal of Law, Medicine and Ethics* 752.

³⁷ As above.

heart-beating Donation in Maastricht.³⁸ These categories are referred to as the ‘Maastricht categories’ and are as follows:³⁹

Category I	Dead on arrival
Category II	Failed resuscitation following cardiac arrest
Category III	Withdrawal of life support from a ventilator-dependent patient
Category IV	Unexpected cardiac arrest following brain death

In this table, categories I, II and IV are referred to as ‘uncontrolled’ whereas category III is ‘controlled’.⁴⁰ The situation, therefore, is ‘uncontrolled’ where the cardiopulmonary functions stop spontaneously, and is ‘controlled’ where the ‘donor is identified after a decision has been made to withdraw life-sustaining therapy’.⁴¹

1.3.2. Human rights law

Human rights are defined as ‘rights that we have as a people from birth until death’ and are defined broadly in various codes and documents.⁴² There are three systems of human rights protection: international (or universal); regional; and domestic (or municipal or national) human rights legal systems.⁴³

Various human rights instruments in the different human rights systems provide clarity on the listed rights and their protection. Such instruments include: the International Covenant on Civil and Political Rights (ICCPR); the International Covenant on Economic, Social and Cultural Rights (ICESCR); and the Universal Declaration of Human Rights (UDHR).⁴⁴

³⁸ P Borry *et al* (n 36 above) 753.

³⁹ As above.

⁴⁰ As above.

⁴¹ As above.

⁴² B Venter ‘A selection of constitutional perspectives on human kidney sales’ (2013) 16 *Potchefstroom Elec LJ* 355. Venter’s argument focuses on the sale of human kidneys which is not a focus for this research. However, reference is made to her use of definitions and analysis of certain constitutional rights in relation to donation and transplantation.

⁴³ As above.

⁴⁴ International Covenant on Civil and Political Rights - Adopted by the General Assembly of the United Nations on 16 December 1966 and came into force on 23 March 1976, U.N. Doc. A/6316; the International Covenant on Economic Social and Cultural Rights was adopted by the General Assembly of the United Nations on 16 December 1966 and came into force on 3 of January 1976,

These three instruments, as well as their protocols, form what has become known as the International Bill of Human Rights.

1.3.3. Regional human rights systems

There are three regional human rights systems.⁴⁵ These three systems are the Council of Europe, the Organisation of American States (OAS) and the African Union (AU).⁴⁶ In each of these systems there is a fundamental treaty in which substantive human rights norms have been set out.⁴⁷

The Council of Europe adopted the European Convention on Human Rights and Fundamental Freedoms (European Convention), incorporating 14 protocols and focusing mainly on civil and political rights.⁴⁸ The American Convention on Human Rights (American Convention) was adopted by the OAS and contains rights similar to those in the European Convention but also includes socio-economic rights.⁴⁹ The African Charter on Human and Peoples' Rights, adopted by the OAU (the predecessor to the AU), contains justiciable socio-economic and peoples' rights.⁵⁰ There is yet to be a binding regional human rights treaty established in the Asia-Pacific region.⁵¹ Promising developments for human rights in the form of the Association of Southeast Asian Nations (ASEAN) have not yet culminated in standard setting.⁵²

1.3.4. Ethics surrounding organ transplantation

McLean discusses the importance of a 'marriage between bioethics and human rights' as expressed by UNESCO's International Bioethics Committee in 2003, where it was stated that 'modern bioethics is indisputably founded on the pedestal of the values enshrined in

A/RES/2200A(XXI); the Universal Declaration of Human Rights 1948 was adopted by the United Nations General Assembly on 10 December 1948, U.N. Doc A/810.

⁴⁵ F Viljoen *International human rights law in Africa* (2007) 10.

⁴⁶ F Viljoen (n 45 above) 11.

⁴⁷ As above.

⁴⁸ As above.

⁴⁹ As above.

⁵⁰ As above.

⁵¹ F Viljoen (n 45 above) 16.

⁵² As above.

the Universal Declaration of Human Rights'.⁵³ She also refers to Baker who states the following:

A global bioethics that envisions principles as mechanisms for protecting human rights will ... inherit an internationally accepted ethical discourse, (a) rights discourse is the best means available for achieving the shared goal of both bioethics and human rights theory.⁵⁴

From this it can be seen that the link between ethics in medicine and human rights is envisioned. Organ transplantation raises universal ethical concerns which are important when considering a human rights-based approach to organ donation.

The four principles of biomedical ethics are: respect for autonomy; non-maleficence; beneficence; and justice. These principles are discussed briefly below and will be tackled in greater detail in the proceeding chapter.

Respect for autonomy

A person who is autonomous acts freely in terms of a 'self-chosen plan' with no interference.⁵⁵ This is opposed to a person with diminished autonomy who is either being controlled by another or who is incapable of 'deliberating or acting on the basis of his desires or plans'.⁵⁶ Autonomous action is said to involve 'normal choosers who (1) act intentionally, (2) with understanding, (3) without controlling influences that determine their action'.⁵⁷ Respect for autonomy is thus the acknowledgment of a person's right to 'hold views, to make choices, and to take actions based on their personal values and beliefs'.⁵⁸

Beneficence

The term beneficence indicates acts of 'mercy, kindness and charity', as well as 'altruism, love and humanity'.⁵⁹ Beauchamp and Childress list two types of beneficence, namely

⁵³ S McLean 'Human rights and bioethics' <<http://www.unesco.org/new/fileadmin/MULTIMEDIA/HQ/SHS/pdf/Bioethics-Human-Rights-McLean.pdf>> page 7 – (accessed on 12/05/2015).

⁵⁴ R Baker 'Bioethics and human rights: a historical perspective' (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 241 – 252; as referred to in S McLean (n 53 above) 8.

⁵⁵ T Beauchamp & J Childress *Principles of biomedical ethics* (2009) 99.

⁵⁶ As above.

⁵⁷ T Beauchamp & J Childress (n 55 above) 101.

⁵⁸ As above.

⁵⁹ T Beauchamp & J Childress (n 55 above) 197.

‘positive beneficence’ and ‘utility’.⁶⁰ Positive beneficence refers to agents being required to supply benefits to others, whereas utility refers to the balancing of the benefits, risks and costs in order to create the best possible results.⁶¹

Justice

Whenever an individual is due to receive benefits or burdens, standards of justice are required.⁶² An injustice would be seen to occur where there has been a ‘wrongful act or omission which would lead to individuals being denied protections or certain resources to which they are entitled by virtue of a right they possess’.⁶³

1.4. Problem statement

In order to combat the rising number of deaths owing to organ failure an increase in organs available for donation needs to be facilitated. Religion and culture contribute towards the reluctance of individuals to donate organs before and after death, as they consider their religious beliefs and cultural norms to be against donation. The thesis analyses the successes and failures experienced thus far in encouraging organ donation, despite the existence of cultural and religious obstacles. The analysis presents a starting point for formulating a human rights-based approach towards encouraging organ donations that overcomes these cultural and religious obstacles.

1.5. Research questions

As noted in the problem statement, in order to obtain an appreciation of how best to encourage organ donation, an in-depth analysis of the current successes and failures in light of the current cultural and religious obstacles needs to be performed. This would be the basis for devising a human rights-based approach. To this end, deriving accurate information is paramount and, as such, requires the correct questions to be asked.

⁶⁰ As above.

⁶¹ As above.

⁶² T Beauchamp & J Childress (n 55 above) 241.

⁶³ As above.

The following questions are interrogated in the thesis:

- 1.5.1 Which cultural practices and religious beliefs impede the donation of organs for transplantation?
 - 1.5.1.1 What is the role played by religion and culture in organ donation?
 - 1.5.1.2 How and why do these practices and beliefs impede donation?
 - 1.5.1.3 Which beliefs and practices support organ donation?
- 1.5.2 What would be the contents of a human rights-based approach to organ donation?
 - 1.5.2.1 How may the principles of human rights be incorporated into such a system to increase organ donation?
 - 1.5.2.2 How may an approach which strives towards the realisation of the human rights of individuals relative to organ transplantation be associated with the incentivisation of organ donation as well?
 - 1.5.2.3 What would the role of the duty-bearers towards the rights-holders be in this regard?
- 1.5.3 What would be the advantages or disadvantages of such a human rights-based approach?
- 1.5.4 Are universal, regional and national (municipal) human rights instruments able to provide a foundation from which to draft legislation which could increase the potential donor pool?
 - 1.5.4.1 What are the gaps in the current human rights system (universal, regional and municipal) in this regard?
 - 1.5.4.2 How can these gaps be remedied in such a way as to increase the potential donor pool?

1.5.5 What would be the nature of such legislation and how might it be used so that it promotes organ donation whilst respecting the cultural, religious and other human rights of individuals?

1.6. Research objectives

The research objectives of this thesis are:

1.6.1 To analyse the cultural practices and religious beliefs that hinder, as well as those which promote, the donation of organs for transplantation;

1.6.2 To arrive at a postulation of the contents of a human rights-based approach to organ donation;

1.6.3 To determine whether universal, regional and municipal human rights instruments are able to provide a foundation from which to draft legislation which could possibly increase on the potential donor pool; and

1.6.4 To determine the nature and scope of legislation which instils human rights values and to establish how it may be used to promote organ donation but still respect the cultural, religious and other human rights of individuals.

1.7. Research methodology

Desk-top research is the method used during the writing of this thesis. Scholarly articles, books, documents and reports are examined in order to arrive at a theoretical and practical understanding of organ transplantation and donation in the different religions and cultures worldwide.

In order to assist in answering the research questions posed in paragraph 1.5 above, a comparative study of selected countries in Asia, Africa, Europe and the Americas will be undertaken. These countries were selected using different criteria. One such country is selected based on their system of deceased organ donation as reflected in their legislation. Where possible, countries were chosen for the comparative study so that the two systems of deceased organ donation - opting-in and opting-out - were compared in a particular area. Selection was further made with reference to the presence of a diversity

of cultures and religions in a particular country or a lack thereof. The focus in the thesis is on South Africa.

In South East Asia, Malaysia and Singapore are compared as they are multi-ethnic, multi-religious and multi-cultural nations, with Malaysia comprising three main religions, *viz* Islam, Confucianism and Christianity; and Singapore comprising Buddhism, Taoism, Islam, Christianity and Hinduism.⁶⁴ In addition, Malaysia has adopted an opt-in system of organ donation whilst Singapore has adopted an opt-out system.

In Africa most countries either lack legislation regarding organ donation and transplantation or there is a lack of access to information in this regard. South Africa is analysed because the policies, legislation and information regarding organ donation and transplantation are easily accessible. South Africa has also been selected as it contains a vast plurality of cultures, as is seen by the fact that there are eleven official languages in the country.⁶⁵ South Africa is also home to a number of religions, including different denominations of Christianity, Judaism, Islam, Hinduism and Buddhism.⁶⁶ It, thus, has a multi-ethnic and multi-cultural population which are useful for this analysis. Reference is furthermore made to Nigerian policies and legislation surrounding organ transplantations as this information is readily available.

In Europe, Spain is analysed as that country is considered to have the highest organ donation rate worldwide.⁶⁷ Spain has adopted an opting-out system as opposed to the UK which has an opting-in system. In the Americas, the USA serves as a reference point.

Please note that throughout the thesis, references to the masculine pronoun include the feminine pronoun.

⁶⁴ R Guruswamy 'Religions in Singapore' <http://worksingapore.com/articles/live_7.php> (accessed on 20/11/2014).

⁶⁵ P Coertzen 'Constitution, charter and religions in South Africa' (2014) 14 *African Human Rights Law Journal* 127.

⁶⁶ As above.

⁶⁷ S Rodriguez (n 6 above) 163.

1.8. Potential contribution of the study

It is envisaged that the research study may:

- contribute towards creating an avenue for the protection of human rights in a cultural and religious setting in the context of organ donation;
- contribute towards encouraging legal reform to assist in increasing the rates of organ donation, while affirming the human rights of organ recipients and organ donors;
- suggest a system which could potentially increase the donor pool which may, in turn, assist in discouraging the illegal trade in organs; and
- encourage further research to be undertaken in the area.

1.9. Literature review

1.9.1. Religion, culture and organ donations

Various authors have analysed the role that culture and religion play in the willingness of individuals to participate in the organ donation process, whether as living or deceased donors. Wong points out that, in Southeast Asian communities, culture, religion and negative attitudes all contribute towards the problems associated with a lack of available organs for organ donation and transplantation.⁶⁸ She suggests interventions which are culturally-based in order to enhance awareness and amend the misconceptions involved, as well as encouraging the involvement of religious leaders and the community in order to help curb factors limiting organ donations.⁶⁹

Slabbert *et al* remark that the majority of the world's religions do support the saving and promotion of life and are, thus, inclined to accept altruistic organ donations.⁷⁰ They note, however, that, despite this fact, the shortage of organs available for transplantation is

⁶⁸ LP Wong (n 12 above) 1439.

⁶⁹ LP Wong (n 12 above) 1444.

⁷⁰ M Slabbert, FD Mnyongani & N Goolam (n 10 above) 263.

enormous worldwide.⁷¹ Their opinion with regard to a solution for this shortage involves the implementation of a financial incentive as reward for donors.

Contradictions in the interpretation of religion are noted, as is pointed out by Oliver.⁷² Oliver indicates, for example, that in Islam it is believed that violating the human body is banned, whether that body is alive or dead, but it is also believed that saving a life is of high importance in the Qur'an.⁷³ Oliver makes mention of the need for a greater awareness of religious concerns by the teams involved in the transplantation process, and he states that merely supplying information may not be sufficient in this regard.⁷⁴ He suggests that having a multicultural transplant team may be helpful, as many western countries are increasingly becoming multicultural.⁷⁵

Price notes a case from the Federal Court of the United States where it was found that the majority of religions in the USA believed that corpses should be 'treated with honor and respect'.⁷⁶ Price further points out that the US Task Force on Organ Transplantation commented on how 'No major religious group in the United States opposes organ donation as a matter of formal doctrine', and how this applies across most Western societies.⁷⁷ He further mentions the North American Indians, Christian Science and Aboriginal religions as religions which are commonly opposed to the concept of organ transplantation, with the Jehovah's witnesses accepting transplantation but without a blood transfusion.⁷⁸ Additionally, in some countries, Muslim scholars have agreed to permit organ transplantation, and successful programmes for cadaveric organ transplantations exist in Saudi Arabia and Singapore.⁷⁹ Price states that, in most

⁷¹ As above.

⁷² M Oliver *et al* 'Organ donation, transplantation and religion' (2010) 26 *Nephrology Dialysis Transplantation* 437.

⁷³ M Oliver *et al* (n 70 above) 438.

⁷⁴ M Oliver *et al* (n 70 above) 442.

⁷⁵ As above.

⁷⁶ *Kohn v United States F. Supp.* 568 at 572 – 3; as referred to in D Price *Legal and ethical aspects of organ transplantation* (2000) 35.

⁷⁷ D Price (n 74 above) 35.

⁷⁸ D Price (n 74 above) 36.

⁷⁹ As above.

instances, 'religious constraints are more imagined than real'.⁸⁰ He also adds the importance of the 'sacredness of human remains' to the deceased's relatives.⁸¹

Irving *et al* analysed 18 studies regarding the barriers preventing organ donation across the UK, Canada, USA, South Africa, Malta and Australia.⁸² Eight main themes were discovered, and these included religious and cultural beliefs.⁸³ It was discovered, in the case of religion, that the participants often had different beliefs relating to their understanding of the religious edicts.⁸⁴ In terms of culture, the authors sight a number of beliefs, such as the need for ancestral approval, as well as superstition surrounding the issue of becoming an organ donor.⁸⁵ They advocate interventions focused on community engagement to 'foster trust and provide information represent promising opportunities of promoting organ donation in the future'.⁸⁶

Additionally, the patriarchal nature of Arab and African cultures may also contribute to the shortage in organs available for transplantation. In this regard, Bhengu remarks that a man of Arab decent may not donate an organ to an adolescent female, even his own daughter, in his clan.⁸⁷ Furthermore, it is believed in the Zulu culture that there is a bond between the living and the dead (who are the collective of 'ancestors'), and Zulus fear breaking this bond as it could anger their ancestors.⁸⁸ Bhengu suggests certain cultural practices which may assist in enlightening ancestors about organ donation, the inclusion of the extended family in discussions surrounding donation, and other incentives such as the inclusion of religious leaders and traditional healers.⁸⁹ One may also argue that the concept of ubuntu, which is discussed in great detail in chapter 3 below, can provide answers toward the reluctance to donate in the African cultural setting due to its communal nature.

⁸⁰ As above.

⁸¹ As above.

⁸² M Irving *et al* 'Factors that influence the decision to be an organ donor: a systematic review of the qualitative research' (2012) 27 *Nephrology Dialysis Transplantation* 2526.

⁸³ M Irving *et al* (n 80 above) 2528.

⁸⁴ As above.

⁸⁵ As above.

⁸⁶ As above.

⁸⁷ BR Bhengu (n 13 above) 25.

⁸⁸ As above.

⁸⁹ BR Bhengu (n 13 above) 30 – 31.

In South East Asia, the Human Transplant Act was enacted in Singapore to ‘make provision for the removal of organs for transplantation’ amongst other issues and implementing a presumed consent system for deceased organ transplantation.⁹⁰ The Act explicitly excludes Muslims, in Chapter 5(2)(f), from its operation.⁹¹ Daar and Marshall state that as a result of this Muslims rarely receive an organ for transplantation.⁹²

Siemionow stresses the importance of having an understanding of religious and cultural backgrounds regarding the views on transplantation of different ethnic groups in multicultural countries in order to be able to approach the donor families in the best manner possible.⁹³ She also highlights the lack of certainty regarding the religious stance on organ donation among different religious scholars and individuals.⁹⁴ In addition, she cites cultural superstitions and traditional spiritual and cultural beliefs as contributing to low organ donation rates.⁹⁵

The thesis, therefore, will endeavour to understand in greater depth the religious and cultural factors which dissuade potential organ donors, and it will look into the possibility of incorporating a human rights-based approach, resulting in legislation which may not only respect the cultural and religious beliefs of individuals, but also ultimately assist in increasing the donor pool.

1.9.2. Living and deceased organ donations

Living donors

Advances in technology dealing with organ transplantations have led to an increase in living organ donations.⁹⁶ Legal and ethical considerations need to be balanced

⁹⁰ Human Organ Transplant (Amendment) Act 2004 – Cap.131A (Singapore).

⁹¹ As above.

⁹² AS Daar & P Marshall ‘Culture and psychology in organ transplantation’ (1998) 19 *World Health Forum* 125. It should be noted that the position has changed as of August 1st 2008 and Muslims are now included in the Act, as accepted by the Islamic Religious Council of Singapore. For this reference see ‘Office of the Mufti’ < <http://www.muis.gov.sg/cms/oomweb/fatwa.aspx?id=14698>>; as well as ‘Singapore Muslims to be included in Human Organ Transplant Act (HOTA)’ < <http://www.hospitals.sg/story/singapore-muslims-be-included-human-organ-transplant-act-hota>> both accessed on 09/02/2015.

⁹³ M Siemionow *et al* (n 15 above) 410.

⁹⁴ M Siemionow *et al* (n 15 above) 411 – 412.

⁹⁵ As above.

⁹⁶ K Lobas (n 31 above) 483.

appropriately in order to facilitate an increase of living organ donations.⁹⁷ Lobas cites three ethical concerns in this regard, namely, 'physical and emotional risks to the donor and recipient, the possible lack of informed consent from the donor, and physicians' concerns about violating the Hippocratic Oath – to first do no harm'.⁹⁸

She further discusses steps which may be taken to increase living organ donations ethically, including improvements being made to the current system in the USA to 'ensure a system of voluntary donations that benefit the donor, recipient, and society as a whole'.⁹⁹ She takes note of the inclusion of the United Network for Organ Sharing (UNOS) in this regard. This is 'a private, non-profit organization that manages the nation's organ transplant system under contract with the federal government'.¹⁰⁰ This would include an increase in the ability of UNOS to have control over living organ donations, which would be regulated by the Department of Health and Human Services, through UNOS, in order to track the safety of transplants.¹⁰¹ She further states that a law should be drafted to provide UNOS with such control, and UNOS would then decide which transplantations are legal.¹⁰² She states that the organisation should then permit all ethically-sound transplantations to occur, whether they are traditional or non-traditional schemes such as paired organ exchanges and internet solicitation.¹⁰³ Incentivising donors financially is to be seen as a last resort.¹⁰⁴

Truog distinguishes between three categories of donation by a living person.¹⁰⁵ These categories are: non-directed donation, in which an organ is donated generally to be received by a patient at the top of a waiting list; directed donation to a friend, relative or loved one; and directed donation to a stranger, in which a person chooses to donate their organ to 'a specific person with whom they have no prior emotional connection'.¹⁰⁶ He

⁹⁷ K Lobas (n 31 above) 477.

⁹⁸ K Lobas (n 31 above) 488.

⁹⁹ K Lobas (n 31 above) 505.

¹⁰⁰ UNOS – United Network for Organ Sharing <www.unos.org/about/index.php> (accessed on 12/05.2015).

¹⁰¹ K Lobas (n 31 above) 506.

¹⁰² As above.

¹⁰³ As above.

¹⁰⁴ As above.

¹⁰⁵ R Truog 'The ethics of donation by living donors' (2005) 353 *New England Journal of Medicine* 444.

¹⁰⁶ As above.

discusses the ethical concerns relating to each category, including coercion, informed consent, issues relating to competence, as well as recipients being chosen on the basis of their ethnic group, religion or race.¹⁰⁷

Truog further mentions the solicitation of organs and refers to a website - www.matchingdonors.com.¹⁰⁸ He states that this website has identified a need which, 'if not met by a service that can address the ethical challenges', will be filled by other enterprises.¹⁰⁹ He further points out the need for greater regulation and higher standards of responsibility for solicitation than those already in place.¹¹⁰ In addition to this, he is also of the opinion that UNOS should be given greater accountability in the process of finding organ donors such as:

standardizing the process for evaluating potential donors, ensuring that independent advocates are assigned to help donors make an informed choice, developing mechanisms to deal with potential injury or death to the donor, setting standards for both directed and non-directed donation, and prohibiting transplantation when the chance of success is insufficient to justify the risks.¹¹¹

Deceased donors

With reference to deceased organ donation, and in terms of the Maastricht classification mentioned above, the retrieval of organs is more difficult in uncontrolled situations. Pace is of the opinion that, in these situations, in order to prevent warm ischemia which leaves the organs less viable for donation from occurring, there is a time-frame of about 45 minutes from the time of death during which all the preparations for retrieval have to be completed.¹¹² These preparations include:

Addressing issues of consent, counselling relatives, preparation of the donor (tissue typing, viral status), mobilizing a surgical team, and finally cold perfusion of the organs. The anaesthetist on the arrest team in the ward, on stand-by in the accident and

¹⁰⁷ R Truog (n 103 above) 444 – 445.

¹⁰⁸ R Truog (n 103 above) 445.

¹⁰⁹ As above.

¹¹⁰ As above.

¹¹¹ As above.

¹¹² N Pace 'Transplantation: Ethical and legal considerations' (2006) 7 *Anaesthesia and Intensive Care Medicine* 185.

emergency department or, more significantly, at an unexpected arrest in an ICU patient could be involved in the declaration of death and notification of the transplant team.¹¹³

This would mean that talking to the families and relatives of the potential donor would be rushed and may appear rude and disrespectful towards the dignity of both the patient and his family. It may also cause the families to be unwilling to allow their loved ones to become donors. In such a situation, an option may be to allow for the preservation of organs whilst family consent is being obtained. Bonnie *et al* consider this option to be ethically sound as family choice is also being preserved in this instance.¹¹⁴

1.9.2.1. Opting-in versus opting-out

A further issue to be considered is the system by which states have chosen to procure organs from deceased persons, either by an opting-in or opting-out system. There are arguments made both in favour of and against both systems. Pace is of the opinion that an opting-out system is essentially coercive because 'silence is regarded as an agreement to do something' and, thus, no valid form of consent is obtained.¹¹⁵ Slabbert also mentions, as a problem of the presumed consent system, that the state takes possession of a person's 'property' without consent, and this could undermine the concept of personal autonomy.¹¹⁶ Bhenghu refers briefly to the presumed consent system as possibly leading to a violation of self-determination, although he does suggest that it may be feasible in a community that is well-informed.¹¹⁷

Kelly, on the other hand, is in favour of a system of presumed consent (opting-out).¹¹⁸ She discusses the necessity for the international community to formulate a binding instrument which would not only criminalise organ trafficking, but also urge domestic legislation to tackle the shortage of organs.¹¹⁹

¹¹³ As above.

¹¹⁴ RJ Bonnie, S Wright & KK Dineen 'Legal authority to preserve organs in cases of uncontrolled cardiac death: Preserving family choice' (2008) 36 *Journal of Law, Medicine and Ethics* 741.

¹¹⁵ N Pace (n 110 above) 188.

¹¹⁶ M Slabbert, FD Mnyongani & N Goolam (n 10 above) 266.

¹¹⁷ BR Bhenghu (n 13 above) 25.

¹¹⁸ E Kelly 'International organ trafficking crisis: solutions addressing the heart of the matter' (2013) 54 *Boston College International & Comparative Law Review* 1317.

¹¹⁹ As above.

Kelly discusses the system of procurement in the USA, which is that of an express consent system for donations, and she explains how economists have postulated that this scheme weakens the transplantation system.¹²⁰ Regarding the other form of procurement, she distinguishes between presumed consent and mandated choice.¹²¹ The presumed consent system has already been defined above. Mandated choice refers to an affirmative indication of one's donation preference through methods such as renewing of a driver's licence or when one files one's tax returns.¹²² A distinction is also made between 'pure' presumed consent and 'soft' presumed consent, where a 'soft' system is more flexible in that the core principles of presumed consent are maintained but a more flexible approach also incorporated, for instance, objections from family members are taken into account.¹²³

Kelly suggests overall that such a proposed instrument should 'require countries to use other means of incentivising donation based in their unique cultural and religious priorities'.¹²⁴ She proposes that such an instrument will oblige countries to formulate legislative frameworks which incorporate soft presumed consent or mandated consent systems.¹²⁵

1.9.2.2. Definition of death

It is important to be able to determine the exact moment in time a person has died for the purposes of organ transplantation. This discussion is also pertinent because of certain time factors found in religion following the death of an individual (discussed in more detail in chapter 3 below). Veatch makes an important distinction between the criteria for death and the concept of death.¹²⁶ In terms of the criteria for death, he states the following;

¹²⁰ E Kelly (n 116 above) 1326.

¹²¹ E Kelly (n 116 above) 1327.

¹²² As above.

¹²³ As above.

¹²⁴ E Kelly (n 116 above) 1344.

¹²⁵ As above.

¹²⁶ R Veatch *Transplantation ethics* (2000) 60.

The tests or procedures or criteria for determining that critical bodily structures or functions have been lost must be established by those with scientific skills in biology or medicine - that is, those with the appropriate knowledge and skills.¹²⁷

He further states that the question of criteria for death is not purely scientific, and that it is essentially a question of public policy.¹²⁸ In determining the length of time which must pass before the pronouncement of death, there are different sets of criteria used which propose different lengths of time.¹²⁹ The moral risks of falsely considering the brain to be dead and/or still alive must be assessed in decisions made about the correct length of time.¹³⁰ Veatch is of the opinion that neurological science cannot advise one on how to 'trade off' these two types of errors, and that it is essentially a policy or moral issue.¹³¹

This contrasts with the concepts or standards of death. Veatch refers to the concepts of death as being the test to establish when the 'death related behaviour' can be said to have been attained.¹³² In this regard, the salient question would be when the organism as a whole can be considered to be dead.¹³³ For instance, there are those who believe it to be dead once there has been 'irreversible cessation of spontaneous respiratory and circulatory functions', whilst others imagine it to be once there is 'irreversible loss of all spontaneous brain functions'.¹³⁴ According to Veatch, this is also a matter of public policy and not one which can be determined scientifically.¹³⁵

As has been discussed above, death has been defined in one of two ways or both, namely, circulatory death and brain death. Different nations have incorporated different definitions; for instance, South African legislation defines death as 'brain death'.¹³⁶

Kerridge *et al* discuss the concept of death with regards to Australian legislation which contains two possible definitions which are the 'irreversible cessation of all brain

¹²⁷ R Veatch (n 124 above) 61.

¹²⁸ As above.

¹²⁹ As above.

¹³⁰ As above.

¹³¹ As above.

¹³² R Veatch (n 124 above) 62.

¹³³ As above.

¹³⁴ As above.

¹³⁵ As above.

¹³⁶ National Health Act 61 of 2003.

functions, or irreversible cessation of blood circulation'.¹³⁷ They discuss the difference between the legislation in place and medical practice.¹³⁸

Important for this research, however, they also mention the attitude of a community towards brain death.¹³⁹ According to a study they refer to, 20% of the families of patients who have been declared brain dead were hesitant to believe that the patient was, in fact, dead, even after the death has been explained to them.¹⁴⁰ About 66% could accept that the patient was dead; they felt emotionally, however, that the patient was still alive.¹⁴¹ In addition to this, the authors state that, in order for the public not to be disillusioned by the concept of brain death, the definition has to be in keeping with the public's perceptions.¹⁴² Another problem cited is that many people tend to have the belief that if they sign on as organ donors, doctors may hasten their death or procure organs before they are really dead.¹⁴³ Kerridge *et al* state that death and dying are unique in that these concepts are 'owned by all religions, communities and individuals' and so any changes to the legislation and practice relating to death and donation must be 'fully owned and supported by the broader community'.¹⁴⁴

Lombard addresses the issue of defining death from in an Irish context where there is no current legislation in place providing such a definition.¹⁴⁵ He states that a definition of death which is based on brain function is debated amongst the religious groups in Ireland.¹⁴⁶ For instance, conservative Catholics, Orthodox Jews, and perhaps even fundamentalist Christians are opposed to the definition of death being based on brain function, yet the Roman Catholic Church and Protestant Church are not opposed to it.¹⁴⁷ He proposes that the religions which need to be taken into account in the formulation of a definition are the Roman Catholics, Presbyterian, Protestant and Jewish faiths as these

¹³⁷ IH Kerridge *et al* 'Death, dying and donation: organ transplantation and the diagnosis of Death' (2002) 28 *Journal of Medical Ethics* 91.

¹³⁸ IH Kerridge *et al* (n 135 above) 92.

¹³⁹ IH Kerridge *et al* (n 135 above) 90.

¹⁴⁰ As above.

¹⁴¹ As above.

¹⁴² IH Kerridge *et al* (n 135 above) 91.

¹⁴³ As above.

¹⁴⁴ IH Kerridge *et al* (n 135 above) 93.

¹⁴⁵ J Lombard 'The definition of death' (2012) 63 *Hibernian Law Journal* 63.

¹⁴⁶ J Lombard (n 143 above) 81.

¹⁴⁷ J Lombard (n 143 above) 81 – 82.

are prevalent in Ireland.¹⁴⁸ This strategy may be adopted in other countries when determining a description of death.

1.9.3. Legislation to be reviewed

1.9.3.1. South Africa

The National Health Act of 2004 ('NHA') deals with the legislative aspects surrounding organ donation and/or transplantation.¹⁴⁹ The NHA defines death as 'brain death' and stipulations regarding organ donations are also covered in the Act. South Africa follows a system of opting-in and thus relies solely on altruistic organ donations.¹⁵⁰ A person may indicate his wish to donate either by either informing his next-of-kin, or by signing a donor card to be kept in a wallet.¹⁵¹ Alternatively, a person may also indicate this desire in a will.¹⁵²

1.9.3.2. Spain

As mentioned above, Spain is considered to have the highest number of organ donations worldwide. It is, thus, pertinent to conduct an analysis of the Spanish model in determining possibilities for the increase of organ donations in other nations where this problem is dire. Legislation governing the transplantation of organs was approved by the Spanish Parliament in 1979 and introduced a presumed consent system for organ donation.¹⁵³

Brain death is defined as 'the total and irreversible loss of brain function', and death must be certified by three doctors (one of whom is a neurosurgeon or neurologist) unrelated to the transplant team.¹⁵⁴

In 1989, the *Organizacion Nacional de Transplantes* (ONT) was formed as an organisation to be attached to the Spanish Department of Health.¹⁵⁵ Spain endorses a transplant coordination network which operates on three levels: 'national, regional and hospital co-

¹⁴⁸ J Lombard (n 143 above) 82.

¹⁴⁹ The National Health Act 61 of 2004.

¹⁵⁰ M Slabbert, FD Mnyongani & N Goolam (n 10 above) 263.

¹⁵¹ M Slabbert, FD Mnyongani & N Goolam (n 10 above) 265.

¹⁵² See the National Health Act, sec 62.

¹⁵³ B Miranda *et al* 'Organ donation in Spain' (1999) 14 *Nephrology Dialysis Transplantation* 15.

¹⁵⁴ As above.

¹⁵⁵ As above.

ordinators'.¹⁵⁶ The bulk of the transplant coordinators are physicians, and there is one in every hospital; they are completely separate from the transplant team.¹⁵⁷ This ensures that their main role is organ procurement.¹⁵⁸ These coordinators are replaced every three or four years in order to prevent the 'burn-out syndrome' from lowering donation rates.¹⁵⁹ It may also be worth noting that the Constitution of Spain recognises basic human rights in article 2 which highlights the emphasis placed on these rights and, thus, the importance of their implementation in different avenues including transplantation.¹⁶⁰

1.9.3.3. Malaysia

The norms which apply to organ donation in Malaysia are codified in that country's Human Tissue Act.¹⁶¹ The Act endorses an opting-in system for organ donation in section 2(1). Section 2(1) reads as follows:

If any person, either in writing at any time or orally in the presence of two or more witnesses during his last illness, has expressed a request that his body or any specified part of his body be used after his death for therapeutic purposes, or for purposes of medical education or research, the person lawfully in possession of his body after his death may, unless he has reason to believe that the request was subsequently withdrawn, authorize the removal from the body of any part or, as the case may be, the specified part, for use in accordance with the request.

This means that, in order for cadaveric donations to occur, the individual (donor) must have expressly noted his wishes prior to his death.

¹⁵⁶ R Matesanz 'A decade of continuous improvement in cadaveric organ donation: the Spanish model' (2001) 5 *Nefrologia* 59.

¹⁵⁷ As above.

¹⁵⁸ As above.

¹⁵⁹ R Matesanz (n 154 above) 60. Matesanz describes the burn-out syndrome as occurring because it is difficult for coordinators to have to continually deal with grieving families. In Madrid there was a decrease in renal transplants during the years 1988/89, and once the ONT introduced new transplant coordinators, there was an increase in transplantations by 50%.

¹⁶⁰ Constitution of Spain, 1978.

¹⁶¹ Human Tissue Act, 1974.

1.9.3.4. Singapore

Singapore's Constitution is the supreme law of the Republic.¹⁶² Singapore has an opting-out system of organ donation as provided for in the relevant legislation.¹⁶³ Section 5(1) of the Human Organ Transplant Act provides for the removal of an organ of a deceased individual with the authorisation of a designated officer of a hospital. Section 5(2) endorses a presumed consent-system, stating that:

No authority shall be given under subsection (1) for the removal of the organ from the body of any deceased person –

- (a) Who has during his lifetime registered his objection with the Director to the removal of the organ from his body after his death;¹⁶⁴

1.9.3.5. Other reference points

Various states in the USA as well as the UK will be used as points of reference for the study.

1.9.3.6. International law

When evaluating the possibility of a human rights-based approach being adopted into international law, one may start by delving into the sources of international law which have been codified in the Statute of the International Court of Justice (ICJ). Article 38(1) of the ICJ Statute lists treaties, international customs and general principles of law as primary sources of international law, and judicial decisions and the teachings of the most highly qualified publicists of the various nations as subsidiary means for the determination of rules of law.¹⁶⁵ Despite the fact that these sources were codified as factors to look into when settling international disputes, they may still be used when determining how to discover or introduce new norms which would be binding on the international community.

The Vienna Convention on the Law of Treaties defines a treaty as follows:

¹⁶² Constitution of the Republic of Singapore, 1965; secs 3 – 4.

¹⁶³ Human Organ Transplant Act – Cap 131A.

¹⁶⁴ Director in this section refers to the Director of Medical Services as stated in sec 2.

¹⁶⁵ Sec 38(1) of the Statute of the International Court of Justice.

'Treaty' means an international agreement concluded between States in written form and governed by international law, whether embodied in a single instrument or two or more related instruments and whatever its particular designation.¹⁶⁶

Once entered into, the parties to a treaty have 'legally binding obligations in international law'.¹⁶⁷ The notion of creating a regional multilateral treaty which endorses a human rights-based approach towards organ donation will be investigated in the thesis. In this regard, an investigation will be conducted into the possibility of such a rights-based approach being codified in a convention, or multilateral treaty, to which nations may become signatory states and state parties. The possibility of the development of such as a protocol to the human rights systems will be considered in the research.

1.10. Chapter Outline

1.10.1. Chapter One

The chapter introduces the research study to be conducted. It provides definitions of the relevant phrases and terms to be used during the investigation and gives direction regarding the resolution of the pertinent research questions, the problem statement and how the investigation will be conducted.

1.10.2. Chapter Two

The second chapter discusses the law and ethics relative to organ donations and transplantations. The chapter describes the different (ethical and law-related) themes which will be touched upon throughout the research. An examination of the ethics surrounding the two types of organ transplantations/donations is embarked upon and the different procurement systems for deceased organ transplantations are evaluated. With regards to living organ transplantations, issues surrounding informed consent are examined in-depth, as well as the physical and emotional risks to the donor and recipient,

¹⁶⁶ Art 1(a) of the Vienna Convention on the law of treaties - concluded at Vienna on 23 May 1969.

¹⁶⁷ M Dixon *Textbook on international law* (2013) 56.

the physician's concerns about violating the Hippocratic oath (to do no harm), as well as the biomedical ethics surrounding transplantations.

1.10.3. Chapter Three

The third chapter analyses the specific religious and cultural beliefs which are supportive of organ donation, as well as those which are against it. Clarity regarding the uncertainties regarding the different religious stances will be searched for. Deceased and living organ donations are discussed in religious and cultural contexts, and the question is posed as to whether and how these beliefs could possibly be incorporated into the different systems of procurement.

1.10.4. Chapter Four

This chapter evaluates the development or formulation of a human rights-based approach towards organ donations and transplantations. There is an assessment of the principles of human rights as they may possibly relate to transplantations and donations. The chapter further determines how such an approach, which strives towards the realisation of the individual's human, religious and cultural rights in the context of organ donations, may be associated with incentivising organ donations.

In addition to this, the possible roles and duties of the state to its citizens are analysed should such an approach be incorporated into the legal system of a particular nation.

1.10.5. Chapter Five

This chapter is a comparative evaluation of different procurement and allocation systems from other countries, such as Singapore, Spain, Malaysia and the USA. The chapter strives to give an overview of the elements of these systems and determine which of these features would be relevant to a HRBA for organ donation. This follows an analysis of the current procurement and allocation system in South Africa.

1.10.6. Chapter Six

This Chapter conclude the study and explores the need for new legislation as well as assistance from international organisations.

In chapter 2 below we turn to an examination of the law and ethics surrounding organ donation and transplantation in South Africa.

CHAPTER TWO

Legal and ethical principles surrounding organ donation and/or transplantations in South Africa

2.1. Introduction

Medical law is often seen as a separate field of law which cuts across other areas of law. De Vries makes mention of this by quoting Pearmain as follows:

Medical law is an area of law, medical law does not respect traditional compartments with which lawyers have become familiar, such as torts, contracts, criminal law, family law and public law. Instead, medical law cuts across these subjects and today must be regarded as a subject in its own right. We maintain that it is a discrete area concerned with the law governing the interactions between doctors and patients and the organisation of health care.¹

This quotation implies that medical law is mainly concerned with doctor-patient relationships; however, organ transplantation and donation should be seen as going beyond this. De Vries states that, as it is correct to assert that medical law is concerned with interactions between patients and their doctors, the scope for stem cell research should be widened as stem cell research should be seen 'in a wider scope of Health Law, of which Medical Law forms a part'.² The same may be envisioned for organ transplantation and donation, and for this discussion, particularly the inclusion of aspects of human rights law. To begin with however, it is important to have an ethical discussion as medical law and ethics overlap. The discussion below will also hint toward the links between medical law, human rights law and organ donation and/or transplantation.

The bioethical debate surrounding organ donation and transplantations is a fairly recent development, dating back only to 1954, the year of the first successful kidney transplant.³

¹ L De Vries 'The ethics in genetics - the legitimacy and application of stem cell research' Unpublished LLM thesis, University of Pretoria, 2005 58. Also see D Pearmain 'A critical analysis of the law of health service delivery in South Africa' Unpublished LLD thesis, University of Pretoria, 2004 xix.

² De Vries (n 1 above) 59. Health Law is a wide field which includes aspects of law of contract, criminal law, law of delict and human rights law.

³ R Veatch *Transplantation ethics* (2000) 1.

Prinsen states that '[v]alues are not objectively determined and cannot be scientifically defined'.⁴ This is due to the subjective nature of values – ethical dilemmas are only created in relation to human beings.⁵ In recent years, values have adapted to become fundamental ethical principles – ‘the basis of ethical discussions regarding medicine...’.⁶ Previously, the only forms of direction available to medical practitioners were ethical guidelines and principles.⁷ Reliance was placed mainly on the guidelines set out by the Health Professions Council of South Africa (HPCSA), international codes, declarations and common ethical principles, any deviation from which led not only to ethical but also legal accountability.⁸ This could sometimes result in conviction for ‘unprofessional and unethical conduct’.⁹

This shows that bioethics can influence the law, particularly medical law. Foster believes that a nuanced bioethical proposition would be useless if it cannot be made ‘palpable on the wards’.¹⁰ He suggests that bioethics can ‘transform the *zeitgeist*, and the *zeitgeist* itself can transform the healthcare professionals who have such awesome power over their patients’.¹¹ The *zeitgeist* would then eventually be translated into ‘domestic and international declarations, into regulatory codes, authoritative and persuasive arguments, and hence [...] into the substantive law’.¹² This is surely the case as seen with human rights evolving from the natural law to now finding protection in international and national declarations, conventions and legislation worldwide.

Indeed, there is currently legislation that has been promulgated which gives statutory recognition to most of the ethical guidelines which were relied upon by medical practitioners before legislation on the matter was promulgated.¹³ This includes the

⁴ L Prinsen ‘An analysis of the proposed regulatory framework for the procurement and distribution of stem cells’ Unpublished LLM thesis, University of Pretoria, 2010 131.

⁵ As above. Prinsen states further that an ethical dilemma arises when two or more inherently good actions conflict with each other. ‘An action might benefit one person but cause harm to another’.

⁶ As above.

⁷ H Oosthuizen & T Verschoor ‘Ethical principles becoming statutory requirements’ (2008) 50 *SA Fam Pract* 36.

⁸ As above.

⁹ As above.

¹⁰ C Foster *Human dignity in bioethics and law* (2011) 6.

¹¹ As above.

¹² As above.

¹³ H Oosthuizen & T Verschoor (n 7 above) 36.

Constitution of the Republic of South Africa, 1996 (the Constitution) and the National Health Act 61 of 2003 (NHA). The connection between the ethical guidelines and legislative enactments is, therefore, important, particularly with regard to organ donation and the current debate. It is, thus, clear that one issue cannot be divorced from the other.

This chapter will explore, and be an explanatory segment of, the law and ethical principles surrounding organ donation and the problems associated with it. The chapter is the foundation necessary for the argument for a human rights-based approach which is to be tackled in subsequent chapters. The focus is on the principles of biomedical ethics devised by Beauchamp and Childress.¹⁴ The legal aspects surrounding organ donation are to be discussed separately.

2.2.Principles of biomedical ethics

Beauchamp and Childress devised the concept of ‘principlism’ in medical ethics. They focus on four main pillars: autonomy; beneficence; non-maleficence; and justice.¹⁵ In terms of this formulation, their aim was to devise a method of ‘moral reasoning’ whereby all of the ‘substantive problems of medical ethics (and of ethics more generally) can be properly analysed, and cogent philosophical solutions can be found’.¹⁶ The authors do not, in any way, attempt to place a hierarchy of any sort regarding these principles,¹⁷ so as to imply that the four principles work interdependently as opposed to one prevailing over another.

These principles may be used to balance the different ethical dilemmas associated with organ transplantation and donation for both living and deceased organ donation and/or transplantations. Each of these principles is discussed below.

¹⁴ T Beauchamp & J Childress *Principles of biomedical ethics* 99.

¹⁵ As above. Also see M Lee ‘The problem of ‘thick in status, thin in content’ in Beauchamp and Childress’ principlism’ (2010) 36 *J Med Ethics* 525.

¹⁶ As above.

¹⁷ T Beauchamp & J Childress (n 14 above) 99.

2.2.1. Respect for autonomy

In medical ethics, Beauchamp and Childress' analysis of the principle of respect for autonomy is dominant, and thus relevant to this discussion. The following analysis of this principle draws more from a general account of the concept of autonomy, as opposed to a more particular conception. This concept of autonomy will encapsulate what it means to be an autonomous person – in relation to the respect for a person's wants or desires for their own life and the ability to make their decisions regarding that life – which the authors discussed below, including Beauchamp and Childress, agree on.

The concept of respect for autonomy entails respect for a patient's or individual person's autonomous decision in healthcare as well as in research.¹⁸ The term 'autonomy' has its origins in the Greek terms '*autos*' and '*nomos*', which mean 'self' and 'rule' respectively.¹⁹ The initial meaning of autonomy originates from politics where it referred to 'the right assumed by states to administer their own affairs'.²⁰ It was extended, in the nineteenth century, to include reference to the conduct of an individual.²¹ A natural extension to this idea of autonomy has been described as when the 'decisions and actions (of individuals) are their own; when they are self-determining'.²² Dworkin is of the opinion also that autonomy is not only an 'evaluative or reflective notion, but includes as well some ability both to alter one's preferences and to make them effective in one's actions and, indeed, to make them effective because one has reflected upon them and adopted them as one's own'.²³

The idea behind autonomy is 'self-government'.²⁴ An autonomous individual is independent of any form of external control and manages his own affairs.²⁵ Frankfurt expands on this further to reiterate Kant's notion of 'pure will', which is to be seen as a concept embedded within autonomy.²⁶ He defines 'pure will' as conforming to 'the

¹⁸ As above.

¹⁹ As above.

²⁰ S Darwall 'The value of autonomy and autonomy of the will' (2006) 116 *Ethics* 263.

²¹ As above.

²² G Dworkin *The theory and practice of autonomy* (1988) 13.

²³ G Dworkin (n 22 above) 17.

²⁴ H Frankfurt *Necessity, volition and love* (1998) 131.

²⁵ As above.

²⁶ H Frankfurt (n 24 above) 132.

requirements of a will that is indifferent to all personal interests – that is entirely devoid of all empirical motives, preferences and desires'.²⁷ When a person's volitions are derived from the essential character of his will, it can then be said that he acts autonomously.²⁸

Oshana further looks at autonomy from different perspectives. Etymologically speaking, she states that 'to be autonomous is to act within a framework of rules one sets for oneself; that is, it is to have a kind of authority over oneself as well as the power to act on that authority'.²⁹ She adds that a person must be self-directed in order to be considered autonomous, and thus a theory of autonomy needs to explain what kind of authority and power is involved.³⁰ Noggle also looks at the etymologically natural way of conceptualising autonomy in the form of 'self-rule' and provides that 'the notion of being an agent in voluntary control of one's actions seems to be very important in most if not all worldviews'.³¹ He is also of the opinion that this theory can be limited by, for instance, factors which can hinder a 'self' from being able to 'rule'. Examples can include psychological deficits such as being mentally ill or other factors which remove a person's authority over themselves for instance individuals who suffer from nervous tics or Tourette's syndrome.³²

Ekstrom further believes that 'autonomy cannot be the mere absence of obstacles to the fulfilment of desire because, in doing what one wants, one might frustrate one's more ultimate ends and so, in an important sense, bind rather than liberate oneself'.³³ A carefree pursuit of satisfying one's desires cannot be an appropriate model 'of the fully autonomous human life'.³⁴

Various philosophers have contemplated the concept of personal autonomy. Joseph Raz, a legal and moral philosopher, defines it as follows:

²⁷ As above.

²⁸ As above.

²⁹ M Oshana *Personal autonomy in society* (2006) 1.

³⁰ As above.

³¹ R Noggle 'The public conception of autonomy and critical self-reflection' (1997) 35 *The Southern Journal of Philosophy* 502.

³² As above.

³³ LW Ekstrom 'Alienation, autonomy, and the self' (2005) 29 *Midwest Studies in Philosophy* 48.

³⁴ As above.

The ideal of personal autonomy ... holds the free choice of goals and relations as an essential ingredient of individual well-being. The ruling idea behind the ideal of personal autonomy is that people should make their own lives. The autonomous person is (part) author of his own life. The ideal of personal autonomy is the vision of people controlling, to some degree, their own destiny, fashioning it through successive decisions throughout their lives.³⁵

It is obvious from this quotation that personal autonomy is viewed by some authors as one of the requirements for one's wellbeing, as well as for the achievement of the goals one sets for one's life. Raz further correlates the ideal of 'self-authorship' with a number of supplementary virtues, including 'self-awareness and integrity'.³⁶ His depiction of an autonomous person is not specifically centred on his 'goals and relations', but rather on 'the manner in which he evaluates, adopts, and pursues them'.³⁷ In this sense, personal autonomy can be associated with giving relevance to a person's decision-making ability in setting his own life goals, as regards to his subjective depiction of what is in his best interests, and, as such, respecting his dignity (or integrity).

Kant's conception of the principle of autonomy focuses on 'rational human will'.³⁸ He postulates that autonomy is inherent in all human beings and, as such, is present prior to action;³⁹ in other words, autonomy is exercised and derived during the deliberation process. He further speaks of an 'autonomous will' that he defines as both 'self-governing and self-legislating' and which is the foundation of all other moral behaviour.⁴⁰

If organ donation is considered in this light, all the relevant parties should ideally have their autonomy respected; in other words, both the donor and the recipient have to achieve their relevant 'goals'. For the organ donor, this 'goal', as such, would most likely be an altruistic goal, to perform a selfless act in order to improve the life of the patient. The patient's goal is self-evident, that is, to improve his or her own health. In terms of

³⁵ J Raz *The morality of freedom* 369. As quoted in RS Taylor 'Kantian personal autonomy' (2005) 33 *Political Theory* 605.

³⁶ As above.

³⁷ As above.

³⁸ M Komrad 'A defence of medical paternalism: maximizing patients' autonomy' (1983) 9 *Journal of Medical Ethics* 38.

³⁹ As above.

⁴⁰ As above.

healthcare, it is impossible, if not unrealistic, for a lay person to understand fully a procedure as complex as organ transplantation, particularly with regard to the risks involved. It would be unethical for a surgeon to make the decision entirely by himself or herself to proceed with an organ transplant without having highlighted important factors to all the parties involved. This is particularly the case with regard to living organ transplantation where the donor may also be at risk. In order, therefore, to make an autonomous decision, it is of paramount importance that both the organ donor and the recipient have the necessary information in order for them to make an autonomous, or informed, decision.

In this respect, it is evident that informed consent can overlap with respect for autonomy. Naidoo postulates the notion that the principle of autonomy is informed by three rules, namely, 'truth-telling; disclosure; and informed consent'.⁴¹ This ethical principle represents the 'capacity of legally competent patients to decide whether they will accept medical treatment', even though a refusal may result in serious health problems.⁴² Informed consent in a surgical setting, furthermore, serves to highlight the best interests of the patient in the light of the planned procedure.⁴³ The process involved in obtaining informed consent thus recognises a patient's inherent self-determination, regardless of the decision that is ultimately taken.⁴⁴ It further takes cognisance of a patient's value-system, individual life goals, and how these elements may enlighten his decision-making during the deliberation process.⁴⁵ A brief overview of informed consent is undertaken below.

Recognition of informed consent

Berger describes the important purpose of acquiring informed consent from individuals, or, in this case, from patients, before any medical intervention as being to protect and respect the person's self-determination as far as possible, and, as such, their human

⁴¹ P Naidoo 'Informed consent in South Africa' (2003) 41 *The South African Radiographer* 8.

⁴² As above.

⁴³ S Naidoo 'Obtaining informed consent for surgery' (2014) 27 *Current Allergy & Clinical Immunology* 112.

⁴⁴ As above.

⁴⁵ As above.

dignity.⁴⁶ In South African medical law, the basis of consent was first recognised in 1923 in the case of *Stoffberg v Elliott*, where the court stated the following:

In the eyes of the law, every person has certain absolute rights which the law protects ... and one of those rights is the right of absolute security of the person. Nobody can interfere in any way with the person of another, except in certain circumstances ... Any bodily interference with or restraint of a man's person which is not justified in law, or excused in law, or consented to, is a wrong, and for that wrong the person whose body has been interfered with has a right to claim such damages as he can prove he had suffered owing to the interference.⁴⁷

It is clear from this passage that personal autonomy was acknowledged as having importance from an early period in South Africa. The issue was again raised in 1976 in the case of *Richter and Another v Estate Hammann*,⁴⁸ where the court was tasked with determining whether the surgeon in this case had the duty to warn the patient of the possible dangers which were associated with the surgery she had undergone. The matter was made prominent, however, in South African medical law in 1994 following the case of *Castell v De Greeff*.⁴⁹

Consent can, however, be seen to have originated long before 1923 in the United States of America. As early as 1914, in the case of *Schloendorff v Society of New York Hospital*, the court stated that '(e)very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault'.⁵⁰ This concept was further advanced in 1957 in the case of *Salgo v Leland* where the court discussed the duty of a physician to disclose information to his patient as follows:

A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to

⁴⁶ K Berger 'Informed consent: information or knowledge?' (2003) 22 *Medicine and Law* 745.

⁴⁷ *Stoffberg v Elliott* 1923 CPD 148 at para 7.

⁴⁸ *Richter and Another v Estate Hammann* 1976 3 All SA 497 (C).

⁴⁹ *Castell v De Greeff* 1994 4 SA 408 (C).

⁵⁰ *Schloendorff v Society of New York Hospital* 211 NY 125, 105 NE 92 (1914), as quoted in K Berger (n 197 above) 744.

the proposed treatment. Likewise the physician may not minimise the known dangers of a procedure or operation in order to induce his patient's consent.⁵¹

This quotation highlights important qualities which are associated with the concept of informed consent, such as the necessity for an 'intelligent consent' (or a consent fostered with a proper understanding of the proposed treatment), as well as the disclosure of information to a patient.

Current position in South Africa

Moving forward, it is necessary to take note of the four elements of informed consent as underlined by Dhai. These are voluntariness, capacity, competence and disclosure.⁵² The most relevant element in this discussion of organ donation and/or transplantation is the aspect of disclosure of information to the patient. The physician is obliged to provide the patient with a broad idea of the procedure in a language that he or she would understand, whilst letting the patient know of the 'nature, scope, consequences, risks, dangers, complications, benefits and disadvantages' relating to the procedure, as well as the prognosis and any alternative options to the prescribed procedure, and to state clearly that the patient may refuse to undergo treatment.⁵³

Van Oosten iterates that 'adequate information becomes a requisite of knowledge and appreciation and, therefore, also lawful consent'.⁵⁴ He further adds the need for a physician to disclose to a patient all 'serious and typical risks and dangers', but he claims that it is not necessary to disclose 'unusual or remote risks and dangers, unless they are ... serious or typical or where the patient makes inquiries about them'.⁵⁵ It is, therefore, important to disclose information which is material to the procedure to a patient, although there are instances where disclosing the information may not be possible, i.e. in emergency cases such as unauthorised administration and/or necessity.⁵⁶ These emergency situations are not particularly relevant to this discussion.

⁵¹ *Salgo v Leland Stanford etc BdTrustees*, 154 Cal. App. 2d 560, paras 12 – 13.

⁵² A Dhai 'An introduction to informed consent: Ethico-legal requirements' (2008) 63 *SADJ* 18.

⁵³ PA Carstens & D Pearmain *Foundational principles of South African medical law* (2007) 885.

⁵⁴ FFW Van Oosten 'The liability of doctors and hospitals for medical malpractice' (1991) 80 *South African Medical Journal* 24.

⁵⁵ As above.

⁵⁶ FFW Van Oosten (n 54 above) 25.

Naidoo notes the importance of understanding the values and interests which are most important to a patient in determining the nature and scope of the information to be provided.⁵⁷ It is particularly relevant to take into consideration the patient's language and culture.⁵⁸ To this should be added the fact that religion is a further essential factor to take into account. This is also emphasised by Dhai who discusses the necessity of recognising each individual patient's values and beliefs.⁵⁹ In relation to this, a Jehovah's Witness may refuse the administration of blood transfusions, and a Christian Scientist may refuse any medical treatment, as *per* their respective religious beliefs.⁶⁰ Without a proper analysis of a patient's beliefs, their religious rights may be morally (and legally) violated.

Naidoo describes an additional challenge to physicians as being the need to provide the patient with information which is clear and not confusing, while avoiding selective truth telling.⁶¹ The test currently in place for determining the information to be disclosed is the *reasonable person standard*, i.e. what the *reasonable* patient would want to know and not what the *reasonable* physician would disclose.⁶² Naidoo describes this test as being ambiguous as it is difficult to interpret what would be considered to be 'reasonable',⁶³ in other words, what would be deemed material in the circumstances. This is highlighted by the current situation in the pre-surgical setting. It has been found that the way in which consent is obtained, as well as the content of the process of attaining informed consent, is inadequate, and studies have revealed that physicians provide information which patients deem unimportant.⁶⁴ Physicians and patients alike have reported dissatisfaction about the fulfilment of the elements of informed consent.⁶⁵

Despite the importance of properly disclosing information to the patient, therefore, it is clear that this is currently not embarked upon sufficiently. Naidoo describes the approach

⁵⁷ S Naidoo (n 43 above) 112.

⁵⁸ P Naidoo (n 41 above) 8.

⁵⁹ A Dhai (n 52 above) 20.

⁶⁰ R Veatch (n 3 above) 171.

⁶¹ S Naidoo (n 43 above) 112.

⁶² S Naidoo (n 43 above) 113.

⁶³ As above.

⁶⁴ As above.

⁶⁵ As above.

towards the acquisition of informed consent in a surgical setting as being merely obtaining a patient's signature as opposed to an important dialogue between the patient and surgeon.⁶⁶ Studies have revealed retention by patients of only 35% to 57% of the information provided to them preoperatively.⁶⁷ This is particularly worrying for organ donors and recipients considering the complex nature of organ transplant surgeries.

It is also important to note the likelihood of factors which may influence a person's ability to provide informed consent to organ transplantation. Such factors include 'persuasion, manipulation and coercion' to name a few.⁶⁸ The ethical guidelines provided by the HPCSA⁶⁹ provide that the patient, and not the health care practitioner, is to determine what is in his best interests.⁷⁰ It is further stated that the practitioner may recommend different treatments or courses of action but may not, in any way, pressure patients to accept their advice.⁷¹ Two duties are provided for health care practitioners in this regard, namely, to '(g)ive a balanced view of the options and explain the need for informed consent'.⁷²

With regard to organ donations, pressure or coercion may derive from any number of scenarios, whether the donor is a stranger, related or non-related, and a physician needs to be aware of this possibility.⁷³ The probability of coercion being prevalent is particularly high when dealing with donations which occur in the family.⁷⁴ Particularly with regard to living organ donations, studies have shown that once a family member is in need of an organ, the rest of the family members are compelled to make the decision to donate their organ without giving it any proper thought lest they be ostracised from the rest of the

⁶⁶ S Naidoo (n 43 above) 112.

⁶⁷ S Naidoo (n 43 above) 113.

⁶⁸ R Britz & A le Roux-Kemp 'Voluntary informed consent and good clinical practice for clinical research in South Africa: Ethical and legal perspectives' (2012) 12 *SAMJ* 747.

⁶⁹ The Health Professions Council of South Africa is a 'statutory body, established in terms of the Health Professions Act and is committed to protecting the public and guiding the professions'. The council oversees ethical and professional practice amongst other things.

'About HPCSA' <www.hpcsa.co.za/About> (accessed on 05/08/2015).

⁷⁰ Health Care Professions Council of South Africa 'Seeking patients' informed consent: the ethical considerations' (2007) 2nd Ed. Booklet 10, 6.

⁷¹ As above.

⁷² As above.

⁷³ K Lobas 'Living organ donations: how can society ethically increase the supply of organs' (2006) 30 *Seton Hall Legis. Journal* 494.

⁷⁴ As above.

family.⁷⁵ This is not to say, however, that a family member is completely incapable of making an autonomous decision to donate and this is dealt with below. By contrast, should a donation come from a person outside of the family, the offer of a donation could be looked upon with suspicion with regard to whether payments were involved or whether there are other factors, such as mental illness or any external pressure.⁷⁶

Because of this, studies have led to allegations that informed consent, from the perspective of living related donors, is merely a 'myth'.⁷⁷ Price quotes an allegation from Majeske *et al* which summarises this theory as follows:

The traditional requirements of informed consent do not appear well suited to evaluations of living related donors' decision making, however, with its frequent emphasis on feelings of relatedness, interconnectedness, and obligation – a sharp contrast to the unpressured, rational decision making typically said to underlie informed consent...The traditional model of informed consent is based on an impartialist understanding of the requirements of autonomy that de-emphasises personal relationships so that each decision maker is conceived as being free to pursue autonomous goals.⁷⁸

This quotation puts into perspective the problem surrounding the unintentional pressure that surrounds families and loved ones who are placed in this type of situation. It also highlights the fact that legislation does not take this perspective into account when defining, and providing for, the right of individuals to informed consent.

On the whole, Beauchamp and Childress stipulate the importance of an autonomous decision being made 'without controlling influences that determine their action'.⁷⁹ Generally speaking, a patient's decision has to be 'freely arrived at without pressure or coercion'.⁸⁰ This imposes a difficult task for healthcare providers involved in the process of organ transplantation as the presence of any controlling factors would result in persons

⁷⁵ As above. Also, this research is not generalised across all cultural and religious contexts.

⁷⁶ As above.

⁷⁷ K Lobas (n 73 above) 270.

⁷⁸ R Majeske, L Parker & J Frader 'In search of an ethical framework for consideration of decisions regarding live donation' in B Spielman (ed) *Organ and Tissue donation: ethical, legal and policy issues* (1997) 89 – as quoted in D Price *Legal and ethical aspects of organ transplantation* (2000) 270.

⁷⁹ Beauchamp & Childress (n 14 above) 101.

⁸⁰ V Dharmananda 'Informed consent to medical treatment – processes, practices and beliefs' (1992) *Law Reform Commission of Australia* 10.

not having given their informed consent properly and so having their personal autonomy breached.

While addressing these issues is of great importance, it is equally relevant to bear in mind the other principles of biomedical ethics. Even though there is no hierarchy associated with the principles, finding a balance proves challenging as they can clash with one another. The other principles will be discussed below.

2.2.2. Beneficence and non-maleficence

Historically, a primary source for arriving at an understanding of a physician's responsibility concerning a patient is based on the Hippocratic physicians in ancient Greece.⁸¹ 'Hippocratic beneficence' involves the focus being placed on the 'patient's medical best interest' entirely, with little to no regard to other needs or views of the patient.⁸² As such, the *Corpus Hippocraticum* has been criticised as failing to take note of the ideal for respect for personal autonomy, as it advises physicians to conceal 'most things from the patient, while you are attending to him ... turning his attention away from what is being done to him', as well as not informing the patient of his present or future condition.⁸³

This domineering attitude towards patient care by physicians has undergone a change over time. Since the middle of the twentieth century, 'forces in ethics and health policy with roots external to the professional concerns of physicians began to be influential'.⁸⁴ The problems associated with medical ethics were principally seen in health care circles as legal issues.⁸⁵ In the decade from 1962 to 1972, the older perception of medical ethics began to fall apart, and terms such as 'bioethics', 'moral problems in medicine', and 'biomedical ethics' superseded the term 'medical ethics'.⁸⁶ This transformation brought in a new era and outlook with regard to physician care towards patients.⁸⁷ As has been seen

⁸¹ T Beauchamp 'The promise of the beneficence model for medical ethics' (1990) 6 *Journal of Contemporary Health Law and Policy* 146.

⁸² As above.

⁸³ As above.

⁸⁴ T Beauchamp (n 81 above) 148.

⁸⁵ As above.

⁸⁶ As above.

⁸⁷ As above.

above, the ideal of respect for autonomy is now prominent in patient care, although the principle of beneficence still features in modern medicine.

The idea of beneficence in ordinary English denotes acts of ‘mercy, kindness, and charity’.⁸⁸ It may go further to incorporate notions of ‘altruism, love and humanity’.⁸⁹ Generally speaking, beneficence indicates that agents must take positive action towards helping others.⁹⁰ Beauchamp and Childress distinguish between two forms of beneficence, namely positive beneficence (providing benefits to others) and utility (the balancing of ‘benefits, risks and costs to produce the best overall results’).⁹¹ The question may be posed as to whether beneficence creates a duty or obligation on individuals and, if so, in which context does it do so.

This concept provides for both a moral obligation towards helping others as well as certain forms of ‘helping others’ which may be said to be obligatory (positive obligations).⁹² In terms of the moral obligations imposed by beneficence, the principle of benevolence may be adopted as it refers to the ‘character trait or virtue of being disposed to act for the benefit of others’.⁹³ From this perspective, beneficence would be no more than a moral concept lacking positive obligations. It has indeed been argued that beneficence is merely a charitable act and that there is no positive obligation; this means that, if a person fails to act beneficently, he is not necessarily being morally deficient.⁹⁴ The authors argue that there is a line which separates certain acts of beneficence which are optional (in other words merely a moral ideal) from those that are obligatory, and they state that this line is often unclear as the principle of positive beneficence does support a host of moral ideals.⁹⁵

The principles of beneficence (to act for the benefit of others) and non-maleficence (the obligation to do no harm) exist in tandem, particularly in the medical field. Gillon discusses

⁸⁸ T Beauchamp & J Childress (n 14 above) 197.

⁸⁹ As above.

⁹⁰ As above.

⁹¹ As above.

⁹² As above.

⁹³ As above.

⁹⁴ T Beauchamp & J Childress (n 14 above) 198.

⁹⁵ T Beauchamp & J Childress (n 14 above) 198 – 199.

how, in the case of medical ethics, it would be implausible, or difficult, to separate beneficence and non-maleficence.⁹⁶ He refers to the Hippocratic Oath, which provides that ‘the moral objectives in medicine are both beneficence – to help sick and suffering people - *and* to prevent harm in terms of both preventing deterioration of illness, damage, and disease and finding ways to prevent them in the first place’, in other words, the obligation to do no harm.⁹⁷ These two principles must be weighed against each other.⁹⁸ In a surgical setting, a physician does harm a patient who is in need of an organ transplant; this ‘harm’, however, is for the benefit of the organ recipient. This reveals an obvious clash between the two principles.

Ross discusses this clash from the perspective of living organ donation between strangers.⁹⁹ A possible, if not main, argument she ponders is the notion that, since a surgeon’s first responsibility would be to do no harm, the removal of an organ from a healthy living person, or donor, would not be feasible as the donor would be at risk of incurring ‘acute complications, and even possible long-term complications from the surgery itself’.¹⁰⁰ This would mean that all living organ donations would be ethically immoral if seen only from this perspective. She notes that this is not the case, however, as the principle of non-maleficence is not absolute and entails only a *prima facie* obligation which may be overridden ‘if there are compelling counter obligations’.¹⁰¹ She suggests a ‘harm-benefit’ ratio in aligning the two principles, whereby the donation by an individual would be morally acceptable if it is expected that the benefits will outweigh the risks (or harms).¹⁰² This calculation does not validate the risks which the donor may suffer if the recipient alone benefits, but it also requires the benefits to accrue to the donor

⁹⁶ R Gillon ‘*Primum non nocere*’ and the principle of nonmaleficence’ (1985) 291 *British Medical Journal* 131.

⁹⁷ As above.

⁹⁸ As above. Also see M Slabbert ‘Ethics, justice and the sale of kidneys for transplantation purposes’ (2010) 13 *PER/PELJ* 18. Slabbert refers to this weighing up of the two principles as the ‘double-effect’. She writes, for instance, that ‘...by removing a kidney from a healthy person’s body, beneficence cannot be applied alone except for the double effect’. The implication here is that ‘a certain course of action with an overall benefit may be ethical even if it causes some harm’.

⁹⁹ L Ross ‘Solid organ donation between strangers’ (2002) 30 *Journal of Law, Medicine & Ethics* 440.

¹⁰⁰ As above.

¹⁰¹ As above.

¹⁰² L Ross (n 99 above) 441.

proportionately to the harm or risks.¹⁰³ These benefits may be psychological, moral, but not self-serving alone as a donor ‘may include other-regarding interests in his calculation, as we are social beings’.¹⁰⁴

Such a balance is not an easy task to achieve. This is because of the difficulty involved in attempting to determine how much benefit accruing to the donor would be sufficient to offset the risks involved. It can, thus, be questioned as to what these benefits would entail. Spital states that a donor’s knowledge that he has saved a life provides emotional and psychological benefits as well as an increase in one’s self esteem and an improvement in one’s quality of life.¹⁰⁵ He states that, even in instances where a donor does not reap these benefits, he may still have the benefit of seeing a loved one recover.¹⁰⁶ Spital further believes that psychological benefits would indeed be sufficient to balance the medical risk.¹⁰⁷ He does, however, make mention of the difficulty in quantifying the extent to which these benefits would be sufficient, as they are determined subjectively.¹⁰⁸ It is also important to determine the donor’s beliefs, whether cultural or religious, since this balance is subjective in nature. A further question in this regard would be what the situation is where a stranger is the donor, or in the case of an organ donation from a deceased person.

Aside from this, it is also important to note the state of mind a person is in once he has found out that a loved one is in need of an organ. An informed autonomous decision has to be given voluntarily; in other words, it must not be the product of any manipulation, coercion or pressure of any sort. This is a notably problematic area, particularly as the situation itself can create pressure on family members, or persons who have a special relationship with the recipient, to donate. It has been theorised, psychoanalytically, that ‘when confronted with inescapable and conflictual situations of great stress, people revert to earlier modes of thinking and feeling, and become less intellectually autonomous, less

¹⁰³ As above.

¹⁰⁴ As above.

¹⁰⁵ A Spital ‘Donor benefit is the key to justified living organ donation’ (2004) 13 *Cambridge Quarterly of Healthcare Ethics* 107.

¹⁰⁶ As above.

¹⁰⁷ As above.

¹⁰⁸ As above.

reasonable and more vulnerable to coercion'.¹⁰⁹ The suffering of a loved one, as well as the search for a potential donor, generates a significant amount of stress on the family as a whole as well as on the 'decision making environment'.¹¹⁰ In this given situation, autonomy may be compromised and, as such, it may be argued that a physician could possibly make or assist the patient in making such a decision. This would then be an instance where beneficence may override patient autonomy, and, as such, be a plausible ethical solution. The issue in this regard is that it may amount to medical paternalism. A brief discussion on medical paternalism is, thus, warranted.

Medical Paternalism

Medical paternalism is at times defined as 'professional beneficence'. Paternalism has been defined as follows:

the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden.¹¹¹

This definition, if it were to be incorporated into the medical context, would indicate the concept of a physician overriding a patient's wishes, or, even more so, his autonomy, for that patient's own medical benefit (in the opinion of the medical personnel). It has also been defined as 'a physician's refusal to accept or to acquiesce to a patient's or donor's wishes, choices and actions for that person's benefit'.¹¹² Other definitions have been provided for this concept. Dworkin defines paternalism as:

(t)he interference with a person's liberty of action, justified by reasons referring exclusively to the welfare, good, happiness, needs, interest or values of the person being coerced.¹¹³

¹⁰⁹ D Price *Legal and ethical aspects of organ transplantation* (2000) 269.

¹¹⁰ As above.

¹¹¹ Beauchamp & Childress (n 14 above) 209.

¹¹² T Gutmann & W Land 'Ethics regarding living-donor organ transplantation' (1999) 384 *Langbeck's Archives of Surgery* 517.

¹¹³ G Dworkin 'Paternalism' (1972) 56 *The Monist* 64 - as quoted in B McKinstry 'Paternalism and the doctor-patient relationship in general practice' (1992) 42 *British Journal of General Practice* 340.

In this quotation, Dworkin appears to relate paternalism to a form of coercion which may be justified subject to the benefit that accrues to the individual being coerced. A more detailed description of medical paternalism is provided by Gert and Culver as follows:¹¹⁴

X is acting paternalistically towards Y if, and only if, X's behaviour correctly indicates that X believes that:

- X's action is for Y's good;
- X is qualified to act on Y's behalf;
- X's action involves violating a moral rule with regard to Y;
- Y's good justifies X acting on Y's behalf independently of Y's past, present or immediately forthcoming free, informed consent; and
- Y believes, perhaps falsely, that Y generally knows what is for his or her own good.

The paternalist must have a reasonable expectation of Y's eventual consent.¹¹⁵

A distinction may be made between 'soft (or weak) paternalism' and 'hard (or strong) paternalism'. Soft paternalism refers to the intervention into a 'patient's decision ... made with the aim of avoiding 'substantially *nonvoluntary* conduct'.¹¹⁶ Such conduct includes: 'poorly informed consent or refusal, severe depression that precludes rational deliberation and addiction that prevents free choice and action'.¹¹⁷ In these cases, there is no significant autonomy of the patient's having been present and, thus, it is imperative for the physician to intervene in this instance in order to prevent harm being caused to the patient.¹¹⁸ Hard paternalism, on the other hand, describes the situation where a physician intervenes with the patient's decision even where that patient has provided his informed and voluntary consent.¹¹⁹ It has been provided that, in a case of hard paternalism, the physician will override the patient's autonomy (by going against the informed consent already provided),¹²⁰ as opposed to a case of soft paternalism where a patient's informed consent is already depreciated from the start.

¹¹⁴ B Gert & C Culver 'The justification of paternalism'; as quoted in B McKinstry 'Paternalism and the doctor-patient relationship in general practice' (1992) 42 *British Journal of General Practice* 340.

¹¹⁵ As above.

¹¹⁶ T Beauchamp & J Childress (n 14 above) 209.

¹¹⁷ T Beauchamp & J Childress (n 14 above) 209 – 210.

¹¹⁸ T Gutmann & W Land (n 112 above) 517.

¹¹⁹ As above.

¹²⁰ As above.

This distinction is of importance in the determination of whether it would be acceptable for beneficence to override autonomy and under what circumstances it would be acceptable. A soft form of paternalism may be implemented in a situation where a patient (or family members of a patient, donor or recipient) is in a state of severe depression; for instance, where his autonomy may already be compromised. In this instance, it is important for a physician to take cognisance of the views which the patient has before making this decision.

It can be seen from this discussion that a balancing of all of the principles of medical ethics is of great importance in relation to justice. For this reason, a discussion on the principle of justice follows.

2.2.3. Justice

The principle of justice is important in the arena of organ donation, particularly regarding the notion of the distribution of organs once received. As this is not a main focus of this particular discussion, it will be touched upon only briefly and highlighted again in the subsequent chapters when dealing with this area.

The concept of justice can be explained by the use of terms such as ‘fairness, desert (what is deserved), and entitlement’.¹²¹ The concept has been further defined as ‘fair, equitable, and appropriate treatment in light of what is due or owed to persons’.¹²² Standards of justice become relevant when a person is due ‘benefits or burdens’.¹²³ Justice has been determined as consisting of two principles, communicative justice and distributive justice.¹²⁴

Communicative justice entails that all human beings are equal and, as such, should receive an equal share of resources.¹²⁵ Distributive justice, on the other hand, entails the ‘distribution of all rights and responsibilities in society, including civil and political rights’.¹²⁶

¹²¹ T Beauchamp & J Childress (n 14 above) 241.

¹²² As above.

¹²³ As above.

¹²⁴ D Blondeau *et al* ‘Do ethical principles explain moral norm? A test for consent to organ donation.’ (2007) 9 *Journal of Applied Biobehavioral Research* 232.

¹²⁵ As above.

¹²⁶ T Beauchamp & J Childress (n 14 above) 241.

This distribution is determined by norms which are justified and ‘structure the terms of social cooperation’.¹²⁷ In other words, distributive justice aims to distribute resources based on each individual person’s needs.¹²⁸ Relevant to this discussion is the principle of distributive justice.

There are various general material principles of distributive justice, including, but not limited to:

- To each person an equal share;
- To each person according to need;
- To each person according to effort;
- To each person according to contribution;
- To each person according to merit; and
- To each person according to free-market exchanges.¹²⁹

There are no restrictions with regard to the acceptance of a number of these principles, and different theories of justice accept all six principles as valid.¹³⁰ Most societies have endorsed several of these principles when structuring public policies; for instance, ‘many health care programmes are distributed on the basis of need’.¹³¹ What is important is the need to specify and balance these principles in order to avoid conflicts arising from the challenges associated with prioritising resources as well as the ‘challenge to a moral system that aims for a coherent framework of principles’.¹³²

When looking at this principle in terms of organ donations, it would mean that every patient in organ failure, and in need of an organ for transplantation, would require fair and equal access and opportunity to such organs. The allocation of organs is, thus, central to this principle. A Rawlsian theory of justice focuses on the structure of society, viz. that in order to establish a social union, cooperation for a mutual advantage is necessary.¹³³ He

¹²⁷ As above.

¹²⁸ D Blondeau *et al* (n 124 above) 232.

¹²⁹ T Beauchamp & J Childress (n 14 above) 243.

¹³⁰ As above.

¹³¹ As above.

¹³² As above.

¹³³ C Murphy ‘Distributive justice, modern significance’ (1972) 17 *American Journal of Jurisprudence* 155.

advocates an equal distribution of primary goods, unless it would be to everyone's advantage if there were to be an unequal distribution.¹³⁴

Hart discusses the concept of justice in relation to the law. Accordingly, the general principle for the application of the idea of justice is that 'individuals are entitled in respect of each other to a certain relative position of equality or inequality'.¹³⁵ He states that this is relevant particularly when looking at the distribution of burdens or benefits in the vicissitudes of social life.¹³⁶ He further provides that not only does this need to be respected, but it should also be restored when disturbed in order to maintain or restore a balance or proportion, with its leading precept often formulated as 'treat like cases alike'.¹³⁷ To this he suggests the addition of a further phrase being: 'treat different cases differently'.¹³⁸ The law is to determine the similarities and differences between human beings in the legal application of justice in particular cases.¹³⁹ The aim is for a guarantee that the law is to be applied objectively, impartially and 'designed to secure that [it] is applied to all those and only to those who are alike in the relevant respect marked out by the law itself'.¹⁴⁰

The difficulty with regards to the distribution of organs, and as such the principle of justice, is that there will always be an element of inequality. Welbourn takes note of the inevitable inequality which would ensue owing to the presence of limited organs available for transplantation as some patients will not receive any organs.¹⁴¹ She further points out that, owing to this, any methods of increasing organ supply would be harmonious with the principle of justice.¹⁴² Based on this, it is arguable that a method of presumed consent, which will be discussed below, would be an ideal solution and would be in line with the

¹³⁴ As above.

¹³⁵ HLA Hart *The concept of law* 159.

¹³⁶ As above.

¹³⁷ As above.

¹³⁸ As above.

¹³⁹ As above.

¹⁴⁰ Hart (n 135 above) 160.

¹⁴¹ H Welbourn 'A principlist approach to presumed consent for organ donation' (2014) 9(1) *Clinical Ethics* 14.

¹⁴² As above. It should be noted that 'any methods' should not be taken literally as there are obviously methods (such a coercing people to donate) which would not be in keeping with this principle.

principle of justice. It has been shown that a notable increase could be seen in donations has been seen in nations that have introduced this model for organ procurement.

2.2.4. Difficulties in aligning ethical principles to the systems of organ donation and/or transplantation

Living organ donations

The use of living donors for transplantation was first successfully accomplished in 1954, and it has since then been improved over time. These transplants are possible for ‘a single kidney, partial liver, lung, intestine and pancreas’.¹⁴³ Living donor transplants (LDTs) are possible provided that the donor can carry on living without the organ that is to be removed.¹⁴⁴ Regarding the principle of autonomy, there is not much difficulty in aligning it with the concept of LDTs because it is permitted only if it is undertaken altruistically by the donor, having given his voluntary informed consent. The problem in this instance, as has been discussed above, is with regards to informed consent.

The United Network for Organ Sharing (UNOS) and the National Kidney Foundation provide standards with regard to LDTs, and these state that this procedure should be conducted only if the benefit to the recipient outweighs the donor’s risk, and, as such, the procedure is not to be undergone in situations where the recipient ‘faces a clinically hopeless situation’.¹⁴⁵ This is already an expression of the principle of beneficence, as well as non-maleficence, in that there should be an expectation that the surgery would benefit the recipient, but also that it should not be undertaken should the surgery not be worth it because the recipient is in a hopeless situation. The harm to be caused to the donor would not, therefore, be justifiable. The benefit to be received in this regard is debatable. As has already been determined, there is controversy surrounding the concept of the benefit to be accrued by the recipient. A further question which may be posed would be with regards to the benefit to be received by the donor, and whether such surgery could be justified.

¹⁴³ K Lobas (n 73 above) 484.

¹⁴⁴ As above.

¹⁴⁵ As above.

The advantages associated with the use of living donors are numerous. Using LDTs has been declared as ‘consistently better than’ cadaveric transplantations.¹⁴⁶ It has been found that ‘tissue compatibility’ is in most instances closer with LDTs and, also, that the time for ischaemia is significantly shortened.¹⁴⁷ In addition to this, the procedures can be co-ordinated as appropriately as possible, for instance ‘when a patient is in optimum condition and even pre-dialysis’.¹⁴⁸ There is also a reduced necessity for immunosuppressant drugs, and this lowers the risk of malignancies and infections to the recipient than would be the case with cadaver transplantations.¹⁴⁹

This is not to say that LDTs are not without risks. There is always the possibility of death, as with most, if not all, medical procedures. Studies have, however, shown that this risk is minimal with LDTs.¹⁵⁰ A survey conducted in the USA between 1980 and 1991 revealed only five donor deaths amongst the recorded 19,368 transplantations conducted.¹⁵¹ Between 1987 and 1992, a survey of all UNOS centres revealed only three deaths (1 in every 3,231 donors).¹⁵² These surveys all deal with kidney procedures undergone during those periods. Other possible risks include the possibility of ‘post-donation depression’.¹⁵³ Early studies revealed this psycho-social complication amongst donors. The evidence was, however, found to be inconclusive, and there was extensive data to show that donors, on the contrary, showed ‘improved self-esteem and well-being post-donation’.¹⁵⁴ On the whole, these risks are nominal at best.

Despite the advantages of LDTs over cadaver transplantations, there are still a host of ethical barriers with regards to them. As discussed in the first chapter, there are three categories of LDTs, namely ‘directed donation to a loved one or friend; non - directed donation, in which the donor gives an organ to the general pool to be transplanted into the recipient at the top of the waiting list; and directed donation to a stranger, whereby

¹⁴⁶ D Price (n 109 above) 217.

¹⁴⁷ D Price (n 109 above) 219.

¹⁴⁸ As above.

¹⁴⁹ As above.

¹⁵⁰ D Price (n 109 above) 220.

¹⁵¹ As above.

¹⁵² As above.

¹⁵³ D Price (n 109 above) 221.

¹⁵⁴ As above.

donors choose to give to a specific person with whom they have no prior emotional connection'.¹⁵⁵ Each of these categories presents different ethical conundrums.¹⁵⁶ As discussed earlier, informed consent is an issue with these different categories and, as such, the principle of respect for autonomy is already jeopardised in this sense. The likely possibility of psychological trauma which could affect the voluntariness of the decision to donate is not accounted for. This may possibly mean that, in this instance, valid consent may not, in fact, have actually been given. Proper evaluation of a donor's consent and psychological state, therefore, needs also to be taken into account before proceeding with an LDT where the donor has a special relationship with the patient.

With regards to the principles of beneficence and non-maleficence, the evaluation of these principles has revealed that non-maleficence poses only a *prima facie* obligation which may be overridden in certain instances. It may then be questioned as to how strong of an obligation beneficence may in fact bestow on the different parties, particularly the donor, in the organ donation process. It may be important to view the concept of positive beneficence in this regard. With LDTs, the question can be asked as to whether such an obligation can be placed on an individual to donate, particularly with regard to and in the presumed consent model. This issue will be discussed in the legal analysis below, as it is taken from a legal perspective.

Cadaveric organ donations

Cadaveric organ transplantation (CDT) is the dominant form of organ transplantation in most developed transplant nations.¹⁵⁷ This therapeutic alternative mode of treatment was prevalent particularly in the 1960s, which saw the first human lung and liver transplant in 1963 (separate surgeries), as well as the first cardiac transplant in 1967 by Christiaan Barnard in South Africa.¹⁵⁸ CDTs now take place in considerable numbers across Europe as well as in the United States of America.¹⁵⁹ In 1997, '11,831 renal, 4,207 liver and 3,257 thoracic cadaveric transplants were carried out in Europe and 8,613 renal, 4,159 liver and

¹⁵⁵ R Trog 'The Ethics of Organ Donation by Living Donors' (2005) 353 *New England Journal of Medicine* 441.

¹⁵⁶ As above.

¹⁵⁷ D Price (n 109 above) 23.

¹⁵⁸ As above.

¹⁵⁹ As above.

3,348 thoracic in the United States'.^{160,161} Despite the prevalence of CDTs, 'the rising demand for organ replacement therapy has ensured that almost everywhere there is a shortage of organs for transplant'.¹⁶² This problem has been intensified in some regions by the 'plateauing out' of cadaveric procurement and transplantation rates 'in the early nineties and beyond'.¹⁶³ There is, thus, a dire need for the resolution of the issues involved with CDTs, such as the ethical dilemmas, which may be contributing to this downward spiral. An ethical analysis of the different procurement systems surrounding CDTs warrants a discussion.

As has been discussed in the first chapter, there are two models currently being implemented in transplant nations for the procurement of organs from the deceased. They are the 'opting – in system' (sometimes referred to as 'explicit consent') and the 'opting – out' or presumed consent system. The opting-in system has been arguably referred to as the most acceptable approach, being implemented by countries such as South Africa and Malaysia, and it has received little to no objection ethically, culturally and/or from a religious perspective. The more controversial of the two, the presumed consent model, has been subject to objections from all aspects, but there are nations who have, nevertheless, endorsed it in their legislation, such as Singapore and Spain. The ethics surrounding these two will be discussed below.

- *Opting–out system of organ donations*

An opting – out system of organ procurement, or presumed consent, entails the concept that all individuals are organ donors upon their death unless they had registered to the contrary prior to their death. This system assumes that people would prefer to donate their organs, after their death, for transplantation.¹⁶⁴ In practice, if a person has died and

¹⁶⁰ As above.

¹⁶¹ Thoracic surgery is a surgical procedure, or type of surgery, which involves treatment of the chest region (or thorax) including the lungs, oesophagus, diaphragm muscle and chest muscle. 'Thoracic surgery Defined' – <http://surgery.about.com/od/glossaryofsurgicalterms/g/ThoracicSurgery.htm> (accessed on 05/09/2015).

¹⁶² D Price (n 109 above) 24.

¹⁶³ As above.

¹⁶⁴ M Gill 'Presumed consent, autonomy, and organ donation' (2004) 29 *Journal of Medicine and Philosophy* 37.

left no indication of his wishes, and family members and/or the next of kin of such person have no reason to believe that the person did not want to donate, then the medical personnel would proceed on the presumption that he wished to donate.¹⁶⁵ This system is implemented in a few countries, such as Spain and Singapore, and has been rejected by others. One of the main arguments against this system is that it proposes a violation of a person's right to individual autonomy in cases where individuals did not, in fact, wish to have their organs removed upon their death.¹⁶⁶

The earliest thinking regarding such a model was premised on the belief that the remains of an individual were no longer of any use to the deceased or to those by whom he is survived.¹⁶⁷ Dukeminier and Sanders thus devised a model which they termed 'routine salvaging', in terms of which it is appropriate for society to 'routinely take any leftover viable parts without formal permission' as it would be for the greater good and no harm would actually follow.¹⁶⁸ Despite the unfortunate title for this model, the underlying argument may be noteworthy.

This outlook is premised upon a utilitarian perspective towards organ donations. In terms of utilitarianism, an ideal life would be one with the maximum amount of pleasure reached with the minimum amount of pain.¹⁶⁹ Jeremy Bentham believed that there were only two absolute themes which govern us in everything that we do, pain and pleasure.¹⁷⁰ When faced with a choice of decisions, we make the one which would minimise our pain and maximise our pleasure.¹⁷¹ This view can be utilised from different perspectives. A cadaver is no longer a 'sentient being' and can thus feel neither pleasure nor pain.¹⁷² Kapoor

¹⁶⁵ M Gill (n 164 above) 38.

¹⁶⁶ As above.

¹⁶⁷ R Veatch (n 3 above) 144.

¹⁶⁸ J Dukeminier & D Sanders 'Organ transplantation: a proposal for routine salvaging of cadaver organs' (1968) 279 *New England Journal of Medicine* 413 - As quoted in Veatch (n 3 above) 144.

¹⁶⁹ C Kapoor 'The removal of organs from cadavers: a utilitarian perspective' (1994) *Jurisprudence Review* 108.

¹⁷⁰ As above.

¹⁷¹ As above.

¹⁷² As above. It is worth it to mention that there are authors who disagree with this point of view. In terms of the Feinberg-Pitcher approach, posthumous harm 'occurs when one of the deceased's surviving interests is thwarted after his death. The subject of a surviving interest and of the harm or benefit that can accrue to it after a person's death is the living person ante-mortem whose interest it was. Events after death do not retroactively produce effects at an earlier time, but their occurrence can lead us to

further states that a deceased's relatives, who are already grieving a loss, are unlikely to be affected by more pain resulting from the removal of the organs of the deceased, unless they are directly asked for permission.¹⁷³ In fact, it may also be possible that the thought of the deceased being able to save a life may actually give them more pleasure instead.

The dichotomy of pleasure and pain can also be viewed from a societal perspective. The improvement of the quality of life of recipients at a lower cost adds benefit to society's pleasure from an economic standpoint.¹⁷⁴ An example of this can be seen from the cost of renal transplant surgery, which Kapoor points out is about a third of the price of dialysis.¹⁷⁵ Transplantation, therefore, also saves on state funds, funds which can be used to improve on other healthcare services. This can be seen as a positive contribution to the concept of beneficence which denotes positive acts that benefit individuals. In this case, not only are the patients benefitting from lifesaving organs, but society is also benefitting from an economic perspective. If this and the above are to be accepted, all parties can actually benefit. The family would be benefitting from the pleasure they could potentially receive in knowing that, in death, the deceased has saved one or more lives from transplantation.

Contrary to this, Kurosu is of the opinion that presumed consent is, in fact, a violation of voluntary beneficence with regard to donation and so contrary to informed consent, and, therefore, not ethically justified.¹⁷⁶ He bases his argument on the view of Machino who discusses the supposition that human beings are inherently beneficent to others and, should this be true, would donate their organs after death, even without an express desire being given.¹⁷⁷ Kurosu argues that an individual's perception of the body is of great importance, and presumed consent should, in effect, not be taken for granted.¹⁷⁸ He also

revise our estimates of an earlier person's well-being, and correct the record before closing the book of his life'. J Feinberg *Harm to others* (1987) 93.

¹⁷³ As above.

¹⁷⁴ C Kapoor (n 169 above) 109.

¹⁷⁵ As above.

¹⁷⁶ M Kurosu 'Ethical issues of presumed consent in the use of patient materials for medical research and the organ donation for transplantation' (2008) 3 *Journal of Philosophy and Ethics in Health Care and Medicine* 64.

¹⁷⁷ M Kurosu (n 176 above) 74.

¹⁷⁸ As above.

argues that to compel an individual to express his will would be ‘a violation of individual autonomy and an outrage against informed consent’.¹⁷⁹

It is, however, worth noting that Kurosu discusses presumed consent based on the implementation of this system in Japan where a contracting–out method is employed for the use of the biological material of patients for cancer research.¹⁸⁰ This particular system requires that patients receive an explanatory document where they are informed that their biological material may be used for research purposes if they do not submit a document of refusal in two months.¹⁸¹ The problem with this particular system is that patients feel pressured into signing the document in order to be able to see a physician, or they will sign it without fully understanding the implications of what they are signing.¹⁸² This would be contrary to the system to be suggested in this research study. It is, however, still worth taking note of the ethical problems posed by the Japanese system as a similar difficulty has been discussed above with regard to the difficulties associated with informed consent.

Fourie is of the opinion also that the doctrine of presumed consent is in fact different from that of routine salvaging in numerous ways.¹⁸³ He states that it is a common misperception to classify presumed consent as routine salvaging and states the following:

The doctrine is in many ways different than routine salvaging, however, the most influential is the right of ‘opting out’. In terms of the doctrine of presumed consent, procurement of organ and tissue will start *only* after it can be proven that *no* objection pertaining to organ procurement has been registered. Routine salvaging regimes do not allow the donor the opportunity to object to procurement for example in countries such as the People’s Republic of China and certain Arab Republics, which remove organs and tissue from executed prisoners. The right to ‘opt out’ of the potential donor pool is paramount to

¹⁷⁹ M Kurosu (n 176 above) 81.

¹⁸⁰ M Kurosu (n 176 above) 69.

¹⁸¹ As above.

¹⁸² M Kurosu (n 176 above) 80.

¹⁸³ EJ Fourie ‘An analysis of the doctrine of presumed consent and the principles of required response and requires request in organ procurement’ unpublished LLM Thesis, University of Pretoria 2005 69.

determine whether actual consent was present when the person decided not to become a donor after death.¹⁸⁴

This is not to say that it is possible to implement a presumed consent model without violating a person's individual autonomy at least to some extent or in some instances. Even in an opting-in system, however, it has been determined above that autonomy can be violated in instances where individuals neglect to express their desire to donate prior to their passing. This is also the case in a 'soft' opting-in system where, even if a person has expressed his wish to donate, the family can override this wish and thus violate the deceased's individual autonomy. The solution would, then, be to look at it from a utilitarian perspective; that is, adopting a system where the majority is benefitted by an increase of organ supply for transplantation.¹⁸⁵ Indeed, Welbourn states that a potential compromise to the individual's autonomy would be an acceptable cost.¹⁸⁶ As such, beneficence is indeed seen as being a segment of utilitarianism.

It can, therefore, be said that organ transplantation would perhaps provide the greatest amount of pleasure (and benefits) to all involved, including the recipients, the loved ones of the deceased person, and even society as a whole. From this ethical perspective, it may further be said that presumed consent may, in fact, be tenable. Certain qualms cannot, however, be ignored. The fear has been expressed that a system where a person's body is used without permission by the state would be reminiscent of Nazi medical research.¹⁸⁷ Veatch does, nonetheless, indicate that this analogy has been overused, and he points out that the difference with a presumed consent system is the use of deceased persons.¹⁸⁸ The torturous and unethical experimentation conducted by the Nazi research led to the formulation of the Nuremberg Code on permissible medical experiments.¹⁸⁹ Though this code focuses on research experiments, it does explicitly

¹⁸⁴ As above.

¹⁸⁵ H Welbourn (n 141 above) 14.

¹⁸⁶ As above.

¹⁸⁷ R Veatch (n 3 above) 145.

¹⁸⁸ As above.

¹⁸⁹ 'The Nuremberg Code of 1947' – U.S Department of Health & Human Services <<http://www.hhs.gov/ohrp/archive/nurcode.html>> (accessed on 13/09/2015).

point out the importance of voluntary consent which is now also applied in medical treatment as has been shown.

Overall, the implementation of a presumed consent system may be seen as a more viable option than an opting-in system. Gill describes one of the positions for such a system as the ‘fewer mistakes claim’.¹⁹⁰ The idea behind this is that there will be fewer mistakes under this system than under an opting-in system. The reasoning is based on the fact that most Americans would indeed prefer to donate their organs, and, also, the chances of an individual who is against donating actively opting-out of it in a presumed consent system are higher than a person who wishes to donate opting-in in an express consent system.¹⁹¹ The premise is based on the belief that those who are opposed to donating have prominent moral or religious objections, of which they are consciously aware, and, as such, are unlikely to neglect opting out, just as a Jehovah’s witness, for example, is unlikely to forget to inform his physician about his opposition of blood transfusion.¹⁹²

Gill argues further that both models are bound to result in mistakes, whether such a mistake be neglecting to opt-out or forgetting to opt in, and, for this reason, we should implement the system that will produce fewer mistakes, the opting – out system.¹⁹³ He further postulates that, even if an opting-out system were to generate more mistakes, it would still be an appropriate policy to endorse if ‘as a result of greatly decreasing the number of mistake non-removals, it leads to fewer mistakes overall’.¹⁹⁴

The implementation of such a system is also not impossible in a nation where culture and religion are paramount. Singapore, for example, has numerous prevalent religions, such as Buddhism, Taoism, Islam and Christianity,¹⁹⁵ and yet the legislature succeeded in endorsing a system of presumed consent in 1987 with the adoption of the Human Organ Transplant Act.¹⁹⁶ It is interesting to note that the Act operated to the exclusion of Muslims

¹⁹⁰ M Gill (n 164 above) 41.

¹⁹¹ As above.

¹⁹² As above.

¹⁹³ As above.

¹⁹⁴ As above.

¹⁹⁵ R Guruswamy ‘Religions in Singapore’ - <http://worksingapore.com/articles/live_7.php > (accessed on 15/09/2015).

¹⁹⁶ Sec 5 Human Organ Transplant Act – Cap. 131A.

originally, and this was changed in 2007 following a 'religious ruling' by the Islamic Religious Council of Singapore.¹⁹⁷ So religion may not actually be a hindrance to such a system. A more thorough examination of the impact of religion and culture on organ donations will be conducted in the next chapter.

It has further been argued that an opting-out system could in actuality increase donation rates. This argument has been made based on the increase of donation rates in countries which have adopted this scheme. In Singapore, the scheme was actually implemented only in 1988, allowing for a six-month period where rejections could be registered, and it applied only to kidney donations.¹⁹⁸ The result was that the donor pool increased by more than 95% of the Singaporean population, with very few cases of individuals actually registering to opt-out.¹⁹⁹

Conversely, arguments have been raised to suggest that this system cannot be seen as a reason for an increase in donor rates. Welbourn states that it is debatable as to how much credit can be given to presumed consent for such increases in the different transplant nations.²⁰⁰ She uses Spain as an example, and states that, even though the model was introduced in 1979, there was an increase only after 1989, subsequent to the introduction of the National Transplant Organisation.²⁰¹ She also states that the greatest impacts on the donor pool were the education systems and infrastructure measures which came with this organisation.²⁰² Support for this theory is given with the mention of Sweden which introduced the presumed consent model in 1996 but which has the lowest organ donor rate in Europe.²⁰³

This argument cannot be ignored. Even though it took Spain's introduction of a further organisation, inclusive of other measures and a change in infrastructure, to see donor rates increase, it can, however, hardly be said that education is a strong enough factor

¹⁹⁷ J Chin & AV Campbell 'Transplant tourism or international transplant medicine? A case for making the distinction' (2012) 12 *American Journal of Transplantation* 1702.

¹⁹⁸ J Chin & THX Kwok 'Ethical challenges in the deceased organ donation programme: Asian perspectives' (2014) 11 *Indian Journal of Medical Ethics* 139.

¹⁹⁹ As above.

²⁰⁰ H Welbourn (n 141 above) 13.

²⁰¹ As above.

²⁰² As above.

²⁰³ As above.

with regard to organ donation because the opposite happened in Singapore. Chin and Kwok point out that presumed consent was introduced only after the failure of other initiatives to acquire donors under the former opting-in system, including 'door-to-door canvassing and media publicity throughout the 1970s and 1980s and continuing transplant awareness education through information booklets posted to citizens and permanent residents six months before the age of 21'.²⁰⁴ After 35 years of these efforts, only 1.3% of permanent residents and citizens had agreed to the donation of their organs.²⁰⁵

It could, therefore, be safe to assert that a system of presumed consent is imperative for organ donor increase. That is not to say that it would work in isolation. Other measures may accompany such a policy in order to bring about the maximum increase of donations. Even with the arguments against opting-out, an opting-in system has failed to provide a necessary solution for low donor rates. South Africa, for example, has shown a *decrease* in donations over the past decade with the opting-in system. The Organ Donor Foundation (ODF) has reported statistics which reveal that, in 2009, there were 724 organ and corneal transplants, whereas in 2013 there had been only 566.²⁰⁶ In addition to this, research has shown that rates in donations after donors have been declared brain stem dead are higher in a presumed consent model as opposed to an opting-in system.²⁰⁷ This suggests that an opting-out system could be essential if donor rates are to be increased. The question then would be which type of opting-out system to impose.

- *Types of opting – out*

In the same way as there is a soft opting-in system for organ procurement, there is also a strong and weak system of presumed consent. In a strong system of opting-out, a lack of objection to organ donation is sufficient for the authorisation of organ donation to

²⁰⁴ J Chin & THX Kwok (n 198 above) 139.

²⁰⁵ As above.

²⁰⁶ 'Organ Donor Foundation – waiting list statistics' - <https://www.odf.org.za/2013-06-11-09-17-45/statistics.html> (accessed 15/09/2015).

²⁰⁷ L Shepherd, RE O'Carroll & E Ferauson 'An international comparison of deceased and living organ donation/transplant rates in opt – in and opt – out systems: a panel study' (2014) 12 *BMC Medicine* 131.

commence.²⁰⁸ In a weak system, the decision made by the deceased, or in this case the failure to object, can be overridden by the relatives or next of kin.²⁰⁹ Another way of looking at this is that authorisation needs to be acquired from the next of kin or relatives for donation to take place.²¹⁰

A weaker system of opting-out would, perhaps, be more ethically sound and possibly also more readily acceptable. This is because there would be fewer mistakes in the sense that, had the deceased in fact not wanted to donate and neglected to register his objection but divulged this information to a relative, his right to individual autonomy could still be preserved. In addition to this, a weaker form of presumed consent is implemented in most transplant nations where the opting-out system is endorsed, such as Singapore.

There are arguments which can be raised, however, for a stronger system of presumed consent. For one, if a person had indeed neglected to register an objection, the decision from family members not to donate would in fact be a violation of the deceased's autonomy. Also, looking at the perspective of informed consent regarding the vulnerability of the patient in the case of living organ donations as mentioned previously, it can be said that, when a person has died, the relatives and/or next of kin are also in a similar vulnerable position. The time is also very limited in which viable organs can be retrieved and this does not leave much time for the family to be in a position to make a rational decision, one which they may regret at a later stage. Kapoor highlights the fact that the relatives are already grieving, and so to ask them to donate the organs of a loved one may indeed add to the pain they are already experiencing.²¹¹ A strong system may assist in removing this painful decision from them, whilst helping others as well, offering a utilitarian approach if you will.

²⁰⁸ Price (n 109 above) 85.

²⁰⁹ Price (n 109 above) 85 – 86.

²¹⁰ As above.

²¹¹ C Kapoor (n 169 above) 108.

2.3. Law governing organ donation and/or transplantations

As stated above, ethical guidelines and principles cannot be divorced from the law. Where previously medical practitioners had only ethical concepts to use for guidance, these have subsequently been incorporated into legislation and have been given statutory recognition.²¹² It cannot be said that all of these principles have indeed been incorporated. In the case of organ donation, it can be argued that changes need to be made in order to give greater clarity on the position with regard to organ donation, particularly in South Africa. The current legislative enactments surrounding organ donations will now be discussed, distinguishing between living and deceased organ donations.

2.3.1. Legislative enactments surrounding organ donation and transplantation

- National Health Act

As stated in the first chapter, the NHA²¹³ provides legislative guidelines with regards to organ donation and/or transplantation in South Africa. This Act repealed the Human Tissue Act²¹⁴ when it came into force in 2012. It is important to note that the Act uses the terms 'organ' and 'tissue' interchangeably, as can be seen from the definitions in section 1. The Act defines an organ as 'any part of the human body adapted by its structure to perform any particular vital function, including the eye and its accessories, but does not include skin and appendages, flesh, bone, bone marrow, body fluid, blood or a gamete'.²¹⁵ The Act further defines a tissue as 'human tissue, and includes flesh, bone, a gland, an organ, skin, bone marrow or body fluid, but excludes blood or a gamete'.²¹⁶ From this it can, therefore, be stated that, for the purposes of the Act, an organ can be a tissue but a tissue cannot necessarily be an organ, as perceived by the NHA. Blood and gametes are excluded from both definitions.

Using the two terms, 'organ' and 'tissue', interchangeably is problematic as the Act fails to distinguish between procedures provided for the procurement of tissues and solid

²¹² H Oosthuizen & T Verschoor (n 7 above) 36.

²¹³ National Health Act 61 of 2004.

²¹⁴ Act 63 of 1983.

²¹⁵ Sec 1 NHA.

²¹⁶ As above.

organs. Donated tissue goes to a tissue bank, for instance, before it is distributed,²¹⁷ which means the NHA implies that the same procedures are followed with regard to organs and tissues, thus creating a clash. Cornea donations, for instance, are first taken to a tissue bank before being distributed and would thus be better suited to be included under the regulations on tissue banks as opposed to being lumped together with solid organs.²¹⁸ It would therefore be preferable to have the Act properly distinguish between solid organs and tissues in order to avoid any possible confusion.²¹⁹ A possible solution for this would be to have a separate Act which deals specifically with solid organs, as will be discussed in proceeding chapters.

Chapter 8 of the NHA deals with organ and tissue transplantations, as well as blood products and is entitled 'Control of use of blood, blood products, tissue and gametes in humans'. There are at least seven identifiable subject matters covered by chapter 8, namely: 'blood and blood products; assisted reproductive technology; cell-based therapy; transplantation; DNA and genetic services; tissue banks; and examination, allocation and disposal of human bodies and tissues'.²²⁰ Only the sections in this chapter which are relevant to this research will be discussed below when looking at living organ donations and deceased organ donations.²²¹ Important to note also are the regulations which were promulgated in accordance with the NHA which will now be discussed.

- Regulations regarding the general control of human bodies, tissue, blood, blood products and gametes

As mentioned above, the Human Tissue Act of 1983 was the legislation previously in place which dealt with donation and transplantation. The idea behind the Act was promising – it was tasked solely with providing for 'the donation or the making available of human bodies and tissues for the purposes of medical or dental training, research or

²¹⁷ M Slabbert 'The law as an obstacle in solid organ donations and transplantations' (2018) 21 *THRHR* 74.

²¹⁸ As above.

²¹⁹ As above.

²²⁰ M Pepper 'Partial relief from the regulatory vacuum involving human tissues through enactment of chapter 8 of the National Health Act and regulations thereto' (2012) 9 *SAMJ* 736.

²²¹ Sec 53 refers to blood transfusion services, for instance, and sec 54 is more applicable to tissue banks and as such, tissue donations.

therapy or the advancement of medicine or dentistry in general ... for the removal of tissue, blood and gametes from the bodies of living persons and the use thereof for medical or dental purposes ... and for the regulation of the import and export of human tissue, blood and gametes ...'.²²² This idea behind having a single documented piece of legislation focusing on donation and transplantation was a step in the right direction. The 'Draft regulations regarding the general control of human bodies, tissue and organs for transplantation' were further published in March 2008.²²³ Attached to these regulations were: 'a donor consent form (Annexure A); Criteria for Organ Donation and Transplantation (Annexure B); and an Application for a Non-related Donor Transplant (RSA and Foreign Nationals) (Annexure C).²²⁴

In 2012, the Human Tissue Act was however repealed by the NHA, and regulations were promulgated in terms of this Act: 'Regulations regarding the general control of human bodies, tissue, blood, blood products and gametes' (the regulations).²²⁵ These regulations are not identical to the Draft regulations of 2008, and it is thus unclear from where they originated.²²⁶ These regulations deal with the following categories:

...consent for the removal of tissue, blood and blood gametes from living persons; the purpose for which tissue, blood or gametes of living persons may be used; institutions to which and persons to whom human tissue, blood, blood products and gametes may be donated; the purpose of a donation; the removal of donated tissue; the establishment of death; the disposal of unclaimed bodies or deceased persons and the notice to the health officer; the handling over of bodies to certain institutions; the preservation of bodies; the disposal of bodies and tissue; registers; the handling, conveyance and burial of bodies; measures regarding the import of export and disinternment of bodies; the appointment of health officers; duties and reports of health officers; the prohibition of publication of certain

²²² Preamble, Human Tissue Act 65 of 1983.

²²³ These regulations addressed the following aspects: 'Institutions or persons to which human bodies or tissue may be donated; the approval and licensing of transplant units; the requirements for living related and unrelated donations; the requirements for and how transplants relating to non-South African citizens should be done; the allocation of donated organs; the payment in connection with a donation; the prohibition of disclosure of certain information; the appointment and functions of an inspector of anatomy and investigating officers and offences and penalties' - M Slabbert (n 217 above) 72.

²²⁴ M Slabbert (n 217 above) 72.

²²⁵ No 35099, 2 March 2012.

²²⁶ M Slabbert (n 217 above) 72.

facts; offences and penalties; and exclusive rights in respect of bodies of deceased persons, tissue, blood and gametes.²²⁷

The regulations relevant to this discussion will be discussed below pertaining to living and/or deceased organ donations.

2.3.2. Living organ donations (LDT)

With regard to LDTs, sections 55 and 56 of the NHA are relevant. In terms of section 55, transplant surgery is permissible only with the written consent of the donor, in the prescribed manner and according to the prescribed conditions. Section 56 further provides that the surgery may take place only for medical or dental purposes and prohibits the use of donors who are mentally ill in terms of the Mental Health Care Act,²²⁸ or minors, but provides that the Minister may authorise donations in certain instances. These sections do not fully embody the ethical criteria which would be necessary for such a procedure to take place. The most important element in this section would be the element of consent. The regulations do provide in clause 2 for the provision of consent from living donors as follows:

A person may not remove tissue, blood or gametes from the body of another living person for a purpose referred to in section 54 and regulation 3 unless written consent thereto has been granted as follows -

- (a) where such person is older than 18 years, by that person;
- (b) where such person is younger than 18 years, by the parents or guardians of that person;
- (c) paragraph (b) is not applicable to gametes donors who shall never be younger than 18 years;

One may also look towards other pieces of legislation which may be useful. Section 12(2)(c) of the Constitution does shed a bit of light and provides the following:

12 (2) Everyone has the right to bodily and psychological integrity, which includes the right
—

²²⁷ See clauses 2;3;4;7;8;9;10;11;12;15;16;17;18;19;22;23;20;24;25 and 26. Also see M Slabbert (n 217 above) 73.

²²⁸ Mental Health Care Act 17 of 2002.

...

(c) not to be subjected to medical or scientific experiments without their informed consent.

The Constitution does not define 'informed consent'. A definition, however, is provided in section 7 of the NHA which defines it as 'consent for the provision of a specified health service given by a person with legal capacity to do so and who has been informed in terms of section 6'.²²⁹ Section 6 provides the information which needs to be disclosed to the patient prior to surgery.²³⁰

There are a number of important circumstances of which legislation does not take cognisance. As mentioned above, unintentional pressure from family members and loved ones may occur in the situation where a family member needs an organ for transplantation. Legislation does not cater for this when defining and providing for the right of individuals to informed consent. This anomaly may also be seen in other jurisdictions. The European Convention on Human Rights and Biomedicine, for instance, provides for consent as follows;

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time.²³¹ Most jurisdictions have prescribed requirements for consent similar to the above Convention included in their legislation, and some have written consent requirements

²²⁹ Sec 7(3) NHA.

²³⁰ Sec 6(1) of the NHA provides that all health care providers must inform a user (persons who are receiving treatment – sec 1) of the following:

'1(a) the user's health status except in circumstances where there is substantial evidence that the disclosure of the user's health status would be contrary to the best interests of the user;
(b) the range of diagnostic procedures and treatment options generally available to the user;
(c) the benefits, risks, costs and consequences generally associated with each option; and
(d) the user's right to refuse health services and explain the implications, risks, obligations of such refusal.

(2) The health care provider concerned must, where possible, inform the user as contemplated in subsection (1) in a language that the user understands and in a manner which takes into account the user's level of literacy.'

²³¹ Art 5 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the application of Biology and Medicine: Convention on Human Rights and Biomedicine was adopted by the Council of Europe in 1997 and entered into force on 1 December 2009.

prescribed as, for instance, by the NHA.²³² The HPCSA of South Africa does provide guidelines to be followed in ensuring the voluntariness of the decision made. These guidelines, however, appear to be more focused on the patient and not on the donor (should they be applied in this context).²³³ Two problems can, therefore, be observed: legislation does not observe the circumstances involving unintentional pressure on the donor; and it appears more focused on the recipient than on the donor.

Regarding the principle of beneficence, it has been stated above that positive beneficence bestows a positive obligation to act to the benefit of others. To what extent this obligation may be enforceable may be questioned. Beauchamp and Childress, as well as Price, discuss the American case of *McFall v Shimp*²³⁴ in the evaluation of positive beneficence. In this case, Robert McFall, the plaintiff, suffered from a rare type of bone marrow disease and needed a compatible donor as his prognosis was poor.²³⁵ Close relatives of the plaintiff were tested for a match, and it was found that the defendant was the only suitable donor.²³⁶ The defendant refused to undergo further tests and, subsequently, also the bone marrow transplant.²³⁷ Following this, the plaintiff sought a preliminary injunction from the court to compel the defendant to undergo the procedures and also the transplantation.²³⁸ The Court ruled that ‘the law does not allow him to force Shimp (the

²³² Sec 55(a) NHA.

²³³ Health Care Professions Council of South Africa ‘Seeking patients’ informed consent: the ethical considerations’ (2007) 2nd Ed. Pg. 6. Cl 7 provides the following:

7.1 It is for the patient, not the health care practitioner, to determine what is in the patient's own best interests. Nonetheless, practitioners may wish to recommend a treatment or a course of action to patients, but they must not put pressure on patients to accept their advice. In discussions with patients, health care practitioners should:

7.1.1 Give a balanced view of the options;

7.1.2 Explain the need for informed consent.

The clause goes on to provide for the declaration of potential conflicts of interest by medical personnel (cl 7.2), the duty on health care practitioners to ensure that the patient has reached the decision on their own taking into consideration potential pressure from insurance companies, employers or others (cl 7.3) and make provision for patients who are detained, by police or immigration officials, under the provision of any mental health legislation.

²³⁴ *McFall v Shimp* No 78 – 17711. 10 Pa. D. & C. 3d 90 (1978).

²³⁵ As above.

²³⁶ As above.

²³⁷ As above.

²³⁸ As above.

defendant) to engage in such acts of positive beneficence, but the judge added that Shimp's refusal was *morally indefensible*.²³⁹

This case has been recorded in the Nuffield report as illustrating the English position (where a solid organ was involved) stating that '(t)he fact that there may be an urgent need for certain tissue cannot legally justify its being taken without consent; the law's commitment to the absolute right to 'bodily security' of one person cannot be abandoned in order to save the life of another person'.²⁴⁰ Some authors believe that the decision in this case was correct and in line with the 'autonomistic rather than libertarian philosophy' which is prevalent in American law.²⁴¹ There are jurisdictions, however, which provide a more communitarian system, for example across Europe where individuals are required to take steps towards assisting a person in danger or distress.²⁴² These values are, however, more in line with a Marxist viewpoint where it is believed that that which one possesses belongs to the state, or, if determined by the state, to someone else who may be in need.²⁴³ Examples cited are, however, more in line with instances such as military conscription²⁴⁴ and, as such, can hardly be associated with organ donations.

Price notes that the decision of the case supports a Kantian perspective regarding the respect of individuals and not using a person 'solely as a means to the ends of others'.²⁴⁵ Peter Singer has proposed an 'ethical obligation of beneficence' which surrounds 'a duty to prevent evil where this can be accomplished without sacrificing *anything of comparable moral importance*, that is up to the point where we would cause more suffering to ourselves than we would relieve through giving'.²⁴⁶ This also highlights the utility factor in the beneficence model defined by Beauchamp and Childress, where there needs to be some sort of balance between the risks and benefits involved. In applying this thought process to the *McFall* case, the reasons for the defendant's refusal can be pointed out.

²³⁹ T Beauchamp & J Childress (n 14 above) 203.

²⁴⁰ Nuffield Council on Bioethics Working Party Report, *Human Tissue: Ethical and Legal Issues*, Nuffield Council of Bioethics, London; as quoted in Price (n 96 above) 233.

²⁴¹ P Singer 'Famine, affluence and morality' (1972) 1 *Philosophy and Public Affairs* 229 - As quoted in D Price (n 95 above) 235.

²⁴² As above.

²⁴³ As above.

²⁴⁴ As above.

²⁴⁵ D Price (n 109 above) 234 – 235.

²⁴⁶ D Price (n 109 above) 235.

Shimp's fears were based on the fact that he would have to undergo 100 to 150 punctures to his pelvic bone for the transplant to occur, risking the chance of death from the anaesthetic as well as a fear of becoming disabled.²⁴⁷ The punctures would, however, have been painless under anaesthetic, and there was only a one in 10 000 chance of death.²⁴⁸

In this case, the risks are substantially lower than the benefit, the benefit being the chances of McFall recovering from the surgery. Ultimately, Robert McFall died in August 1978.²⁴⁹ Fordham, in the discussion of this case, is of the opinion that a more satisfactory method is necessary in dealing with the instances that led to this case, and that a method which 'is intended to achieve, admittedly through coercive means, a minimum level of common decency and humanity as an element of social contract' should be endorsed.²⁵⁰

The construct that is suggested would require the plaintiff to prove certain criteria, namely:

- That he is in *imminent* danger of dying from a disease that can be treated by transplantation of an organ, tissue, or fluid from another;
- That he stands to experience *substantial benefit* from such a transplant with the defendant serving as donor;
- That transplantation from the defendant is the *exclusive* mode of treatment that offers the prospect of *substantial benefit* to the plaintiff; and
- That the organ, tissue, or fluid sought is *expendable* by the donor – given the quantity of tissue or fluid to be removed and its regenerative capacity – and that the removal of the organ, tissue, or fluid will not result in disfigurement.²⁵¹

The author does state that the purpose of his construct is to incite debate among 'members of the legal, medical, philosophical, theological, and sociological communities', and that legislative endorsement would contribute towards 'achieving substantial justice in this area'.²⁵² This construct would indeed be in concord with the description of Beauchamp and Childress of the *McFall* case as being a 'borderline case' when perceived

²⁴⁷ T Beauchamp & J Childress (n 14 above) 203.

²⁴⁸ As above.

²⁴⁹ H Fordham 'Coerced Donation of Body Tissues: Can we live with *McFall v Shimp?*' (1979) 40 *Ohio State Journal* 414.

²⁵⁰ As above. Fordham uses the term 'social contract' to refer to 'the bond that forms the basis of all civilised societies'.

²⁵¹ H Fordham (n 249 above) 416.

²⁵² H Fordham (n 249 above) 415.

against their ethical framework which requires ‘action where a person at substantial risk of harm can achieve a high probability of avoiding harm through actions of another, which do not present significant risks, costs or burdens to that other, and where the anticipated benefit outweighs any risks, costs or burdens implicated by it’.²⁵³ Much would, therefore, depend on the type of tissue being required.²⁵⁴

The general consensus when it comes to LDTs is that, in the case of solid organs, donations would be viewed as a ‘supererogatory act and not a morally obligatory one’ and donations in this instance would display ‘*moral goodness* but not a *moral duty*’.²⁵⁵ While it may be perceived as being overly demanding for the method or construct provided by Fordham to be adopted in jurisdictions worldwide, it may, however, be thought-provoking at the very least as an identification of a mode of beneficence which may assist in saving, or even save, the lives of individuals who are in organ distress.

2.3.3. Cadaveric organ donation and/or transplantation

The NHA makes provision for CDTs in sections 61 to 64. Section 61 provides for the allocation of organs after they have been obtained from deceased donors for transplantation or treatment.²⁵⁶ This section and its shortcomings are dealt with in more detail below.²⁵⁷ Section 62 provides for the opting–in system of organ procurement in this regard, stating that a person is considered to be an organ donor only upon either making his intentions known in a will, or signing a document in front of two competent witnesses, or making an oral statement in front of two competent witnesses.²⁵⁸ Slabbert makes note on the fallacies involved with this section as follows:

A person who is competent to make a will is a person who is 16 years or older. A competent witness is a person who is 14 years or older. The question may be asked as

²⁵³ T Beauchamp & J Childress (n 14 above) 256 as quoted in D Price (n 96 above) 235.

²⁵⁴ As above.

²⁵⁵ As above.

²⁵⁶ Sec 61(1).

²⁵⁷ See chap 5 sec 5.4. This section deals with the allocation of organs in terms of sec 61 of the NHA as well as cl 5 of the regulations and provides a comparison with the allocation systems from other countries as is relevant to this research.

²⁵⁸ Sec 62(1).

why the Act does not specify the ages as such. Once again the question could be asked why a person should be 16 years of age in order to be able to donate his or her organs after death, if the Children's Act allows a child of 12 years to make major decisions concerning his or her health.²⁵⁹

In addition to this, Slabbert also finds fault in the notion of including the indication that one is a donor in a will as a will first needs to be validated by a Master of the High Court which is in itself a lengthy procedure whereas organ transplantation is a 'time-restricted procedure'.²⁶⁰ In addition, the requirement of having two competent witnesses present at the signing of the document is indicative of a living will which has no legal force in South Africa.²⁶¹ This requirement in any case may be seen as only a suggestion to the family members or next of kin, as in practice they may go against the wishes of the deceased.²⁶² Also, the need for an oral statement is futile in Slabbert's view as it would be 'difficult to show that such a statement was made'.²⁶³ It can therefore be seen that sections 62(1) and 62(2) are flawed and should be either removed or replaced or both.

Section 62(3) further states that after the death of a potential donor, should the next of kin or family members be untraceable, the Director-General of Health may donate the donor organs and/or tissues to a prescribed institution provided that the 'prescribed steps' have been taken to locate a person authorised to give consent. These 'prescribed steps' however are neither explained in the NHA nor in the regulations thereto. This reveals another shortcoming of not only the Act but also the regulations. A possible solution for this is provided by McQuoid-Mason who suggests that the same steps 'published for

²⁵⁹ See M Slabbert (n 211 above) 78. Examples can be seen from sec 129(2) of the Children's Act 38 of 2005 which allows a child over the age of 12 years to 'consent to his or her own medical treatment or to the medical treatment of his or her child...' Sec 129(3) allows a child over the age of 12 also to consent to his (or his child's) surgical operation. Although this thesis is concerned primarily with adults as opposed to minors, it is still relevant to take note of this shortcoming in relation to this section of the Act dealing with donations as a whole.

²⁶⁰ M Slabbert (n 211 above) 78.

²⁶¹ As above. Also see *Clarke v Hurst* 1992 4 SA 630 (D).

²⁶² As above. This also renders sec 62(2) unnecessary as in practice the family will always be contacted over determining the will of the deceased. (Sec 62(2) states that 'In the absence of a donation under subsection (l)(a) or of a contrary direction given by a person whilst alive, the spouse, partner, major child, parent, guardian, major brother or major sister of that person, in the specific order mentioned, may, after that person's death, donate the body or any specific tissue of that person to an institution or a person contemplated in section 63').

²⁶³ As above.

donations of human biological material for genetic testing, genetic training and genetic and genetic health research for therapeutic purposes, in the Regulations for the use of human biological matter' should be applied in this regard.²⁶⁴

Clause 5 of the regulations needs also be mentioned and states the following:

(1) A donation that does not have a specific institution as donee, the institution in the appropriate category which is nearest to the place where the body is kept of the person whose body or tissue has been so donated, shall be deemed to be the donee.

(2) If a donation has been made to a specific donee who is not in easy reach at the time and place of the death of the person whose body or any specific tissue thereof was so donated the institution in the appropriate category which is nearest to that place shall be deemed to be the donee.

Slabbert writes that the act of specifying a donee in terms of this clause would be pointless as 'donated solid organs always go to the nearest transplant facility, or if possible, it will be transferred to where the need is most urgent'.²⁶⁵ This shows that what happens in practice and what is provided for by the legislation needs to correspond with one another in order to prevent confusion or a case where the legislation becomes obsolete.

When dealing with CDTs, the reluctance of people to become organ donors can also be seen in the confusion surrounding the meaning and scope of the concept of death. Death is approached and defined differently in various areas, such as in the religious sector and in the medical field. Kerridge *et al* note that a definition for death is important for purposes of organ procurement, the reading of wills, defining murder, allowing cremation or burial to commence, and also for purposes of the grieving process.²⁶⁶ Most transplant nations have defined death as 'brain death' but, in some jurisdictions, for instance the South African jurisdiction, a proper definition for death is not provided, and it could be said that this may be a further reason as to why individuals turn to other areas, like spirituality,

²⁶⁴ D McQuoid-Mason 'Human tissue and organ transplant provisions: chapter 8 of the National Health Act and its regulations, in effect from March 2012 – what doctors must know' (2012) 1012(9) *SAMJ* 734.

²⁶⁵ M Slabbert (n 211 above) 80.

²⁶⁶ IH Kerridge *et al* 'Death, dying and donation: organ transplantation and the diagnosis of death' (2002) 28 *Journal of Medical Ethics* 89.

religion and/or culture, for assistance in this delicate arena.²⁶⁷ It is, therefore, important to determine an appropriate definition for death, by first analysing the most prevalent definition applied, viz. 'brain death'.

Definition of death

Nair-Collins distinguishes between three different concepts of death, namely the biological criterion, physiological criterion and the legal concept of death.²⁶⁸ The biological concept of death depicts 'the permanent cessation of the functioning of the organism as a whole'.²⁶⁹ In dealing with the physiological depiction of whether a biological death has been reached, Nair-Collins suggests this to be when all of the brain functions have irreversibly ceased.²⁷⁰ The technicalities involved in this concept of death were determined by the Harvard Ad Hoc Committee to Examine the Definition of Brain Death.²⁷¹ This is a committee comprising of lawyers, theologians, social scientists and physicians, and they determined 'operational criteria' for what they termed to be an 'irreversible coma', which was taken then to be 'sound scientific evidence'.²⁷² The four criteria are as follows:

- 1) Unreceptivity and unresponsiveness;
- 2) No movements or breathing;
- 3) No reflexes; and
- 4) Flat electroencephalogram ('of great confirmatory value').²⁷³

²⁶⁷ Cl 9 of the regulations does state how death should be established as follows: 'The death of a person concerned shall be established by at least two medical practitioners, one of whom shall have been practising as a medical practitioner for at least five years after the date on which she or he was registered as a medical practitioner, and none of those medical practitioners shall transplant tissue removed from that person into a living person or take part in such transplantation: Provided that where the tissue concerned is eye tissue, the death of the person from whom the tissue is removed shall be deemed to have been established by the issuing of a certificate of death in terms of the relevant law by a medical practitioner in respect of that person.'

²⁶⁸ M Nair-Collins 'Death, brain death, and the limits of science: why the whole-brain concept of death is a flawed public policy' *Journal of Law and Med Ethics* (2010) 667.

²⁶⁹ M Nair-Collins (n 268 above) 667-668.

²⁷⁰ M Nair-Collins (n 268 above) 668.

²⁷¹ R Veatch (n 3 above) 46.

²⁷² As above.

²⁷³ As above.

These technicalities, however, fail to determine when patients who are in this ‘irreversible coma’ are ‘dead’, that is, when they should cease to be treated as human beings ‘who possess the same moral rights and obligations as other living humans’.²⁷⁴ Veatch concludes that this determination is hardly a scientific or medical one, but rather a moral or philosophical question.²⁷⁵ Indeed, the widely accepted definition of brain death is not without its own controversies. It has been argued that, when examined in greater detail, it is evident that, even with the ‘irreversible cessation of all functions of the entire brain, including the brain stem’, some elements of the brain remain intact, such as the ‘posterior pituitary secretion of anti-diuretic hormone and thermoregulation’ which raises inconsistencies about the definition.²⁷⁶

One may also consider the ideology of ‘personhood’, where a human being is viewed as a ‘person’ as opposed to being simply a biological entity.²⁷⁷ Death is associated with the biology of a person and with the organism ceasing to be a person.²⁷⁸ In other words, the biological aspect of death would be more of a cellular death. Personhood looks into different abilities and the quality of the person’s awareness from a psychological perspective.²⁷⁹ This view goes into the perception of human beings as moral agents, a Kantian outlook, focusing on the individual as one who is self-governed, can be accountable for his actions, and can provide motives for their actions.²⁸⁰

It is, however, important to note that, while all moral agents are individuals in the psychological sense, this does not mean that all persons in the psychological sense happen to be moral agents.²⁸¹ This can be the case where a human being has dementia, and, as such, may be seen as a person in the psychological sense, although not as a moral agent owing to the fact that he may not always be held accountable for his actions.²⁸² The determination in this instance would relate to the extent to which the

²⁷⁴ As above.

²⁷⁵ As above.

²⁷⁶ E Choi *et al* ‘Brain death revisited: the case for a national standard’ (2008) 36 *Journal of Law, Medicine and Ethics* 826.

²⁷⁷ D Price (n 109 above) 64.

²⁷⁸ As above.

²⁷⁹ As above. Also see M Nair-Collins (n 268 above) 668.

²⁸⁰ M Nair-Collins (n 268 above) 668.

²⁸¹ As above.

²⁸² As above.

definition of death can include the notion of personhood, if at all. It may be posited that the notion of personhood is essential as the consciousness of an individual should play a major role in deciding whether a person can be considered dead to all intents and purposes. This inclusion may also be appropriate with regard to certain religious or cultural views regarding the death of the individual.

The legal concept of death denotes the legislative description of death which is suited to socio-legal purposes.²⁸³ As has been stated, some jurisdictions define death as either the ‘whole brain death’ or ‘brain stem death’. A definition of brain stem death would be restricted to the brain stem only. In the United Kingdom, three cases may be referred to when dealing with the issue of death. In the case of *Re A*, the court held that a child, who was being kept alive by a ventilation machine and whose brain stem was dead, was considered to be dead.²⁸⁴ This principle was also held in the case of *Mail Newspapers v Express Newspapers*.²⁸⁵ Interestingly enough, Tony Bland, who was not being kept alive on a ventilator was declared not to be dead (in that his brain stem was still functioning), even though he was in a permanent vegetative state.²⁸⁶ From the case law, therefore, it can be determined that the functioning of the brain stem is indeed imperative in the depiction of death in Wales and the United Kingdom, although it has been argued that the case law does not, in fact, dictate the *legal* definition of death in the United Kingdom, but rather validates the conception that an individual who is brain stem dead is dead for legal purposes.²⁸⁷

Regarding other jurisdictions, although they may provide a definition for death in their legislation, their definitions tend to be vague and not adequate for application to organ transplantations. In South Africa, for example, the NHA defines death as ‘brain death’, and does not provide any further examination of the term in this regard.²⁸⁸ The same

²⁸³ As above.

²⁸⁴ *Re A* (1992) 3 Med LR 303; as quoted in Price (n 74 above) 56.

²⁸⁵ *Mail Newspapers v Express Newspapers* (1987) Fleet Street Reports 90.

²⁸⁶ *Airedale NHS Trust v Bland* (1993) 1 ALL ER 821 (HL); as quoted in Price (n 95 above) 56.

²⁸⁷ JK Mason *Law and Medical Ethics* (2003) 417.

²⁸⁸ Act 61 of 2003; sec 1.

applies to the National Health Bill in Nigeria, where death is also defined as ‘brain death’.²⁸⁹

One may look towards international analyses for guidance. The World Health Organisation (WHO) provides a glossary of terms and definitions for the purpose of donation and transplantation, where ‘death diagnosis’ is defined as the ‘confirmation of death from evidence acquired through clinical investigation/examination, meeting criteria of brain or cardiac death’.²⁹⁰ This glossary does provide for a distinction between brain death and cardiac death, both of which allow for the transplantation of organs to take place after either form of death. A deceased donor is defined as follows:

A human being declared, by established medical criteria, to be dead and from whom cells, tissues or organs were recovered for the purpose of transplantation. The possible criteria are:

- Deceased Heart Beating Donor (Donor after Brain Death): Is a donor who was declared dead and diagnosed by means of neurological criteria; and
- Deceased Non-Heart Beating Donor (Donor after Cardiac Death) = Non-heart beating donor (NHBD): Is a donor who was declared dead and diagnosed by means of cardio-pulmonary criteria.²⁹¹

These definitions lack enough substance to be able to establish clarity definitively on the meaning of ‘death’. The problem with such a narrow and limited meaning is that, without a definitive moment of death, there can be uncertainties as to whether an individual has *died* for the purposes of organ procurement. Uncertainties may lead to a hesitation on the part of family members to agree to donate the organs of their loved ones or even to become organ donors themselves.

One may, thus, look towards case law in order to attempt to gain clarity on the matter. The case of *Re A*, as discussed above, does not provide clarity as there is indeed controversy as to whether brain stem death can be considered to be the legal definition

²⁸⁹ National Health Bill, of 2014; sec 64.

²⁹⁰ World Health Organisation Global glossary of terms and definitions on donation and transplantation – As endorsed in Geneva, November 2009; 9.
<<http://www.who.int/transplantation/activities/GlobalGlossaryonDonationTransplantation.pdf>>
(accessed on 23/05/2018).

²⁹¹ As above.

of death in the United Kingdom and Wales. The South African case of *S v Williams*²⁹² was the first case to deal expansively with the issue of death in South African medical law. In this case, the court decided that to remove a respirator (a breathing apparatus) from a patient who is being kept alive by it would not result in an act of causing death.²⁹³ It was determined that the disconnection of the respirator does not interrupt the causal connection between wounding the deceased and his eventual death as this connection exists from beginning to end.²⁹⁴ The court took into account the community's traditional view and stated that death will occur where there is no longer any breathing or heartbeat.²⁹⁵ The court did not, however, decide on whether brain stem death, being the moment of death, should be accepted in law (as was the view held by medical science).²⁹⁶ This decision also brings to light how the concept of death is not solely scientific but rather a moral question, as the societal depiction of death was the deciding factor.

This can also be seen in the South African case of *Clarke v Hurst*,²⁹⁷ where the concept of brain death was evaluated. In this case, the patient, who was a medical doctor, had been in an irreversible and persistent vegetative state since the year 1988, and was being fed through a naso-gastric tube artificially.²⁹⁸ The applicant made an application to the court for an appointment as *curatrix personae* of the patient including powers in that capacity to discontinue treatment, i.e. to authorise the removal of the feeding tube.²⁹⁹ The court determined whether it would be reasonable to terminate the treatment judged by the *boni mores* of society, and it posited that this would be dependent on the quality of life of the patient.³⁰⁰ *In casu*, the patient's brain had irreversibly lost 'the capacity to induce a physical and mental existence at a level that qualified as human life' and, as would be determined by the legal convictions of society, the function of the feeding tube did not serve to support human life as it is commonly acknowledged.³⁰¹ It was further held that

²⁹² *S v Williams* 1986 4 SA 1188 (A).

²⁹³ As above.

²⁹⁴ As above.

²⁹⁵ As above.

²⁹⁶ As above.

²⁹⁷ *Clarke v Hurst NO and Others* 1992 4 SA 630 (D).

²⁹⁸ *Clarke v Hurst NO and Others* (n 443 above) 398.

²⁹⁹ As above.

³⁰⁰ *Clarke v Hurst NO and Others* (n 443 above) 414.

³⁰¹ As above.

maintaining a life by way of certain biological functions including the respiration, digestion, blood circulation and heartbeat of a patient, where there is no cerebral and cortical functioning of the brain, cannot be connected with life in a human being or animal.³⁰²

These cases reveal the integral part that the convictions of society play in the adoption of legal norms. Culture and religion play a major role in determining what the majority of society perceives in the case of such sensitive topics as the determination of when death has occurred, amongst other areas. These religious and cultural perceptions will be dealt with extensively in the third chapter.

2.4. Conclusion

The principles of biomedical ethics, as devised by Beauchamp and Childress, are important in determining what may be ethically permissible in the medical arena, particularly with regards to organ donation and/or transplantation. It has been found, however, that many difficulties arise when determining whether these principles have been adhered to, and whether legislation should intervene and be adapted accordingly.

With regard to the principle of respect for autonomy, for instance, it has been shown that legislation tends to focus more on the rights of the recipient and not necessarily on those of the donor, yet both parties must have their autonomy respected. Issues such as unintentional pressure placed on family members need to be highlighted with regard to informed consent, as it has been shown that, in the instance of LDTs between family members, the ability to provide informed consent may already be compromised. It may be posited that a modicum of medical paternalism should possibly be allowed to take over in these instances, a soft form of paternalism if you will.

When dealing with CDTs, a soft form of paternalism may also be warranted. As stated above, family members are already suffering a loss and, as such, may not be able to deal with the idea of organ donation. A system of presumed consent may be acceptable in this instance, where a decision has been made for the family members, abolishing the need for them to have to deal with any additional trauma. This system is, however, not without

³⁰² *Clarke v Hurst NO and Others* (n 443 above) 415.

its ethical problems. There will always be the possibility of a violation of an individual's or patient's personal autonomy, as described above. Such a violation, however, may be prevalent in an opting-in system as well in instances where an individual has noted his wish to be an organ donor and the next of kin overrides it, or where a person changes his mind and forgets to revoke the registration. This is the position in South Africa today. A logical solution, therefore, would be to implement a presumed consent model, which will allow fewer mistakes, as discussed above, and also lead to a higher donation rate. The problem would be determining whether culture and religion would be able to align with such type of system.

Finally, the definition of death is of great importance to the discussion. This is because of the sensitive nature of the concept. Currently an appropriate definition has not been provided in legislation or in case law. This term has been difficult to define legally as has been shown above. Brain death, which is the more widely-accepted definition in most transplant nations, is not without its difficulties. It is ordinarily referred to as the irreversible cessation of all functions of the brain but, even with this, it has been seen that certain elements of the brain remain intact. It would, therefore, be of importance to look not only at the biological concepts of death, but also the more moral, philosophical and psychological aspects, that is the concept of personhood. In determining these factors, it is imperative to look at the cultures and/or religions of the majority of the population and deem what would be appropriate and morally acceptable. These should all be taken into account in the formulation of a proper definition of death for the purposes of organ transplantation.

A complete separation of legal concepts and ethical norms can hardly be justifiable. As has been expressed above, ethical norms, which are determined by society, are often incorporated into legislation. Since ethics are determined by societal precepts, it only makes sense that they should be given statutory recognition. Although in medical law certain ethical guidelines have been given this recognition, it can be seen that there is still a lack of clarity regarding the extent and scope that ethical norms have in the legal arena in general. Attainment of this clarity is pertinent for the sake of organ procurement and donation. Although South Africa can be said to be a secular nation, where both religious

and cultural rights are given recognition, it is important to highlight this fact when dealing with topics as sensitive as death and donation.

A further question to be asked would be the objections of culture and religion with respect to organ donations, if any, and whether a presumed consent model could be aligned with these different beliefs. This is the discussion that will inform the next chapter.

CHAPTER THREE

Religion, culture and organ donation

3.1. Introduction

When faced with situations in which a difficult decision needs to be made, people tend to revert to their religious and/or cultural traditions. Religion and culture, therefore, remain of great significance in society. Secular states acknowledge this importance by providing a right to the religious beliefs of individuals (sometimes including a right to cultural belief) in their constitutions or legislation. South Africa, for example, provides for the right to freedom of religion in section 15 of the Constitution of the Republic of South Africa, 1996 (Constitution). This right is further protected by the equality clause of section 9, in which it is stated that every person is equal before the law and may not be unfairly discriminated against, directly or indirectly, on various grounds, including a person's religion and culture.¹

South Africa often is described as 'a kaleidoscope of cultural, linguistic and religious heterogeneity, which is a source both of infinite richness as well as intense historical, contemporary and potential conflict'.² Trying to find a resolution for the difficulties associated with the accommodation and protection of linguistic, religious and ethnic minorities in 'a democratic body politic operating according to the philosophy and practice of constitutionalism and a justiciable bill of rights' overshadowed all other issues relating to both the Interim³ and 1996 Constitutions.⁴ This dominance makes sense considering this issue's divisiveness during the political and/or historical evolution of South Africa from the time of colonialism to the fall of apartheid.⁵

¹ Subsecs 9(1) and 9(4) Constitution of the Republic of South Africa, 1996. The grounds include one's 'race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth'.

² GE Devenish *A commentary on the South African Constitution* (1998) 77.

³ Constitution of the Republic of South Africa, Act 200 of 1993.

⁴ GE Devenish (n 2 above) 77.

⁵ As above.

The protection of minority cultural, linguistic and religious groups is an international concern as well. Thornberry states that '[t]he protection of ethnic, religious and linguistic groups is one of the oldest concerns of international law'.⁶ Indeed the United Nations' (UN) viewpoint on this is that minorities cannot be 'washed away' and that, in the interest of international peace and their own interest states need to 'grapple realistically with the problems of minorities on their territory'.⁷

The Constitution, 1996 provides for the protection of language, culture and language in sections 30 and 31 as follows:

30 Language and culture

Everyone has the right to use the language and to participate in the cultural life of their choice, but no one exercising these rights may do so in a manner inconsistent with any provision of the Bill of Rights.

31 Cultural, religious and linguistic communities

(1) Persons belonging to a cultural, religious or linguistic community may not be denied the right, with other members of that community—

(a) to enjoy their culture, practise their religion and use their language; and

(b) to form, join and maintain cultural, religious and linguistic associations and other organs of civil society.

(2) The rights in subsection (1) may not be exercised in a manner inconsistent with any provision of the Bill of Rights.

Section 31 does not use the term 'minorities' but instead refers to cultural, religious and linguistic *communities*, which places the emphasis therefore on 'the protection of cultural, religious and language diversity, rather than minority protection' according to Devenish.⁸ These sections also provide that they may exercise these rights only in so far as they do not go against any other right in the Bill of Rights.⁹

⁶ P Thornberry *International law and the rights of minorities* (2001) 1.

⁷ P Thornberry *International law and the rights of minorities* (1991) 387 – as discussed in Devenish (n 2 above) 78.

⁸ GE Devenish (n 2 above) 78.

⁹ Chap 2 of the Constitution.

The importance of religion and culture in society may also be seen in nations in which a specific religion is recognised as that nation's 'official' religion. Malaysia, for instance, recognises Islam as the religion of the Federation, but allows for the peaceful and harmonious practice of other religions.¹⁰ Some nations, such as Nigeria, strictly forbid a single state religion but allow for freedom of religion.¹¹ The Constitution of the Republic of Singapore, as well, provides for freedom of religion and the right not be discriminated against on this ground.¹²

These examples are evidence that religion and culture play an important role in any society. Several authors note the importance of this factor, particularly with regards to organ donation and transplantation. Siemionow argues that, in diverse and multicultural nations, an understanding of religious and cultural backgrounds is of major importance in order to comprehend the fears of donor families with reference to organ donation.¹³ Robson *et al* also state that in a multicultural, multi-ethnic and multi-religious community, such as Malaysia, religious and social issues relating to organ donation play an important role.¹⁴

Culture, too, plays a big role in a person's decision regarding organ transplantation: Daar and Marshall state that culture contributes greatly to the 'perception of illness, response to treatment, and the organisation of medical care'.¹⁵ With regards to transplantation they indicate that cultural considerations will arise in the acceptance or rejection of the type of treatment, consent to donation, how the transplant programme is organised, the particular surgery to be performed, as well as the possible outcome.¹⁶

It is clear that religion and culture are factors which need to be considered when devising a human rights-based approach toward organ donation. The majority of religions appear

¹⁰ Sec 3(1) of the Federal Constitution of Malaysia, 1 November 2010.

¹¹ Sec 10 of the Constitution of the Federal Republic of Nigeria, 1999 prohibits the adoption of state religion. Sec 38 further allows for the freedom of conscience and religion, amongst other grounds.

¹² Constitution of the Republic of Singapore, 9th August 1965; sec 15.

¹³ M Siemionow A Rampazzo & BB Gharb 'Cultural differences in views on transplantation, including composite tissue allotransplantation' (2011) 66 *Annals of Plastic Surgery* 410.

¹⁴ NZ Robson, AH Razack & N Dublin 'Organ transplants: ethical, social and religious issues in a multicultural society' (2010) 22 *Asia-Pacific Journal of Public Health* 274.

¹⁵ AS Daar & P Marshall 'Culture and psychology in organ transplantation' (1998) 19 *World Health Forum* 131.

¹⁶ As above.

to support the notion of organ donation; despite this, however, there is still a very large shortage of organs available for transplantation worldwide.¹⁷ In part, this shortage is due to a lack of clarity on what exactly the religious and cultural stance on organ donation is. Organ donation and transplantation are fairly recent modes of treatment, whereas religious scriptures and cultural beliefs date back a lot further; it is, therefore, understandable that there are conflicting interpretations in this regard which shed light on the possible religious and cultural attitudes toward donation.

This chapter, then, offers an analysis of specific religious and cultural beliefs, both those which are supportive of and those which are dismissive of organ donation. In addition, it explores the possibility of attaining clarity on the attitudes of religion and culture towards organ donation. This clarity will apply to both living and deceased organ donation, as well as relating to the possibility of incorporating an opting-out system of organ procurement in this context.

3.2. Religious belief and organ donation – can they be reconciled?

As stated above, religious beliefs greatly influence an individual's decision-making, including decisions on the matter of organ donation. The process of reconciling these issues is firstly in determining the misconceptions and different interpretations with regard to the different religions and, then, in conducting a search for clarity in this regard. Focus is placed on the main religions in South Africa – Christianity, Islam, Judaism, Hinduism and Buddhism.

3.2.1. Christianity and organ donation

The origins of Christianity date back as far as the First Century CE.¹⁸ The Christian religious scriptures were written long before there was any consideration of organ donation.¹⁹ Accordingly, the religious position on organ donation is subject to scholarly

¹⁷ M Slabbert, FD Mnyongani & N Goolam 'Law, religion and organ transplants' (2011) 76 (2) *Koers* 263.

¹⁸ A Rudra & OP Murty 'Attitude to organ donation and autopsy in different religious denominations' (2014) 31 *Journal of Forensic Medicine & Toxicology* 55.

¹⁹ G Randhawa 'Death and organ donation: meeting the needs of multi-ethnic and multi-faith populations' (2012) 108 *British Journal of Anaesthesia* 109.

interpretation of the particular religious scriptures and ‘the values espoused by the faith’.²⁰ Faith leaders, also, assist in such interpretation. Of the different denominations of Christianity, the Pope is the head of Roman Catholic Church.²¹ Catholics view death as a step towards the fulfilment of life and, along with members of the Anglican Church they believe they will share in Christ’s resurrection.²² These beliefs are shared by members of other denominations: Baptists, Methodists, and Seventh Day Adventists to name but a few.²³

Rudra and Murty are of the opinion, irrespective of the branch of Christianity, that organ donation is considered to be an act of charity.²⁴ Slabbert states that most religions support the promotion and saving of lives and, as such, would be inclined to accept the altruistic donation of organs.²⁵ Veatch is of the opinion, with regard to the Protestant and Catholic denominations of Christianity, that there appears to be no serious hindrance towards the removal of organs from cadavers, provided that respect is shown for the deceased and the required permission is obtained.²⁶ Randhawa goes so far as asserting that families who cite religion as a hindrance to donation, in fact, may not have ‘an informed view of their faith’s position regarding organ donation based upon extensive debate and thought with their faith mentor’, and they may be expressing a personal interpretation gathered from their own intuition or perspective.²⁷ This response applies to both living and deceased donations.

The objection to donation based on religion most frequently raised is with regard to belief in the resurrection upon the Rapture. Veatch describes the belief in bodily resurrection by certain fundamentalist Protestant groups which creates a reluctance to donate.²⁸ This belief is derived from the ‘second coming’ of Jesus Christ as discussed in the Bible; different books in the Bible discuss this event. Essex, in his discussion of the Rapture and

²⁰ As above.

²¹ A Rudra & OP Murty (n 18 above) 55.

²² As above.

²³ As above.

²⁴ As above.

²⁵ M Slabbert, FD Mnyongani & N Goolam (n 17 above) 263.

²⁶ R Veatch *Transplantation ethics* (2000) 6.

²⁷ G Randhawa (n 19 above) 109.

²⁸ R Veatch (n 26 above) 7.

book of Revelation, points to the belief that the coming of Christ will include 'the bodily resurrection of the dead in Christ and the bodily transformation of those Christians still living' as referred to by the apostle Paul.²⁹ He further makes reference to the texts in 1 Thessalonians 4:13 - 18 and 1 Corinthians 15: 35 - 58.³⁰ The relevant verse from the book of 1 Thessalonians reads as follows;

For this we declare to you by a word from the Lord, that we who are alive, who are left until the coming of the Lord, will not precede those who have fallen asleep. For the Lord himself will descend from heaven with a cry of command, with the voice of an archangel, and with the sound of the trumpet of God. And the dead in Christ will rise first. Then we who are alive, who are left, will be caught up together with them in the clouds to meet the Lord in the air, and so we will always be with the Lord.³¹

Literally interpreted, one can perceive how it could be believed that, when the Rapture is upon us, and the living as well as the dead are taken from the earth, one would want one's body, as well as the bodies of one's deceased loved ones, to be intact (not missing any organs). Essex defines the verses mentioned in 1 Corinthians to be a confirmation of the resurrection of the body from that which is perishable to that which is imperishable.³²

Brindle also speaks on the Rapture and evidence of its imminence.³³ In his discussion of Jesus' second coming, he refers to chapter 14 of the book of John. The relevant verses read as follows:

Let not your hearts be troubled. Believe in God; believe also in me. In my Father's house there are many rooms. If it were not so, would I have told you that I go to prepare a place for you? And if I go and prepare a place for you, I will come again and will take you to myself, that where I am you may be also.³⁴

²⁹ K Essex 'The Rapture and the book of Revelation' (2002) 13 *The Master's Seminary Journal* 219.

³⁰ As above.

³¹ Thessalonians 4:15 - 18. *The Holy Bible, English Standard Version (ESV)*, Crossway Bibles, a publishing ministry of Good News Publishers, 2007.

³² K Essex (n 29 above) 219.

³³ W Brindle 'Biblical evidence for the imminence of the Rapture' (2001) 158 *Bibliotheca Sacra* 138.

³⁴ *The Holy Bible ESV*, as above, at John 14: 1 - 4.

These relevant verses are seen as an affirmation of the return of Christ and how He will take His believers away with him.³⁵ An interpretation of this passage supports the belief that Jesus will return (bodily) to earth to gather His people and, then, literally take them back to heaven with Him at the time of the Rapture.³⁶ This literal interpretation of the Bible can be construed to denote an actual bodily ascension to heaven of His people upon the Rapture. The fear, which may be associated with organ donation, of the thought of being risen with part of the body missing is understandable. For instance, with regard to corneal transplantations, one may fear that one's loved one will be blind in the afterlife.

The belief in the resurrection is of profound importance among the African-American community. Veatch quotes a statement made by a member of the clergy: 'On their great getting-up morning, blacks don't want to go to the pearly gates without organs ... they want to go to Jesus whole'.³⁷ Slabbert *et al* have likewise expressed the view that members of most Christian denominations are still hindered from donating their organs and the organs of their loved ones because of their belief in the resurrection; 'death does not mark the final end to one's life'.³⁸

A reluctance to donate organs based on a Christian belief is contrary to the altruistic nature of Christianity. Despite the fact that there are numerous disparities among the different denominations of Christianity, the underlying message of salvation remains the same: 'God loved the world so much that He sent his only son, Jesus Christ, that whoever believes in Him should not perish but have life (John 3:16)'.³⁹ His sacrifice is seen as the ultimate act of altruism; it can be stated that the Christian faith is based on altruism, which, surely, supports organ donation.

In order to understand the fear associated with organ donation from a Christian perspective further, it is important to review the religious principles relating to the physical violation of a cadaver as well as to burial practices.

³⁵ W Brindle (n 33 above) 140.

³⁶ As above.

³⁷ R Veatch (n 26 above) 8.

³⁸ M Slabbert, FD Mnyongani & N Goolam (n 17 above) 275.

³⁹ M Slabbert, FD Mnyongani & N Goolam (n 17 above) 274.

3.2.1.1. Desecration and burial of the corpse

Over the centuries there have been religious objections raised by the church toward medical advancements, particularly when dealing with the treatment of cadavers.⁴⁰ According to the Edict of Tours, AD 1163, the shedding of blood was prohibited and viewed as being defiant towards the doctrine of the resurrection of Christ; dissection and surgery were forbidden.⁴¹ Over time, the church recognised the self-determination of man, as well as medical progress, and religious objections towards vaccination, surgery, dissection, and other medical procedures and approaches, were dropped.⁴² Sanders *et al*/reiterate a statement by Lynch as follows:

It would seem to be theologically beyond doubt that the principle of charity - i.e. love-toward one's fellow man does legitimize a certain degree of bodily self-sacrifice for altruistic motives. For example, not only are blood transfusions, skin grafts, and the like, unanimously admitted by theologians to be permissible, but the donors in these instances have been singled out for explicit commendation in papal documents.⁴³

Sanders and Dukeminier go on to state that, if the removal of an organ from a live person is permissible, so should the removal of an organ from the deceased be permissible.⁴⁴ In 1956, Pope Pius XII made a declaration at an international meeting of ophthalmologists in which he stated that there was no religious or moral objection towards the removal of the cornea from a cadaver for grafting purposes.⁴⁵ Similarly, with regard to cremation, Church law required burial at the beginning of the twentieth century and cremation was prohibited up until the end of the twentieth century.⁴⁶ Now the Catholic Church allows cremation and the dissection of the corpse to benefit the living provided that the body is treated with the respect which is due 'the one-time abode of a spiritual and immortal soul'.⁴⁷

⁴⁰ D Sanders & J Dukeminier 'Medical advance and legal lag: hemodialysis and kidney transplantation' (1967) *UCLA Law Review* 405.

⁴¹ D Sanders & J Dukeminier (n 40 above) 162.

⁴² As above.

⁴³ D Sanders & J Dukeminier (n 40 above) 405.

⁴⁴ As above.

⁴⁵ As above.

⁴⁶ J Provost 'Canonical aspects of the treatment of the dead' (1999) 59 *The Jurist* 203.

⁴⁷ As above. Also see D Sanders (n 40 above) 405.

In the development of the Christian outlook on medicine one sees a link between religion and medical ethics being developed. The acceptance of medical advances, such as surgery and dissection, reveals a respect for personal autonomy and the recognition of self-determination. In addition, the acceptance of the dissection of a corpse to benefit the living is a reflection of beneficence; it may be seen as an altruistic act of kindness to benefit others.

This raises questions relevant to the rejection of cadaveric organ transplantation on religious grounds (particularly Christianity). Veatch is of the opinion that the view which regards the resurrection as a hindrance to donation is held by 'theologically unsophisticated Fundamentalist(s)'.⁴⁸ He relates the concerns of this group to medical fears of diseased and damaged bodies; 'deaths have always occurred with painful debilitating disease'. Deaths which have occurred as a result of fire or in an accident which crushed the body would be very worrying for those who believe in bodily resurrection.⁴⁹ Veatch describes a more 'sophisticated understanding' of religious teaching as being the acquisition of a 'new' or 'perfect' body upon the time of the resurrection.⁵⁰ In this light, the saved would reclaim their earthly bodily form but in a more perfect state, without any damage or disease.⁵¹ This is a belief held by contemporary fundamentalist Christians.⁵²

As mentioned above, religious leaders and scholars have a duty to interpret scripture when dealing with concepts unheard of when they were written, such as organ donation. Most Catholic and Anglican scholars endorse organ transplantation and view it as an act of selflessness.⁵³ In addition, Pope Benedict XVI announced that he walks around with a donor card at all times; the previous Pope, John Paul II, was also supportive of organ donation. The Church of England declared organ donation to be a Christian duty in 2007.⁵⁴ It is, thus, difficult to use Christianity as a reason to object to organ donation; it is,

⁴⁸ R Veatch (n 26 above) 7.

⁴⁹ As above.

⁵⁰ As above.

⁵¹ As above.

⁵² As above.

⁵³ M Oliver *et al* 'Organ donation, transplantation and religion' (2010) *Nephrology Dialysis Transplantation* 438.

⁵⁴ As above.

in fact, in favour of transplantation. The difficulty lies in reconciling different beliefs with an opt-out system for organ donation, which is discussed later in the chapter.

3.2.2. Islam and organ donation

‘One out of five people in our world today belong to the Islamic faith’.⁵⁵ This large ratio of Islamic allegiance of people includes people in South Africa. It is necessary to understand the Islamist perceptions about organ donation and important to take into account an understanding of where Islamic law may be found and how it operates.

3.2.2.1. Islamic law and concepts

Islamic law is also referred to as *Sharia* law. The term is translated as ‘the path to follow’, and it is ‘the all-embracing legal system that regulates the lives of Muslims everywhere’.⁵⁶ Originally, there were four types of legal personnel who played a fundamental role in the elaboration, and construction, as well as the continued functioning, of the *Sharia*.⁵⁷ These are the *Muftis*⁵⁸ (the private legal specialists who are morally, as well as legally, responsible to the society they lived in), the Muslim jurists, the judges and the law professors.⁵⁹ In addition, it is important to note that a religious ruling is referred to as an *Ijtihad*.⁶⁰ These four groups of people helped the *Sharia* to become what it is today.⁶¹

This literal meaning of the term *Sharia* can be either narrowly or broadly interpreted.⁶² A broad interpretation denotes all the writings of Muslim jurists throughout the centuries.⁶³ Principles relayed by the jurists were derived from the Quran (the word of God – the Islamic holy book), the acts and statements made by the Prophet Muhammed (also known as the *sunna*), and from other sources, such as the *ijma*, which is the ‘consensus of the community represented by its scholars and learned men’.⁶⁴ Yamani is of the opinion

⁵⁵ W Hallaq *An introduction to Islamic Law* (2009) 1.

⁵⁶ AZ Yamani ‘The eternal *Sharia*’ (1980) 12 *NYU Journal of International Law and Politics* 205.

⁵⁷ W Hallaq (n 55 above) 8.

⁵⁸ As above. It is also relevant to note that the *Muftis* were also in charge of issuing *Fatwas* (which were legal answers to questions he was asked to address).

⁵⁹ As above.

⁶⁰ M Oliver *et al* (n 53 above) 438.

⁶¹ W Hallaq (n 55 above) 8.

⁶² AZ Yamani (n 56 above) 205.

⁶³ As above.

⁶⁴ As above.

that a narrow interpretation should be adopted which confines the *Sharia* to the principles in the Quran as well as the *sunna*.⁶⁵ Viewed narrowly, the *Sharia* should have binding authority on every Muslim who is obliged to ‘follow and employ it to resolve his affairs and to derive what is not explicit of its principles by certain ways and means’.⁶⁶

The teachings of the Quran, as well as their interpretation, are, therefore, of relevance in determining the position taken towards organ donation from an Islamist perspective. Other sources may also be visited in this regard, such as the Islamic Code of Medical Ethics.

3.2.2.2. Attitudes towards organ donation in the Islamic faith

In Islam the belief regarding the human body is that its violation, whether living or dead, is forbidden.⁶⁷ The reason for this belief is that the human body is viewed as sacred and, on earth, it is entrusted to man’s care.⁶⁸ Muslims of different descent tend to feel differently regarding organ donation. Muslims of Arabic descent tend to agree with organ procurement; those, however, of Indian descent, in most instances, will not.⁶⁹ Muslim jurists from Pakistan maintain that organ donation is unacceptable and, although the general population is in favour of donation, the guidelines set in this regard are very limiting.⁷⁰ They include the proviso that a transplant may be permitted only when there is no other available treatment and there is a high probability of success, that death has been pronounced correctly and that consent has been obtained from either the donor or from the donor’s next of kin for the procedure.⁷¹

Despite the hesitant acceptance of donation in Muslim societies, based on the sacredness of one’s body, an important principle in Islam is altruism.⁷² Oliver reiterates this important principle in Islam as being the saving of a life, which has a high standing in the Quran.⁷³ Chapter 5:32 reads: ‘Whosoever saves the life of one person it would be as

⁶⁵ AZ Yamani (n 56 above) 206.

⁶⁶ As above.

⁶⁷ M Oliver *et al* (n 53 above) 438.

⁶⁸ R Veatch (n 26 above) 9.

⁶⁹ As above.

⁷⁰ As above.

⁷¹ As above.

⁷² M Oliver *et al* (n 53 above) 438.

⁷³ As above.

if he saved the life of all mankind'.⁷⁴ Confusion in relation to organ donation may lie in the conflict of the principles of the sacredness of the body and the principle of saving a life. It has been found that a further principle, which can resolve the situation, is known as '*al-darurat tubih al-mahzurat*'.⁷⁵ which can be translated as meaning that 'necessity overrides prohibition', and it has been used previously to commend the use of porcine bone grafts⁷⁶ and pork insulin.⁷⁷ A further principle worth noting is known as 'the choice of the lesser of two evils', which has been cited as being in favour of organ procurement.⁷⁸

There have also been various Islamic religious rulings made in favour of organ donation. In 1996, the United Kingdom Muslim Law Council released an *Ijtihad* which proclaimed that the donation of organs, or organ transplantation, is in keeping with Islam.⁷⁹ In keeping with this ruling, Muslims in the United Kingdom are permitted to become organ donors, and living organ donation is also seen as 'an act of merit'.⁸⁰ As early as 1988, the Islamic Jurisprudence Assembly Council in Saudi Arabia made a ruling in favour of living and deceased organ donation.⁸¹ Formal rulings, such as these, are also found in other nations, such as Egypt, Iran and Pakistan.⁸² In addition, the Islamic Code of Medical Ethics stipulates the following regarding organ donation:

The individual patient is the collective responsibility of Society that has to ensure his health needs by any means inflicting no harm on others. This comprises the donation of body fluids or organs such as blood transfusion to the bleeding or a kidney transplant to the patient with bilateral irreparable renal damage. This is another "*Fardh Kifaya*", a duty that donors fulfil on behalf of society.⁸³

These rulings and declarations are proof that organ procurement in the Islamic faith is permitted and even seen as being morally and ethically sound. To describe organ

⁷⁴ As above.

⁷⁵ As above.

⁷⁶ Porcine grafts are grafts procured from pig skin which are used as temporary treatment of severe burns on human beings. 'Porcine Graft' – <http://medical-dictionary.thefreedictionary.com/porcine+graft> (accessed 12/03/2016).

⁷⁷ M Oliver *et al* (n 53 above) 438.

⁷⁸ Veatch (n 26 above) 10.

⁷⁹ M Oliver *et al* (n 53 above) 438.

⁸⁰ As above.

⁸¹ As above.

⁸² As above.

⁸³ R Veatch (n 26 above) 9 – 10.

donation as a 'duty' is further emphasis of the importance that the procedure holds in the faith. Ideally, it would, therefore, be expected that one would find high rates of donation among Muslims; this, however, is not the case. Regardless of support in favour of donation, both by Islamic scholars and religious rulings, many Muslims are still hesitant, particularly with regard to deceased organ donation.⁸⁴ For this reason the practices surrounding death in Muslim communities are relevant.

3.2.2.3. Muslim customs surrounding death

Most Muslim customs derive from the *sunna* (the sayings and practices of the Prophet Muhammed), as well as the Islamic law, and not from the Quran.⁸⁵ It is believed that a person who is ill is to be visited as a form of mercy and worship, and a person of the Islamic faith who is in the hospital will often have many visitors.⁸⁶ When a person is close to death he is given holy water to drink and verses of the Quran are read out loud.⁸⁷ The sick person is also prompted to read, recite and re-declare his faith.⁸⁸ Measures to prolong a person's life, such as being placed on a life-support machine, are strongly discouraged unless there is evidence that they may result in a reasonable quality of life.⁸⁹ This already poses a problem regarding donation as a person who is brain-dead may be placed on a life support machine pending transplantation in order to lessen the chances of ischemia.

Hospital personnel, who are not familiar with Muslim custom surrounding death, may create a level of anxiety once a person has died.⁹⁰ These rites include turning the body towards Mecca, or, if the person has died in a hospital, it is sufficient to turn the body towards the right.⁹¹ In addition, the legs and arms of the deceased need to be straightened and his eyes must be closed.⁹² The body has further to be covered with a sheet once all clothing has been removed by a person of the same sex.⁹³ It is a religious requirement

⁸⁴ M Oliver *et al* (n 53 above) 438.

⁸⁵ AR Gatrad 'Muslims customs surrounding death, bereavement, postmortem examinations and organ transplants' (1994) 309 *British Medical Journal* 521.

⁸⁶ As above.

⁸⁷ As above.

⁸⁸ As above.

⁸⁹ As above.

⁹⁰ As above.

⁹¹ As above.

⁹² As above.

⁹³ As above.

that once a Muslim patient has died ‘the corpse [is to] be ritually bathed before burial’.⁹⁴ The bathing and covering of the body with a sheet is a process which may take up to an hour to complete.⁹⁵

There are four important religious requirements surrounding the death of a Muslim, some of which may be seen as a hindrance for organ donation. Firstly, the body needs to be buried as quickly as possible.⁹⁶ It is traditional for Muslims to be buried no longer than 24 hours after death; a lengthy procedure involving the retrieval of organs may, therefore be frowned upon.⁹⁷ Secondly, the embalment of the body of a Muslim is forbidden.⁹⁸ This requirement underscores the first as, since the bodies are not permitted to be embalmed, it is necessary to bury them as soon as possible before the body starts to decay. Thirdly, Muslim communities tend to be very close-knit and many people visit the home of the deceased after the passing.⁹⁹ The sooner the burial of the deceased takes place the better as it will lessen the burden and distress to the family.¹⁰⁰ Finally, immediate relatives may not eat until after the funeral.¹⁰¹

These rituals all pose a potential hindrance to organ donation. Should medical personnel involved with the process of the post-mortem not be aware of these rituals, it is possible that their actions may be viewed as showing a lack of respect for the deceased. The distress faced by the family, both from losing a loved one and from the practices involved directly after death, can be seen as possible reasons for the discouragement of donation among Muslim families.

Generally speaking, however, organ procurement is permitted in Islam, as has been stated above. Gatrad highlights the numerous conditions which need to be followed in

⁹⁴ As above.

⁹⁵ As above.

⁹⁶ As above.

⁹⁷ M Oliver *et al* (n 53 above) 438. Cl 8(1) of the Regulations regarding the general control of human bodies, tissue, blood, blood products and gametes, 2012 (the regulations) provide a time limit of 24 hours after the death of a donor where the organs (and tissues) may be removed. After this the body is to be returned to the family. Although this is provided for in this piece of legislation, it is questionable whether this is implemented in practice.

⁹⁸ AR Gatrad (n 85 above) 521.

⁹⁹ As above.

¹⁰⁰ As above.

¹⁰¹ As above.

order for transplantation from a Muslim person to occur.¹⁰² In addition to consent from the next of kin, a high probability of success, no other available treatment and the proper pronouncement of death mentioned above, he adds that the death has to be:

... fully established by a Muslim doctor of repute, or there is no imminent danger to the life of a living donor; and the recipient has been informed of the operation and its implications. Donation to a Muslim should only be to save his or her life; and organs are accepted from a non-Muslim only if not available from a Muslim.¹⁰³

These rituals are important for a transplant team, as well as medical personnel, to understand, and they should be taken into consideration when devising legislation and regulations surrounding organ procurement, particularly in a predominantly Muslim society. The definition of death is a matter of debate in these communities and will be considered later in the chapter.

3.2.3. Judaism and organ donation

Judaism, similarly to other religions, is a faith which has been in existence from long before organ procurement was even thought of. In order to understand the religious stance that Judaism takes towards organ donation and procurement, an interpretation of the relevant religious scripts, as well as the Talmud,¹⁰⁴ are of great importance in this regard. To begin with, an understanding of the relationship between Judaism and medicine, as well as where this relationship stem from, is necessary.

3.2.3.1. Judaism, medicine, and the obligation towards one's body

In the Jewish faith it is believed that God has ownership over everything, including our bodies.¹⁰⁵ This has been interpreted to mean that God has lent our bodies to us for the duration of our lifetime on earth and no one has a right to govern his body as he chooses. Because they are owned by God, He affirms His right 'to restrict how we use our bodies

¹⁰² AR Gatrad (n 85 above) 522.

¹⁰³ As above.

¹⁰⁴ The Talmud is a large collection of writings which comprises a full account of the religious and civil laws of the Jews.

'Talmud' - <<http://www.biblestudytools.com/dictionary/talmud/>> (accessed on 22/03/2016).

¹⁰⁵ EN Dorff *Matters of life and death* (2003) 15.

according to the rules articulated in Jewish law'.¹⁰⁶ Evidently, Jews have a duty to 'preserve their own lives'.¹⁰⁷ Dorff reiterates Leviticus 18:5 which states: 'we should obey God's commandments and live by them'.¹⁰⁸ Rabbis (Jewish religious leaders, scholars or teachers of Jewish law) have interpreted these words to mean that we should not die as a consequence of observing God's commandments, save for cases of 'murder, idolatry, and incestuous or adulterous sexual intercourse'.¹⁰⁹

Dorff further stipulates that in Judaism, since God owns our bodies, we have an obligation to help others to evade illness, death and injury;¹¹⁰ 'we are all under the divine imperative to help God preserve and protect what is God's'.¹¹¹ It is, however, believed in the Jewish faith that sickness is one of the 'divine punishments for disobedience', and medicine is an 'improper human intervention in God's decision to cause illness or cure it'.¹¹² In other words, medical physicians and medicine itself would be seen as going against God's will.

Rabbis, however, stated that God has given overt permission to physicians to cure the sick.¹¹³ In support of this view two Bible verses are cited: 'Exodus 21:19 – 20, according to which an assailant must ensure that his victim is 'thoroughly healed', and Deuteronomy 22:2 ('And you shall restore the lost property to him')'.¹¹⁴ The verse of Leviticus 19:18, which commands one to 'love your neighbour as you love yourself', can be expanded to include healing methods which require a wound to be inflicted during the process.¹¹⁵

There are various other verses in the Bible which have been cited as a means of reconciling medicine with the Jewish faith. For instance, on the basis of 'an extra letter in the Hebrew text of the Deuteronomy passage' mentioned above, the Talmud states that this verse imposes an obligation to 'restore another person's body as well as his property' in addition to assisting someone who is in a life-threatening position.¹¹⁶ This obligation

¹⁰⁶ As above.

¹⁰⁷ As above.

¹⁰⁸ As above.

¹⁰⁹ As above.

¹¹⁰ EN Dorff (n 105 above) 26.

¹¹¹ As above.

¹¹² EN Dorff (n 105 above) 26 to 27.

¹¹³ EN Dorff (n 105 above) 27.

¹¹⁴ As above.

¹¹⁵ As above.

¹¹⁶ As above.

further resonates with Leviticus 19:16: ‘Do not stand idly by the blood of your neighbour’.¹¹⁷

Furthermore, Jewish law recognises the need for medical expertise in cases where a person is sick.¹¹⁸ The Talmud even prohibits Jews from living in a community where there is no physician.¹¹⁹ Dorff further states that this injunction reverts to the principle mentioned above, in that our duty to God to preserve and care for our bodies can be carried out only where there is a physician available.¹²⁰ Dorff furthermore quotes a statement made by Rabbi Joseph Caro (1488 – 1575) as follows:

The Torah gave permission to the physician to heal; moreover, this is a religious precept and is included in the category of saving life, and, if the physician withholds his services, it is considered as shedding blood.¹²¹

This precept imposes a duty on physicians to heal those who are ill. In the Jewish faith the relationship between medicine and Judaism is seen as being of great importance. The emphasis placed on preserving the body (that which belongs to God) is of such significance that the Talmud specifically mentions the importance of having a physician available. It can be perceived that the procedure of organ transplantation primarily is in keeping with this principle. This is not to say that there are no prohibitions which could be interpreted as being against transplantation. These will now be discussed.

3.2.3.2. Jewish religion’s perspectives towards organ donation

As with most religions, the most problematic areas surrounding organ donation are with regard to cadaveric donation. The following discussion will focus on the customs and burial rites in the Jewish faith in relation to organ donation. Judaism has similar restrictions to Islam in dealing with death. Dorff mentions three main principles involved in the appropriate treatment of the body after death in Jewish law.¹²² These three principles are known as: *kavod ha-met*, which means to honour the dead; *hesed* which involves

¹¹⁷ EN Dorff (n 105 above) 27.

¹¹⁸ As above. Rabbi Joseph Caro is author to one of the most important Jewish Codes; the *Shulhan Arukh*.

¹¹⁹ As above.

¹²⁰ As above.

¹²¹ EN Dorff (n 105 above) 28.

¹²² EN Dorff (n 105 above) at 221.

community assistance, be it financial or other; and *pikuah nefesh*, which, as referred to above, is an obligation to assist those in need.¹²³

Kavod ha-met, as stated above, refers to honouring the dead. This entails the honouring of the deceased's memory and respect for the body as, even after death, the body still belongs to God.¹²⁴ It also underlies the Jewish burial customs which involve 'closing the eyes of the deceased', preserving the modesty of the deceased by having a person of a similar gender preparing the body for death, clothing the body in burial shrouds after washing the body before the burial, having a closed casket funeral so as not to have onlookers see the body's disintegration, and convening friends and family for the eulogy.¹²⁵ Similar customs have been mentioned above as part of the Islamic faith.

Oliver goes on to state that great importance is placed on not interfering unnecessarily with the body after death, and emphasis is also placed on burying the body, in its complete form, and in 24 hours after death.¹²⁶ With regard to deceased organ donation he mentions three prohibitions concerning the dead body, namely, '(i) desecrating a cadaver, (ii) delaying burial of a cadaver, and (iii) receiving benefit from a cadaver'.¹²⁷ Often Jewish scholars have been against deceased organ donation because of these prohibitions.¹²⁸ Indeed, the Orthodox Haredi group went as far as to 'issue anti-organ donation passes'.¹²⁹ Oliver further mentions the issue of *Goses*, which is a *Halachic* term¹³⁰ referring to a person who is likely to die in three days due to a deathly illness.¹³¹ Such a person may not be interfered with in any way which may accelerate his death, and medical intervention for the purpose of preparing the person for organ retrieval may be frowned upon.¹³²

¹²³ EN Dorff (n 105 above) 221 to 223.

¹²⁴ EN Dorff (n 105 above) 223.

¹²⁵ As above.

¹²⁶ M Oliver *et al* (n 53 above) 439. As stated above, cl 8(1) of the regulations does provide 24 hours for organs and tissues to be removed before the body if to be returned to the family, however, with such a short time limit, it is questionable as to whether this is implemented in practice.

¹²⁷ As above.

¹²⁸ As above.

¹²⁹ As above.

¹³⁰ *Halacha*, also referred to as halakhah, is defined as Jewish law. See R Khalaila 'Religion, altruism, knowledge and attitudes toward organ donation: a survey among a sample of Israeli college students' (2013) 32 *Medicine and Law* 116.

¹³¹ M Oliver *et al* (n 53 above) 439.

¹³² M Oliver *et al* (n 53 above) 440.

Pikuach nefesh, however, which entails the obligation to assist those in need, as mentioned above, has been used as a principle which overrides the three prohibitions of Jewish Law concerning cadavers,¹³³ and, it may, therefore, be said, cadaveric donations should be permissible in the Jewish faith. Khalaila further mentions that the most controversial issue in this regard is the determination of death in Judaism, which is to be discussed below.¹³⁴ Indeed, Resnicoff states that Jewish Law imposes an affirmative duty to save the life of a person by means of a direct intervention or with the use of one's resources.¹³⁵ As a biblical basis for this rule, he states the verse from Leviticus 19:16 which states: 'Do not stand idly by your fellow's blood'.¹³⁶ He further maintains that, should it be necessary to rescue a person, every provision of Jewish Law may be violated save for those relating to murder, immoral sexual acts and idolatry.¹³⁷ In support of this, he quotes a statement made by Rabbi Shlomo Zalman Auerbach (1910-1995) as follows:

We have no yardstick to measure the value and importance of life, even in terms of Torah and the commandments, for we violate the Sabbath even for an aged invalid afflicted with boils, even though he is deaf and dumb and completely insane, and even though he is incapable of performing any of the commandments and his life seems merely a burden and great suffering to his family and prevents them from studying Torah and performing commandments and even if, in addition to their great anguish, his family becomes more and more impoverished. Even so, it is a duty for the leaders of the Jewish nation to be involved in saving him and in violating the Sabbath [if necessary to do so].¹³⁸

This quotation depicts the notion that 'every instance of life is transcendental', and that the importance of human life does not depend on its quality or anticipated length.¹³⁹ Rescuing is of great importance in Jewish Law, even if there is only a slight chance that

¹³³ R Khalaila (n 130 above) 116.

¹³⁴ R Khalaila (n 130 above) 117.

¹³⁵ S Resnicoff 'Supplying human body parts: A Jewish Law perspective' (2006) 55 *De Paul Law Review* 853.

¹³⁶ As above.

¹³⁷ As above.

¹³⁸ S Resnicoff (n 135 above) 853-854.

¹³⁹ As above.

such rescue efforts would be successful:¹⁴⁰ which shows support for the procedure of organ donation.

Most scholars are of the opinion that organ donation is indeed acceptable in the Jewish faith, but there are those who are against it. Dorff states that, in terms of living organ donors, some scholars have argued that preserving one's own life takes precedence over the life of another and, in such a situation, one should provide any medical care one can without endangering one's own life.¹⁴¹ In the light of this view contemporary Rabbis argue that living organ donations are, in fact, unacceptable owing to the risks involved in surgery.¹⁴² At the same time, if it can be shown that a donation may be accomplished without immense risk to the donor's life, transplantation may be permitted.¹⁴³ Considering that the risks to the donor are generally very low, the acceptance of living organ donations should not be problematic.

In addition, Rabbi Immanuel Jakobovits (a former chief Rabbi of the British Commonwealth, as well as the author of the first comprehensive book on Jewish medical ethics) states: 'Since the mortality risk to kidney donors is estimated to be only 0.24 percent and no greater than that is involved in any amputation, the generally prevailing view is to permit such donations as acts of supreme charity but not as an obligation'.¹⁴⁴ Dorff declares that both Reform and Orthodox Rabbis take the same stance.¹⁴⁵ To the contrary, Howard is of the opinion that, since it is a good deed (or a *mitzvah*) to donate organs, becoming an organ donor in fact is compulsory as good deeds are not voluntary, but required.¹⁴⁶ This opinion could apply to both living and deceased organ donations.

Regarding cadaveric donations, Dorff is of the opinion that saving another person's life, and even their health, supersedes the prohibitions against the delay in burials.¹⁴⁷ In fact, just as it is not considered a desecration of the body to remove organs for the purposes

¹⁴⁰ S Resnicoff (n 135 above) 854.

¹⁴¹ EN Dorff (n 105 above) 226.

¹⁴² As above.

¹⁴³ As above.

¹⁴⁴ As above.

¹⁴⁵ As above.

¹⁴⁶ RJ Howard 'We have an obligation to provide organs for transplantation after we die' (2006) 6 *American Journal of transplantation* 1788.

¹⁴⁷ EN Dorff (n 105 above) 226.

of saving a life, the delaying of the burial for this purpose also does not diminish respect for the dead, but rather enhances it.¹⁴⁸ In this light the principle of *kavod ha-met* is being fulfilled. There are, however, disagreements regarding the type of transplantations which would be considered life-preserving. Some authorities are of the opinion that transplantation should occur only if the patient 'stands to lose his life or an entire physical faculty'.¹⁴⁹ An example of this would be in the case of a cornea transplant; if a person can see out of one eye, a cornea may not be removed from a cadaver in order for him to see with his other eye.¹⁵⁰

In addition, a transplant for cosmetic purposes, unless the recipient could be saved from immense emotional or psychological distress, is not to be permitted.¹⁵¹ The donor is also not permitted to donate to an organ bank. The recipient must be known.¹⁵² Dorff, however, defines this as an extreme position.¹⁵³

In fact, no law in the Jewish faith prevents organ donation from being permissible. As shown above, the principle of *kavod ha-met* is in keeping with organ donation; should the cadaver be used to save a person's life, the person is being honoured, even in death. It also implies that a deviation from certain customs, such as burying the body after 24 hours, is allowed. The principle of *pikuah nefesh*, the obligation to help those in need, is adhered to regarding donation by both living and deceased individuals. Some scholars even state that organ donation is an obligation. In its Committee on Jewish Law and Standards, the Orthodox movement adopted the rabbinical ruling of Rabbi Joseph Prouser in 1995, in which he states that, owing to the shortage of organs, failing to arrange

¹⁴⁸ As above.

¹⁴⁹ EN Dorff (n 105 above) 227.

¹⁵⁰ As above.

¹⁵¹ S Resnicoff (n 135 above) 861.

¹⁵² EN Dorff (n 105 above) 227. The regulations also provide for the protection of the information of the donor and the recipient as follows:

'24(1) No person shall publish or make known any fact whereby the identity of –

(a) a deceased person whose body or any specific tissue thereof has been donated;

(b) the donor of the body of a deceased person or any specific tissue thereof;

(c) a living person from whose body any tissue, blood or gamete has been removed or withdrawn for any purpose; or

(d) the person who has given her or his consent to the removal of any tissue, blood or gametes from a living person for such purpose;

may possibly be established, unless consent thereto was granted'.

¹⁵³ EN Dorff (n 105 above) 227.

for the donation of organs after death should be viewed as being a violation of the commandment 'Do not stand idly by the blood of your neighbour',¹⁵⁴ because it should be seen as a failure to rescue those in need of a transplant.¹⁵⁵

3.2.4. Hinduism and early transplantation

Hinduism is followed and practiced by approximately 1.3% of the population of South Africa.¹⁵⁶ Hindu laws are recognised as so-called 'unofficial laws' and they are followed by those who associate themselves with Hinduism.¹⁵⁷ Sarma states that Hinduism is one of the youngest religions in the world - it was devised and used by the Persians originally as a geographical term, as opposed to a religious one.¹⁵⁸ In the singular, the term is used to refer to the 'country where the 'Indus' (river) flows'; the plural form refers to those who inhabit the land.¹⁵⁹ Hinduism evolved into a religious term when Christian and Muslim missionaries, as well as British colonisers, used the term.¹⁶⁰

Hinduism differs from other religions in the sense that it does not have a founder or a text which is universally shared such as, for instance, the Bible or Quran for Christians or Muslims.¹⁶¹ It is not 'belief-centred' and many scholars have been uneasy at referring to Hinduism as a religion *per se*.¹⁶² Nevertheless, there are traditions and beliefs followed by those who consider themselves to be 'Hindus'.

The idea of using organ transplantation as a means of therapy to replace organs which are not functioning is said to have originated in India in mythological medicine in the Twelfth Century BC.¹⁶³ Sarma quotes Dr VN Acharya, a member of the cadaver transplant cell of the government of Maharashtra, as follows:

¹⁵⁴ EN Dorff (n 105 above) 227 to 228.

¹⁵⁵ EN Dorff (n 105 above) 227.

¹⁵⁶ P Coertzen 'Constitution, charter and religions in South Africa' (2014) 14 *African Human Rights Law Journal* 127.

¹⁵⁷ P Coertzen (n 156 above) 131.

¹⁵⁸ D Sarma 'Hindu ethics' (2008) 36 *Journal of Law, Medicine and Ethics* 52.

¹⁵⁹ As above.

¹⁶⁰ As above.

¹⁶¹ As above.

¹⁶² V Narayanan 'Diglossic Hinduism: liberation and lentils' (2000) 68 *Journal of American Academy of Religion* 762.

¹⁶³ D Sarma (n 158 above) 53.

The concept of organ transplantation as a therapy for replacement of non-functioning organs began in India, [and] originated in mythological medicine in the twelfth century B.C. Lord Ganesh, is popular in this vanquisher of obstacles, is an example of the very first xenograft performed by Lord Shiva using an elephant's head. This Aryan legend in the Rig Veda has been followed by several similar examples in many other civilizations round the world involving use of limbs, heart and the spirit.¹⁶⁴

This shows that transplantation, in general, would not be entirely opposed in Hinduism as the practice appeared in myth centuries ago. Tissue transplantations were conducted over 5000 years ago by both Egyptians and Hindus. Skin would be used to replace noses which had been destroyed as a result of syphilis.¹⁶⁵ The question arises as to why there might be a reluctance to donate organs among the Hindu population. An analysis of the Hindu beliefs in this regard, thus, is warranted.

3.2.4.1. Hindu beliefs, traditions and organ donation

Although Hindus do not have a 'leader' or a universal document followed by all who associate themselves with Hinduism, they do have certain basic beliefs, such as in karma, reincarnation and liberation.¹⁶⁶ Karma is the most important of these beliefs. The doctrine of karma is understood as being '1) any act or deed; 2) the principle of cause and effect; 3) a consequence or 'fruit of action' ... or 'after effect', which sooner or later returns upon the doer'.¹⁶⁷ This doctrine is linked to reincarnation in that it is believed that the actions one undertakes in this world will have an effect on the way one is reborn.¹⁶⁸ Hateful or selfish acts in one life will bring suffering in the next life, whereas benevolent acts will bring love.¹⁶⁹

There are no objections to living organ donation in the literature. Veatch states that the regular practice of living donations amongst the Hindus of India depicts an acceptance of organ procurement and transplantation.¹⁷⁰ The problem, as with other religions it seems,

¹⁶⁴ As above.

¹⁶⁵ JE Dunphy 'The story of organ transplantation' (1969) 21 *The Hastings Law Journal* 67.

¹⁶⁶ H Mannan 'Deaths as defined by Hinduism' (1996) 15 *Saint Louis University Public Law Review* 424 – 425.

¹⁶⁷ H Mannan (n 166 above) 424.

¹⁶⁸ R Veatch (n 26 above) 10.

¹⁶⁹ H Mannan (n 166 above) 425.

¹⁷⁰ R Veatch (n 26 above) 10.

is one regarding cadaveric donations and/or transplantation. The beliefs surrounding death may contradict the practice.

The Hindus believe that a person has two components to his body, the *Atman* (the soul) and the physical body.¹⁷¹ When a person dies the physical body is left behind and the *Atman* moves on to a different *loka* (plane of existence).¹⁷² The *loka* that one's soul departs to is based on the karma one had whilst alive.¹⁷³ It would appear as though the body becomes irrelevant after death, as a person may be reborn and given a new form. In a sense, this should mean that cadaveric donation is possible and permissible. There is a belief, however, that the body is literally untouchable after death and should be cremated,¹⁷⁴ and this needs to take place as soon as possible after death.¹⁷⁵ After washing and dressing the body in normal clothes (by close family members), the body is then viewed by relatives and close friends, upon which it is taken to the crematorium.¹⁷⁶

In addition, there is a belief that karma can be 'transferred in intimate exchanges with others'.¹⁷⁷ This belief would have an effect on a Hindu person's decision to receive or even donate organs, regardless (or depending on) whether bad or good karma is being transferred.¹⁷⁸ These practices and beliefs possibly deter cadaveric donation. There is a contradictory Hindu myth, however, in which it is considered to be a virtuous act to donate one's eyes and body parts.¹⁷⁹ Rudra is of the opinion that, in fact, there is no religious objection to donation.¹⁸⁰ He mentions that the viewing of the face is of great importance and that cosmetic considerations have to be taken into account and weighed appropriately before retrieving organs.¹⁸¹

¹⁷¹ H Mannan (n 166 above) 425.

¹⁷² As above.

¹⁷³ As above.

¹⁷⁴ R Veatch (n 26 above) 10.

¹⁷⁵ G Randhawa (n 19 above) 90.

¹⁷⁶ As above.

¹⁷⁷ As above.

¹⁷⁸ As above.

¹⁷⁹ R Veatch (n 26 above) 10.

¹⁸⁰ A Rudra & OP Murty (n 18 above) 54.

¹⁸¹ As above.

Oliver also points out that there are various Hindu scholars who endorse organ donation.¹⁸² He quotes Hasmukh Velji Shah (of the World Council of Hindus) as stating the following:

The important issue for a Hindu is that [that] which sustains life should be accepted and promoted as Dharma (righteous living). Organ donation is an integral part of our living.¹⁸³

It should be accepted that organ donation is permissible in Hinduism. Taking the doctrine of karma and reincarnation into account, becoming an organ donor should be seen as a benevolent act which would ensure a more positive outcome in the next life. Indeed, Bardrolhisam and Zakaria reiterate the notion that there is no law which prohibits the donation of organs by Hindus as it is believed that donating an organ would 'give [a] positive effect for the[ir] rebirth process after death'.¹⁸⁴

3.2.5. Buddhism and the Buddhist Canon

Approximately 0.1% of the South African population identify themselves as Buddhists.¹⁸⁵ More than 2 500 years ago, Siddhattha Sakyamuni Gotama separated himself from Hinduism 'and become known by his followers as the Buddha, the Enlightened One'.¹⁸⁶ All the schools of Buddhism recognise Buddha as the 'supreme teacher' and reject the notion that there is a being who is supreme and who created and governed the world.¹⁸⁷

Since Buddhism originated from in Hinduism, its beliefs are similar. For instance, Buddhism follows the doctrine of karma, as does Hinduism. It is believed that 'all sentient beings cycle through multiple rebirths, influenced by their past moral behaviour, *karma*'.¹⁸⁸ According to Buddhist tradition, the Buddha regularly expounded on what was determined to be the 'correct legal rules for his followers' for the close to fifty years of his teaching.¹⁸⁹ These teachings were then collected and form a body of work known as the *Vinaya*, the

¹⁸² M Oliver *et al* (n 53 above) 440.

¹⁸³ As above.

¹⁸⁴ N Badrolhisam & Z Zakaria 'Knowledge, religious beliefs and perception towards organ donation from death row prisoners from the perspective of patients and non-patients in Malaysia: a preliminary study' (2012) 2 *International Journal of Humanities and Social Science* 198.

¹⁸⁵ P Coertzen (n 156 above) 127.

¹⁸⁶ A Dobrin *Religious ethics: a sourcebook* (2002) 51.

¹⁸⁷ As above.

¹⁸⁸ J Hughes 'Buddhist bioethics' in RE Ashcroft *et al* (eds) *Principles of healthcare ethics* (2007) 127.

¹⁸⁹ R French 'What is Buddhist Law? Opening Ideas' (2015) 63 *Buffalo Law Review* 835.

'first of three 'baskets' of the Buddhist canon'.¹⁹⁰ French is of the opinion that it may possibly be the only religion in which the founder is believed to have made, on a regular basis, 'detailed decisions on legal matters in a narrative casuistic format covering hundreds of topics over a period of approximately five decades'.¹⁹¹ It has been stated further that, although these rules may have been adjusted and altered, before being first redacted in the first century BCE, the Buddha is still seen as the sole source of the rules and the 'architect of Buddhist Law'.¹⁹²

3.2.5.1. Buddhist beliefs and medicine/ transplantation

Buddhist tradition presents itself as the clinical diagnosis for the cause of the suffering of a person, as well as prescribing treatment for the alleviation of suffering.¹⁹³ The treatment is in the form of simple statements about the illness being given (as opposed to 'divine commandments') and how it can be treated.¹⁹⁴ The emphasis is spiritual in nature, although Buddhism does accept that medicine is necessary for laity and for monks.¹⁹⁵ Nuns and monks are forbidden from practising medicine, but nevertheless they are given instructions to keep at hand.¹⁹⁶ The use of medicine to sustain a healthier and longer life is seen as being an aid to spiritual practice.¹⁹⁷

Medicine and, perhaps even medical procedures, would not be frowned upon in the Buddhist faith. Hughes mentions how the religion has merged with the medical traditions of each country where it has taken root.¹⁹⁸ For instance, in India, there are links between early Buddhist and Indian traditional medicine, and there have been similar mergers made in China and Tibet.¹⁹⁹ The nature of Buddhism can be adapted to different practices, depending on the region, and there is no reason to believe that it may not be able to adapt itself to certain Western practices, such as transplantation. The Dalai Lama, himself, has

¹⁹⁰ As above.

¹⁹¹ As above.

¹⁹² As above.

¹⁹³ J Hughes 'Buddhist bioethics' in Ashcroft *et al* (eds) (n 188 above) 128.

¹⁹⁴ As above.

¹⁹⁵ As above.

¹⁹⁶ As above.

¹⁹⁷ As above.

¹⁹⁸ As above.

¹⁹⁹ As above.

embraced 'the application of the scientific method to the spiritual experience and in asserting that beliefs and practices that are shown to be unscientific and not empirically supported should be set aside'.²⁰⁰

A possible problem is with regard to the belief in reincarnation. Clarity is lacking about the Buddhist belief regarding personhood. A unique aspect of Buddhism is the emphasis of Buddhist philosophy on the nonexistence of 'the self'.²⁰¹ This 'no-self doctrine' has led to numerous debates over personal identity, mainly with regards to its association with the doctrine of reincarnation.²⁰² The question which arises is: If there is no self, then what is it that reincarnates?²⁰³ Traditionally, it has been postulated that there are certain mental substrates (also known as *skandhas* –'the body, feelings, perceptions, will and consciousness') which are encoded with karma and are not affixed to the soul and which pass from one body to the next.²⁰⁴ Buddhist humanists and sceptics, on the other hand, have averred that the doctrine of reincarnation is not essential to spiritual practices, and they have maintained an agnostic approach towards it,²⁰⁵ perhaps owing to Buddhism's rejection of the Hindu belief in an 'eternal soul'.²⁰⁶

Nevertheless, most Buddhists do believe in the doctrine of reincarnation and attach great importance to it as it shapes Buddhist practices, as well as their beliefs surrounding dying and abortion.²⁰⁷ It is believed that, if there is an interruption of the transmigration of the being which is reincarnating through cadaveric organ transplantation or abortion, this may have negative karmic implications which may potentially be as harmful as if a murder had been committed.²⁰⁸ It is further believed that, after a person has stopped breathing, the 'spiritual consciousness of the individual may stay in the body for a few days after the

²⁰⁰ As above. The Dalai Lama is 'the exiled monarch of the Tibetan Kingdom and head of the Gelugpa sect of Tibetan Buddhism' who is also known as a distinctive religious leader. J Hughes 'Buddhist bioethics' in Ashcroft *et al* (eds) (n 188 above) 128.

²⁰¹ As above.

²⁰² As above.

²⁰³ As above.

²⁰⁴ As above.

²⁰⁵ As above.

²⁰⁶ As above.

²⁰⁷ As above.

²⁰⁸ As above.

breath has stopped'.²⁰⁹ These views complicate recognition of the moment of death in Buddhism, a concept dealt with below.

Several authors are of the opinion that Buddhists do condone organ donation. Oliver states that the Buddhist principle of selfless giving, or generosity, conflicts with scholars who determine that organ donation is not permissible in Buddhism.²¹⁰ He states that some Buddhist scholars are against transplantations, whereas others maintain that it is a personal decision left to the individual.²¹¹ Steinbuch is of the view that organ donation is perceived by Buddhists to be a 'matter of individual choice', as there is no writing in the Buddhist teachings prohibiting it.²¹² Khalil maintains the same view and adds that organ donation is viewed by Buddhism as being noble, the act of which honours those who become donors and save lives or assist in the advancement medical science.²¹³

The beliefs surrounding Buddhism can be said to support organ donation. Not only is organ donation in keeping with the central principle of generosity, but it is also in keeping with the adaption of the religion to different medical practices. Siemionow maintains that Buddhism regards the body as 'the source of attachment to worldly affairs' which is unfavourable towards the realisation of 'Nirvana'.²¹⁴ She states that, in order to accrue merit in this regard, organ donation counts towards the realisation of 'Liberation'.²¹⁵ These opinions lead one to believe that the main area of difficulty is actually with regard to the moment of death, which is to be discussed later in the chapter.

3.2.6. African cultural beliefs

Traditional establishments were in existence long before European colonisation.²¹⁶ These authorities have survived not only the sinister mechanisms of racial discrimination and colonialism, but also the 'consequent demise of the self-governing and independent

²⁰⁹ M Oliver (n 53 above) 441.

²¹⁰ As above.

²¹¹ As above.

²¹² R Steinbuch 'Kidneys, cash, and kashrut: a legal, economic and religious analysis of selling kidneys' (2009) 45 *Houston Law Review* 1566.

²¹³ K Khalil 'A sight of relief: invalidating cadaveric corneal donation laws via the free exercise clause' (2003) 6 *DePaul Journal of Health Care Law* 164.

²¹⁴ M Siemionow (n 13 above) 411.

²¹⁵ As above.

²¹⁶ GE Devenish (n 2 above) 291.

states that were created by the policy of 'grand' apartheid'.²¹⁷ South Africa is home to a diverse population in terms of race, religion as well as culture. This diversity is reflected in the fact that there are 11 official languages, each representing a different group of people with different beliefs and/or cultures. South Africa is a multicultural, multi-religious and multi-ethnic nation. The majority of the population, approximately 79.2%, are black people.²¹⁸

Despite the diverse populace of South African communities, indigenous law does not feature 'in the mainstream of South African jurisprudence'.²¹⁹ Mokgoro believes that *ubuntu* should be incorporated into 'mainstream jurisprudence by harnessing it carefully, consciously, creatively, strategically, and with ingenuity so that age-old African social innovations and historical cultural experiences are aligned with present-day legal notions and techniques if the intention is to create a legitimate system of law for all South Africans'.²²⁰ Making such strives would in turn develop the 'legitimacy of a jurisprudence', which has the task of managing the 'challenges that constitutionalism with entrenches human rights pose...'²²¹ There is indeed constitutional recognition for indigenous law and its application as seen in section 211 of the Constitution as follows:

- (1) The institution, status and role of traditional leadership, according to customary law, are recognised, subject to the Constitution.
- (2) A traditional authority that observes a system of customary law may function subject to any applicable legislation and customs, which includes amendments to, or repeal of, that legislation or those customs.
- (3) The courts must apply customary law when that law is applicable, subject to the Constitution and any legislation that specifically deals with customary law.²²²

The Constitution therefore brings about an end to the marginal advancement of indigenous principles and/or customary law and highlights the necessity of bringing 'out-

²¹⁷ As above.

²¹⁸ P Coertzen (n 156 above) 127.

²¹⁹ Y Mokgoro 'Ubuntu and the law in South Africa' in D Cornell & N Muvangua (eds) *Ubuntu and the law* (2012) 319.

²²⁰ As above.

²²¹ As above.

²²² Sec 211, Constitution.

dated and distorted customary law institutions in line with the values of the Constitution'.²²³ Culture is thus an important part of the nature of African societies. There is, therefore, a great need to analyse African cultures and traditions in order to determine whether organ donation is against African beliefs. An analysis of various cultural concepts, such as the concept of *ubuntu*, and the role of traditional healers will be undertaken, along with cultural practices and their importance for the communities which follow them.

3.3. The concept of *ubuntu*, traditional healing, Western medicine and organ donation

- The concept of ubuntu

Ubuntu is difficult to define. Mnyongani states this is because *ubuntu* cannot be categorised and, instead, can only be described and not defined.²²⁴ In describing the term, scholars refer to the Nguni maxim *umuntu ngumuntu ngabantu* which translates as 'a person is a person through other people'.²²⁵ This is a description of 'a state of being'²²⁶ and, in a sense, it reflects the notion of beneficence in the African context. The concept of *ubuntu* is of great importance in African communities and for African people. It has been described as having philosophical, religious and cultural significance, as well as being the 'fundamental ontological and epistemological category in African thought of the Bantu-speaking people'.²²⁷

Ubuntu has been used in case law and has assisted judges in making their decisions. It was first invoked in the case of *S v Makwanyane* where the Constitutional Court used it in the declaration of the death penalty as being unconstitutional.²²⁸ The court was hesitant to provide a definition for the concept of *ubuntu*; however. Langa J observed the following:

²²³ Y Mokgoro 'Ubuntu and the law in South Africa' in Cornell & Muvangua (n 219 above) 321.

²²⁴ F Mnyongani 'De-linking *ubuntu*: towards a unique South African Jurisprudence' (2010) 31(1) *Obiter* 135.

²²⁵ As above.

²²⁶ As above.

²²⁷ F Mnyongani (n 224 above) 136.

²²⁸ As above.

[224] The concept [of *ubuntu*] is of some relevance to the values we need to uphold. It is a culture which places some emphasis on communality and on the interdependence of the members of a community. It recognises a person's status as a human being, entitled to unconditional respect, dignity, value and acceptance from the members of the community such person happens to be part of. It also entails the converse, however. The person has a corresponding duty to give the same respect, dignity, value and acceptance to each member of that community. More importantly, it regulates the exercise of rights by the emphasis it lays on sharing and co-responsibility and the mutual enjoyment of rights by all. It is perhaps best illustrated in the following remarks in the judgment of the Court of Appeal of the Republic of Tanzania in *DPP v Pete*,

The second important principle or characteristic to be borne in mind when interpreting our Constitution is a corollary of the reality of co-existence of the individual and society, and also the reality of co-existence of rights and duties of the individual on the one hand, and the collective of communitarian rights and duties of society on the other. In effect this co-existence means that the rights and duties of the individual are limited by the rights and duties of society, and vice versa.²²⁹

The Court, therefore, acknowledged the overlap between *ubuntu* and human dignity, and the horizontal nature of it from a communal perspective: an individual has the right to have his dignity respected but, conversely, this individual has a corresponding duty to respect the dignity of every member in the community. Ackermann goes further to state that 'there are indeed constitutional obligations, the discharge of which is essential for the achievement of democracy and the rule of law, for securing the rights promised in the Bill of Rights for all, and for the enjoyment of the benefits of the constitutional state'.²³⁰ Ackermann is of the opinion that *ubuntu* adopts similar obligations, if viewed from the interpretation made by Langa J.²³¹ Subsequent to this decision *ubuntu* has been referred to in other court decisions.²³² These examples display the vitality of the concept in South

²²⁹ *S v Makwanyane* 1995 3 SA 391 at para 224.

²³⁰ L Ackermann *Human dignity: lodestar for equality in South Africa* (2012) 112.

²³¹ As above.

²³² See *AZAPO v President of the Republic of South Africa* 1996 4 SA 671 (CC); *Hoffman v South African Airways* 2001 1 SA 1 (CC) para 38; *Port Elizabeth Municipality v Various Occupiers* 2005 1 SA 217;

African communities and they relate to how it should be considered when dealing with sensitive topics, such as organ donation and/or transplantation.

Botha states that there are two ethical principles underlying 'African life' which can be identified.²³³ One of these principles is *ubuntu* – a person exists as a 'real' person only through his relationships with others.²³⁴ This principle denotes an ideal; it is the community which makes the person and a person cannot exist alone. The other principle identified refers to the recognition of a 'vital force', the acquisition of which is sought.²³⁵ Possession of the greatest 'vital force' would lead an individual to attain 'supreme happiness', whereas the diminution of this force would lead an individual to suffering, illness, depression and 'other social or physical evils'.²³⁶ The two principles together reveal that a person is seen as a link in a chain of vital forces, and a person's 'self' is 'essentially a social person in relation to others'.²³⁷

In traditional African societies, therefore, the healing process of a patient involves not only the healing of the individual *per se*, but it is all-inclusive and the person's social environment is also taken into account.²³⁸ Bogopa discusses different belief systems in different African cultures.²³⁹ He mentions that the Xhosa-speaking people believe that a mental or physical dysfunction needs not only the 'co-operation and active-treatment of the patient, but also that of other members of the family'.²⁴⁰ This sense of communal utilitarianism may be seen as a positive platform for organ donation, for what could be said to be more in line with the concept of *ubuntu* than giving one's organs to save another. It can further be said that *ubuntu* is in tandem with the ethical principle of beneficence, to act for the benefit of others.

Dikoko v Mokhatla 2007 1 BCLR 1; *Bhe v Magistrate, Khayelitsha*; *Shibi v Sithole*, *South African Human Rights Commission v President of the Republic of South Africa* 2005 BCLR (CC).

²³³ C Botha 'The sangoma and the MD: The clash of western medical science and traditional medicine in South Africa' (2004) 5(2) *Phronimon* 42.

²³⁴ As above.

²³⁵ As above.

²³⁶ As above.

²³⁷ As above.

²³⁸ As above.

²³⁹ D Bogopa 'Health and ancestors: the case of South Africa and beyond' (2010) 10 *Indo-Pacific Journal of Phenomenology* 1.

²⁴⁰ D Bogopa (n 239 above) 2.

African societies, however, deal with and understand illness differently from the way it is understood in the West, and these views may hinder organ donation. For this reason, it is necessary to gain an understanding of traditional healing and other views in this regard.

- *Traditional healing and ancestral worship v modern medicine*

African traditional medicine has been defined as follows:

...(the) total body of knowledge, techniques for the preparation and use of substances, measures and practices in use, whether explicable or not, that are based on... personal experience and observations handed down from generation to generation, either verbally or in writing, and are used for the diagnosis, prevention or elimination of imbalances in physical, mental or social well-being.²⁴¹

Traditional medicine does not focus on the physical and/or mental illness factor only, as does modern medicine, but it also focusses on the social well-being of the patient. In addition, Bogopa stresses the importance of certain ritual ceremonies which are to be performed, some of which cannot be undergone without the relatives of the patient.²⁴² The healing process in an African cultural context, therefore, is a process which involves the treatment of the patient for mental, physical and social dysfunctions through certain ritual ceremonies and the use of traditional medicine, with the involvement of the community and the relatives of the patient.

Ross states that, in the African setting, disorders and diseases are seen as the result of psychological, natural or social disturbances which create an imbalance which is revealed in a mental or physical problem.²⁴³ The role of traditional healing, thus, is to restore equilibrium and harmony by 'alleviating physical symptoms ... reintegrating people with their community, the earth and the spiritual world'.²⁴⁴ Western medicine views disease differently as a biological malfunctioning, with the illness revealing itself through physiological, chemical or anatomical changes.²⁴⁵ Healing entails a scientific approach,

²⁴¹ C Botha (n 233 above) 41 - 42.

²⁴² D Bogopa (n 239 above) 2.

²⁴³ E Ross 'The intersection of cultural practices and ethics in a rights-based society' (2008) 51(3) *International Social Work* 385.

²⁴⁴ As above.

²⁴⁵ As above.

normally requiring ‘medical, surgical and chemical interventions’.²⁴⁶ These differences depict the need for medical personnel to have an understanding of the cultural approach towards medicine.

In addition, there is a relationship between traditional healers (known in South Africa as *sangomas*), ancestral worship and the healing process. Ancestors are ‘deceased senior males of the clan, which comprises the descendants of a common great grandfather’.²⁴⁷ They are said to have the capability of influencing the lives of those who are still alive, and they can bless or curse the living.²⁴⁸ Bogopa determines that their worship is motivated by fear and respect.²⁴⁹ Different cultural groups in South Africa use different terms to refer to the ancestors. The Sesotho refer to them as *badimo*, in isiXhosa they are known as *izinyanya*, whereas in the isiZulu language they are referred to as *amadlozi*.²⁵⁰

Traditional healers are known to have the ability to communicate with the ancestors, and they are able to discover the root of a person’s social or health problems by ‘throwing bones to interpret the will of the ancestors’.²⁵¹ There are estimated to be between 250 000 and 400 000 traditional healers in South Africa alone, in comparison with 23 000 medical doctors.²⁵² Eight out of ten black South Africans depend on traditional medicine, either on its own or in conjunction with Western medicine.²⁵³ One is not more valued than the other. Western medicine aids in the alleviation of illnesses, but benefit has been documented from the use of traditional medicine, including reduced anxiety, psychological relief from sickness, as well as ‘a sense of comfort’.²⁵⁴

In order to understand the reluctance of African people to donate their organs one must understand the functioning of the cultural setting and the role of traditional healers. Traditional healers live by strong ethical principles and believe that alleviating suffering

²⁴⁶ As above.

²⁴⁷ D Bogopa (n 239 above) 2.

²⁴⁸ D Bogopa (n 239 above) 1.

²⁴⁹ As above.

²⁵⁰ D Bogopa (n 239 above) 1 - 2.

²⁵¹ D Bogopa (n 239 above) 1.

²⁵² E Ross (n 243 above) 385.

²⁵³ As above.

²⁵⁴ As above.

and developing life in all forms is their duty²⁵⁵ and, in a sense, this is a similar goal to that of Western medicine. There are contradictory beliefs, however, amongst the healers themselves and not all favour surgery, let alone organ donation. Ross gives the example of a study in which a group of traditional healers were interviewed to determine their views on cleft lips and palates.²⁵⁶ Several of the healers believed that the facial condition signified that the person was called upon by the ancestors to become a traditional healer and that these conditions should not be tampered with as that would be interference with the ancestor's wishes.²⁵⁷ Others felt it was necessary to refer them to Western doctors for reconstructive surgery in order to prevent them from being labelled as witches.²⁵⁸ In addition, many disorders, diseases and disabilities are viewed as punishment for wrongdoing.²⁵⁹

Ancestral worship and cultural taboos affect a person's willingness to become an organ donor.²⁶⁰ Many black South Africans are of the opinion that organ donation would anger their ancestors. It is believed that people should be buried with all of their organs in place.²⁶¹ Others maintain the view that, without the permission of the deceased before he died, they cannot agree to donate the organs of a person.²⁶² Despite these hindrances and a reluctant acceptance of Western medicine and surgical interventions for the various reasons stated above, the ultimate goal and aim of both treatments are the alleviation of illness. As stated, many South African black people make use of both Western and traditional medicine and this supports the potential for an integration of the two or, at the very least, the idea that they may work side-by-side to enhance each other's potential and goals.

Botha postulates various reasons why an integration of the two would not be possible. She states that they are based on different sets of concepts, and she mentions a bias amongst Western-trained medical professionals, who label traditional healers as

²⁵⁵ E Ross (n 243 above) 386.

²⁵⁶ As above.

²⁵⁷ As above.

²⁵⁸ As above.

²⁵⁹ As above.

²⁶⁰ E Ross (n 243 above) 389.

²⁶¹ As above.

²⁶² As above.

'quacks'.²⁶³ She further mentions how political instability, limited economic resources, as well as practical problems, such as selecting suitable traditional practitioners, may be a hindrance.²⁶⁴ She suggests a working dialogue between the two systems as opposed to integration.²⁶⁵ Traditional medicine places reliance on past resources and, in order to remain viable, it is necessary for it to be open to 'the future and in dialogue with the total culture of which it forms a part'.²⁶⁶ In line with the Traditional Health Practitioners Bill of 2003, Botha claims that a regulatory framework 'that ensures the efficacy, safety and quality of traditional health care services can provide a means to allow the Sangoma and the (medical doctor) to work together as partners, without suspicion',²⁶⁷ which, in turn, may allow for a more positive outlook with regard to organ donation and/or transplantation in an African cultural setting.

3.3.1. The Traditional Health Practitioners Act

The Traditional Health Practitioners Act (the THP Act)²⁶⁸ was formulated with the purpose of regulating traditional health services in South Africa.²⁶⁹ Such regulation involves the introduction of a regulatory framework which provides for the 'safety and quality of traditional health services'.²⁷⁰ The Act also requires the registration of traditional health practitioners, as well as students and particular categories in the profession.²⁷¹ By implementing this Act the government attempts to regulate, and formalise, these practices.²⁷²

Traditional health practice is defined in the Act as follows:

'traditional health practice means the performance of a function, activity, process or service based on a traditional philosophy that includes the utilisation of traditional medicine or traditional practice and which has as its object-

²⁶³ C Botha (n 233 above) 44 - 45.

²⁶⁴ C Botha (n 233 above) 45.

²⁶⁵ C Botha (n 233 above) 46.

²⁶⁶ As above.

²⁶⁷ As above.

²⁶⁸ Act 22 of 2007.

²⁶⁹ Act 22 of 2007, preamble.

²⁷⁰ As above.

²⁷¹ As above.

²⁷² R Thornton 'The transmission of knowledge in South African traditional healing' (2009) 71(1) *Africa: Journal of the International African Institute* 21.

- (a) The maintenance or restoration of physical or mental health or function; or
- (b) The diagnosis, treatment or prevention of a physical or mental illness; or
- (c) The rehabilitation of a person to enable that person to resume normal functioning in the family or community; or
- (d) The physical or mental preparation of an individual for puberty, adulthood, pregnancy, childbirth and death.

The Act excludes the professional activities of a person practising any of the professions contemplated in the Pharmacy Act, 1974 (Act 53 of 1974), the Health Professions Act, 1974 (Act 56 of 1974), the Nursing Act, 1974 (Act 50 of 1974), the Allied Health Professions Act, 1982 (Act 63 of 1982), or the Dental Technicians Act, 1979 (Act 19 of 1979), and any other activity not based on traditional philosophy.²⁷³

This definition reveals the nature of the traditional health practice as it incorporates not only the health of the patient, but also takes cognisance of the social and familial connotations which have been mentioned above as being of great importance. Thornton is of the opinion that the Act fails to include certain factors which are pertinent to traditional healing and *sangomas*, such as 'religion or cult, initiation, spirits, mediums, possession or trance states', and states that traditional healers are depicted as being 'lesser forms of medical practitioners'.²⁷⁴ The Act, however, is a recognition of their importance in African communities, and it may be a start towards a greater appreciation of the practice in the long run, provided that it is regulated, as is the medical profession in general.

It is also of importance to note that a regulation of these practices is necessary considering the vast number of '*muti* murders' countrywide. *Muti* is a broad term which refers to 'drugs and medicine in central and southern Africa'.²⁷⁵ At times, it is composed of human tissue and used by *sangomas* for people who are looking for success in their businesses.²⁷⁶ White states that it is believed that, when used properly, the strength from a brain, heart or even fingers, for example, can be used to bestow good fortune on

²⁷³ THP Act, sec 1.

²⁷⁴ R Thornton (n 272 above) 21. Thornton discusses the 2004 Act which is still pertinent in this discussion as it is quite similar in many respects to the 2007 Act.

²⁷⁵ L White 'The traffic in heads: bodies, borders and the articulation of regional histories' (1997) 23(2) *Journal of Southern African Studies* 328.

²⁷⁶ As above.

another.²⁷⁷ It is said, however, that spirits can take their revenge for the loss of a heart or a kidney; a person must be murdered for that specific purpose.²⁷⁸ Criminal cases regularly go to court involving *sangomas* who have been accused of *muti* murders and mutilation for the purpose of ‘harvesting ingredients for medicine’.²⁷⁹ Regulation, therefore, is pertinent.

The idea of an integrative regulatory system of healthcare is not unheard of, even on an international platform. The World Health Organisation issued a strategy which was designed to assist in the ‘appropriate integration, regulation and supervision’ of traditional and contemporary medicine.²⁸⁰ These goals are to be reached by three strategic objectives, namely:

- 1) Building the knowledge base and formulating national policies;
- 2) Strengthening safety, quality and effectiveness through regulation; and
- 3) Promoting universal health coverage by integrating (traditional and contemporary medicine) services and self-health care national health systems.²⁸¹

The THP Act can be seen as a stepping stone towards these goals and, also, as the integration of traditional healers into medical practice as a possibility. There is no reason why traditional healers may not be educated about organ transplantations and/or donation, and this may facilitate an increase in donations should this knowledge be shared with their patients. Educating medical personnel about certain traditional and cultural beliefs and practices may also assist in alleviating the bias and create a rapport between the two systems.

²⁷⁷ L White (n 275 above) 329.

²⁷⁸ As above.

²⁷⁹ P Bannister ‘Regulating ‘tradition’ – South African *Izangoma* and the Traditional Health Practitioners Act 2004’ (2008) 27(1) *Cambridge Journal of Anthropology* 30.

²⁸⁰ World Health Organisation Traditional Medicine Strategy 2014 – 2023; 7. <http://www.searo.who.int/entity/health_situation_trends/who_trm_strategy_2014-2023.pdf?ua=1> (accessed on 23/05/2018).

²⁸¹ World Health Organisation Traditional Medicine Strategy 2014 – 2023; 8. <http://www.searo.who.int/entity/health_situation_trends/who_trm_strategy_2014-2023.pdf?ua=1> (accessed on 23/05/2018).

3.4. Cadaveric donation, the moment of death and their reconciliation in religion and culture

From the above it appears that, generally, there is no objection to organ donation and transplantation among the main religions and cultures in South Africa. The question arises, though, as to whether religion and culture can be reconciled with the concept of cadaveric organ donation. Defining death as 'brain-death' is accepted worldwide and the South African National Health Act endorses this definition of death.

Christianity

It has been shown that there is no opposition to cadaveric organ donation in the Christian faith. With regards to the determination of death, Pope Pius XII stipulated in 1957 that '(i)t remains for the doctor, and especially the anaesthesiologist, to give a clear and precise definition of death and the moment of death of a patient who passes away in a state of unconsciousness'.²⁸² In terms of the Catholic faith there have not been any vehement objections to a brain-oriented definition of death, and Protestant groups favour this definition.²⁸³ Furthermore, in terms of 'moral Christian law', organ donation is viewed as a 'genuine act of love and selflessness'.²⁸⁴

Islam

In terms of the Muslim faith the determination of death has been resolved by allowing those in the medical profession to have the authority to define signs of death.²⁸⁵ Since a more brain-oriented definition has been accepted as proper, *Shariah* law has accepted that definition for purposes of organ transplantation.²⁸⁶ At a seminar entitled 'Human Life: Its Inception and Its End as Viewed by Islam', it was concluded that the Quran does not define death.²⁸⁷ Emphasis was placed on the functioning of the brain stem.²⁸⁸ The area responsible for vital functions is the brain stem, and should there be no functioning of the brain stem, even though there is still visible function in other organs, the patient should

²⁸² R Veatch (n 26 above) 2.

²⁸³ R Veatch (n 26 above) 2 - 3.

²⁸⁴ R Khalaila (n 130 above) 117.

²⁸⁵ As above.

²⁸⁶ As above.

²⁸⁷ R Veatch (n 26 above) 3.

²⁸⁸ As above.

be 'considered to have withdrawn from life'.²⁸⁹ A definition of death based on brain death, particularly brain stem death, is acceptable in Islam.

Judaism

With regard to Judaism, it has been determined that organ donation is considered a *mitzvah*, a religious instruction, or even a *pikuach nefesh*, a measure for saving lives.²⁹⁰ A controversial issue in Judaism is with regard to the determination of death. There are different views in this regard, one being that a person may be considered dead only once there has been an irreversible cessation of cardiac and respiratory activity.²⁹¹ This view was adopted by Rabbi David Bleich, a philosopher at Yeshiva University.²⁹² Rabbis from the Reformed and Orthodox traditions, on the other hand, have accepted a brain-oriented definition.²⁹³ Khalaila proposes a third approach, which can be seen as a reconciliation of the two approaches.²⁹⁴ She states that, should the breathing function located in the brain stem no longer be operating so that a person can no longer breathe on his own, this should be the ultimate determination for death.²⁹⁵ A brain-related definition is, therefore, acceptable in Judaism.

Hinduism

In Hinduism there is no objection towards the use of brain death as a determining factor. Traditionally speaking, death in Hinduism was associated with respiratory failure.²⁹⁶ The basis for support for brain death has, however, been determined 'in the notion from folklore that at death the *prana* (breath) may escape from the brain'.²⁹⁷ The Malaysian Medical Council issued guidelines in 2006 which determined that the major religions of

²⁸⁹ As above.

²⁹⁰ R Khalaila (n 130 above) 116.

²⁹¹ R Veatch (n 26 above) 2.

²⁹² As above.

²⁹³ As above.

²⁹⁴ R Khalaila (n 130 above) 117.

²⁹⁵ As above.

²⁹⁶ R Veatch (n 26 above) 4.

²⁹⁷ As above.

Malaysia (Christianity, Islam, Buddhism and Hinduism) accepted the concept of brain death.²⁹⁸ It can be stated that there is no formal opposition to this notion in Hinduism.

Buddhism

Controversy surrounding the concept of brain death exists in the Buddhist canon. According to some scholars, the body has no meaning after a person has died and, although respect for the body is paramount, it is not seen as crucial.²⁹⁹ In this scenario one would assume that cadaveric donation would not be a problem. The problem and debate, however, are with regard to the moment of death. Keown states that death occurs when three things leave the body: vitality, heat and consciousness.³⁰⁰ This belief poses a problem with regard to organ transplantation as the body generally takes a while before its heat has subsided and organs may not be viable for harvesting by the time this occurs. In addition, if this biological definition is adopted it is impossible to harvest organs from a cadaver being sustained on a life-support machine.

Tibetan Buddhists dispose of the body after three days.³⁰¹ Keown states that to cut into a body before the three days have passed would be viewed as cutting open a living person which may not only cause pain, but also create a disturbance in the rebirth of this person.³⁰² The process of retrieval of the organs may be problematic as well for a biological definition of death. Brain-dead patients will often be given nutrition, medication, and even resuscitated, if necessary, in order to preserve the organs.³⁰³ In this scenario, it would be difficult to conclude that a biological death has occurred. It has, however, been found that 'heat' and 'reflexes' are only indicators of death.³⁰⁴ Becker states that Buddhism admits certain situations, such as meditative trances or hypothermia, where no

²⁹⁸ 'Guideline for the Malaysian Medical Council – Brain Death' MMC Guideline 008/2006; 7. <<<http://www.moh.gov.my/images/gallery/orga/Brain%20Death%20-%20Malaysian%20Medical%20Council.pdf>> (accessed on 23/05/2018).

²⁹⁹ R Blank 'End-of-life decision making across cultures' (2011) *Journal of Law, Medicine and Ethics* 212. Also see M Oliver *et al* (n 53 above) 4.

³⁰⁰ Keown, D 'Buddhism and medical ethics: principles and practice' (2002) <<https://www.buddhismuskunde.uni-hamburg.de/pdf/4-publikationen/buddhismus-in-geschichte-und-gegenwart/bd7-k03keown.pdf>> (accessed on 01/05/2016) 61.

³⁰¹ D Keown 'Buddhism, brain death, and organ transplantation' (2010) 17 *Journal of Buddhist Ethics* 3.

³⁰² As above.

³⁰³ D Keown (n 301 above) 4.

³⁰⁴ C Becker 'Buddhist views of suicide and euthanasia' (1990) 40 *University of Hawaii Press* 544.

reflexes or warmth are detectable in the body but the person is not dead:³⁰⁵ Buddhism, therefore, does not equate life with warmth or reflexes; these are mere ‘supports of life’ which cannot be seen as being empirical proof of death.³⁰⁶ This leaves room for the possibility for traditional views to adopt a more coherent definition of death, perhaps even one based on neurological death determination.

African culture

In the African context there appears to be no definition of when death occurs. Bhengu suggests that, in order to prevent doubt about the concept of brain-stem death, a traditional healer could be included in the diagnosis of death as a trusted figure in the Zulu community (or African communities in general).³⁰⁷

Of importance, as well, are the various traditions that should be acknowledged after death and the ancestral beliefs which have been dealt with above. It has been stated that most Africans believe both in traditional beliefs and associate themselves with a religion. In this sense it has been shown that a definition of death based on neurological criteria (brain death or brain stem death) is acceptable to the main religions in South Africa. The next problem to tackle is whether South Africa is ready to implement an opting-out system of organ donation.

3.4.1. Determining the incorporation of an opting-out system of organ donation in the South African legal dispensation

The above study demonstrates that there is no direct objection to be found in religion and/or culture against organ donation in general nor is there any direct objection to the concept of a brain-oriented definition of death. It can be assumed that living organ donations to strangers are not especially likely to occur, so the focus then moves to cadaveric donation. An opting-out system for organ donation is supported by this research, and it has been described in the previous chapter. The next question that needs to be answered is whether such a system is in conflict with religion and/or culture.

³⁰⁵ As above.

³⁰⁶ As above.

³⁰⁷ BR Bhengu ‘Organ donation and transplantation within the Zulu culture’ (2004) 27 *Curationis* 30.

It has been shown that religion and culture place considerable emphasis on altruistic acts, which are often depicted as acts which are commendable. In certain religions which believe in an afterlife, an altruistic act would have a beneficial karmic effect after death. Organ donation is seen as such an act so then it could be argued that an opting-out system is not completely unthinkable. It was argued in the previous chapter that an opting-out system for organ procurement is ethically sound from utilitarian, beneficent and autonomous (in terms of the principle of respect for autonomy) points of view.

It has further been argued that presumed consent should rather be termed 'implied consent'.³⁰⁸ Li refers to Saunders who contends that consent should be seen as 'an action of sorts' and not necessarily as a mental attitude as it is understood by most people to be.³⁰⁹ He gives the example of a doctor who informs a patient that he needs an injection and proceeds to administer it without any objection from the patient.³¹⁰ In this scenario, this action cannot be said to have 'presumed' consent, but rather that the consent is 'implied'.³¹¹ Li postulates that an opting-out system (or 'implied' consent) would indeed be possible where the general public is given the proper amount of education for a reasonable length of time, rendering an awareness amongst citizens that a failure to opt-out would amount to consent.³¹² Bhengu states that it has been determined that such a system would be suitable only for a 'well informed public' in order to address criticism that it is a violation of self-determination.³¹³ She states that Zulu-speaking people should be introduced to the topic of cadaveric donation slowly in order to 'allow them to get used to the idea, as there is a relationship between knowledge, experience and attitude'.³¹⁴

Taking these views into consideration, the implementation of an opting-out system in South Africa may be feasible only once the public has been properly educated in both the procedures and terms involved with cadaveric organ donation and also that a failure to

³⁰⁸ R Li 'Should the rest of the UK follow the lead of Wales and introduce an opt-out system of organ donation?' (2015) 2 *Edinburgh Student Law Review* 69.

³⁰⁹ B Saunders 'Opt-out organ donation without presumptions' (2012) 38 *Journal of Medical Ethics* 70 – as quoted in R Li (n 308 above) 69.

³¹⁰ As above.

³¹¹ As above.

³¹² R Li (n 308 above) 69.

³¹³ BR Bhengu (n 307 above) 25.

³¹⁴ BR Bhengu (n 307 above) 30.

opt-out would mean an implied acceptance of donation. A mandated choice system may be realistic as a start towards an opting-out system of donation, a system 'of requiring competent adults to prospectively register their wishes regarding organ donation in advance of death through various registration mechanisms' such as renewing a driver's licence or filing a tax return.³¹⁵ This system would place the wishes of the deceased above any family objections and increase personal autonomy as it would guarantee that a person's wishes are met regarding how their bodies are to be dealt with at death.³¹⁶ Such a system may be seen as a stepping stone towards a system of presumed consent.

3.5. Conclusion

Organ donation and transplantation are fairly recent modes of treatment while the different religions and cultures date back much further. The scriptures and ancestral beliefs are unlikely to have foreseen such an operation or procedure, and this has led to numerous interpretations by religious and traditional leaders as well as by lay persons. Often these interpretations are contradictory.

The above investigation has shown that nothing in religion and/or culture is against organ donation in general, be it living or deceased donations. The religious attitude towards organ donation is a positive one, often viewing it as a charitable act through the saving of lives. It is possible, and it has, therefore, been stated that objections raised based on religion (or culture) are ill-informed and express a personal interpretation based on one's own perspective or intuition. Organ donation can be seen to be a reflection of *ubuntu*, as *ubuntu* depicts the notion that a person cannot survive without other people.

What is pertinent is the acknowledgment and appreciation by medical personnel of the different religious and cultural traditions and rituals which follow a person's death, ultimately respecting the deceased person and his family members. In terms of culture, integrating traditional healers into the medical profession may be seen as a stepping-

³¹⁵ H Cotter 'Increasing consent for organ donation: mandated choice, individual autonomy, and informed consent' (2011) 21 *Health Matrix* 604 - 605.

³¹⁶ H Cotter (n 315 above) 604.

stone towards the acceptance of organ procurement for both living and deceased donations, and this may be accomplished with the aid of the THP Act and Regulations.

In addition, it has been shown that a brain-stem death-definition of death would be acceptable to both religion and culture, and an opting-out system for organ procurement may be feasible, but only in the future. Until this can be accomplished, however, a mandated choice system for organ procurement would be a more suitable option. Paramount to this change would be the inability of the next of kin, or family members, to veto the decision made by the deceased. Not only would this increase donations, but it would also preserve the autonomy and self-determination of the person's wishes prior to his death.

Now that the beliefs and misconceptions of the different cultures and religions regarding organ donation and transplantation have been canvassed, the next chapter turns to an examination of a human rights-based approach to organ donation as a possible remedy to the declining rate of organ donations.

CHAPTER FOUR

A human rights-based approach to organ donation and/or transplantation

4.1. Introduction

The previous chapters have not only addressed misconceptions regarding culture and religion in the context of organ donation and transplantation, but they have also reconciled ethical principles and donation, and highlighted the need for reform in this area, specifically in South Africa. The rate of donations has decreased to a point where it is now obvious that the system in place is ineffective with regards to catering for the needs of those suffering from organ failure.

Devising a human rights-based approach (HRBA) arguably is a positive step towards rectifying this anomaly as it sets out to affirm and protect the inherent human rights of those involved. As will be shown below, this is because a HRBA redresses inequalities in different areas and strives to enable people in different communities to take part in the 'economic, social and cultural affairs toward the progressive realisation of rights'.¹ HRBAs are designed to assist policy-makers in effectively localising and targeting inequalities - which have resulted from economic, cultural or social circumstances - and prioritising those with the greatest need.² For the purposes of the thesis this would be with reference to individuals facing organ failure.

Diverse institutions, whether academic or other, differ on how to incorporate such an approach in their different fields. They all, however, are centred on certain basic main principles. A HRBA is a system which applies rights-based principles in the formulation and implementation of policy.³ The purpose of such a system is to empower people with

¹ R Thomas, S Kuruvilla, R Hinton, SLB Jensen, V Magar & F Bustreo 'Assessing the impact of a human rights-based approach across a spectrum of change for women's, children's, and adolescents' health' (2015) 17 *Health and Human Rights Journal* 12.

² As above.

³ M Escobar, L Cubillos & R Iunes 'Looking for evidence of the impact of introducing a Human Rights-Based approach in health: The SaluDerecho experience' (2015) 17 *Health and Human Rights Journal* 58.

not only the knowledge of their rights, but also the ability to claim them.⁴ This system further enhances the accountability of institutions and individuals who are responsible for fulfilling, protecting and respecting rights, and it also provides greater opportunities for people to participate in moulding the decisions which have an impact on their lives – their human rights.⁵ It is about guaranteeing the integration of the standards and principles of human rights into policymaking and the ‘day to day running of organisations’.⁶ These principles refer to an ethical incentive towards the insurance of dignity and justice for each and every individual.⁷ The principles applied in a HRBA (human rights principles) include: inalienability, indivisibility and interdependence; empowerment and participation; equality and non-discrimination; and accountability.⁸

Gruskin *et al* describe a HRBA as one which requires the implementation of a system which is ‘shaped by [these] human rights principles’.⁹ They provide that, in terms of this approach, when looking at health policies and programmes, states are responsible for national health plans which are ‘consistent with their international human rights obligations, ensuring non-discrimination and the participation of affected communities’.¹⁰ The idea behind this is for human rights to be incorporated into health and development strategies and work in order for programmes and policies to contribute towards the fulfilment of human rights.¹¹ Academic literature has often highlighted ‘the interdependence of rights as support for multi-sectoral approaches’.¹² For instance, fulfilling certain rights, such as the right of access to healthcare services, would require the fulfilment of other rights such as information and education.¹³

⁴ ‘Care about Rights? What is a human rights-based approach?’ <<http://careaboutrights.scottishhumanrights.com/whatisahumanrightsbasedapproach.html>> (accessed on 31/07/2017).

⁵ As above.

⁶ As above.

⁷ JK Boesen & T Martin *Applying a rights-based approach: An inspirational guide for civil society* (2007) 42.

⁸ Boesen & Martin (n 7 above) 43.

⁹ S Gruskin, D Bogecho & L Ferguson ‘Rights-based approaches’ to health policies and programs: articulations, ambiguities, and assessment’ (2010) 31 *Journal of Public Health Policy* 130.

¹⁰ As above.

¹¹ As above.

¹² S Gruskin *et al* (n 9 above) 131.

¹³ As above.

The former UN Special Rapporteur on the right of individuals to the enjoyment of the highest attainable standard of health (mental and physical) has further been noted as highlighting a HRBA as enforcing ‘the incorporation of human rights principles in the *processes* of health policy and development’.¹⁴ His opinion with regard to the method emphasises a ‘people-centred approach’ to healthcare among other things.¹⁵ International organisations also have a somewhat similar interpretation to HRBAs. The United Nations Children’s Fund (UNICEF), for example, emphasise the principles of accountability, universality and indivisibility when looking at the foundational principles highlighted in the Convention on the Rights of the Child.¹⁶ In addition, the United Nations Population Fund structures its HRBA programme by stressing the importance of culture and gender-sensitivity, while the World Health Organisation (WHO) defines its ‘health and human rights approach’ as being founded on ‘international human rights treaties, explicitly recognising health as a human right, empowering vulnerable and marginalised groups, and enhancing government accountability, among other factors’.¹⁷

From this, one ascertains that a HRBA is aimed at the empowerment of marginalised groups by affirming their human rights and empowering them by allowing them access to be able to participate in the policy making process. In addition, this approach focuses on the implementation of international human rights norms and is also centred on human rights principles as can be seen from the examples above, such as accountability and non-discrimination and equality. Depending on the area to be improved, other factors may be highlighted, such as gender and culture where applicable, but the main aim of a HRBA appears to be its focus on the protection, attainment and furtherance of human rights.

Human rights have gained global legitimacy for three interrelated reasons: 1) it has been recognised widely that human rights stem from ‘the dignity and worth of the human person’;¹⁸ 2) each region in the world has endorsed human rights instruments: the

¹⁴ As above.

¹⁵ As above.

¹⁶ S Gruskin *et al* (n 9 above) 134.

¹⁷ S Gruskin *et al* (n 9 above) 134 – 135.

¹⁸ Universal Declaration of human rights. As quoted in ‘OHCHR - Human rights and poverty reduction – a conceptual framework’ (2004)
<<http://www.ohchr.org/Documents/Publications/PovertyReductionen.pdf>> (accessed on 27/06/2017)
1 (OHCHR report).

Universal Declaration of Human Rights (UDHR) has been affirmed by all states and almost 150 states have ratified the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR); and 3) 'all states have chosen to ratify at least one human rights' treaty' which has the effect of bestowing certain international legal obligations on these states, with regard to human rights', and these are binding in terms of the law of treaties.¹⁹ Furthermore, the United Nations Charter (UN Charter) provides for the promotion of respect for human rights and fundamental freedoms without discrimination as to sex, religion, language or race.²⁰

A HRBA has been applied to different policies and programmes by several authors and organisations as an attempt to address and resolve inadequacies in problematic areas such as healthcare and poverty. The concept behind a HRBA tends to be relatively similar in these areas and adapted according to a specific area of focus such as healthcare. Budiani-Saberi and Columb, for instance, discuss a HRBA to human trafficking for organ removal.²¹ Their analysis focuses on the protection of vulnerable people as well as on the suppression and prevention of organ trade.²² They also provide that an analysis of this nature is to be 'guided by human rights norms and principles, placing the protection of rights holders at the centre of all efforts/strategies to combat this phenomenon'.²³ In addition to this, the Department of Health in the United Kingdom (UK) identified five key aims of a HRBA to healthcare as follows:

1. putting human rights principles and standards at the heart of policy and planning;
2. empowering staff and patients with knowledge, skills and organisational leadership and commitment to achieve a human rights-based approach;
3. enabling meaningful involvement and participation of all key stakeholders;
4. ensuring clear accountability throughout the organisation; and

¹⁹ OHCHR report (n 18 above) 1.

²⁰ Art 1(3), UN Charter.

²¹ D Budiani-Saberi & S Columb 'A human rights approach to human trafficking for organ removal' (2013) 16 *Medicine, Healthcare and Philosophy* 897.

²² D Budiani-Saberi & S Columb (n 21 above) 904.

²³ D Budiani-Saberi & S Columb (n 21 above) 904 – 905.

5. non-discrimination and attention to vulnerable groups.²⁴

These principles form part of a HRBA, and they can be applied to cater for organ donation and/or transplantation as will be discussed below. HRBAs have, in addition, been successful in the international and national spheres. Hunt *et al* discuss the impact of applying a HRBA to health.²⁵ They highlight the inclusion of a human rights language as well as human rights aspirations which has developed in health and development in 15 years from the beginning of the Millennium Development Goals.²⁶ Not only do human rights now form a part of these goals, but they also inform new global health strategies.²⁷ There has, further, been a notable integration of human rights into health programmes and policies by national governments as they attempt to honour their human rights commitments.²⁸ Furthermore, Thomas Silberhorn, the Parliamentary State Secretary of Germany's Federal Ministry for Economic Cooperation and Development, discusses the success which the German government's implementation of a HRBA has had on health outcomes in an article.²⁹ Using the examples of Nepal, Kenya, India and Cambodia, he writes that 'applying a HRBA effectively helps enhance the access of poor, vulnerable, and marginalised groups to health-related services, and helps improve quality of health'.³⁰ This is not to say that a HRBA is not without its challenges, but the success which is associated with its implementation can hardly be ignored.

A HRBA may be applied in diverse ways. Amartya Sen, for instance, devised the capability approach (CA) as a means of implementing a human rights approach to poverty reduction.³¹ In terms of this approach, Sen assesses quality of life and determines which policies should be in place in order to be conducive to the development of human beings by analysing what people are able to do and able to be – 'a reliable indicator of social

²⁴ M Curtice & T Exworthy 'FREDA: A human rights-based approach to healthcare' (2010) 34 *The Psychiatrist* 151.

²⁵ P Hunt *et al* 'Making the case: what is the evidence of impact of applying human rights-based approaches to health?' (2015) 17 *Health and Human Rights Journal* 1.

²⁶ P Hunt *et al* (n 25 above) 3.

²⁷ As above.

²⁸ As above.

²⁹ P Hunt *et al* (n 25 above) 4. Also see T Silberhorn 'Germany's experience in supporting and implementing human rights-based approaches to health, plus challenges and successes in demonstrating impact on health outcomes' (2015) 17(2) *Health and Human Rights Journal* 21.

³⁰ P Hunt *et al* (n 25 above) 4.

³¹ OHCHR report (n 18 above) 3.

justice'.³² In terms of this model, Sen states a 'conceptual bridge between the discourses on poverty and human rights' by looking into the main features associated with a human rights approach towards poverty reduction.³³

What follows in this chapter will be a re-enactment of this same model; however, the model will be adapted to suit the needs of individuals facing organ failure. The chapter will begin by describing the CA from the perspective of organ donation; this will be followed by providing, firstly, a brief insight into the human rights norms which can be adapted to organ failure, donation and transplantation, and, secondly, an analysis of the main features which are to be associated with a HRBA to organ failure including: 'empowerment and participation; recognition of the national and international human rights framework; accountability ... and progressive realisation'.³⁴

4.2. Sen's capability approach and organ failure

The CA was formulated by Amartya Sen and expanded on by Nussbaum and others as an approach to the theoretical difficulties found in the methods adopted towards welfare economics.³⁵ This approach was adopted initially to provide a scheme which would look towards the concerns of individuals, being the rights which would provide legitimate claims, as opposed to the more conventional system which focuses on the optimal allocation of inputs and outputs.³⁶ The CA further became influential in various academic writings and policy-making endeavours, and it has since made its way into the fields of medicine and health.³⁷

The concept behind the CA is the underlying factor behind a person's well-being.³⁸ Sen states that the well-being of a person is the 'well-ness' of a person, or the quality of a

³² S Berges 'Why the capability approach is justified' (2007) 24 *Journal of Applied Philosophy* 16.

³³ A Sen 'Human rights and capabilities' (2005) 6 *Journal of Human Development* 152. Also see OHCHR report (n 18 above) 3.

³⁴ As above.

³⁵ P Anand 'Capabilities and health' (2005) 31 *Journal of Medical Ethics* 299.

³⁶ As above.

³⁷ As above.

³⁸ OHCHR report (n 18 above) 6.

person's living or being.³⁹ 'Living' in this regard would consist of 'a set of interrelated 'functionings' – the things that a person can do or be'.⁴⁰ Consequently, the level of these functionings will determine the level of a person's well-being, for instance, the extent to which a person can take part in the community or be free from hunger.⁴¹ Capability would, thus, be the freedom, or opportunity, of an individual 'to achieve well-being in this sense'.⁴² When referring to poverty, Sen defines it as 'low levels of capabilities' or 'the failure of basic capabilities to reach certain minimally acceptable levels'.⁴³ Applying this to organ failure, it would imply that a person who is faced with this condition lacks the basic freedom, or capability, to be free from the health symptoms associated with organ failure. This would be due to a lack of enough donors as well as a lack of an effective system for donation and transplantation as will be discussed in greater detail below.

The CA defines poverty as 'the absence or inadequate realization of certain basic freedoms, such as the freedoms to avoid hunger, disease, illiteracy, and so on'.⁴⁴ The reason for the focus on basic freedoms lies in the notion that their recognition is essential for the attainment of 'minimal human dignity'.⁴⁵ This concern for human dignity also reinforces the human rights-based approach as it provides that individuals possess inalienable rights to these basic freedoms.⁴⁶ Should a person be denied these freedoms, or perhaps not be given an opportunity to attain them, it would be a non-realisation of the rights to these freedoms.⁴⁷ In this manner, Sen equates freedoms and rights and creates the idea that should a person not be afforded the opportunity to exercise these freedoms, this could lead to a human rights violation. The essential idea would be the elevation of basic freedoms to enforceable rights.

Stoecklin and Bonvin provide that the CA insists on two dimensions:

³⁹ As above.

⁴⁰ As above.

⁴¹ As above.

⁴² As above.

⁴³ OHCHR report (n 18 above) 7.

⁴⁴ OHCHR report (n 18 above) 9.

⁴⁵ As above.

⁴⁶ As above.

⁴⁷ As above.

... people should be provided with real opportunities, which extends beyond resources and formal rights; they should be left autonomous in deciding about the way they want to use these opportunities and not be constrained toward compliance with specific norms or official directives.⁴⁸

In this regard, Anand gives the example of a person who is not eating because he has no food as opposed to a person who is not eating because he is fasting.⁴⁹ This draws a distinction between capabilities (what people can do) and what people choose actually to do (functionings).⁵⁰ The author states that these two concepts should be the essence of evaluations towards well-being and of government policy.⁵¹ To use this same example, a person should have the option as to whether they choose to eat or not, in the sense that the opportunity should be available to him. These opportunities should, thus, be made available to all people regardless of their position in life.

Walker analyses the CA in terms of education.⁵² She determines that the CA focuses on what people are able to do or be as opposed to the resources to which they may have access.⁵³ The idea behind the CA is for people to have the capability to 'choose a life they have reason to value'.⁵⁴ Freedom and capabilities are connected in that opportunities to achieve and develop capabilities and the process of collectively deciding on which capabilities are valuable both create and necessitate freedom.⁵⁵ She further defines capability as being 'a combination (a capability set) of functionings someone can achieve, and from which he can choose one collection'.⁵⁶ The CA approach, therefore, is based on the idea of life being a combination of different 'doings and beings' and the quality thereof being based on the ability to procure valuable functionings.⁵⁷ Seen from this angle,

⁴⁸ D Stoecklin & J Bonvin (eds) (2015) *Children's rights and the capability approach: challenges and prospects* 3.

⁴⁹ P Anand (n 35 above) 299.

⁵⁰ As above.

⁵¹ As above.

⁵² M Walker 'Amartya Sen's capability approach and education' (2005) 13 *Journal of Educational Action Research* 103.

⁵³ As above.

⁵⁴ As above.

⁵⁵ M Walker (n 52 above) 104.

⁵⁶ As above.

⁵⁷ As above.

the element of choice is important. In order to be able to choose the lifestyle one desires, there needs to be an understanding of the different options (which need to be made available), as well as the ability or freedom to pursue them.

Similarly, with organ failure, a person should have the opportunity to be able to avail themselves of, at the very least, a chance to pursue transplantation as the best option to live a life free from the struggles associated with this condition as well as being enabled to live a longer life. Regarding organ failure, a system should be in place which would afford everyone the opportunity to undergo transplantation safely and equally, whether they choose this route or not and regardless of their financial or other status. In addition to do this, there should be a facilitation of an increase in donations to meet the need of those suffering from organ failure.

4.3. Capabilities, human rights and organ failure

Sen refers to human rights in the context of capabilities, as ‘rights to certain freedoms’ which have correlated obligations on others to determine their duties in expanding and safeguarding these freedoms.⁵⁸ His theory is not only concerned with a person having the freedom to have certain opportunities to certain functionings (for instance to not be malnourished), but he also links the CA with various deprivations in the world which have resulted from ‘a lack of freedom to escape destitution’.⁵⁹ He mentions how people have suffered and even starved to death because of a lack of alternative possibilities.⁶⁰ The significance of freedom can be highlighted by looking at other issues aside from poverty, issues which are central to human rights.⁶¹ Sen refers to the example of an immigrant having the opportunity to maintain his ancestral lifestyle, whether he chooses to pursue it or not.⁶² The pivotal issue in this scenario would be that this person should have ‘the freedom to choose how she should live – including the *opportunity* to pursue ancestral

⁵⁸ A Sen ‘Human rights and capabilities’ (2005) 6 *Journal of Human Development* 152.

⁵⁹ A Sen (n 58 above) 155.

⁶⁰ As above.

⁶¹ As above.

⁶² As above.

customs'.⁶³ The author refers to this ideal of obligations and duties more with reference to state duties and obligations.

In this light, the importance of, and link between, human rights and the CA is clear and paves the way to a discussion on the human rights norms which are relevant to organ donation and/or transplantation. The purpose of such a discussion is to bridge the CA with those human rights which are relevant to parties involved in donation and transplantation with particular focus on those individuals who are facing organ failure. This was the same principle adopted by Stoecklin and Bonvin when looking towards children's rights and the CA approach.⁶⁴ Their application looked towards the aim of the CA by Nussbaum and Sen who see the approach as a 'way to operationalise formal freedoms (entitlements)'.⁶⁵ If one were to apply the same line of thinking to organ donation, it would imply using the CA as a means of identifying dimensions to focus on when it comes to the implementation of the formal rights of the parties involved, as the ones established in different human rights instruments.⁶⁶

The UDHR gave rise to both first and second-generation rights. The former aims at the protection of the individual from state oppression as well as ensuring the participation of individuals in the political process without interference from the government of the state, provided that the actions of individuals are not detrimental to others.⁶⁷ Venter states, as an example, 'the right to not be subjected to medical or scientific experimentation without consent'.⁶⁸ Economic, social and cultural rights focus more on an adequate standard of living. These second-generation rights put the emphasis on access to certain resources, such as healthcare and food, in order to achieve this standard.⁶⁹

⁶³ As above.

⁶⁴ Stoecklin & Bonvin (n 48 above) 1.

⁶⁵ As above.

⁶⁶ As above. Stoecklin & Bonvin focus on the children's rights contained specifically in the United Nations Convention on the Right of the Child. For purposes of this discussion, focus will be placed on different human rights instruments as contained in national, regional and international agreements.

⁶⁷ B Venter 'A selection of constitutional perspectives on human kidney sales' (2013) 16 *PER* 355. Also see JS Taylor *Stakes and Kidneys: Why Markets in Human Body Parts are Morally Imperative (Live Questions in Ethics and Moral Philosophy)* (2005) Chap 7.

⁶⁸ As above.

⁶⁹ As above.

Both first and second-generation rights are catered for on national, regional and international levels. The Constitution of the Republic of South Africa, 1996 (Constitution) contains a Bill of Rights in chapter 2, which lays out the rights of all people in the country. It 'affirms the democratic values of human dignity, equality and freedom',⁷⁰ and contains some of the human rights relevant to our discussion, including the right to life, privacy, human dignity, and access to healthcare services. The Constitution, thus, implements human rights at the national level in South Africa. All rights contained in chapter 2 are subject, however, to the limitation clause contained in section 36 of the Constitution. This section provides for the limitation of rights only in terms of the law of general application 'to the extent that the limitation is reasonable and justifiable in an open and democratic society'.⁷¹

When interpreting the rights contained in the Bill of Rights, section 39 of the Constitution provides that a court, tribunal or forum may consider foreign law and must consider international law.⁷² This emphasises the importance placed on international and foreign law. Section 231(4) of the Constitution provides for the implementation of international law in the form of treaties in the Republic, requiring that it be enacted into national legislation for it to become binding on the state. These two sections highlight the necessity of interpreting the human rights provided for in the Bill of Rights by referring to human rights norms outside of the national sphere. As such, the regional and international levels of human rights protection have immediate relevance to the South African legal system.

At the regional level, South Africa is a party to the African Charter for Human and Peoples' Rights (African Charter).⁷³ At the international level, South Africa is a party to human rights instruments such as the ICCPR and ICESCR. A discussion of the pertinent rights relating to organ donation/transplantation will be undertaken below with the emphasis placed on the national, regional and international levels of human rights protection.

⁷⁰ Sec 7 of the Constitution.

⁷¹ Sec 36 of the Constitution.

⁷² Subsecs 39(a) and (b) of the Constitution.

⁷³ B Venter (n 67 above) 536.

4.3.1. Right to human dignity

'[A] recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world'.⁷⁴ This quotation is part of the first sentence of the UDHR. It creates an elevated status for human dignity, one which forms the basis of living as part of the 'human family'. Dignity is also found in religion, where the belief among Christians, for instance, is how man is made in God's image.⁷⁵ This alone demands a level of respect (or dignity) for mankind. The right to dignity is also protected in the African Charter as well as the ICCPR.⁷⁶ The preamble to the ICESCR takes note of the inherent dignity which all individuals possess.

Section 10 of the Constitution provides further that 'everyone has inherent dignity and the right to have their dignity respected and protected'.⁷⁷ Ackermann asserts, that when read in tandem with section 1(a) of the Constitution – which asserts 'human dignity' as one of the foundational values of the Republic – section 10 not only makes it clear that human dignity is a right and a value, but also 'a categorical imperative'.⁷⁸ By stating that everyone has inherent dignity, section 10 is merely proclaiming 'the essence of the natural person respected and protected by the Constitution'.⁷⁹ In this sense, the Constitution does not assign individuals with this right because it already exists in every human being regardless of possible infringements of the right itself.⁸⁰ Ackermann further states that section 10 also needs to also be read together with section 8(1) – 'the Bill of Rights applies to all law, and binds the legislature, the executive, the judiciary and all organs of state' – as well as section 7(2) – 'the state must respect, protect, promote and fulfil the rights in the Bill of Right' – providing a 'double emphasis' on the duty of the state to protect the

⁷⁴ The preamble, UDHR.

⁷⁵ 'Then God said, 'Let us make man in our image, after our likeness. And let them have dominion over the fish of the sea and over the birds of the heavens and over every living thing that moves on the earth'. Genesis 1: 26.

⁷⁶ In its preamble, the ICCPR recognises the inherent right to dignity that is possessed by all human beings. Similarly, Art 5 of the African Charter states that 'Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status'.

⁷⁷ Sec 10 of the Constitution of the Republic of South Africa.

⁷⁸ L Ackermann *Human dignity: lodestar for equality in South Africa* (2012) 86.

⁷⁹ Ackermann 95.

⁸⁰ As above.

human dignity of every individual.⁸¹ The court in the *Glenister* case further emphasise the nature of the state's obligation in terms of section 7(2), which is also applicable to its obligation in terms of section 10, as follows:

[189] ... This Court has held that in some circumstances this provision imposes a positive obligation on the state and its organs —to provide appropriate protection to everyone through laws and structures designed to afford such protection. Implicit in section 7(2) is the requirement that the steps the state takes to respect, protect, promote and fulfil constitutional rights must be reasonable and effective.

[190] And since in terms of section 8(1), the Bill of Rights 'binds the legislature, the executive, the judiciary and all organs of state', it follows that the executive, when exercising the powers granted to it under the Constitution, including the power to prepare and initiate legislation, and in some circumstances Parliament, when enacting legislation, must give effect to the obligations section 7(2) imposes.

[191] ... This Court will not be prescriptive as to what measures the state takes, as long as they fall in the range of possible conduct that a reasonable decision-maker in the circumstances may adopt. A range of possible measures is therefore open to the state, all of which will accord with the duty the Constitution imposes, so long as the measures taken are reasonable.⁸²

Respect for the dignity of man is a concept which many jurisdictions have embraced in their national legislation. Human dignity has often been referred to as 'a basis for human rights'.⁸³ This is noted from the inclusion of the concept of dignity in different areas of the law as it is applied by the courts, including areas such as 'the dignity of same-sex couples, patients, prisoners, detainees, asylum seekers, women seeking abortions, and people wishing to end their lives'.⁸⁴ Dignity is often referred to *in tandem with* the right to life, freedom and equality. Becker *et al* argue that the role of dignity, equality and freedom is to 'transform our society from one in which only the fittest survive, to one in which we care

⁸¹ As above.

⁸² *Glenister v President of the RSA and Others; Helen Suzman Foundation as Amicus Curiae* 2011 3 SA 347 (CC) paras 189 – 191; as referenced in Ackermann (n 78 above) 96.

⁸³ AC Steinmann 'The core meaning of human dignity' (2016) 19 *PER/PELJ* 2.

⁸⁴ M Neal 'Respect for human dignity as a 'substantive basic norm'' (2014) 10 *International Journal of Law in Context* 26 – 27.

for and empower vulnerable people'.⁸⁵ They further provide that dignity, as a right in terms of section 10 of the Constitution, has both a vertical and horizontal application, vertical in the sense that it places a duty on the government and organs of state to respect individuals and their dignity, and horizontal in that all persons (natural and juristic) should respect the dignity of every individual.⁸⁶ The CA also highlights the importance of human dignity. The approach is both normative and prescriptive as it promotes policies and social arrangements 'meant to enhance respect for people's dignity'.⁸⁷

Dignity is an enforceable right not only at a national level but also in the international and regional spheres as stated above. Nevertheless, problems arise when formulating a definition for human dignity, as this is not provided in any of the national, regional or international documents. Donnelly refers to the Oxford English Dictionary for a definition of dignity which he proclaims goes back to the thirteenth century and which reads as follows, 'The quality of being worthy or honourable; worthiness, worth, nobleness, excellence'.⁸⁸ Dignity, thus, demands respect.⁸⁹ Shestack discusses a number of theorists who have attempted a construction of a system of human rights based on 'a value-policy oriented approach founded on the protection of human dignity'.⁹⁰ In this regard he mentions a number of values that fall in the sphere of human dignity as being demands related to dignity, 'respect, power, enlightenment, wellbeing, health, skill, affection and rectitude'.⁹¹

Foster attempts to define human dignity by relating it to the act of 'flourishing' which he believes to be 'primarily about *being*, and only secondarily (although often more spectacularly) about *doing*'.⁹² Dignity should also be seen as not just *being* but also about

⁸⁵ A Becker, A de Wet & W van Vollenhoven 'Human rights literacy: moving towards rights-based education and transformative action through understandings of dignity, equality and freedom' (2015) 35 *South African Journal of Education* 4.

⁸⁶ As above.

⁸⁷ Stoecklin & Bonvin (n 48 above) 10.

⁸⁸ J Donnelly 'Human dignity and human rights' Report prepared for the Geneva Academy of International Humanitarian Law and Human Rights in the framework of the Swiss Initiative to commemorate the 60th Anniversary of the Universal Declaration of Human Rights, (2009) 10.

⁸⁹ As above.

⁹⁰ JJ Shestack 'The philosophical foundations of human rights' in J Symonides (Ed) *Human rights: concept and standards* (2002) 53.

⁹¹ JJ Shestack in Symonides (n 90 above) 54.

⁹² C Foster *Human dignity in bioethics and law* (2011) 6.

‘the process of *becoming*’.⁹³ This is due to the understanding that dignity is ‘time-inclusive’ and ‘an individual’s personality is never finished and keeps evolving throughout their life’.⁹⁴ Foster opposes this belief however to a certain extent as certain individuals, for instance those suffering from certain mental disabilities, will never have the opportunity for their dignity to evolve, yet all human beings have an inherent dignity.⁹⁵ As a result he defines dignity as ‘objective human flourishing’.⁹⁶

Woolman further elaborates on the concept of ‘flourishing’ in an attempt to determine whether ‘dignity’ and ‘flourishing’ can co-exist as synonyms.⁹⁷ He believes that the two concepts cannot be ‘mapped’ onto one another because they stem from two different schools of thought: ‘dignity’ is a fundamental constitutional norm which can be associated with Immanuel Kant’s ‘deontological and reason-based ethics’, whereas ‘flourishing’ takes on an Aristotelian ‘practical wisdom’ ethics.⁹⁸ He determines however that individuals need to be bestowed with ‘some minimal level of dignity’ in order to be able to flourish, as opposed to the two concepts being seen as synonyms.⁹⁹

Foster further argues that it is possible to define dignity in such a way that it is ‘effective at the bioethical and medico-legal coalface’.¹⁰⁰ Indeed, he states that the ‘sound of a well-tuned Beauchamp and Childress choir is the voice of dignity’.¹⁰¹ This is because, while he originally was under the belief that the bioethical principle of autonomy could veto any medically ethical argument, he is now under the impression that it tends to be inadequate to resolve some of the problems in medical ethics,¹⁰² which highlights Woolman’s theory that the concepts ‘flourishing’ and ‘dignity’ should not be viewed as synonyms but rather

⁹³ As above.

⁹⁴ C Dupre ‘Unlocking human dignity: towards a theory for the 21st Century’ (2009) 2 *European Human Rights Law Review* 190. As discussed in Foster (n 853 above) 6.

⁹⁵ Foster (n 92 above) 6.

⁹⁶ As above.

⁹⁷ S Woolman *The selfless Constitution: experimentalism and flourishing as foundations of South Africa’s basic law* (2013) 393.

⁹⁸ Woolman (n 97 above) 392. One of Kant’s categorical imperatives is to ‘[a]ct in such a way that you always treat humanity, whether in your own person or in the person of another, never simply as a means, but always at the same time as an end’ – See I Kant, AW Wood & JB Schneewind *Groundwork of the metaphysics of morals* (2002) as quoted in Woolman (n 97 above) 394.

⁹⁹ As above.

¹⁰⁰ Foster (n 92 above) 3.

¹⁰¹ As above.

¹⁰² As above.

there needs to be an element of dignity in order to ‘flourish’. This would imply that biomedical ethics and dignity need to work hand in hand in order to resolve challenges presented in medical ethics. The author agrees with this notion.

Ackermann defines human dignity from two perspectives as follows:

(a) Certain qualities of the human being namely:

Those aspects of human personality that flow from human intellectual and moral capacity; which in turn separate human beings from the impersonality of nature;

(b) Certain functions that these qualities enable human beings to perform, namely,

- i. To exercise their own judgement;
- ii. To have self-awareness;
- iii. To have a sense of self-worth;
- iv. To exercise self-determination;
- v. To shape themselves and nature;
- vi. To develop their personalities; and
- vii. To strive for self-fulfilment in their lives.¹⁰³

Ackermann thus defines human dignity as containing the above abilities and qualities.¹⁰⁴ The idea behind human dignity in her opinion is that it includes notions of self-determination, self-fulfilment as well as ‘the shaping of self and personality’.¹⁰⁵ These functions listed above reveal an all-encompassing nature associated with human dignity in terms of, for example, medical ethics: self-awareness and exercising one’s own judgment is akin to the biomedical ethical principle of autonomy discussed in chapter 2 above. It can also be argued that individuals who are suffering from end-stage organ failure are given less opportunity to exercise certain functions such as having ‘a sense of self-worth’ as determined by the functions listed above. This is due to the symptoms associated with organ failure which do not allow for a person to live a life worth living.¹⁰⁶

¹⁰³ Ackermann (n 78 above) 86.

¹⁰⁴ As above.

¹⁰⁵ Ackermann (n 78 above) 87.

¹⁰⁶ Symptoms associated with organ failure vary depending on the specific organ. Acute liver failure for example presents itself with symptoms including fever, anorexia, malaise, fatigue and jaundice; see M Pathikonda & S Munoz ‘Acute liver failure’ (2010) *Annals of Hepatology: Official Journal of the Mexican Association of Hepatology* 9. Whilst on dialysis, a patient suffering from kidney failure experiences

One may also refer to case law as a means of defining human dignity. The court, in the case of *S v Makwanyane*, stated that, '[r]ecognising a right to dignity is an acknowledgement of the intrinsic worth of human beings; human beings are entitled to be treated as worthy of respect and concern'.¹⁰⁷ This quotation highlights 'respect' as, perhaps, part of the concept of human dignity, in addition to 'concern' which would denote the somewhat 'caring' nature that the term possesses. The Court further discussed the concept of human dignity as being linked to *Ubuntu*, which was defined as relating to 'personhood and morality'.¹⁰⁸ It referred to the nature of *Ubuntu* which deals with group solidarity being fundamental to the 'survival of communities'.¹⁰⁹ The Court, further, stated the following:

In international law, on the other hand, human dignity is generally considered the fountain of all rights. The International Covenant on Civil and Political Rights (1996) G.A. Res 2200 (XXI), 21 U.N. GAOR, SUPP. (No, 16) at 52, U.N. DOC. A/6316(1996), in its preamble, makes references to 'the inherent dignity of all members of the human family' and concludes that 'human rights derive from the inherent dignity of the human person'. This, in my view, is not different from what the spirit of *Ubuntu* embraces.¹¹⁰

Seen in this light, one can conclude that human dignity has a community aspect, one where individuals in a society need to help one another to survive not only individually but as a group. This is an element which is essential for organ donation and/or transplantation, as donating one's organs contributes to the furtherance of the community's health-related needs and depicts an act of humaneness. Taking this sentiment literally, it can hardly be said that persons facing organ failure are being treated humanely, or with respect or concern given the fact that the number of donors is decreasing each year and attempts are not being made to rectify this i.e less people are donating their organs and as such, the community's health-related needs are not being

both physical and psychological distress including, but not limited to, headaches, nausea, loss of sight, depression and mental anguish. See B Venter (n 828 above) 362. These symptoms would hinder a person's ability to fulfil the functions needed to realise the qualities necessary to enhance one's dignity as portrayed by Ackermann. The concept of 'a life worth living' is discussed in more detail below.

¹⁰⁷ *S v Makwanyane* 1995 3 SA 391 para 328.

¹⁰⁸ *S v Makwanyane* para 308.

¹⁰⁹ As above.

¹¹⁰ *S v Makwanyane* (n 107 above) para 309.

met. In addition, as has been shown previously, the use of culture and religion as a reason for objecting to donation and transplantation is a misconception, and, as such, a misuse of one's belief in order to foster a spirit of inhumaneness and a deterioration of the spirit of a community.

Dignity can also be viewed from a religious perspective. French discusses *inter alia* common principles held by most religions worldwide.¹¹¹ She refers to universal common principles held by all religions as depicted by various scholars such as:

[The] fundamental moral beliefs – that it is wrong to murder or to steal or to lie or to break one's promises, that one should act responsibly towards others, that children should respect parents and parents should care for children, that it is right to aid persons in distress, that the dignity of all persons should be respected, that every human being should be treated humanely, and that (...) 'you should do unto others what you would want them to do unto you'.¹¹²

This reveals not only the inherent nature of dignity as vested in all individuals, but also the importance that it places on all other human rights which would seem to adopt the basic nature that dignity bestows. To adapt this to organ donation would be to acknowledge the positive and negative obligations incumbent through this right, viz. the positive obligation on the state to ensure the realisation of this right (by facilitating an increase in donations and providing a system which would ensure that the rights of each party are protected and enforced) and the negative obligation on the public to ensure that this right is not violated (arguably by adopting a communal spirit and becoming donors and/or allowing for donation to take place either by donating themselves, or donating the organs of a deceased loved one).

4.3.2. Right to life

The right to life has frequently been depicted as being the most fundamental of all human rights.¹¹³ The reason for this is that it gives rise to all other human rights¹¹⁴; you have to

¹¹¹ R French 'On Buddhism and Natural Law' (2014) 8 *Journal of Comparative Law* 153.

¹¹² As above.

¹¹³ B Venter (n 67 above) 536.

¹¹⁴ As above.

be alive in order to be considered a legal person with rights. Most jurisdictions have some form of protection of the right to life. The Constitution of South Africa provides in section 11 that '[e]veryone has the right to life'.¹¹⁵ This right has been referred to as being 'antecedent to all other rights in the Constitution', as it would be impossible to be the bearer of rights and have the ability to exercise them without 'life in the sense of existence'.¹¹⁶ This right has also been linked to the right to human dignity as stated by various scholars, as well as the Court in *S v Makwanyane*, where the following statement was made:

The right to life, thus understood, incorporates the right to dignity. So the rights to human dignity and life are intertwined. The right to life is more than existence, it is a right to be treated as a human being with dignity; without dignity, human life is substantially diminished. Without life, there cannot be dignity.¹¹⁷

This right to life is also protected at the regional level. The African Charter provides that '[h]uman beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right'.¹¹⁸ In this, read together with the protection afforded to dignity in the UDHR, the superior nature of the right is made clear as well as the value afforded to it which requires legal protection.¹¹⁹

Wicks states that the African Commission on Human and Peoples' Rights (African Commission) places emphasis on some of the more positive obligations which are necessary to achieve a full realisation of the right.¹²⁰ She refers, in this regard, to the communication of *Social and Economic Rights Action Centre and another v Nigeria*.¹²¹ The Commission in this case highlighted not only the duty of states not to interfere with the right in question, but also a 'positive expectation' of states to use '[s]tate machinery in

¹¹⁵ Sec 11, Constitution of South Africa.

¹¹⁶ *S v Makwanyane* (n 107 above) para 326.

¹¹⁷ *S v Makwanyane* (n 107 above) para 327.

¹¹⁸ Art 4 of the African Charter.

¹¹⁹ E Wicks 'The meaning of 'life': dignity and the right to life in international human rights treaties' (2012) 12 *Human Rights Law Review* 204 – 205.

¹²⁰ E Wicks (n 119 above) 205.

¹²¹ *Social and Economic Rights Action Centre and the Centre for Economic and Social Rights v Nigeria* 155/1996, 15th Annual Activity Report of the ACHPR (2002). As referenced in E Wicks (n 810 above) 205.

the actual realisation of rights, including the provision of basic needs such as food'.¹²² The position is, thus, clear: without having access to certain basic needs, the inherent right to dignity is not bestowed with the 'respect required under the right to life obligation'.¹²³ This could be argued from the perspective of transplantation. Individuals suffering from organ failure lack the basic needs to enjoy their right to life. These would be a proper system in place to facilitate donation and the actual donated organs.

The right to life is protected at the international and regional level as well. The UDHR, as well as the American Declaration of the Rights and Duties of Man, are the first documents which recognised the right to life.¹²⁴ Article 3 of the UDHR provides that 'everyone has the right to life, liberty and security of the person'. Similarly, article 1 of the American Declaration of the Rights and Duties of Man states that, 'Every human being has the right to life, liberty and the security of his person'.¹²⁵ The ICCPR also provides for the protection of life, and it is clearer about the obligations that this right places on the state. It states that 'every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life'.¹²⁶ This article clearly provides a duty on the state to protect this right 'by law'.

This right may also be viewed as a prominent concept in most, if not all, religions worldwide. Oliver *et al* analyse the connection between organ donation and religion.¹²⁷ They point out the importance of saving a life as well as acts which promote the sustaining of life.¹²⁸ This can be seen in Hinduism, where it is believed that such acts are viewed as *Dharma*, which translates as 'righteous living'.¹²⁹ Altruism is an important aspect of both Christianity and Islam. In Islam, it is considered altruistic to save another's life: 'Whosoever saves the life of one person it would be as if he saved the life of all mankind'.¹³⁰ Also, it is common knowledge in the Christian faith, regardless of the

¹²² As above.

¹²³ As above.

¹²⁴ E Wicks (n 119 above) 200 – 201.

¹²⁵ As above.

¹²⁶ Art 6(1) of the ICCPR.

¹²⁷ M Oliver *et al* 'Organ donation, transplantation and religion' (2010) *Nephrology Dialysis Transplantation* 437.

¹²⁸ As above.

¹²⁹ M Oliver *et al* (n 127 above) 440.

¹³⁰ M Oliver *et al* (n 127 above) 438.

denomination, that God sent his only son to sacrifice his life for the lives of all of mankind. This view was also expressed also in a previous chapter with regards to the importance and value placed on saving a life in Judaism.¹³¹ In terms of culture, it has already been shown by the attitude towards life adopted by African culture and society.¹³² This illustrates the inherent nature of life as seen not only from the national, regional and international documents, but also from a religious and cultural point of view which could arguably highlight the importance of protecting this life in the context of donation and transplantation.

4.3.3. Right to an adequate standard of living

The above has shown that the right to life is protected at the national, regional and international levels. This right further encompasses the right to dignity, in other words the right to be treated with respect and in a humane manner. The African Commission has previously stated that the right to life not only deals with the non-interference in this right by the state, but also the need for there to be access to certain basic needs as provided for by the state to realise this right.¹³³ In addition, the preamble to the Constitution provides that the 1996 Constitution was adopted as the supreme law of the nation in order to, *inter alia*, 'improve the quality of life of all citizens and free the potential of each person'.¹³⁴ This indicates that, inclusive to the right to life are guarantees regarding the quality of that life, a view which is pertinent to organ donation and/or transplantation. Article 25(1) of the UDHR expounds on this and states the following:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

This right is also elaborated in the ICESCR which states the following:

¹³¹ See chap 3.

¹³² See chap 3, specifically regarding the discussion on *Ubuntu*.

¹³³ *Social and Economic Rights Action Centre and the Centre for Economic and Social Rights v Nigeria* 155/1996, 15th Annual Activity Report of the ACHPR (2002). As referenced in E Wicks (n 810 above) 205.

¹³⁴ The Preamble, Constitution of South Africa.

The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international cooperation based on free consent.¹³⁵

The question then arises as to what an adequate standard of living entails. From the text, article 25(1) of the UDHR clearly stipulates that health, medical care and the well-being of a person and his family are included in the consideration of an adequate standard of living. The use of the word 'including' in the content of this right in references in both international documents illustrates that this is not a closed list.¹³⁶ Udombana analyses the right to an adequate standard of living as being a subcategory of the rights to dignity, life and the 'pursuit of happiness'.¹³⁷ He claims that this right implies 'the maintenance of a level of living which is above the poverty line of the society concerned' and which integrates certain needs which include, *inter alia*, health, food, social service, as well as clothing and transport.¹³⁸ He refers to these as basic necessities which are needed by every individual, 'without shame and without unreasonable obstacles, to be a full participant in ordinary, everyday interaction with other people'.¹³⁹

An adequate standard of living can be viewed from the perspective of a patient who is suffering from organ failure, for instance a person in chronic renal failure having to have the constant use of a dialysis machine. A patient on dialysis is required to have treatment three to four times a week, with each treatment lasting around three to four hours.¹⁴⁰ Venter divides the side effects of this treatment into physical and psychological side effects.¹⁴¹ The physical side effects include 'a decrease in energy levels and endurance, fatigue, headaches, pains, itchiness, loss of sight, nausea, cramps, infections and weight

¹³⁵ Art 11(1) of the ICESCR.

¹³⁶ N Udombana 'Life, dignity, and the pursuit of happiness: human rights and living standards in Africa' (2008) 27 *University of Tasmania Law Review* 51.

¹³⁷ N Udombana (n 136 above) 48.

¹³⁸ N Udombana (n 136 above) 49.

¹³⁹ As above.

¹⁴⁰ B Venter (n 67 above) 362.

¹⁴¹ As above.

loss'.¹⁴² The psychological effects are mentioned as being anything from mental anguish, depression, stress, to fear and aggression.¹⁴³ These symptoms would surely cause the depreciation of the quality of life of any person being subjected to this treatment until a kidney becomes available, and they can certainly not be seen as experiencing a 'life worth living'.¹⁴⁴ Similarly, patients suffering from end stage heart failure stop responding to medical treatment, experience symptoms which are disabling and have repeatedly to stay in hospitals.¹⁴⁵ This amounts not only to a poor quality of life but also uses very costly health care resources.¹⁴⁶ These patients have a poor prognosis, and, after undergoing failed attempts at 'medical therapy, surgery and/or cardiac resynchronisation therapy', the only mode of treatment to prolong their lives, as well as the quality thereof, is to have a heart transplant.¹⁴⁷

4.3.4. Right to health and access to healthcare services

The right to health is significant in any society. A person's health is necessary for him to enjoy his life to the full. Without it, one is unable to care for a family, do work, or attain an adequate standard of living which has been described above to be vital to life. The link between the rights to life, health as well as dignity, therefore, becomes clear. Asher argues that the right to health should not be viewed as a right to be 'healthy' as the state cannot be expected to 'provide people with protection against every possible cause of ill health or disability ...'.¹⁴⁸ Instead, she affirms that the right to health should be seen as a right to the 'enjoyment of a variety of facilities and conditions which the state is responsible for providing as being necessary for the attainment and maintenance of good health'.¹⁴⁹

Swanepoel stresses that the right to have access to healthcare services provided for in section 27(1)(a) of the Constitution is limited by subsection (2) which determines that the

¹⁴² As above.

¹⁴³ As above.

¹⁴⁴ As above.

¹⁴⁵ E Roig *et al* 'Specialised care program for end-stage heart failure patients. Initial experience in a heart failure unit' (2006) 59 *Revista Espanola de Cardiologia* 110.

¹⁴⁶ As above.

¹⁴⁷ MLA Haeck *et al* 'Treatment options in end-stage heart failure: where to go from here?' (2012) 20 *Netherlands Heart Journal* 167.

¹⁴⁸ J Asher *The right to health – a resource manual for NGOs* (2010) 27.

¹⁴⁹ As above.

state needs only take reasonable and legislative measures according to its available resources to achieve the progressive realisation of this right.¹⁵⁰ In this way, the Constitution does not guarantee a right to health *per se*, but rather a right of right of access to health care services.¹⁵¹

Swanepoel highlights the case of *Soobramoney*¹⁵² in relation to the ‘nature and level of care to which people are entitled’.¹⁵³ In this case the appellant - a 41 year old diabetic in chronic renal failure – was suffering from vascular and heart disease and in need of dialysis treatment.¹⁵⁴ He sought treatment at the Addington State Hospital in Durban; however, he was not admitted to the dialysis programme because of the limited resources available.¹⁵⁵ The hospital policy, due to the lack of facilities for dialysis, was to only admit patients who were eligible for a kidney transplant.¹⁵⁶ Mr Soobramoney was unfortunately not eligible for a kidney due to his age and other factors. In 1997 he filed an urgent application in the Durban and Coast Local Division of the High Court for an order directing Addington Hospital to provide him with ongoing dialysis treatment and interdicting the hospital from refusing him admission to its renal unit.¹⁵⁷ This application was dismissed, and the appellant took the matter to the Constitutional Court which *inter alia* held the following:

[11] Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

[12] The appellant urges us to hold that patients who suffer from terminal illnesses and require treatment such as renal dialysis to prolong their lives are entitled in terms of section

¹⁵⁰ Sec 27(2) of the Constitution. Also see M Swanepoel ‘Embryonic stem cell research and cloning: a proposed legislative framework in context of legal status and personhood’ Unpublished LLM thesis, University of Pretoria, 2006 152.

¹⁵¹ As above.

¹⁵² *Soobramoney v Minister of Health (Kwazulu – Natal)* 1998 1 SA 765.

¹⁵³ M Swanepoel (n 150 above) 152.

¹⁵⁴ *Soobramoney v Minister of Health* (n 152 above) at para 1.

¹⁵⁵ As above.

¹⁵⁶ *Soobramoney v Minister of Health* (n 152 above) at para 3.

¹⁵⁷ *Soobramoney v Minister of Health* (n 152 above) at para 5.

27(3) to be provided with such treatment by the state, and that the state is required to provide funding and resources necessary for the discharge of this obligation.

[13] The words 'emergency medical treatment' may possibly be open to a broad construction which would include ongoing treatment of chronic illnesses for the purpose of prolonging life. But this is not their ordinary meaning, and if this had been the purpose which section 27(3) was intended to serve, one would have expected that to have been expressed in positive and specific terms.

[14] Counsel for the appellant argued that section 27(3) should be construed consistently with the right to life entrenched in section 11 of the Constitution and that everyone requiring life-saving treatment who is unable to pay for such treatment herself or himself is entitled to have the treatment provided at a state hospital without charge.

[15] This Court has dealt with the right to life in the context of capital punishment but it has not yet been called upon to decide upon the parameters of the right to life or its relevance to the positive obligations imposed on the state under various provisions of the bill of rights.¹⁵⁸

It is thus clear that the provision of access to healthcare services depends greatly on the available resources.

Of equal importance in this context is the *Treatment Action Campaign* case which dealt with the provision by the government of access to HIV and AIDS treatment to expectant women in order to prevent mother-to-child transmission of HIV.¹⁵⁹ The court in this case ruled in favour of the respondents and concluded the following:

We therefore conclude that section 27(1) of the Constitution does not give rise to a self-standing and independent positive right enforceable irrespective of the considerations mentioned in section 27(2). Sections 27(1) and 27(2) must be read together as defining the scope of the positive rights that everyone has and the corresponding obligations on the state to respect, protect, promote and fulfil' such rights. The rights conferred by

¹⁵⁸ *Soobramoney v Minister of Health* (n 152 above) paras 11 - 15. Swanepoel further notes that the Constitutional Court in this case provided, in obiter, that '[t]he Bill of Rights should further not be interpreted in a way which results in courts feeling themselves unduly pressurised by the fear of the gambling with the lives of claimants into ordering hospitals to furnish the most expensive and improbable procedures, thereby diverting scarce medical resources and prejudice the claims of others'. Swanepoel (n 150 above) 155 in fn 545.

¹⁵⁹ *Treatment Action Campaign v Minister of Health* 2002 5 SA 721 (CC).

sections 26(1) and 27(1) are to have access to the services that the state is obliged to provide in terms of sections 26(2) and 27(2).¹⁶⁰

This judgement shows that the Constitutional Court will indeed hold the government accountable to its constitutionally-bestowed duties, and it further reveals that the government is 'a servant of the Constitution'.¹⁶¹

The Constitution of the World Health Organisation (WHO) recognises the '[t]he enjoyment of the highest attainable standard of health' as being a fundamental right possessed by every human being regardless of race, political affiliation, religion, and/or social or economic condition.¹⁶² This is also highlighted in the UDHR in article 25 which provides the following:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

The right to health is further recognised in article 12(1) of the ICESCR as being the enjoyment of 'the highest attainable standard of physical and mental health', and similar language is used in article 16(1) of the African Charter on Human and Peoples' Rights (African Charter).¹⁶³ The right is also prevalent, in different formulations, in the constitutions of 39 African states.¹⁶⁴ This right to health is, in most cases, recognised without any further elaboration, leaving out a discussion about the content of the right

¹⁶⁰ *Treatment Action Campaign v Minister of Health* (n 920 above) at para 39.

¹⁶¹ M Swanepoel (n 150 above) 156. Swanepoel discusses the rights contained in sec 27 in relation to stem cell therapies and therapeutic cloning. She provides that the acknowledgement of the right of access to healthcare services contained in the Constitution 'include aspects of stem cell therapies and therapeutic cloning'. It is submitted that the same can be applied to organ donation and/or transplantation as this method of treatment does benefit the health and overall mental and physical well-being of the many South Africans suffering from organ failure.

¹⁶² Preamble to the Constitution of the World Health Organisation: adopted by the International Health Conference held in New York in 1946 by the representatives of 61 states and entered into force on 7 April 1948.

¹⁶³ Art 16(1) of the African Charter provides that '[e]very individual shall have the right to enjoy the best attainable state of physical and mental health'.

¹⁶⁴ C Heyns & W Kaguongo 'Constitutional human rights law in Africa' (2006) 22 *South African Journal of Human Rights* 706.

itself.¹⁶⁵ In this case, one may refer to the ICESCR which does enshrine the right in greater detail by including the reduction of infant mortality and still-birth, environmental and industrial hygiene, the control of epidemics, as well as ‘the creation of conditions which would assure to all medical service and medical attention in the event of sickness’.¹⁶⁶

These elements as seen in the ICESCR are, however, not widely included or recognized in African constitutions which mostly only give recognition to the right, without further elaboration.¹⁶⁷ Heyns does, however, recognise five countries which guarantee access to medical services as part of the right to health; four which recognise the healthy development of the child as well as reduction of infant death; four which provide for the control, prevention and treatment of diseases; and one country which makes room for the inclusion of industrial and environmental health.¹⁶⁸ South Africa includes the right of access to health care services in the context of the right to health in section 27 of the Constitution, 1996.¹⁶⁹ The Interim Constitution did not foreshadow these rights in the Interim Bill of Rights, and their inclusion initially was met with jurisprudential controversy.¹⁷⁰ However, in its certification judgement, the Constitutional Court held that their inclusion would not be a breach of the doctrine of separation of powers.¹⁷¹ The Court stated the following:

It is true that the inclusion of socio-economic rights may result in the courts making orders which have direct implications for budgetary matters. However, even when a court

¹⁶⁵ As above.

¹⁶⁶ Art 12(2)(a) – (d) of the ICESCR.

¹⁶⁷ As above.

¹⁶⁸ The five countries which guarantee access to medical services as part of the right to health are Lesotho, South Africa, Uganda, Seychelles and the Gambia; Equatorial Guinea, Angola, Seychelles and Lesotho recognise the healthy development of the child as well as reduction of infant health; the Seychelles, Guinea, Algeria and Lesotho include the treatment, prevention and control of diseases; and Lesotho is the one country to include industrial and environmental health. See C Heyns & W Kaguongo (n 164 above) 706.

¹⁶⁹ Sec 27 provides: (1) Everyone has the right to have access to— (a) health care services, including reproductive health care; (b) sufficient food and water; and (c) social security, including, if they are unable to support themselves and their dependents, appropriate social assistance.

¹⁷⁰ The South African Chamber of Business and the South African Chamber of Mines were of the opinion that the inclusion of socio-economic rights would be disruptive as these rights were ‘unattainable and they were ‘bad for business’’. See GE Devenish *A commentary on the South African Constitution* (1998) 72.

¹⁷¹ *In re Certification of the Constitution of the Republic of South Africa Constitution Act 1996* 1996 10 BCLR 1253 (CC) para 77.

enforces civil and political rights such as equality, freedom of speech and the right to a fair trial, the order it makes will often have such implications. A court may require the provision of legal aid, or the extension of state benefits to a class of people who formerly were not beneficiaries of such benefits. In our view it cannot be said that by including socio-economic rights, a task is conferred upon the courts so different from that ordinarily conferred upon them by a bill of rights that it results in a breach of separation of powers.¹⁷²

Devenish writes that the inclusion of these rights in the Bill of Rights does not eradicate problems such as poverty overnight; however, 'it does establish certain priorities and it ensures that problems are addressed'.¹⁷³ The protection of the right of access to healthcare services has also been given effect in national legislation with the enactment of the National Health Act.¹⁷⁴ Although a definition of health has not been afforded, health services are defined as follows in the National Health Act in section 1:

- (a) health care services, including reproductive health care and emergency medical treatment, contemplated in section 27 of the Constitution;
- (b) basic nutrition and basic health care services contemplated in section 28(l)(c) of the Constitution;
- (c) medical treatment contemplated in section 35(2)(e) of the Constitution; and
- (d) municipal health services.

In this regard, one may refer to the right of access to healthcare services as a subcategory of the right to health, although it is distinct, as the right to health is a more general view of the right and looks at well-being and highest attainable standard of health while healthcare services focuses on certain primary obligations on the state, including, but not limited to, 'the provision of healthcare services to vulnerable groups in society' and the enactment of legislation to ensure this provision by providing for the regulation of 'health professions, private healthcare services'.¹⁷⁵

The right of access to healthcare services and the right to health can both be applied to organ donation when one takes the above into account. When looking at the right to

¹⁷² As above.

¹⁷³ GE Devenish (n 170 above) 73.

¹⁷⁴ Act 61 of 2003.

¹⁷⁵ N Kirby 'Access to healthcare services as a human right' (2010) 29 *Medicine and Law* 488 – 489.

health, 'the highest attainable standard of physical and mental health',¹⁷⁶ temporary solutions may not be sufficient to fulfil this need. A person on dialysis, as seen above, is not able to achieve an adequate standard of living. The best option will always be the replacement of the failed or failing organ. Should the donation come from a living donor, his health also merits protection. The WHO guiding principles on human cells, tissue and organ transplantation indeed emphasise the importance placed on protecting the health of such donors 'during the process of selection, donation, and necessary aftercare to ensure that the potential untoward consequences of the donation are unlikely to disadvantage the remainder of the donor's life'.

The right of access to healthcare services presupposes an obligation on the state to provide healthcare services for specific vulnerable groups, which, in this discussion, would focus on individuals who are suffering from organ failure, regardless of their status in society. It can also be argued that, in order to realise this right, it would be pertinent for the state to enact legislation which deals specifically with donation and transplantation not only to provide structure for a failing system, but also to ensure that the regulation of this sensitive area protects the human rights of all parties involved.

The right to health can also be viewed from a cultural perspective. Himonga discusses the African Charter with specific reference to articles 16(1) and (2).¹⁷⁷ Subsection (2) provides that '[s]tates parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick'.¹⁷⁸ He argues that these subsections, read with articles 27 to 29 as well as the preamble to the African Charter, 'directly implicate the concept of *Ubuntu* in that they encompass several of its attributes'.¹⁷⁹ He states that the articles in question refer to the duties of individuals, including, *inter alia*:

the duty towards his family and society; the duty to respect and consider his fellow beings without discrimination, and to maintain relations aimed at promoting, safeguarding and

¹⁷⁶ Art 16 of the African Charter.

¹⁷⁷ C Himonga 'The right to health in an African cultural context: the role of *Ubuntu* in the realisation of the right to health with specific reference to South Africa' (2013) 57, 2 *Journal of African Law* 169.

¹⁷⁸ Art 16(2) of the African Charter.

¹⁷⁹ C Himonga (n 177 above) 169.

reinforcing mutual respect and tolerance; the duty to preserve harmonious development of the family; the duty to respect his parents at all times and maintain them in case of need; the duty to serve his national community; the duty to preserve and strengthen social and national solidarity; and the duty to preserve and strengthen positive cultural values in his association with other members of society in the spirit of tolerance, dialogue and consultation. These duties resonate with communalism.¹⁸⁰

This reveals the connection between the right to health and *Ubuntu* in strengthening the overall health of a community. It, therefore, stands to reason that, when dealing with the deteriorating health of individuals who are suffering from organ failure, there is no greater way to highlight the spirit of *Ubuntu*, and the horizontal application of the right to health, than for one to become an organ donor.

An individual's health is recognised and protected not only legally and culturally, but also by religious elements. Christianity, for example, often preaches about 'the poor, the sick, the marginalised and the weak'.¹⁸¹ Christ's death on the cross is portrayed as the ultimate act of altruism, such that mankind can have a better life. The communal and altruistic nature adopted by most religions, which can be applied in a spiritual context, has also been noted above.

4.3.5. The right to bodily integrity

The right to bodily integrity has been briefly discussed in chapter 2 under the title of informed consent and patient autonomy. Taking this into account, the right will be looked at below very briefly. This right first appeared in South African law in the case of *Stoffberg v Elliott* where the court stated the following:

In the eyes of the law, every person has certain absolute rights which the law protects... and one of those rights is the right of absolute security of the person. Nobody can interfere in any way with the person of another, except in certain circumstances... Any bodily interference with or restraint of a man's person which is not justified in law, or excused in law, or consented to, is a wrong, and for that wrong the person whose body has been

¹⁸⁰ C Himonga (n 177 above) 169 – 170.

¹⁸¹ M Slabbert, FD Mnyongani & N Goolam 'Law, religion and organ transplants' (2011) 76 (2) *Koers* 274.

interfered with has a right to claim such damages as he can prove he had suffered owing to the interference.¹⁸²

The court refers to certain absolute rights which are protected by the law, and it mentions ‘the right of absolute security of the person’ as one of these rights. These rights are determined by the court to be absolute, except in certain circumstances, which is also the case today. The right to bodily integrity now appears in the Constitution in section 12 which, in relation to an individual’s body, creates a right of individual inviolability.¹⁸³ Section 12(2)(b), in particular, provides that ‘[e]veryone has the right to bodily and psychological integrity, which includes the right to security in and control over their body’. This subsection has two components: ‘security in’ and ‘control over’ one’s body.¹⁸⁴ The former protects a person’s ‘bodily autonomy or self-determination against interference’ whereas the latter refers to ‘the right to be left alone in the sense of being allowed to live the life one chooses’.¹⁸⁵

Currie and de Waal claim that section 12(2)(b) needs to be read with section 12(2)(c) which provides the right to be free from violence.¹⁸⁶ The purpose here is to determine whether a particular form of assault would be serious enough to constitute an invasion of the right in section 12(2)(b).¹⁸⁷ They use the example of a police officer shoving a person aside to make way for an ambulance; in this scenario, it has is highly unlikely to amount to an invasion of an individual’s personhood or privacy.¹⁸⁸ Similarly with organ transplantation, generally speaking the surgery itself would technically be an invasion of this right. Consenting to the transplantation would, however, invoke the maxim ‘*volenti non fit iniuria*’ (no harm can be done to a person who has consented to the harm) as a legal ground of justification.¹⁸⁹ This consent would, however, need to be informed, as discussed in chapter 2 above, in order to prevent legal consequences associated with the absence of consent which could include negligence, criminal or civil assault or *iniuria*,

¹⁸² *Stoffberg v Elliott* 1923 CPD 148 at para 7.

¹⁸³ I Currie & J de Waal *The Bill of Rights handbook* (2013) 287.

¹⁸⁴ As above.

¹⁸⁵ As above.

¹⁸⁶ As above.

¹⁸⁷ As above.

¹⁸⁸ As above.

¹⁸⁹ PA Carstens & D Pearmain *Foundational principles of South African medical law* (2007) 875.

breach of contract and/or a violation of a person's bodily integrity.¹⁹⁰ As has previously been discussed, informed consent contains four elements which need to be satisfied, namely voluntariness, capacity, competence and disclosure.¹⁹¹ A potential donor would further need to be able to decide 'without controlling influences that determine their action'.¹⁹²

This requirement also applies to the patient suffering from organ failure and not just to the donor. It is pertinent that should a person make the decision to undergo surgery to receive an organ, he should be given all the relevant information which he will use to make an informed decision. This requirement may also be viewed conversely. The writer submits that, should a person decide against becoming an organ donor based on misconceptions relating to religion and/or culture, this may very well also be seen as a violation of this person's informed consent owing to the requirement of disclosure. This is because it has been shown that religion and culture do indeed not go against donation and/or transplantation and, therefore, a person who has other views is misinformed and not in possession of all the information to be able to make an informed decision. It is, therefore, important for every individual considering donation to be aware of these misconceptions as they could possibly be a deciding factor as to whether a person donates his own organs or those of a loved one.

4.3.6. The right to privacy

Social scientists have recognised the right to privacy as being pertinent for the preservation of one's dignity, and this would include one's psychological, physical as well as spiritual well-being.¹⁹³ Legally speaking, privacy is referred to as the 'an individual condition of life characterised by exclusion from publicity'.¹⁹⁴ Privacy is also at the centre of the democratic values in South Africa; even in a constitutional democracy, however, this right is not absolute.¹⁹⁵ The right to privacy warrants protection in international law as

¹⁹⁰ PA Carstens & D Pearmain (n 189 above) 890.

¹⁹¹ For a discussion of these elements see A Dhai 'An introduction to informed consent: ethico-legal requirements' (2008) 63 *SADJ* 18.

¹⁹² T Beauchamp & J Childress *Principles of biomedical ethics* (2009) 101.

¹⁹³ C Van der Bank 'The right to privacy – South African and Comparative perspectives' (2012) 1 *European Journal of Business and Social Sciences* 78.

¹⁹⁴ As above.

¹⁹⁵ As above.

seen in article 12 of the UDHR which provides that '[n]o one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation'. Similar protection is afforded in article 17 of the ICCPR. From a regional perspective, the right to privacy is catered for in the European Convention for the Protection of Human Rights and Fundamental Freedoms in Article 8,¹⁹⁶ as well as in the American Convention on Human Rights in article 11 and article 14. The American Declaration on Rights and Duties of Mankind provides the same protection of privacy as that in the UDHR and ICCPR. It is interesting to note that the African Charter does not cater for privacy rights.

At the national level, privacy is protected in the South African Constitution in section 14, which provides the following:

Everyone has the right to privacy, which includes the right not to have—

- (a) their person or home searched;
- (b) their property searched;
- (c) their possessions seized; or
- (d) the privacy of their communications infringed.

The entrenchment of fundamental rights in South Africa, including the right to privacy, assigns a higher status and level of protection to these rights as they are 'applicable to all law, and are binding on the executive, the judiciary and the state organs as well as natural and juristic persons'.¹⁹⁷ The general right to privacy, however, is not catered for in national legislation and, thus, an evaluation thereof is to take place in the light of the Constitution as well as common law.¹⁹⁸

This right also plays a major role in a healthcare setting. Medical practitioners may not divulge patient information without their consent. This is expressed clearly in the National

¹⁹⁶ Art 8(1) provides: Everyone has the right to respect for private and family life, his home and his correspondence.

¹⁹⁷ C Van der Bank (n 193 above) 79.

¹⁹⁸ As above.

Health Act which contains a section dealing specifically with confidentiality relating to a patient's 'health, status, treatment or stay in a health establishment'.¹⁹⁹

There are various instances, however, where this confidentiality may be broken, such as where a patient provides his consent, if there is a law or court order requiring such disclosure, or if non-disclosure could possibly lead to a threat to public health.²⁰⁰ The Health Professions Council of South Africa (HPCSA) similarly provides guidelines for medical practitioners when dealing with patient confidentiality.²⁰¹ These guidelines reiterate the protection provided for in the National Health Act, as well as in the Constitution, and provide instances where a practitioner may disclose information in terms of rule 13 of the Ethical Rules of the HPCSA and these are as follows:

- in terms of a Statutory provision;
- at the instruction of a court;
- in the public interest;
- with the express consent of the patient;
- with the written consent of a parent or guardian of a minor under the age of 12 years; and
- in the case of a deceased patient with the written consent of the next of kin or the executor of the deceased's estate.

Currie and de Waal provide that an extensive look at this right was catered for in the case of *Bernstein v Bester*.²⁰² In the court's analysis of the right to privacy, Ackermann, J contends that the scope of an individual's privacy 'extends *a fortiori* only to those aspects in regard to which a legitimate expectation of privacy can be harboured'.²⁰³ Currie and de Waal provide that this legitimate expectation has two components, namely 'a *subjective expectation* of privacy ... that the society has recognised...as *objectively reasonable*'.²⁰⁴ The standard of reasonableness has, however, not been elaborated on, but the authors provide a summary of the court's analysis as follows: 'a) privacy is a subjective

¹⁹⁹ Art 14, Act 61 of 2003.

²⁰⁰ As above.

²⁰¹ Health Care Professions Council of South Africa – Guidelines for Good Practice in the Health Care Professions 'Confidentiality: protecting and providing information' (2007) 2nd Edition.

²⁰² *Bernstein v Bester* 1996 2 SA 751 (CC). As referred to in I Currie & J de Waal (n 183 above) 297.

²⁰³ *Bernstein v Bester* 1996 2 SA 751 (CC) at para 75.

²⁰⁴ I Currie & J de Waal (n 183 above) at 298.

expectation of privacy that is reasonable; b) it is reasonable to expect privacy in the ‘inner sanctum’, in the ‘truly personal realm’.²⁰⁵

From this it can be gathered that this right is personal, and perhaps intimate, in nature. In *Hyundai Motor Distributors*, Langa DP discusses the intimate nature of the right as follows:

As we have seen, privacy is a right which becomes more intense the closer it moves to the intimate personal sphere of the life of human beings, and less intense as it moves away from that core. This understanding of the right flows, as was said in *Bernstein*, from the value placed on human dignity by the Constitution.²⁰⁶

Venter finds that a kidney transplant could easily be said to be a part of a person’s ‘intimate sphere of life’.²⁰⁷ Using this same logic, one can undoubtedly believe that organ transplantation in general is intimate to the individual involved in the process, be it the donor or the recipient. The WHO guidelines, therefore, also cater for the privacy of the donor and recipient and transplantation and donation activities, and these include the view that clinical results are to be ‘transparent and open to scrutiny’. This, however, is to be achieved whilst ensuring that the donors and recipients remain anonymous.²⁰⁸ The purpose of having transparency regarding these activities is to allow for public access regarding certain data dealing with ‘allocation, transplant activities and outcomes for both recipients and living donors’ in addition to the funding, budget and data on the organisation.²⁰⁹ This transparency is not intended to reveal, in any way, the identities of the patient or donor, but to allow data for ‘scholarly study and governmental oversight’, as well as to ‘identify risks – and facilitate their correction – in order to minimise harm to donors or recipients’.²¹⁰ In this way, we see the importance of being able to have a

²⁰⁵ I Currie & J de Waal (n 183 above) 298 – 299.

²⁰⁶ *The Investigating Directorate: Serious Economic Offences and others v Hyundai Motor Distributors (PTY) Ltd and others* 2001 1 SA 545 (CC) at para 18.

²⁰⁷ B Venter (n 67 above) 380.

²⁰⁸ Guiding Principle 11 - WHO guiding principles on human cells, tissue and organ transplantation, 2010; 8.

²⁰⁹ Commentary on Guiding Principle 11 – ‘WHO Guiding Principles on human cells, tissue and organ transplantation’, 2010; 8.

²¹⁰ As above.

limitation to the right to privacy, which, in this instance, benefits not only scholars but also the donor and the recipient.

The right to privacy is a patient right thus making it a worthy-mention in this discussion. However it is also important in this discussion because it can and has been linked to a person's right to individual autonomy. The Constitutional Court in the case of *Khumalo and others v Holomisa* stated that the right to privacy 'recognises that human beings have a right to a sphere of intimacy and autonomy that should be protected from invasion'.²¹¹ Similarly, van der Bank makes mention of how the right to privacy in the United States of America has 'developed to such a degree that it now embraces not merely the right to seclusion but the right to individual autonomy or free choice'.²¹² The right to individual autonomy has been discussed above in great detail and thus does not warrant a repetition of its importance to this discussion.

Having analysed the specific human rights norms which are relevant to organ donation and/or transplantation, the main features of a rights-based approach to organ failure will be discussed further as part of the CA in this regard.

4.3.7. Equality and non-discrimination

The rights to equality and non-discrimination are prevalent not only in different national legislative instruments, but in regional and international documents as well.

The preambles to both the ICCPR and the ICESCR express the notion of 'equal and inalienable rights' and provide for the right of the equality of men and women in the enjoyment of the relevant rights as per Covenant. Equal enjoyment of civil and political rights is provided for in the ICCPR whereas equal enjoyment of economic, social and cultural rights is provided for in the ICESCR.²¹³ Article 2(2) of the ICESCR further obligates states to guarantee the exercise of the rights provided for 'without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status'. The ICCPR further provides the following:

²¹¹ *Khumalo and others v Holomisa* 2002 5 SA 401 (CC) at para 27.

²¹² C Van der Bank (n 193 above) 83.

²¹³ Art 3, ICCPR. Also see Art 3, ICESCR.

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.²¹⁴

The rights to equality and non-discrimination are also catered for in the African Charter which guarantees the equality of every individual before the law, as well as an obligation placed on state parties to move towards the elimination of discrimination against women and children, and provides individuals with the right, and duty, 'to consider his fellow beings without discrimination, and to maintain relations aimed at promoting, safeguarding and reinforcing mutual respect and tolerance'.²¹⁵ The preamble to the African Charter mentions the need to dismantle, *inter alia*, all forms of discrimination. The South African Constitution furthermore provides that the state is founded on 'human dignity, the achievement of equality...non-racialism and non-sexism'.²¹⁶ The Constitution provides for the equality of individuals and equal protection of the law.²¹⁷ The section on equality caters for a right not to be discriminated against on various grounds, by the state or by another individual.²¹⁸

Woolman further discusses the right to dignity as 'as an entitlement to equal concern and to equal respect', in terms of the right to equality as envisioned in section 9 of the

²¹⁴ Art 26, ICCPR.

²¹⁵ Arts 18, 28 and 3(1), African Charter.

²¹⁶ Sec 1(a) and (b), Constitution of South Africa.

²¹⁷ Sec 9(1). Section 9 of the Constitution provides the following:

- (1) Everyone is equal before the law and has the right to equal protection and benefit of the law.
- (2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.
- (3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.
- (4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.
- (5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair'.

²¹⁸ Sec 9(2) and (3).

Constitution, which ‘has led to the construction of two different, though not entirely distinct, tests’.²¹⁹ These two tests are as follows:

- (1) A right to equal treatment which ensures-
 - a. That the law does not irrationally differentiate between classes of person, and
 - b. That the law does not reflect the ‘naked preferences’ of government officials;
and
- (2) A right to equal treatment that guarantees that individuals are not subject to unfair discrimination on the basis of largely ascriptive characteristics.²²⁰

Weighing in on this ‘demand for equal respect’, Woolman quotes Justice Ackermann as follows:

[A]t the heart of the prohibition of unfair discrimination lies the recognition that the purpose of our new constitutional and democratic order is the establishment of a society in which all human beings will be accorded equal dignity and respect regardless of their membership in particular groups. The achievement of such a society in the context of our deeply inegalitarian past will not be easy, but that that is the goal of the Constitution should not be forgotten or overlooked.²²¹

The right to equality and non-discrimination can be linked to the biomedical ethic of ‘justice’. As mentioned in the second chapter, the principle of justice entails a degree of fairness and equality. To this end, as mentioned previously, when looking at organ donation, the relevant form of justice would be distributive justice.²²² There are various general material principles relative to distributive justice, including, but not limited to, each person having an equal share according to need, effort, contribution, merit and free market exchanges.²²³ These principles are all deemed to be valid and accepted by various theories of justice.²²⁴ In determining the distribution of organs, it would be necessary to analyse these principles in the context of donation. When looking at the

²¹⁹ Woolman (n 97 above) 394.

²²⁰ As above.

²²¹ As above.

²²² Beauchamp and Childress define distributive justice as the ‘distribution of all rights and responsibilities in society, including civil and political rights’. Beauchamp & Childress (n 192 above) 241.

²²³ Beauchamp & Childress (n 192 above) 243.

²²⁴ As above.

allocation of organs it is important, for ethical and other reasons, that the allocation system in place be deemed equitable and fair. If the system is viewed by the public to have inequities, fewer people will feel obligated to donate.²²⁵ Determining a balance of these principles, however, is not an easy task. For instance, if an organ is allocated to a patient with an urgent need but who may not survive the procedure or who may not survive for very long after the procedure, the organ would go to waste.²²⁶ In this instance, the needs of the patient may not justify the effective use of the organ.

4.4. Main features of a HRBA to organ failure

4.4.1. Empowerment and participation

The CA advocates the empowerment of vulnerable groups. For instance, in Sen's CA for the reduction of poverty, the empowerment of the poor involves affording them rights by introducing the concept of rights itself, into policy-making and so giving them entitlements which gives rise to legal obligations on the part of others.²²⁷ In this way, poverty reduction becomes a legal obligation as opposed to it being a form of charity or a moral obligation.²²⁸ The idea behind the empowerment of poor men and women is to enhance their capabilities in order to give them greater control over their lives.²²⁹ It is argued that human rights play a role in mitigating the powerlessness of the poor, provided the poor have access to them by equalising the 'distribution and exercise of power both in and between societies'.²³⁰

Human rights alone, however, are not enough to foster the enhancement of the capabilities of vulnerable groups. Human rights discourse is not an automatic translation of social change, but there needs also to be a realisation of these rights through the creation of opportunities, capacity and participation.²³¹ Stoecklin and Bonvin elaborate on

²²⁵ M Slabbert 'One heart, two patients: who gets a donor organ?' (2009) 20 *Stellenbosch Law Review* 126.

²²⁶ As above.

²²⁷ OHCHR report (n 18 above) 33.

²²⁸ As above.

²²⁹ OHCHR report (n 18 above) 13 – 14.

²³⁰ OHCHR report (n 18 above) 14.

²³¹ Stoecklin & Bonvin (eds) (n 48 above) 28 - 29.

the fact that participation involves ‘the process of sharing decisions that affect one’s life and – in a broader sense – the dynamics of the community individuals live in’.²³² They argue that participation is not only a right but a necessity in the expansion and facilitation of the fulfilment of these rights.²³³ The expansion of capabilities through participation, thus, assists with the realisation of human rights and, *vice versa*, by ‘focusing on available opportunities and values’.²³⁴ As a result, the CA and participation assist in the actualisation of the HRBA, as well as its locality to a specific realm.²³⁵ In order to facilitate the realisation of a person’s rights, that person (or group of people) have the right to participate in programmes developed for this purpose. In their discussion of the CA to children’s rights, the authors consider that these programmes may range from social budgeting to ‘national plans of action’ in different fields such health, protection, education and so on.²³⁶

The participation of individuals in the development of their civil, political, social, economic and cultural rights is important in a rights-based approach. Gruskin *et al* argue that every individual is indeed a rights-holder which entitles him to ‘the same rights without distinction regardless of race, colour, sex, age, language, religion political or other opinion, national or social origin, disability, property, birth or other status, such as sexual orientation’.²³⁷ The authors also discuss participation as a term applied in a rights-based approach. They determine that every individual is entitled to ‘active, free, and meaningful participation in, and contribution to enjoyment of civil, economic, social, cultural, and political development’.²³⁸ They further establish that it is of paramount importance that key stakeholders and affected communities are assured of inclusion and full participation in a rights-based approach to health.²³⁹

The inclusion of rights-holders is essential in any rights-based approach programme aimed at a specific marginalised group. Gruskin *et al* emphasise the necessity of certain

²³² Stoecklin & Bonvin (eds) (n 48 above) 29.

²³³ As above.

²³⁴ As above.

²³⁵ As above.

²³⁶ As above.

²³⁷ S Gruskin *et al* (n 9 above) 132.

²³⁸ As above.

²³⁹ As above.

elements which need to be present when referring to a programme as encompassing a rights-based approach. The programme needs to adopt an approach which is not only ‘shaped by human rights principles’, but states also bear the responsibility of ensuring that national health plans meet the standard of their international law obligations, ‘ensuring non-discrimination and the participation of affected communities’.²⁴⁰ In addition to this, the former UN Special Rapporteur on the right of individuals ‘to the enjoyment of the highest attainable standard of mental and physical health’ emphasised ‘the promotion of human rights and the incorporation of human rights principles in the processes of health policy and program development as fundamental to (rights-based approaches) to health’.²⁴¹ He defines a ‘rights-based system’ as advocating a ‘people-centred approach’ to healthcare in addition to ‘the collection of disaggregated data, and the use of human rights-based indicators’.²⁴²

Enhancing the principle of participation would also arguably promote respect for human dignity. Woolman states the following:

The more demanding requirements of our dignity jurisprudence – dignity *qua* self-actualisation, dignity *qua* self-governance, dignity *qua* material conditions of existence – reflect three of the most important features of this account of flourishing. The Constitutional Court’s commitment to these more maximal accounts of dignity leads me to conclude that a robust constitutional defence of dignity is a precondition for flourishing in an experimental constitutional state.²⁴³

In his discussion of self-actualisation, Woolman refers to Ackermann J who states that ‘[h]uman dignity cannot be fully valued or respected unless individuals are able to develop their humanity, their ‘humaneness’ to the full extent of its potential’.²⁴⁴ In this regard, Ackermann J refers to the uniqueness of individuals and how one’s human dignity can only be respected once allowed to optimally develop his own unique talents.²⁴⁵ Self-governance on the other hand refers more to the concept of democracy – ‘[f]or if we are

²⁴⁰ S Gruskin *et al* (n 9 above) 130.

²⁴¹ S Gruskin *et al* (n 9 above) 131.

²⁴² As above.

²⁴³ Woolman (n 97 above) 393.

²⁴⁴ *Ferreira v Levin* 1996 1 SA 984 (CC)- as quoted in Woolman (n 97 above) 395.

²⁴⁵ As above.

capable of shaping our own ends as individuals, equal treatment demands that we be able to shape the contours of our community as citizens'.²⁴⁶ Ultimately every individual should be afforded with the opportunity, at the very least, to engage in decision-making processes which affect the community as a whole, in order to 'determine the ends of our community', thus promoting respect for human dignity.²⁴⁷

Enhancing the capabilities of individuals suffering from organ failure through participation and empowerment would imply educating not only the individuals facing organ failure, but the community about the human rights involved, as discussed above. In order for these rights to be fully realised it would be important to create legislation which deals with donation and transplantation specifically, and to make new policies accordingly. The parties involved should be included and allowed to participate in this process in order to cater for specific groups in the community. The creation of legislation would enable entitlements for vulnerable groups facing organ failure as well create corresponding obligations of the duty-bearers, the state. This would create opportunities for those involved to enhance their capabilities and pursue a life which they would deem worthy and dignified.

When determining a rights-based approach towards organ donation, the fulfilment of this feature should involve people from different religious and cultural sectors being included in the development of such a programme. As mentioned in the previous chapter, the integration of traditional healers in this area would be beneficial as a large number of people follow traditional beliefs and use traditional medication. It was estimated in 2004 that there are approximately between 250 000 and 400 000 traditional healers in South Africa, with medical doctors numbering only around 23 000.²⁴⁸ In addition to this, it is further estimated that eight out of every ten black South Africans will rely on either a combination of Western medicine and traditional medicine, or traditional medicine

²⁴⁶ As above.

²⁴⁷ As above.

²⁴⁸ E Ross 'The intersection of cultural practices and ethics in a rights-based society' (2008) 51(3) *International Social Work* 385.

alone.²⁴⁹ Since black people make up about 79.2% of the state's population,²⁵⁰ the role played by traditional healers is too great to ignore, especially when dealing with a topic as sensitive as organ donations and/or transplantation.

In addition to this, religion is equally important. 79.8% of people in South Africa refer to themselves as being Christians, 1.1% follow Islam, 1.3% are Hindu followers, 0.1% are Buddhists and 0.2% follow the Jewish religion.²⁵¹ Taking this into account, as well as noting the fact that people tend to use religion and culture as reasons not to donate, having a representative from each domain present and included in any discussions about, or during the process of development of, a human rights-based programme would not only be representative of a large portion of the population, but also satisfy the principle of 'participation and inclusion'.

4.4.2. Recognition of national and international human rights frameworks

Treaty ratification is a representation of "country ownership" of the relevant provision' or treaty.²⁵² Once a treaty has been ratified, it becomes legally binding on all branches of the government.²⁵³ This means that the state is obligated to adhere to the standards contained in the treaties it has ratified.

As stated above, section 231(4) of the Constitution, 1996 provides for the ratification of treaties, requiring the enactment of national legislation in order to bring about the implementation of the treaty provisions in the Republic.²⁵⁴ South Africa has ratified the ICCPR, the ICESCR, the UDHR, and it also a member of the African Union. Unfortunately, South Africa has not yet passed legislation implementing the ICESCR in its domestic legal system. The international agreements dealing with the human rights norms relevant to

²⁴⁹ As above.

²⁵⁰ P Coertzen 'Constitution, charter and religions in South Africa' (2014) 14 *African Human Rights Law Journal* 127.

²⁵¹ As above.

²⁵² OHCHR report (n 18 above) 14.

²⁵³ As above.

²⁵⁴ Sec 231(4) provides that '[a]ny international agreement becomes law in the Republic when it is enacted into law by national legislation; but a self-executing provision of an agreement that has been approved by Parliament is law in the Republic unless it is inconsistent with the Constitution or an Act of Parliament'.

organ donation and transplantation have already been discussed above and a repetition is thus unwarranted.

4.4.3. Accountability

The overarching international human rights framework is derived from international declarations, conventions and covenants which provide for these rights as well as the mechanisms of protection and standards to which states commit themselves.²⁵⁵ Boesen and Martin offer, as a foundational precept for the international human rights framework, the notion that a state's legitimacy is to be based on 'its respect, protection and fulfilment of the rights of each and every individual'.²⁵⁶ A fundamental dynamic of human rights (and as such a rights-based approach) is that 'every human being is a rights-holder and that every human right has a corresponding duty'.²⁵⁷ A rights-holder is entitled to claim rights and hold the duty-bearer accountable as well as having the responsibility of respecting the rights of others.²⁵⁸ Duty-bearers, thus, have an obligation to 'respect, protect and fulfil the rights of the rights-holders'.²⁵⁹ The overall responsibility rests on the state and that includes 'all organs of [s]tate such as parliaments, ministries, local authorities, judges and justice authorities, police, teachers or extension workers'.²⁶⁰

It has been illustrated above that there are a number of human rights norms which would be violated if a system is not put in place to assist in the alleviation of the organ shortage as well the implementation of a functioning, productive and beneficial organ procurement and allocation system. The rights-holders in this scenario would, therefore, be the patients who are in organ failure and awaiting an available organ. The state, various healthcare practitioners, and those involved in the procurement process, such as transplant coordinators, would ideally be the duty-bearers. The legislature has a corresponding duty to implement legislation which would be in line with the realisation of these human rights as they relate to organ donations and/or transplantation, and the executive would be

²⁵⁵ Boesen & Martin (n 7 above) 11.

²⁵⁶ As above.

²⁵⁷ As above.

²⁵⁸ As above.

²⁵⁹ As above.

²⁶⁰ As above.

tasked with the enforcement of this legislation upon which the judiciary can deliberate should these rights be violated.

Health workers and health professionals too have a role to play in the realisation of these rights, and they should, thus, be afforded a 'duty-bearer' status. London discusses a human rights-based approach to healthcare and mentions the responsibility of individual healthcare workers and professionals in this regard.²⁶¹ She depicts as one of the fallacies in a rights-based framework the lack of deliberation as to the responsibility of these workers, as human rights apply primarily to states parties.²⁶² She describes three possible ways of designating such responsibility as follows:

- 1) if employed by a state party, a health professional may become the instrument through which the state violates the right to health and should therefore guard against involvement in such violations;
- 2) certain human rights obligations may have horizontal applicability among individuals, such as, for example, the prohibition against torture, or, in the South African context, the obligation on individuals not to discriminate against other people on the basis of race, gender, sexual orientation, or other factors; and
- 3) human rights may be viewed as an essential part of one's professional conduct.²⁶³

The first two scenarios allow for legal sanction as a possibility and the last relies on ethical compliance and professional self-regulation.²⁶⁴ These are suggestions which may be implemented in a HRBA to donation and transplantation and may facilitate and strengthen the accountability feature in the CA to organ failure.

4.4.4. Progressive realisation

A human rights-based approach imposes an obligation on duty-bearers to work towards the realisation of human rights. It does not, however, place an unreasonable demand on

²⁶¹ L London 'What is a human rights-based approach to health and does it matter?' (2008) *Health and Human Rights Journal* 68.

²⁶² As above.

²⁶³ As above.

²⁶⁴ As above.

them to do so immediately.²⁶⁵ International agreements which deal with human rights often recognise that many of these rights will be progressively realised, subject to the availability of resources.²⁶⁶ Article 2(1) of the ICESCR obligates states parties to take steps in achieving the full realisation of the rights contained therein, ‘to the maximum of is available resources’. The African Charter is silent on the notion of progressive realisation. Chenwi, however, refers to a 2011 statement made by the African Commission on Human and Peoples’ Rights (the African Commission):

While the African Charter does not expressly refer to the principle of progressive realisation this concept is widely accepted in the interpretation of economic, social and cultural rights and has been implied into the Charter in accordance with articles 61 and 62.²⁶⁷

The Bill of Rights in the South African Constitution likewise provides for certain rights to be progressively realised such as the right to have access to adequate housing as provided for in section 26,²⁶⁸ as well as the right to health care in section 27.²⁶⁹ As illustrated above, the Constitutional Court has provided an understanding of the content of the principle of progressive realisation in various cases. The *Soobramoney* case confirms the international code on progressive realisation, as it accepts that all of the woes of society cannot be resolved overnight, but that the state must ‘go on trying to resolve these problems’.²⁷⁰ The court also confirms a scarcity of resources as one of the limiting factors of the state’s realisation of these rights.²⁷¹

²⁶⁵ OHCHR report (n 18 above) 22.

²⁶⁶ As above.

²⁶⁷ The African Commission ‘Principles and Guidelines on the implementation of economic, social and cultural rights in the African Charter on Human and People’s Rights’ para 14: as quoted in L Chenwi ‘Unpacking ‘progressive realisation’, its relation to resources, minimum core and reasonableness, and some methodological considerations for assessing compliance’ (2013) *De Jure* 746 – 747.

²⁶⁸ Sec 26(2) provides the state with the obligation to ‘take reasonable legislative and other measures, in its available resources, to achieve the progressive realisation’ of the right to have access to adequate housing.

²⁶⁹ Sec 27(2) provides the state with the obligation to ‘take reasonable legislative and other measures, in its available resources, to achieve the progressive realisation’ of the rights to health care, food, water and social security.

²⁷⁰ *Soobramoney v Minister of Health (Kwazulu – Natal)* 1998 1 SA 765 at para 43.

²⁷¹ As above.

In the *Grootboom* case, the court dealt with the right to have access to adequate housing from the context of an eviction, and it referred to progressive realisation as placing the obligation on the state effectively to meet the 'basic needs of all in our society'.²⁷² Similarly, in the case of *Modderklip Boerdery*, which also dealt with the progressive realisation as referred to in section 26, the court held that the right 'requires careful planning and fair procedures made known in advance to those most affected'.²⁷³

This understanding may be applied to organ donation and transplantation as well. The reference made to the 'basic needs of all in society' includes those who are suffering from end stage organ failure and are in need of an organ and transplantation surgery. A basic need may include having access to facilities which have a structured system in place allowing patients a fair opportunity to receive an organ once it becomes available. The application of the approach taken in the *Modderklip Boerdery* case above would imply the rights of equality as well as participation as discussed above.

4.5. Contribution of a system of mandated choice to a HRBA to organ donation

The previous chapter looked at several religions as well as African culture in South Africa in relation to donation and transplantation and showed how they affect the desire of individuals to become organ donors or donate the organs of their loved ones. It was determined that the reasoning for not wanting to donate is based on misconceptions created against donation and transplantation, and it was further explored as to whether a presumed consent system for donation could be a possible solution to the lack of donors.

The conclusion was reached that the implementation of a presumed consent system will be feasible only once the public is educated on the procedures and terms relating to cadaveric donation and where there is a general understanding throughout the population that, in terms of this system, acquiescence in this regard would be deemed as consent to donation. It was henceforth suggested that a mandated choice for donation could be a stepping stone, or first step, towards a system of presumed consent possibly at a much

²⁷² *Government of the Republic of South Africa and Others v Grootboom* 2001 1 SA 46 at para 45.

²⁷³ *President of the Republic of South Africa and others v Modderklip Boerdery (Pty) Ltd and others* 2005 8 BCLR 786 (CC) at para 49.

later stage. The writer argues below that a mandated choice towards donation further enhances a HRBA to donation.

4.5.1. Content of a system of mandated choice for organ donation

A system of mandated choice obliges competent adults to decide, before their deaths, whether they would want to be organ donors or not.²⁷⁴ This system requires individuals not only to make this decision, but it also allows them to choose which organs they would like to donate.²⁷⁵ It is important to note is that individuals must register their wishes, so there is no provision for acquiescence, and they may also illustrate whether they would like their relatives to 'have the final say'.²⁷⁶ Aside from this, the power to veto a registered decision by a family member or next of kin is not permitted regardless of what decision is made.²⁷⁷ Policy-makers are to determine how this choice is to be made. A requirement may be made that, before applications, claims or returns are processed, these wishes would need to be registered lest they be penalised by, for instance, not being able to claim any benefits, to drive or face the possibility of penalties being received from not completing tax forms appropriately.²⁷⁸

The registration system does need to be all-inclusive. Some members of society may, for instance, not have a car or be able to drive, and not every person acquires enough income to complete a tax return.²⁷⁹ Registration needs, thus, to be able to reach people in all communities and from all walks of life so as to increase inclusion, thereby doing away with any particular group feeling that it is being targeted. This would also protect against any possible discrimination towards a particular group of people and so contribute to the element of non-discrimination required in a HRBA.

As with any system in place, there are criticisms made with regard to a mandated choice for donation. It has often been suggested that the financial and logistical implementation of such a programme, which requires the maintenance of the records of every individual's

²⁷⁴ P Chouhan & H Draper 'Modified mandated choice for organ procurement' (2003) 29 *Journal of Medical Ethics* 158.

²⁷⁵ As above.

²⁷⁶ As above.

²⁷⁷ As above.

²⁷⁸ As above.

²⁷⁹ As above.

wishes, may prove to be problematic.²⁸⁰ Accordingly medical personnel would also have to 'modify their system of asking a potential donor's next-of-kin out of courtesy'.²⁸¹ Labuschagne further mentions, as cons to the inclusion of a requires response system, that it would require resources for instance educational and advertising materials, support staff, financial aid and there would also need to be a preparatory or transitional stage before such an organ procurement method can be implemented.²⁸² Some authors further believe that such a system would be ineffective, citing the failure of its enactment by the state of Texas in the USA.²⁸³ Following the application of this system in the state, it had an 80% refusal rate.²⁸⁴ It is believed by some that the reason for such a high percentage is the lack of a non-altruistic incentive, as well as an element of perceived caution being adopted.²⁸⁵ A further and more common criticism is that it undermines a person's autonomy.²⁸⁶

These criticisms are often debunked, particularly when one looks at the principle of autonomy. Spellman states that, unlike compelled donation and presumed consent, a mandated choice system would in effect protect autonomy by allowing individuals the choice to become a donor or not.²⁸⁷ It would also relieve the burden placed on families and doctors in having to make this decision at such a challenging time.²⁸⁸ Regarding the argument of financial cost, Spellman states that other systems which are already in place can be utilised, such as the Organ Procurement Transplant Network (OPTN) in the USA, which already has a national registry in place, and it can be combined with the licence registries and taxing structures already in place making it more cost effective.²⁸⁹ Similar systems in South Africa may also be combined in order to achieve the same effect.

²⁸⁰ D Spellman 'Encouragement is not enough: the benefits of instituting a mandated choice organ procurement system' (2006) 56 *Syracuse L. Rev.* 371.

²⁸¹ D Spellman (n 280 above) 371 – 372.

²⁸² D Labuschagne 'An analysis of organ transplantation in South Africa with specific reference to organ procurement' Unpublished LLM thesis, University of Pretoria, 2013 61.

²⁸³ D Spellman (n 280 above) 372.

²⁸⁴ As above.

²⁸⁵ As above.

²⁸⁶ P Chouhan & H Draper (n 274 above) 158.

²⁸⁷ D Spellman (n 280 above) 372.

²⁸⁸ As above.

²⁸⁹ As above.

Labuschagne correspondingly lists various positive aspects of such a system as follows:

- The public will be educated regarding organ procurement, allocation and transplantation;
- Every person will be forced to make an informed decision regarding organ donation;
- A national database will exist documenting every person's decision, creating an easy, quick way to determine a deceased's donor status and simultaneously rendering the family's choice unnecessary in most instances;
- Jobs will be created; and
- Required response will be more effective than required request as prospective donors will consider the matter with ample time and without being at their own sickbed or at the sickbed of a relative.²⁹⁰

The bottom line is that every system has its flaws, and a mandated choice system is by no means perfect. It may, however, be a positive step towards increasing donation and the rights of the individuals involved. It is, thus, argued that this system would also be effective in enhancing a HRBA to donation and transplantation as will be discussed below.

4.5.2. Incorporating a mandated choice system with a HRBA

As stated above, a HRBA promotes the empowerment of individuals by informing them of their rights and giving them the ability to claim them. One of the key elements of the implementation of a system of mandated choice is the need for there to be extensive education of the public carried out in order for people to understand fully, or as best as possible, the implications of their decision as well as the need for choice.²⁹¹ To add to this, education in this respect should include tutelage with regard to the various religious and cultural views towards donation and transplantation, as well providing guidance concerning any misconceptions or uncertainties individuals may have in this regard. This would respect patient autonomy and allow for individuals to be in a better position to make an informed decision regarding donation. This education could be further modified to include the rights which individuals have with respect to organ donation and transplantation, so incorporating a system of mandated choice into a HRBA.

²⁹⁰ D Labuschagne (n 282 above) 61.

²⁹¹ P Chouhan & H Draper (n 274 above) 158.

Labuschagne discusses the possibility of a required response system for organs being implemented in South Africa, although she discusses it in combination with an opting-in system.²⁹² She holds that in order for such a system to be a reality there would have to be ‘an intensive information campaign on organ procurement, allocation and transplantation’ employed in order to educate the public on relevant aspects regarding ‘organ procurement, allocation and transplantation in order [for the public] to be able to make an informed decision better’.²⁹³

Spellman suggests the incorporation of a ‘significant public educational program’ which would require the employment of the mass-media by way of advertisement.²⁹⁴ This programme, similar to anti-drunk driving and anti-smoking campaigns, would effectively reach a vast number of the population, despite being costly.²⁹⁵ As an alternative, or perhaps inclusive, measure, the author suggests that states have ‘informational sessions about organ donation incorporated into driver’s education classes’.²⁹⁶ This would inform future drivers not only about the system in place but also about donation and allow them to make better and informed decisions regarding whether to opt-in or out of donation at the licence registry.²⁹⁷ This education programme could be modified further to include, as stated above, religious and cultural perspectives on donation.

It can be argued that a mandated choice system also protects, and refrains from violating, certain rights of individuals. An educated society may increase donations by doing away with religious and cultural misconceptions attached to the decision to become organ donors or donate the organs of their loved ones. An increase in donations would consequently improve the quality of life and health of those in need of organs, as well as protect the right to informed consent of a donor who, had he been misinformed, would have opted against donation. In addition, by removing the veto power from the next of kin and/or family member, it can be argued that the right to bodily security is further protected as it prevents the consent given, either to or against donation, from being revoked.

²⁹² D Labuschagne (n 282 above) 60.

²⁹³ As above.

²⁹⁴ D Spellman (n 280 above) 377.

²⁹⁵ As above.

²⁹⁶ As above.

²⁹⁷ As above.

4.6. Conclusion

4.6.1. Human rights and the capability approach

The CA as elaborated by Sen is a conceptual framework which works towards understanding the needs of a particular vulnerable group of individuals and identifying these needs as human rights norms. This identification provides legitimate claims for individuals in this group and correlating obligations to which the state must adhere. The idea behind this approach is the empowerment of vulnerable groups by providing them with the capabilities they require to live the life they wish to pursue, or to 'achieve well-being'.²⁹⁸ The application of this approach to organ donation and/or transplantation deals with the lack of capabilities for those facing organ failure, and the need for there to be an increase in donations as well as an effective system in place to ensure not only an increase in donations but also the opportunity for every individual to be able to have a fair chance of receiving an organ should it be needed.

This chapter has analysed the human rights norms relevant to organ donation and transplantation and the application of a HRBA in the context of the CA. The central idea is to allow this vulnerable group of people the opportunity to attain 'minimal human dignity'.²⁹⁹ The rights which were analysed were the rights to human dignity, life, an adequate standard of living, the right to health and healthcare services, bodily integrity, and privacy as well as the rights to equality and non-discrimination. These rights are, mostly, protected from a national, regional as well as an international sphere. It has been shown that the bill of rights in the Constitution provides for the protection of these human rights norms as well as the African Charter, the UDHR, the ICESCR and the ICCP. These regional and international documents are ratified by South Africa and, as such, the republic has an obligation to adhere to them.

In terms of the rights to health and healthcare services, a person's health is essential to enjoy life to the fullest. A person suffering from organ failure experiences physical and

²⁹⁸ OHCHR report (n 18 above) 6.

²⁹⁹ OHCHR report (n 18 above) 9.

psychological symptoms which are detrimental to his well-being. The right to health should not be seen as a right to be healthy, but rather a right to 'the enjoyment of a variety of facilities and conditions which the State is responsible for providing as being necessary for the attainment and maintenance of good health'.³⁰⁰ This would imply that, in the context of the donation and transplantation of organs, adequate facilities need to be in place to allow the access of all individuals to organs. Himonga discussed the direct relation of the right health and *Ubuntu* which envisages a sense of communalism to strengthen the overall health of society.³⁰¹ In this way, becoming an organ donor resonates with the spirit of *Ubuntu*. South Africa includes the right of access to healthcare services in the contents of the right to health as can be seen in section 27 of the Constitution. International and regional health agreements refer to the right to health as being the attainment of the 'highest standard of physical and mental health'.³⁰² The fulfilment of this standard would not include a temporary solution when looking at organ failure. A person who is on a dialysis machine, for instance, cannot be expected to have achieved the highest form of health or, for that matter, an adequate standard of living as discussed above. The right, thus, presupposes a state obligation to provide adequate healthcare services to those in need, as well as attempts to increase the number of donations.

The right to bodily integrity relates to a person's right to have control over his own body. This right is protected in section 12 of the Constitution and a violation thereof could result in a charge of, *inter alia*, assault. In medical law, however, a person may give his consent for instance in the case where a surgical procedure is necessary for the treatment of an ailment. In this instance, the maxim of *volenti non fit iniuria* would be a justifiable defence against a possible claim of assault; the patient (and/or donor in the case of transplantation) will however, have had to be properly informed of the risks involved in order to be able to supply an informed decision. It has been suggested that misconceptions with regards to culture and religion to donation and transplantation may have a negative effect on a person's decision to donate, thus prohibiting him from making

³⁰⁰ Asher (n 148 above) 27.

³⁰¹ C Himonga (n 177 above) 169.

³⁰² Sec 12(1) of the ICESCR and sec 16(1) of the African Charter.

an informed decision. This may also affect the decision to donate the organs of a loved one.

Regarding the right to privacy, this right has been shown to have protection in a national, regional and international sphere. This right plays a major role in the medical setting, and it has a personal, if not intimate, nature as discussed above. Using this same logic, it can be stated that the process of transplantation is intimate in nature and it is, thus, important to be attentive to the privacy of all the parties involved. The WHO's guidelines provide for transparent application when dealing with clinical test results; the anonymity of the donor and patient are, however, to be kept private.³⁰³ The purpose of transparency is to allow for 'scholarly study and governmental oversight' as well as to be able to identify any risk factors which may harm the recipient or donor.³⁰⁴ A limitation of the right to privacy in this sense is, thus, warranted as it further enhances the other rights, such as dignity, an adequate standard of living, and health by ensuring that all measures are taken to eliminate risks involved during the process of donation and transplantation.

The purpose of the rights to equality and non-discrimination in the transplantation setting is to ensure the equality of all persons regardless of their race, language, religion, orientation, etc., and, in doing so, to adhere to the rights in national, regional and international documentation on discrimination and equality.³⁰⁵ This right may also be viewed from an ethical perspective, particularly regarding the biomedical ethic of justice, particularly 'distributive justice', which implies, from a transplantation and donation perspective, that the distribution of organs needs to be deemed equitable and fair.

4.6.2. Main features of a HRBA to organ failure in the implementation of the capability approach

The CA advocates an empowerment of vulnerable groups by introducing rights as a concept in policy making, which would provide the people of these groups with

³⁰³ Commentary on Guiding Principle 11 – 'WHO Guiding Principles on human cells, tissue and organ transplantation', 2010; 8.

³⁰⁴ As above.

³⁰⁵ The preambles to the ICCPR, ICESCR and arts 18, 28 and 3(1) of the African Charter require for the fulfilment of this right. Sec 9(1) of the Constitution also provides for this right and subsec 1(a) and (b) includes equality as a foundational principle.

entitlements and, thus, give rise to legal obligations on behalf of the state and duty-bearers.³⁰⁶ Human rights are, therefore, used as a tool to mitigate the powerlessness of vulnerable people by enhancing their capabilities. Recognising the human rights of these individuals, however, does not in itself provide a solution. There needs further to be a realisation of these rights by creating opportunities, capacity and allowing for the participation of individuals in the development of strategies aimed at the enhancement of these rights.³⁰⁷ When looking at this feature from the context of organ donation and/or transplantation, it would imply the involvement of people (or leaders) from different cultural and religious sectors.

The accountability feature of a HRBA is also important as it enhances the realisation of human rights. To determine who is accountable, the difference between the rights-holders and duty-bearers must be considered. For a HRBA to organ donation and/or transplantation, individuals who are facing organ failure would be rights-holders and, as such, be entitled to claim rights and hold the duty-bearers (essentially the state) accountable for any violations of their rights in this regard. It has also been explained above as to why such an approach should allow for health practitioners and health workers also to be held accountable. This would further enhance compliance by these individuals in the medical field because accountable generally falls on state parties.³⁰⁸ By also holding individuals in the medical profession liable, they are more likely to be complaint to the rules and regulations.

The obligations which are placed on duty-bearers are, however, not expected to be immediately adhered to. The international code on the realisation of human rights in most instances recognises that the states parties will have to realise these rights progressively, subject to the availability of resources as discussed above.³⁰⁹ The Constitution also recognises that some of the rights in the bill of rights will require progressive realisation. This, however, is not to say that nothing is to be done. The court, in the case of

³⁰⁶ OHCHR report (n 18 above) 33.

³⁰⁷ Stoecklin & Bonvin (eds) (n 48 above) 28 – 29.

³⁰⁸ L London (n 259 above) 68.

³⁰⁹ Art 2(1) of the ICESCR makes provision for progressive realization, as does the African Commission in their interpretation of the African Charter explained above.

Soobramoney, remarks that states have to try continuously to resolve the problems, even though they cannot be fixed overnight.³¹⁰ The courts generally provide that progressive realisation does not mean that everything is to be at a standstill, but rather that certain basic needs have to be met and plans and procedures have to be made known to the groups affected.³¹¹

A system of mandated choice can further be incorporated into a HRBA to organ failure as it would not only further enhance certain rights mentioned above and assist in fostering an educated society, but also motivate the community to take control of their rights in this regard by requiring them to make a decision on donation. This not only respects the right to autonomy by doing away with the *veto* right, but also prevents the consent given from being revoked. A system of registration which reaches out to all communities may, in addition, promote inclusion and prevent any possible avenues of discrimination.

4.6.3. Concluding remarks

The realisation of the human rights of individuals suffering from organ failure must be facilitated by the implementation of legislation which deals specifically with organ donation and/or transplantation. Such a system must provide an appropriate structure which not only meets the standard of the rights mentioned above, but which also allows for the participation and inclusion of religious and cultural leaders, as well as citizens in general during the policy-making process. This is to allow for education against misconceptions associated with donation and transplantation. In addition, the state should also raise awareness about these misconceptions in the community to eliminate cultural and religious misconceptions further.

The next chapter embarks on a comparative analysis of the donation and transplantation systems in different states as a means of determining what South Africa may learn when implementing a HRBA to organ donation and transplantation.

³¹⁰ *Soobramoney v Minister of Health (Kwazulu – Natal)* (n 268 above) para 43.

³¹¹ See *Government of the Republic of South Africa and Others v Grootboom* (n 272 above) para 45, and *President of the Republic of South Africa and others v Modderklip Boerdery (Pty) Ltd and others* (n 273 above) para 49.

CHAPTER FIVE

A comparative evaluation of organ donation procedures – lessons for South Africa

5.1. Introduction

The previous chapters established numerous misconceptions in culture and religion regarding donation and transplantation, and they revealed inadequacies in the procedures adopted for donation in South Africa. The current system of donation in South Africa was furthermore shown to be flawed. A human rights-based approach (HRBA), in a mandated system for donation, is proposed as a means of rectifying the shortage of donors. In the determination of the content of such a system it would stand to reason that a comparative overview of different procedures already adopted by other countries, could inform the study and possibly provide alternative solutions to those procedures which have proved to be inadequate.

There are numerous systems for the procurement of organs in different countries. The most commonly used, and easily accepted system, is the opting-in system. This system is used in South Africa and in several other countries, and it has already been discussed in previous chapters.¹ A system of presumed consent is often met with disapproval from scholars, and it is considered to be controversial; nevertheless, it has been implemented in several countries, such as Spain and Singapore. As has previously been mentioned, Spain currently has the highest rate of donations worldwide, a success rate which was achieved after the country's implementation of a presumed consent model for donation. While the previous chapters have alluded to the implementation of a system for mandated choice as opposed to one of presumed consent, it is still worth analysing the implementation of this system of opting-out as it is applied in other states in order to determine whether there are elements which may be incorporated into a HRBA for organ donation in South Africa.

The allocation of organs, in addition, is a procedure which warrants further attention. The way in which the different organs are distributed is relevant in ensuring a non-

¹ Chaps 3 and 4.

discriminatory allocation procedure founded on principles of equality, which would further enhance the features of a HRBA in general. This chapter, thus, strives to give an overview of the procurement and allocation systems which are in place in different states and further determines which features may be relevant to a HRBA for organ donation. To begin with, the South African procurement system is going to be outlined, followed by the procurement systems of two other countries, and it will be determined which elements could inform a HRBA in South Africa. The same procedure will follow for the allocation, or distribution, of organs.

5.2. Organ procurement systems

5.2.1. South Africa

As pointed out previously,² organ donation, procurement and allocation are regulated in terms of the National Health Act³ (NHA) in South Africa as well as by the Act's regulations.⁴ As mentioned earlier, South Africa follows a system of opting-in which indicates that an individual may register as an organ donor in order to be viewed as one upon his death. The next of kin is also permitted to veto the decision made by the deceased for, or against, donation upon the death of a potential donor. The NHA deals with deceased donation in Chapter 8. Section 62 provides that a competent person may indicate in a will, a document signed in the presence of two competent witnesses, or in an oral statement heard in the presence of two witnesses, his desire to donate his body or specific tissues to be used after their death.⁵ Section 64(1)(d) further permits the use of organs for therapeutic purposes in a living person.

A person may donate an organ to a prescribed institution or person.⁶ The Act additionally lists the purposes for which donations may be used, including health research, 'training of students in health sciences', therapeutic purposes, 'the advancement of health

² Chap 1.

³ National Health Act 61 of 2003.

⁴ Regulations regarding the general control of human bodies, tissue, blood, blood products and gametes, 35099 of 2012 (Regulations regarding the general control of human bodies).

⁵ Sec 1 of the National Health Act includes an organ in the definition of 'tissues'. This would imply that sec 62 refers not only to tissues but also to organs.

⁶ Sec 63 NHA.

sciences' and 'the production of a therapeutic, diagnostic or prophylactic substance'.⁷ Section 65 allows for the revocation by the donor of a donation made in a will or document in the same way in which the donation was made, or by the intentional destruction of such a document.

Section 68(1)(c) permits the Minister of Health to formulate regulations regarding the general control of human bodies. These regulations were adopted in 2012 and provide a list of the entities and persons to which a donation may be made, including a dentist, hospital, university, medical practitioner, authorised institution and 'a tissue bank or any person who requires therapy in which the tissue concerned can be used'.⁸ The regulations are limited with regard to procurement; they do, however, provide a time period for donation after death in clause 8. This regulation provides that, except in cases where the entire body has been donated, the donee has 24 hours after the death of the donor to remove, 'or cause to be removed', the organ or tissue donated.

The legislation and regulations in place for procurement purposes are inadequate as they do not sufficiently provide for measures which can assist in the process itself, such as the introduction of committees assigned to deal specifically with donation and transplantation. It is argued that this has contributed to the dwindling number of donations currently seen. In order to increase the number of donations, therefore, it is imperative for a sound and more organised system to be implemented so that a positive change in the donor pool may be affected. Guidance may be sought from the organ transplantation and donation programmes or structures in place in other countries which may help to inform the system in South Africa. What follows is a comparative study of the systems in place in Singapore and in Spain.

5.2.2. Singapore

Singapore is a multi-cultural, multi-religious and multi-racial small city-state with a population consisting mainly of descendants of Chinese, Malay and Indian subcontinent

⁷ Sec 64(1) NHA.

⁸ Regulations regarding the general control of human bodies, tissue, blood, blood products and gametes, 35099 of 2012 (Regulations regarding the general control of human bodies), CI 4.

immigrants.⁹ Chinese Singaporeans form 76.8 per cent of the population, Malays 13.9%, and Indians 7.9%.¹⁰ Although the ethnic groups in Singapore share certain characteristics, they differ in terms of their views on life and values.¹¹ Each group has its own distinct cultural background, religion and language.¹² The Chinese Singaporeans adhere mainly to Buddhism, the Malays to Islam and the Indians are predominantly Hindu.¹³ Although there are various misconceptions about organ donation among these religions, an awareness survey conducted in Singapore by the Multi-Organ Donation Development Unit in 1999 revealed that the majority of the populace (95.6%) were cognisant of the fact that they could donate their organs. Despite this, however, only a small percentage (9.7%) had actually signed up as donors.¹⁴ This suggested a high level of awareness about organ donation even though it did not correlate with the number of donations.

Singapore has two pieces of legislation which deal with organ donation. The Medical (Therapy, Education and Research) Act (MTERA) was enacted in 1972 and allows for the pledging of organs of deceased persons for research, advancement of dental or medical science, dental or medical education, and transplantation.¹⁵ The Act portrays donation as being a form of gift-giving, as seen in the definition of a donor provided in section 2, and in this way suggests an altruistic attitude towards organ donation.¹⁶ Section 8 provides that '(a) gift of all or any part of a body ... may be made by the donor either in writing at any time or orally in the presence of two or more witnesses during last illness'. The Act also provides that this gift may be made to a specified or non-specified recipient, who may then accept or reject the 'gift of a body or part of a body'.¹⁷ This voluntary system

⁹ M Lwin, JD Williams & LL Lan 'Social marketing initiatives: National Kidney Foundation's organ donation programs in Singapore' (2002) 21 (1) *Journal of Public Policy and Marketing* 66.

¹⁰ M Lwin *et al* (n 9 above) 67.

¹¹ As above.

¹² As above.

¹³ As above.

¹⁴ As above.

¹⁵ The Medical (Therapy, Education and Research) Act 23 of 1972.

¹⁶ A donor is defined in sec 2 as 'an individual who makes a gift of all or any part of his body'.

¹⁷ Secs 10 and 11.

of donation ‘enjoyed a good track record’ in the case of renal transplantations, but it failed to produce a sufficient or even decent number of cadaveric kidneys.¹⁸

The Singaporean government enacted the Human Organ Transplant Act (HOTA) in 1987 in an effort to counter the shortage in cadaveric organs.¹⁹ The HOTA is a combination of a presumed and voluntary consent model in that it presumes that a particular group of its citizens consent to the donation of their organs, and ‘presumes that another group does not’.²⁰ Under HOTA, it is presumed that ‘all mentally competent citizens or permanent residents between the ages of twenty-one and sixty who are victims of fatal accidents are kidney donors unless they have registered prior dissent. Next of kin do not have to consent’.²¹ This presumed consent provision referred only to kidneys, and it placed a limit on the age of consent and the means by which a potential donor died (a fatal accident).²² In addition to this, consent of the next of kin was unnecessary for the donation. The introduction of HOTA led to an increase of kidney procurement from 4.7 to 31.3 per million people per year.²³ This success rate, however, was not maintained, as it was later reported that this number had dropped to 20 kidney procurements per year.²⁴

The majority of donations appeared to come from donors who had opted-in, but in the past only a fraction of these individuals carried donor cards.²⁵ In addition to this, the presumed consent provision excluded Muslim Singaporeans ‘on religious grounds’, leaving out nearly half of ‘its potential supply of cadaveric organs’.²⁶ This was a consequence of the Muslim Council’s interpretation of the removal of organs; it was believed to amount to a desecration of the deceased.²⁷ Muslim Singaporeans could, thus,

¹⁸ S Fitzgibbons ‘Cadaveric organ donation and consent: a comparative analysis of the United States, Japan, Singapore, and China’ (2000) 6:73 *ILSA Journal of International and Comparative Law* 93.

¹⁹ As above.

²⁰ As above.

²¹ S Fitzgibbons (n 18 above) 94.

²² As above.

²³ As above.

²⁴ As above.

²⁵ As above.

²⁶ As above.

²⁷ J Chin & AV Campbell ‘Transplant tourism or international transplant medicine? A case for making the distinction’ (2012) 12 *American Journal of Transplantation* 1702.

either pledge their organs in terms of MTERA, or they could opt-in to organ donation in terms of HOTA.²⁸

This led to a number of amendments to HOTA being implemented over the years. A religious ruling was passed in 2007 by the Islamic Religious Council of Singapore which permitted Muslims to be included in the presumed consent provision under HOTA.²⁹ The Act was also amended to include and permit the retrieval of organs other than kidneys (corneas, hearts and livers) and the provision relating to fatal accidents was altered to include all causes of death.³⁰ A further amendment in 2009 removed the age limit of 60 and provided for the assessment of transplantable organs for their medical suitability.³¹ Paired exchanges were also permitted.³² The introduction of these amendments appeared to have increased the donor pool 'by more than a 50-fold, from 45,202 organ pledgers under MTERA, to more than 3 million non-objectors under HOTA as of 2007.'³³

5.2.3. Spain

The National Health System (NHS) in Spain encompasses all the public services and facilities which are dedicated to health in the country.³⁴ Health counsellors from each region form the Inter-territorial Council for the NHS, a body which is presided over by the Minister of Health and Consumer Affairs and oversees the coordination of health policies.³⁵ In 1979, the Spanish government introduced legislation regarding organ procurement under the Spanish Law 20/1979.³⁶ This legislation introduced a presumed consent method for organ procurement in Spain. The introduction of this legislation brought with it an increase in donations. In 2008, an international comparison of organ

²⁸ As above.

²⁹ As above.

³⁰ As above.

³¹ As above.

³² As above.

³³ T Kwek *et al* 'The transplantable organ shortage in Singapore – has implementation of presumed consent to organ donation made a difference?' (2009) 38 *Annals Academy of Medicine* 347.

³⁴ B Miranda *et al* 'Organ donation in Spain' (1999) 14 *Nephrology Dialysis Transplantation* 15.

³⁵ As above.

³⁶ Spanish Law 30/1979, 27 October, on Organ Extraction and Transplant. As referred to in M Quigley *et al* 'The organ crisis and the Spanish model: theoretical versus pragmatic considerations' (2008) 34 (4) *Journal of Medical Ethics* 223.

donation rates revealed that Spain had the highest number of organ donations, 'with a rate of 34.2 organ donors per million'.³⁷

Several authors, however, have rejected the notion that this increase in donations was brought about by the introduction of the Spanish Law. Some commentators are of the opinion, for instance, that the legislation is generally inactive.³⁸ They refer to the fact that Spain does not possess an opt-out registry to record the objections of individuals who do not wish to donate their organs, and they also quote the country's failure to spend money on public awareness campaigns regarding its presumed consent legislation.³⁹ One may also point out that Spain actually has a 'soft' opt-out system, whereby the next of kin of the donor have the opportunity 'to object to organ donation, even if the deceased did not previously opt-out'.⁴⁰

Several theories have been suggested for this increase in donations in Spain, including the high rate of healthy individuals killed in motor vehicle accidents, as well as the investment made to the structure of the procurement system for organs, as managed by the Organizacion Nacional de Trasplantes (ONT), the organisation responsible for managing Spain's organ donation system.⁴¹ This organisation, therefore, is discussed further below.

The ONT was established in 1989 to be attached to the Spanish Department of Health.⁴² The initial assumption about the shortage of organs was not that there was an absence of donors, but rather the system's 'failure to convert potential into real donors'.⁴³ The national transplant coordinating network was, thus, conceived at a national (ONT), regional (17 regional coordinators) and local or hospital level.⁴⁴ The national and regional levels 'act as an interface between the technical and the political strata and act in support

³⁷ S Rodriguez 'No means no, but silence means yes? The policy and constitutionality of the recent state proposals for opt-out organ donation laws' (2011)7 *Florida International University Law Review* 163.

³⁸ As above.

³⁹ As above.

⁴⁰ As above.

⁴¹ S Rodriguez (n 37 above) 163 – 164.

⁴² B Miranda *et al* (n 34 above) 15.

⁴³ As above.

⁴⁴ As above.

of the process of deceased donation'.⁴⁵ National decisions made on transplantation and donation activities are agreed upon by the Transplantation Commission of the Health Inter-territorial Council which consists of the ONT, which acts as Chair, and the 17 regional coordinators.⁴⁶ The local, or hospital, level of coordination comprises a network of procurement hospitals which officially are authorised and are directly in charge of 'effectively developing the deceased donation process'.⁴⁷ The number of hospitals in this network has increased from 20 hospitals in 1989 to 118 in 1992, and 170 in 2009. This increase reflects not only the efforts made by the system, but also the political support provided in its early stages.⁴⁸

It is also important to note the definition of death adopted in the new legislation. Brain death is defined as 'the total and irreversible loss of function' and must be confirmed by three doctors, one of whom is either a neurologist or neurosurgeon.⁴⁹ These doctors are also required not to be part of the transplantation team.⁵⁰ The following procedure is also followed:

Signs of brain death must be explored clinically and documented by a silent EEG for 30 [minutes], and these tests must be repeated twice at an interval of no less than 6 [hours]. The diagnosis is valid unless the patient is hypothermic or exposed to drugs with known brain-depressive action. Organs may be retrieved only after obtaining informed consent from the donor's family.⁵¹

The introduction of the Spanish model also brought with it the appointment of a transplant coordinator (TC) at every procurement hospital.⁵² TCs are key persons assigned the responsibility of developing a 'proactive donor detection program and effectively converting potential into actual donors'.⁵³ The figure of the TC has been replicated in

⁴⁵ R Matesanz *et al* 'Spanish experience as a leading country: what kind of measures were taken?' (2011) 24 *Transplant International* 334.

⁴⁶ As above.

⁴⁷ As above.

⁴⁸ R Matesanz *et al* (n 45 above) 334 – 335.

⁴⁹ B Miranda *et al* (n 34 above) 15.

⁵⁰ As above.

⁵¹ As above.

⁵² R Matesanz *et al* (n 45 above) 335.

⁵³ As above.

several countries; Spain's TCs, however, have a 'unique profile conceived to facilitate early identification and referral of possible donors'.⁵⁴ TCs are in-house members of staff and professionals of a procurement hospital.⁵⁵ They do not report to the transplantation team but rather to the medical director of the hospital itself.⁵⁶ They are involved part-time in donation activities and these also allow them to be appointed at hospitals which produce a low deceased donor potential.⁵⁷ The ONT is not an organ-sharing office *per se*, but rather acts as a supporting agency for the network of procurement hospitals.⁵⁸ The support which is provided by some of the regional offices, as well as the ONT, is crucial for small hospitals which may not always be able to manage the entire process of deceased donation on their own.⁵⁹

Various components of the system may be seen to have contributed to its success. For instance, training in the entire process of deceased donation is facilitated via regular courses for all professionals directly or indirectly involved in the process.⁶⁰ The mass media has been utilised to foster a 'positive social climate toward donation' and to create the trust of society in the system.⁶¹

Four basic principles are followed when dealing with the communication policy of the ONT:

- i) A 24-hour telephone line available for consultation;
- ii) Easy and permanent access to the media;
- iii) Connection with journalists built through dedicated meetings aimed at learning about mutual needs; and the
- iv) Delivery of messages with no intermediaries.⁶²

⁵⁴ As above.

⁵⁵ As above.

⁵⁶ As above.

⁵⁷ As above.

⁵⁸ As above.

⁵⁹ As above.

⁶⁰ As above.

⁶¹ As above.

⁶² As above.

These principles have had the result of enabling the media to handle information concerning donation and transplantation appropriately.⁶³ It is also important to mention that hospitals are reimbursed for transplantation and donation activities by the corresponding regional health authorities which allocate 'a specific budget to cover both human and material resources needed for the effective development of these activities at every hospital'.⁶⁴

5.2.4. Malaysia

Malaysia is a multi-ethnic, multi-cultural and multi-religious country located in South East Asia. Malaysia consists of a majority of Malays and other ethnic groups (Indians, Chinese and other minority groups).⁶⁵ Various religions, including Islam, Confucianism, Hinduism, Sikhism, Taoism and Buddhism are followed in Malaysia, highlighting the country's diversity.⁶⁶

Malaysia similarly faces a shortage of organs for transplantation, owing not only to negative attitudes surrounding donation, but also to cultural and religious issues.⁶⁷ Although Malaysia has a similar ethnic composition to that of its neighbour, Singapore,⁶⁸ the number of donations in Malaysia is dwindling by comparison. This is possibly because of the system of organ procurement followed in Malaysia being an opting-in system for donation.

Transplantation in Malaysia dates to the early 1970s, with the first being a cornea transplant.⁶⁹ The first kidney transplant was performed in the mid 70s, and other surgeries, including bone marrow, liver and heart transplants, were performed for the first time during the following two decades.⁷⁰ Several milestones were achieved in the country as the first whole-arm transplant was performed in 2000 between two identical twin

⁶³ As above.

⁶⁴ As above.

⁶⁵ LP Wong 'Factors limiting deceased donation: focus groups' perspectives from culturally diverse community' (2010) 42 *Transplantation Proceedings* 1439.

⁶⁶ As above.

⁶⁷ As above.

⁶⁸ As above.

⁶⁹ PNJ Kassim 'Organ transplantation in Malaysia: a need for a comprehensive legal regime' (2005) 24 *Medicine and Law* 176.

⁷⁰ As above.

babies, where the deceased child had a congenital brain abnormality which led to his death.⁷¹ From the first cornea transplant to 2003, there were 7 671 organ and tissue transplants conducted in the country which ‘included 4 170 tissue graft, 1,267 cornea, 1,007 kidney, 634 bone marrow, 483 bone, 45 liver, 43 heart valve, 15 heart and 7 skin transplants’.⁷² These numbers reveal a steady growth in transplantation in the country.

Interestingly, all religions in Malaysia appear to support organ transplantation provided it is performed to save the lives of patients.⁷³ In 1970, for instance, a *fatwa* which permitted organ transplantation was approved by the International Islamic Conference in Kuala Lumpur.⁷⁴ A *fatwa* accepting brain death to be synonymous with cardiac death was further adopted in 1986 by the Third International Conference of Islamic Jurists.⁷⁵ In addition, a consensus was reached at a seminar on Islam and Organ Transplantation, which was held jointly by the Minister of Health, Institute Kefahaman Islam Malaysia, Muslim Doctors’ Association and Malaysian Transplantation Society in 2000, that Islam does permit organ donation and transplantation, but not the sale of organs.⁷⁶ Legislation was adopted in 1974 which governs the transplantation of cadaveric tissues.⁷⁷

The Human Tissue Act (HTA) was adopted in Malaysia in 1974 to regulate ‘the use of human bodies of deceased persons for therapeutic purposes and for purposes of medical education and research’.⁷⁸ Section 2 allows a person to request that his body, or a specific body part, be used for therapeutic purposes after his death, either orally in the presence of two or more witnesses, or in writing.⁷⁹ The Act further requires that only a registered medical practitioner, ‘who together with at least one other fully registered medical

⁷¹ As above.

⁷² As above.

⁷³ As above.

⁷⁴ As above. A *fatwa* is ‘an Islamic legal pronouncement, issued by an expert in religious law (*mufti*), pertaining to a specific issue, usually at the request of an individual or judge to resolve an issue where Islamic jurisprudence... is unclear’.

The Islamic Supreme Council of America – ‘Understanding Islam - what is a fatwa?’ <<http://www.islamicsupremecouncil.org/understanding-islam/legal-rulings/44-what-is-a-fatwa.html>> (accessed on 27/10/2017).

⁷⁵ PNJ Kassim (n 69 above) 176.

⁷⁶ As above.

⁷⁷ The Human Tissue Act 130 of 1974.

⁷⁸ Preamble HTA.

⁷⁹ Sec 2(1) HTA.

practitioner' may remove and use tissue after the two practitioners have confirmed the death of the donor.⁸⁰

The Ministry of Health in 2007 published the National Organ, Tissue and Cell Transplantation Policy (NOTC Policy) which deals with policies surrounding organ, tissue and cell transplantation.⁸¹ This policy provides for the reimbursement of costs which may be incurred by the family of the deceased donor in relation to the process of organ and/or tissue procurement.⁸² These expenses are 'reimbursable by an authorised body or organisation recognised by the Ministry of Health' and direct payments to the family of the deceased donor are forbidden.⁸³ A budget is further dedicated and formulated specifically for transplantation activities in the country.⁸⁴

The National Transplantation Programme's main governing body is the National Transplantation Council (NTC) which consists of, *inter alia*, a chairperson, clinicians from the Ministry of Health, a representative from the Malaysian Society of Transplantation, two representatives from the universities, a representative from the organisation representing all other religious bodies, and a representative from the Academy of Medicine Malaysia.⁸⁵ The NTC is in charge of recommending policies on transplantation, monitoring and promoting the progress of the transplantation programme, advocating transplantation as well as ensuring that ethical and professional standards are met in the country.⁸⁶ The objectives of the NTC are promoted by the National Transplantation Technical Committee (NTTC), which is headed by the Deputy Director General of Health (Medicine) and 'four other persons with relevant expertise in the field of transplantation'.⁸⁷ The NTTC further establishes Expert Committees with specific responsibilities and scopes, including training, law and ethics, public education, a registry for recipients of organs, tissues and cells, as well as any other scopes which may become necessary.⁸⁸

⁸⁰ Sec 3(1) HTA.

⁸¹ National Organ, Tissue and Cell Transplantation Policy, 2007.

⁸² Sec 3.5 NOTC Policy.

⁸³ As above.

⁸⁴ Sec 3.8 NOTC Policy.

⁸⁵ Sec 4.1 NOTC Policy.

⁸⁶ Sec 4.3 NOTC Policy.

⁸⁷ Sec 4.4 NOTC Policy.

⁸⁸ Sec 4.5 NOTC Policy.

Finally, the organ, tissue and cell transplantation programme is coordinated by the National Transplant Unit (NTU) in the Medical Development Division of the Ministry of Health.⁸⁹ The NTU has various responsibilities crucial to transplantation and donation, including the establishment of procurement units in hospitals, an allocation system and national transplantation waiting list, the implementation of training programmes for personnel who are involved in the procurement and transplantation process, and ensuring that 'all practitioners in organ, tissue and cell transplantation are properly credentialed'.⁹⁰ The NTU is also responsible for monitoring the standard of practice in procurement and transplantation, promoting educational activities and facilitating amendments to existing legislation, or the enactment thereof, on transplantation, according to recommendations of the Law and Ethics Expert Committee and as approved by the NTC and NTTC.⁹¹

The NTC, NTTC and NTU, therefore, are necessary structures in the implementation of a system of donation and transplantation. They work on a national, as opposed to regional, level as seen from the different sections of the NOTC policy, and it can be argued that this would be better suited and promote a more organised arrangement. It will also be highlighted below how this system can benefit a mandated choice system for organ donation and transplantation in a rights-based approach.

5.3. Lessons learnt to aid, and implications for, a human rights-based approach (HRBA) to organ donation and/or transplantation in South Africa

All of the systems discussed above, apart from the South African system, have one crucial element, *viz* separate legislation which deals specifically with donation and/or transplantation. South Africa incorporates rules and regulations relating to organ donation and/or transplantation in the NHA and its regulations. This has proved to be ineffective and it is thus imperative that new legislation be adopted in this regard. One may consider the strides made in other countries regarding organ donation and/or transplantation such as in Singapore. The initial introduction of the MTERA brought with it an increase in

⁸⁹ Sec 4.6 NOTC Policy.

⁹⁰ Sec 4.7 NOTC Policy.

⁹¹ As above.

donations, and, when the number of donations dwindled, various amendments were made in addition to the introduction of HOTA. HOTA brought with it a presumed consent system; over the years, however, the removal of the age limit, the inclusion of organs other than kidneys, the passing of a *fatwa* permitting organ transplantation and the inclusion of Muslims under this legislation further contributed to the increase in donations.

The religious ruling made by the Islamic Religious Council in Singapore in 2007 highlights, and can inform, a HRBA to organ donation, with specific reference to the principle of empowerment and participation. By including one of the main religious groups in decisions relating to donation and transplantation, the community was empowered, as that particular religious group was given a chance to contribute towards the fulfilment of its rights. The idea of including different religious and cultural leaders in such discussions has been discussed in the previous chapter, not only as a means of developing the capabilities of those suffering from organ failure, but also as a means of educating the different communities about the benefits of, and necessity for, organ donors. It also assists in debunking the various misconceptions perceived about donation. The fact that this has been done in Singapore, which is also a multi-ethnic, multi-cultural and multi-religious country, shows that it is a possibility for South Africa.

One may also consider the strides made in Spain and Malaysia regarding organ donation and transplantation. Spain has developed an organisation which deals solely with the process of organ donation and transplantation at a national level, the ONT. Spain has a regional and local/hospital level, each with its own responsibilities. This system has been effective, not only in providing structure at a national level but also in providing support to the different procurement hospitals at a local level as mentioned above. Such an inclusion can be seen as contributing to the empowerment of the rights of those in local communities, and it also enhances the right to equality and non-discrimination in that the different sectors (national, regional and local) in the country are involved, so including all communities. Small hospitals, which may not be able to foster the entire deceased donation process, are supported by the national and regional levels. Such an inclusion would be beneficial to a HRBA approach to donation. Spain also has media involvement to assist in broadcasting a more positive attitude towards organ donation which further

educates the public and builds a positive climate in different communities regarding donation, which could be adopted by South Africa.

A council that coordinates the transplantation process, such as Malaysia has (the NTC), could also be beneficial for South Africa. Having an inclusive council which recommends policies, training activities, and the like, on donation and transplantation is essential for the development of new procedures which may be adopted in this regard. The NTC also further facilitates the amendment of existing legislation on donation and transplantation which can be viewed as a means of furthering the feature of progressive realisation for a HRBA to donation. This is because medical technology is ever-changing and, with these changes, comes the need for a re-evaluation of the ethics involved in medical treatment as well as the possibility of having to adapt legislation to meet these changes. Having a council which discusses these aspects could, thus, be beneficial for a HRBA to donation.

5.4. Allocation and distribution of organs

Different considerations need to be deliberated on when dealing with the allocation of organs. The World Health Organisation Guiding Principles provide that the allocation of cells, tissues and organs 'should be guided by clinical criteria and ethical norms, not financial or other considerations. Allocation rules, defined by appropriately constituted committees, should be equitable, externally justified, and transparent'.⁹² The commentary goes on to state that this criterion is to be determined at national or sub-regional level, and 'by a committee that includes experts in the relevant medical specialities, bioethics and public health'.⁹³ This is to ensure that any criteria agreed upon include not only medical factors but also general ethical rules and the values of the community.⁹⁴ In this light, the following is mentioned which is of considerable value:

The criteria for distributing cells, tissues and organs should accord with human rights and, in particular, should not be based on a recipient's gender, race, religion, or economic condition. This principle implies that the cost of transplantation and follow-up, including

⁹² Guiding Principle 9 - WHO guiding principles on human cells, tissue and organ transplantation, 2010; 7.

⁹³ Commentary on Guiding Principle 9 - WHO guiding principles on human cells, tissue and organ transplantation, 2010; 7.

⁹⁴ As above.

immunosuppressive treatment where applicable, should be affordable to all patients concerned — that is, no recipient should be excluded solely for financial reasons.⁹⁵

This consideration for the allocation of organs highlights the need for the criteria to follow the basic principles of human rights. It is interesting to note that the requirement for the recipients of organs, tissues or cells includes the fact that no-one is to be denied access to necessary transplantation and post-transplantation treatment owing to financial difficulties. This highlights the need to prevent the marginalisation of poverty-stricken communities and a notion of fairness in the transplantation process. An analysis of different allocation and distribution procedures will now be embarked upon.

5.4.1. South Africa

South Africa follows an opting-in system for organ procurement. The NHA deals with the transplantation procedures to be adopted in the country. Section 61 refers to the allocation of organs and provides that human organs may be obtained and used for transplantation and other purposes only ‘in the prescribed manner’ provided for in the regulations regarding the general control of human bodies discussed above.⁹⁶ With regard to the question of to whom organs may be donated, the Act provides that a deceased donation may be made to a prescribed institution or person in terms of a will or as contemplated in section 62.⁹⁷ The Minister of Health also has the authority to prescribe ‘the criteria for the approval of organ transplant facilities’ and the ‘procedural measures to be applied for such approval’.⁹⁸

The regulations regarding the general control of human bodies do not contain any information regarding waiting lists or the procedure to be followed for the allocation of donated organs. Clause 5 provides the following with regard to donations:

- (1) A donation that does not have a specific institution as donee, the institution in the appropriate category which is nearest to the place where the body is kept of the person whose body or tissue has been so donated, shall be deemed to be the donee.

⁹⁵ As above.

⁹⁶ Sec 61(1) and (2).

⁹⁷ Sec 63.

⁹⁸ Sec 61(4).

(2) If a donation has been made to a specific donee who is not in easy reach at the time and place of the death of the person whose body or any specific tissue thereof was so donated the institution in the appropriate category which is nearest to that place shall be deemed to be the donee.⁹⁹

Clause 5 (1) above indicates that there is no national registry of donors or recipients. If a deceased individual is recognised as a donor, and it is not a directed donation, then the donation is simply made to the closest institution depending on the particular category. Clause 5(2) provides that the same process will be followed in a directed donation where the donee cannot be reached. In addition to this, Clause 8 stipulates that a donation may occur only in 24 hours after death before the body may be claimed 'for burial or otherwise'. This could pose a potential problem as in the Islamic faith and Judaism it is a religious requirement for the body to be buried in 24 hours.¹⁰⁰

Section 62(1)(b) of the NHA states that a 'person who makes a donation ... must nominate an institution or a person ...'. This section is futile as 'organs or whole bodies that are donated always go to the closest place where the death occurred'.¹⁰¹ Sections 62(1)(c) nullifies a donation where no donee is nominated and section 62(1)(d) provides that a nomination of a donee needs not be made where a donation is made for the purposes of 'transplantation or treatment, or medical or dental training or research'.¹⁰² Slabbert is of the opinion that these two subsections could have been omitted as, again, donated organs or bodies will in any case go to the nearest place where the death occurred.¹⁰³

It is clear these regulations do not provide much guidance. Venter discusses the requirements which need to be complied with before donation can take place as follows:

- Establishment and confirmation of brain death of the donor.
- The potential kidney(s) need to be declared as suitable and viable.

⁹⁹ Cl 5.

¹⁰⁰ See chap 3 above.

¹⁰¹ M Slabbert 'The law as an obstacle in solid organ donations and transplantations' (2018)81 *THRHR* 78.

¹⁰² Sec 61(1) NHA.

¹⁰³ M Slabbert (n 101 above) 78.

- Consent needs to be obtained from the family (even if the donor did previously give consent).
- The exclusion of any communicable diseases, malignancy or any other serious health issues regarding the kidney(s).
- The ability to maintain circulation or kidney viability until the kidney can be removed for transplantation.¹⁰⁴

Slabbert points out that there is no national waiting list in South Africa.¹⁰⁵ Muller states that there is a shared regional waiting list in most regions 'between the State and the private sector for all solid organs'.¹⁰⁶ With regard to renal failure, Muller indicates that a patient becomes eligible for a kidney transplant only once he has reached kidney failure and 'glomerular filtration rates are less than 10 ml/kg/h'.¹⁰⁷ The candidate must also be fit to have the procedure from a cardiac and general perspective, and those candidates who can also tolerate the post-operative immunosuppressive treatment are listed.¹⁰⁸ A person's waiting time on the list will be dependent on the blood group of the patient:

As O blood group is the most prevalent among potential recipients, their waiting time is the longest. O blood group livers and hearts are often used for patients with other compatible blood groups, but because of lengthy kidney transplant waiting lists only O-positive recipients are cross-matched against O-positive deceased donors.¹⁰⁹

¹⁰⁴ B Venter 'A selection of constitutional perspectives on human kidney sales' Unpublished LLM thesis, University of South Africa, 2012 74. Venter further states that the donor is evaluated according to numerous other factors such as 'the type of transplant and the needs of the patients on the recipient waiting list' as well as 'suitable ABO (blood-type) matching, suitable cytotoxic antibody screening, suitable HLA (human leukocyte antigen) matching, suitability of size and age of the kidney recipient, medical condition and degree of urgency, and the time that the kidney recipient has been on the waiting list'. Venter's argument focuses on the sale of human kidneys which is not a focus for this research. Reference will be made however to her use of definitions and analysis of certain constitutional rights in relation to donation and transplantation.

¹⁰⁵ M Slabbert 'One heart, two patients: who gets the donor organ?' (2009) 20 *Stellenbosch Law Review* 135.

¹⁰⁶ E Muller 'Organ donation and transplantation in South Africa – an update' (2013) 31 *Continuing Medical Education Journal* 220.

¹⁰⁷ As above.

¹⁰⁸ As above.

¹⁰⁹ As above.

A panel meeting consisting of surgeons, physicians, transplant coordinators, social workers, psychologists and nursing staff is held where patients are discussed.¹¹⁰ In the public sector, dialysis is limited and, as such, patients will be provided with it only where they are also good candidates for transplantation.¹¹¹ In the private sector, there are patients who are on chronic dialysis programmes who are not suitable candidates for transplantation.¹¹² This already reveals a measure of inequality in the system. For kidney transplantations, there is a points system in most regions where a patient will be allocated points depending on the following criteria: previous transplants, age, time on waiting list, sensitisation and 'other medical issues, e.g. a lack of vascular access on dialysis'.¹¹³ When an organ donor becomes available, suitable recipients of a similar blood group are cross-matched against the donor and, after this is done, the organ is allocated depending on the position of the patient on the waiting list.¹¹⁴

The waiting list for heart and liver transplantations is much shorter and, for this reason, physicians are able to allocate donor organs according to a patient's 'current clinical condition and urgency'.¹¹⁵ In South Africa, Netcare ('the biggest private hospital group in the transplantation field' in the country) manages six transplant facilities and handles the organ donation process.¹¹⁶ In the public sector, the procedure is less formal and the location of the recipient will tend to play a key role in the allocation of organs.¹¹⁷ The public sector appears to have its limitations; patient allocation is solely dependent on the doctor's opinion of the patient, and, in state hospitals, there is a cap on the number of transplantations that are allowed to be performed for the different organs per annum.¹¹⁸

A national waiting list is vital for the allocation process. Labuschagne states that creating one would be instrumental in reducing the organ shortage as it would make the

¹¹⁰ As above.

¹¹¹ As above.

¹¹² As above.

¹¹³ As above.

¹¹⁴ As above.

¹¹⁵ As above.

¹¹⁶ M Slabbert (n 105 above) 135.

¹¹⁷ M Slabbert (n 105 above) 136.

¹¹⁸ As above.

information of the potential donor and recipient more easily accessible.¹¹⁹ She also mentions the importance of having, in addition to the national waiting list, a national donor list.¹²⁰ Such a list would contain the donor status of prospective donors which would eliminate the necessity of having to establish this status from distraught loved ones.¹²¹

The allocation of organs relies on an agreement between the state and the private sector whereby an available organ will go to the private or public sector depending on the urgency of the recipient's condition.¹²² The relevant people working with organ donations in each sector consult one another regularly in order to decide who has a patient in more urgent need of the organ.¹²³ There are no procedures or specific regulations in place to govern this process.¹²⁴ This reveals a lack of structure and organisation which could possibly be contributing to the lack of donors.

The disparities in access to health care services, particularly when looking at the allocation of organs, are quite obvious. Pieterse is of the opinion that the South African health system is in fact still under the shadow of apartheid, 'and the inhumanity and inequality occasioned by it...'¹²⁵ She quotes from the South African Human Rights Commission report as follows:

The South African health care system, prior to 1994, resembled the fragmented and failed system that Apartheid was. As such, the health care system was characterised by abject discrimination, unequal distribution of resources, unethical execution of responsibilities by

¹¹⁹ D Labuschagne 'An analysis of organ transplantation in South Africa with specific reference to organ procurement' Unpublished LLM thesis, University of Pretoria, 2013 72. Labuschagne further states that the lack of a national waiting list goes against Art 3 of *The Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin*, 2002. Art 3 provides the following: 'Parties shall guarantee that a system exists to provide equitable access to transplantation services for patients. Subject to the provisions of Chapter III, organs and, where appropriate, tissues shall be allocated only among patients on an official waiting list, in conformity with transparent, objective and duly justified rules according to medical criteria. The persons or bodies responsible for the allocation decision shall be designated in this framework'.

¹²⁰ D Labuschagne (n 119 above) 72.

¹²¹ As above. A donor list would also provide essential basic information of potential donors relating to their weight, blood type and age to name but a few. Should there be an unexpected death, medical personnel will be able to easily access this information as well. (D Labuschagne (n 119 above) 72.

¹²² M Slabbert (n 101 above) 136.

¹²³ As above.

¹²⁴ As above.

¹²⁵ M Pieterse *Can rights cure? The impact of human rights litigation on South Africa's Health System* (2014) 5.

health practitioners and large scale complicity in upholding the system of apartheid. A lack of coordination and lack of accountability was also common. Apartheid South Africa offered a co-existence of first-world and third-world health care services (often operating just metres apart) with the first-world experience being the almost exclusive preserve of whites.¹²⁶

Judging from this quotation it can be argued that the South African health system is indeed still under the shadow of apartheid, particularly when looking at the allocation of organs as discussed above. Individuals who are financially able to afford treatment in the public sector receive better health care than those in the public sector when looking at the victims of organ failure. During apartheid, there was an 'overconcentration of health facilities in urban areas and a disproportionate emphasis on tertiary over primary health care' which made it difficult for the elected government of 1994 to meet 'the needs of broader [the] society'.¹²⁷ Pieterse writes that there have been numerous laudable reform efforts made in the preceding years; however, the status has largely remained the same.¹²⁸ It could be argued, therefore, that there is an urgent need to reconsider the system in place, and a HRBA may be the first step in doing this. On this note, guidance may be gathered from allocation systems and procedures in other countries.

5.4.2. Singapore

When determining the selection criteria for patients, the Singaporean model follows three steps: 'patients must first be *referred* for evaluation by a transplant program, then be *admitted* to the waiting list of such a program, and finally be *selected* from that list once an organ becomes available'.¹²⁹ With regard to the allocation of donor organs, the medical profession is given absolute leeway in this regard.¹³⁰ The function and sole purpose of the admissions programme is:

¹²⁶ South African Human Rights Commission Report *Public Inquiry: Access to Health care services* (2008) 12 as quoted in Pieterse (n 125 above) 5.

¹²⁷ Pieterse (n 125 above) 5. In addition, the health care system was also fragmented, grossly inefficient, structurally deficient and focused mainly on the needs of white South Africans.

¹²⁸ As above.

¹²⁹ VH Schmidt & CH Lim 'Organ transplantation in Singapore: history, problems and policies' (2004) 59 *Social Science and Medicine* 2176.

¹³⁰ As above.

...to determine a patient's need for, and potential benefit from, treatment. If the ratio between risks, harms and benefit for the patient is diagnosed to be positive, then he or she is theoretically indicated for a transplant, which means that from a purely medical viewpoint he or she should be admitted to the waiting list.¹³¹

Schmidt and Lim analysed numerous studies which reveal that, in situations of organ scarcities, medical considerations are used as more of a filter for a lot of the potential demand and also to reject various patients who would otherwise be medically suitable.¹³² Indications criteria are, therefore, 'largely a function of the relation between supply and demand'.¹³³ The authors also state that, upon closer inspection of the final selection of recipients from the waiting list, the criteria adopted are centred more on ethical concerns and political factors as opposed to 'predominantly 'objective' medical criteria' which transplant surgeons worldwide claim to be using.¹³⁴ This highlights a potential problem as, ideally, there should be a balance between the medical, ethical and community needs.

In Singapore, a reciprocity system is used whereby priority is accorded to individuals who pledge their organs over non-pledgers.¹³⁵ This accords with the principle of fairness and equality, and it is as such an element which can be implemented in a human rights-based approach in South Africa. This is because it would not be fair for one to receive an organ without being willing to donate one.

5.4.3. Spain

As explained previously, the Spanish model created a transplant co-ordination network at a national, regional and hospital co-ordinator level.¹³⁶ A regional co-ordinator was created for each of the 17 regions, and, from 1988 to 1991, there was a significant increase in transplant coordinators from 20 to 118 coordination teams and 139 coordination teams as of 2001.¹³⁷ Every hospital is equipped with a transplant

¹³¹ As above.

¹³² As above.

¹³³ As above.

¹³⁴ As above.

¹³⁵ As above.

¹³⁶ As above.

¹³⁷ As above.

coordinator, and the majority of these coordinators are physicians supported by nurses.¹³⁸ These physicians are, in most cases, 'part-time contracted staff as opposed to full-time staff and totally independent of the transplant team'.¹³⁹ This most likely helped to increase the rates of donation. In addition to this, the ONT introduced a system whereby transplant co-ordinators are changed every few years in order to avoid the so-called 'burn out syndrome'.¹⁴⁰ This occurs as a result of having to ask grieving families for the organs of their loved ones which becomes overwhelming after three to four years.¹⁴¹ When this system was first introduced in Madrid in 1988/89, a 50% increase in donors was seen in the first year alone.¹⁴²

In addition to this, the ONT website provides information regarding transplantations, including the system of allocation. The system in place provides that, in order to be deemed eligible for a transplant, the patient must be sick (irreversible damage to an organ: the heart, liver, lung, intestine, kidney or pancreas) with transplantation being the only 'solution to avoid death'.¹⁴³ In order to respect the principles of equality and equity, allocation criteria follow two fundamental principles, territorial and clinical.¹⁴⁴ The territorial principle depicts a distribution of organs as per a given area, to be transplanted in that area, in order to reduce the chances of ischemia.¹⁴⁵ The clinical principle, on the other hand, refers to recipient/donor compatibility, patient severity, blood group compatibility, anthropometric characteristics, and so on.¹⁴⁶ The transplant team uses these criteria to determine which patient on the waiting list is most suitable to receive a donation.¹⁴⁷ Only in cases of what is termed 'urgencia 0' will such a patient have absolute priority in the national territory.¹⁴⁸ If there is no such patient, the territorial principle will apply.¹⁴⁹

¹³⁸ As above.

¹³⁹ As above.

¹⁴⁰ VH Schmidt & CH Lim (n 129) 60.

¹⁴¹ As above.

¹⁴² As above.

¹⁴³ Organizacion Nacional De Trasplantes – 'Transplants'

<<http://www.ont.es/informacion/Paginas/Trasplante.aspx>> accessed on 03/05/17 (transl from Spanish).

¹⁴⁴ As above.

¹⁴⁵ As above.

¹⁴⁶ As above.

¹⁴⁷ As above.

¹⁴⁸ As above.

¹⁴⁹ As above.

It is easy to imagine how such a system can be feasible with approximately 139 co-ordination teams and each hospital being equipped with a transplant co-ordinator.

5.4.4. United States of America

Although the United States of America (USA) is not a model for the opting-in system of organ donation, much may be learnt from the allocation and distribution system adopted in that country. The USA has the National Organ Transplant Act¹⁵⁰ (NOTA) in place which requires the Department of Health and Human Services to form an Organ Procurement and Transplantation Network (OPTN) under federal contract.¹⁵¹ The OPTN is a non-profit organisation tasked with activities relating to organ procurement and distribution only.¹⁵² In terms of the Act, the OPTN is required to establish either in one location, or through regional centres, a national list of individuals who require organs, as well as a national system which would be used to match organs and individuals.¹⁵³ This system is to be used on a computer basis, and be used in accordance with established medical criteria in order to match these individuals with organs, 'especially individuals whose immune system makes it difficult for them to receive organs'.¹⁵⁴ The OPTN is also tasked with responsibility for, *inter alia*, the preparation, distribution, and transportation of organs, as well as providing a 24-hour telephonic service which is to facilitate the matching of organs with individuals who are on the waiting list.¹⁵⁵

In 1986, the OPTN issued a contract to UNOS¹⁵⁶ for the development of a patient selection process which would handle the rationing and allocation of harvested organs.¹⁵⁷ UNOS follows a three-level screening process. The first step involves the referral by all private physicians of suitable organ donor candidates to a regional transplant centre.¹⁵⁸ Slabbert mentions that this level may already possess the potential for inequities as potential donors could be excluded from this list owing to a physician's 'personal, medical,

¹⁵⁰ National Organ Transplant Act, 1984.

¹⁵¹ M Slabbert (n 105 above) 132.

¹⁵² Sec 372(b)(1), NOTA.

¹⁵³ Sec 372(b)(2)(A), NOTA.

¹⁵⁴ As above.

¹⁵⁵ Sec 372(b)(2)(A) to (E), NOTA.

¹⁵⁶ United Network for Organ Sharing, as discussed in Chap 1.

¹⁵⁷ M Slabbert (n 105 above) 132.

¹⁵⁸ As above.

social or prejudicial beliefs'.¹⁵⁹ The author suggests a potential solution for this could be requiring physicians to follow a standard check-list for every potential donor in order to ensure a non-prejudicial process.

The second level requires each regional transplant centre to apply its own criteria for selection of potential patients, which is to be developed by its own evaluation committee, representative of the physicians in that particular community.¹⁶⁰ An issue mentioned with this level would be the lack of uniformity at the different regional centres which could result in a patient being placed on a waiting list in one region, but not in another.¹⁶¹

The final stage involves a graded waiting list onto which patients are placed.¹⁶² A points system is used to determine the specific position of the patient on the list where points are awarded for 'blood-type matching, length of time on the waiting list, degree of urgency and patient proximity to the transplant centre'.¹⁶³ When an organ becomes available, the patient with the highest points will receive it.¹⁶⁴ There are many controversial issues with regard to this system of allocation. For instance, Slabbert argues that waiting lists create room for the manipulation of the system by placing a patient on a list as early as possible before the patient's condition warrants such placement.¹⁶⁵ She further states that the problem is accentuated by the fact that the American health care system does not address the crisis of organ shortage, but instead delegates this responsibility to an organisation which does not use general criteria for the distribution of organs,¹⁶⁶ but instead uses a system which attempts to determine who the most deserving recipient will be.¹⁶⁷ This increases the potential for manipulation, prejudice, and unfairness in the system.¹⁶⁸

¹⁵⁹ As above.

¹⁶⁰ As above.

¹⁶¹ As above.

¹⁶² As above.

¹⁶³ As above.

¹⁶⁴ As above.

¹⁶⁵ M Slabbert (n 105 above) 132 – 133.

¹⁶⁶ The general criteria Slabbert refers to are those of age, medical benefit, merit and ability to pay; see M Slabbert (n 105 above) 133.

¹⁶⁷ As above.

¹⁶⁸ As above.

5.4.5. Lessons learnt to aid a human rights-based approach to organ donation and/or transplantation and the implications of them for such a system

The lack of a proper waiting list, national registry and procedure in place for allocation in South Africa has proved to make meeting the demand for organs ineffective. The system in Singapore reveals certain shortcomings in its allocation system, particularly with regard to the criteria adopted as mentioned above. This is not to say, however, that the system in place has nothing to offer a HRBA.

A system of reciprocity is adopted in Singapore, and this entails that priority is given to recipients who themselves are donors. Individuals who do not have any intention of being a donor, but who would be willing to receive an organ should they need one, are termed 'free riders' in Singapore. The problem with the concept of 'free riding' is the element of unfairness; an individual who refuses to donate to the organ pool will still have equal access to an organ should they find themselves in organ failure.¹⁶⁹ Robertson states that this act of benefitting from a system which is not being contributed to leaves no surprise with regards to the shortage of available organs for transplantation.¹⁷⁰

Furthermore, free riding goes against the biomedical ethical principle of justice. As mentioned previously,¹⁷¹ Beauchamp and Childress discuss distributive justice as having certain material elements to which a person owes and is owed including, *inter alia*, an equal share, according to need, effort and contribution.¹⁷² This would imply that, by not contributing to the donor pool and still benefitting from it, the principle of distributive justice is not being upheld. In this light, by introducing a priority system which works in favour of those who are donors, one can assume that this would be ethically sound. In addition to this, it may also contribute to a HRBA in that it would redress injustice.

In addition to this, having a system of reciprocity has had a positive effect in Israel. Slabbert and Venter discuss the organ procurement system in Israel which introduced the

¹⁶⁹ W Glannon 'Free riding and organ donation' (2009) 35 (10) *Journal of Medical Ethics* 590.

¹⁷⁰ CT Robertson 'From free riders to fairness: a cooperative system for organ transplantation' (2007) 48(1) *Jurimetrics* 5.

¹⁷¹ Chap 2.

¹⁷² T Beauchamp & J Childress *Principles of biomedical ethics* (2009) 243.

Organ Transplant Act in 2008 as a means of increasing organ donations.¹⁷³ As part of the Act, a system of reciprocity was introduced whereby individuals, on the waiting list or not, acquire priority points by:

- Signing a donor card pre-mortem;
- Making a non-directed/non-specified organ donation during their lifetime;
- Way of a first-degree relative signing a donor card or consenting to procurement of organs after death.¹⁷⁴

The idea behind the points system is that an individual receives a certain measure of priority should they need an organ for transplantation.¹⁷⁵ Since introducing this Act, there has been a record number of individuals signing donor cards, as well as a substantial increase in the number of transplant surgeries.¹⁷⁶

In Spain, the allocation of organs is dealt with in terms of the location of recipients but in a more organised fashion. In South Africa, where there is a non-directed donation, or in the case where the recipient cannot be reached, the organ simply goes to the nearest institution as per category.¹⁷⁷ Unregulated discussions are held with the relevant persons from the private or public sector to determine who receives the organ, as stated above. Since this process is unregulated, it is susceptible to inequality. The procedure adopted in Spain should be legally implemented in order to provide a more structured system and ultimately respect the principles of equity and equality, principles fundamental to a HRBA.

An essential addition to a possible HRBA system would be the implementation of a proper national waiting list, as opposed to the shared regional waiting list found in most regions across South Africa as discussed above. This is necessary to provide structure and effectiveness. The system adopted by the USA may be looked at in this regard, despite the criticisms against it. The organisation responsible for patient selection (UNOS) is also

¹⁷³ Slabbert & Venter 'Organ procurement in Israel: Lessons for South Africa' (2015) 8(2) *SAJBL* 45. Also see JS Taylor 'Autonomy and organ sales, revisited' (2009) *Journal of Medicine and Philosophy* 632-648.

¹⁷⁴ Slabbert & Venter (n 173 above) 45.

¹⁷⁵ As above.

¹⁷⁶ Slabbert & Venter (n 173 above) 44 – 45.

¹⁷⁷ CI 5(1) and 5(2) NHA regulations.

in charge of the creation of a national waiting list. This same approach may be adopted in South Africa, and this would be beneficial in identifying potential recipients effectively and distributing organs efficiently and in a fair manner. The USA further makes use of an electronic computer-based system for the matching of organs to recipients based on established medical criteria. Such a system may be considered a possible means of avoiding any potential human error or manipulation, and this would ultimately enhance a system based on fairness and non-discrimination.

5.5. Conclusion

The system and procedures for organ procurement and donation currently in place in South Africa are ineffective. A logical step forward would be to implement a new system based on new legislation adopted solely for the purpose of donation and/or transplantation procedures, as has been the *status quo* for countries which have had a better success rate. As mentioned previously,¹⁷⁸ the inclusion of representatives from different religions, as well as cultural leaders, in discussions involving donation and transplantation would not only enhance the participation and empowerment element of a HRBA, but it would also assist in educating individuals on donation and its acceptance in African culture and religion, and also lead to an increase in donations as was seen in Singapore by the religious ruling discussed above.

Empowerment and participation can also be enhanced by creating a national organisation which would provide support for regional and local hospitals regarding donation and transplantation. This may further contribute towards the enhancement of the rights to non-discrimination and equality as equal opportunities are being afforded to different communities, which is another element in a HRBA. Inclusion of the media in broadcasting information on donation, as is done by Spain, assists in educating the public and is a simple but effective element that can help to boost the donor pool. In addition, it is important to learn from Malaysia about the notion of a council which recommends policies and training activities regarding donation and transplantation, and another which

¹⁷⁸ Chap 3.

implements these suggestions. Having organisations which deal specifically with donation and transplantation activities is essential and this has been shown to be more effective than the system currently in place in South Africa.

The allocation of organs is a further important component of a new system of donation and transplantation, specifically when one looks at the rights to equality, non-discrimination, and the bio-ethical principle of justice. The procedures in place for the allocation of organs can potentially lead to instances where these rights and principles may be violated. The WHO's Guiding Principles emphasise the importance of guiding the allocation procedures not only by ethical, but also clinical, criteria, which suggests that there needs to be a balance between the two. The WHO also emphasises the need for these procedures to be in line with the human rights of individuals and not based on, *inter alia*, religion or economic condition.¹⁷⁹ Presently this standard is not being upheld in South Africa, as is seen from, for example, the limitations placed on dialysis in the state sector as opposed to the private sector as discussed above. In addition, the private sector appears to have a more structured allocation procedure than does the public sector. The procedure to determine which organ is to go to the private or public sector is also unregulated, which means that there is no way of enforcing accountability.

A proper waiting list, a national registry and defined procedures are essential in developing an allocation strategy which would be in line with a HRBA to donation. Looking at the USA for guidance, a national waiting list should be created in order to bring about a proper structure, perhaps even going as far as considering an electronic system in order to lessen the possibility of human error or bias. In addition, a system of reciprocity would further benefit a HRBA, as shown above, as it would limit the so-called 'free riders' and reduce unfairness, ultimately supporting the ethical principle of justice.

¹⁷⁹ Commentary on Guiding Principle 9 - WHO Guiding Principles on human cells, tissue and organ transplantation, 2010 7.

CHAPTER SIX

Conclusion

6.1. Introduction

Organ transplantation has saved the lives of countless people suffering from organ failure. It is a viable and feasible option to treat organ failure as it has been proven to increase both the lifespan and quality of life when compared to other treatment options. Technological advances in medicine have brought with them a demand for organs - a demand that has not been met.

This study has shown that the legislation in place in South Africa with regard to organ donation and transplantation fails to meet the required ethical standards, neither does it satisfy human rights norms associated with human health. The importance of ethical guidelines related to organ donation and transplantation (with specific reference to the biomedical ethical principles devised by Beauchamp and Childress) has been emphasized in the study.¹

In previous chapters, the thesis exposed religious and cultural beliefs regarding donation which prevent individuals from donating their organs or the organs of their loved ones, and discredited these beliefs as mere misconceptions. To help increase the donor pool while still respecting individuals, the study canvassed a human rights-based approach to organ donation and transplantation.

This chapter concludes the thesis and discusses the codification of this model from a national and international perspective.

6.2. Biomedical ethics and donation

The four principles of biomedical ethics are autonomy, beneficence, non-maleficence and justice.² The common idea behind respect for autonomy is for an individual to have 'self-authorship' including certain virtues such as integrity and self-awareness.³ It was

¹ T Beauchamp & J Childress *Principles of biomedical ethics* (2009) 99.

² For a more detailed discussion of these principles, see chap 2.

³ RS Taylor 'Kantian personal autonomy' (2005) 33 *Political Theory* 605.

determined that an individual's ability to be autonomous centres greatly on his decision-making ability. In order for a person to be able to make an autonomous decision, it is necessary for him to be equipped with adequate information to be able to make that decision, thus preserving his dignity (or integrity).⁴ In terms of healthcare, it is impossible, if not unrealistic, for a lay person to be expected to understand fully a procedure as complex as organ transplantation, particularly with regard to the risks involved. It would be unethical for a surgeon to make the decision to proceed with an organ transplant without having highlighted important factors regarding the risks to all the parties involved. Informed consent as a right, therefore, is crucial in the donation and transplantation process for both the donor and the recipient.

The test for determining the information to be disclosed to the patient is a subjective test, viz the reasonable person standard, which is what the reasonable patient would want to know, as opposed to what the reasonable physician would disclose.⁵ This subjective test is highlighted by the guidelines of the Health Professions Council of South Africa (HPCSA) which determine that the patient, and not the health care practitioner, is to determine what is in his best interests.⁶ Making this decision could be challenging for practitioners, especially when there are other factors to consider which could affect this, factors such as familial pressure and/or coercion.

Beneficence and non-maleficence exist in tandem, particularly in the medical field.⁷ Beneficence refers to the moral obligation to act for the benefit of others, whereas non-maleficence refers to the prevention of harm. These two principles are closely associated with the Hippocratic Oath which requires medical personnel not only to help the sick and suffering, but also to prevent the deterioration of illnesses, damage and disease, and to find ways to prevent them.⁸ The two principles need to be weighed against each other in a surgical setting because a surgeon is technically causing harm to a patient when he

⁴ Chap 2.

⁵ S Naidoo 'Obtaining informed consent for surgery' (2014) 27 *Current Allergy & Clinical Immunology* 113.

⁶ Health Care Professions Council of South Africa 'Seeking patients' informed consent: the ethical considerations' (2007) 2nd Ed. Pg. 6.

⁷ Chap 2.

⁸ R Gillon '*Primum non nocere*' and the principle of nonmaleficence' (1985) 291 *British Medical Journal* 131.

operates (which goes against the principle of non-maleficence) for the benefit of the patient. Organ transplantation is a surgical procedure aimed at improving the life of the person with organ failure. The difficulty is the determination of how much benefit would be required to offset the risks involved and requires a careful balancing act.

Achieving this balance is difficult when considering the state of mind of person who faces organ failure. An informed autonomous decision has to be given voluntarily. Manipulation, pressure and coercion are, however, more likely to be effective when a person is facing this type of scenario.⁹ Medical paternalism, also referred to as ‘professional beneficence’ is relevant in this situation. Beauchamp and Childress distinguish between *hard* and *soft* paternalism, where soft paternalism would be implemented to avoid the patient’s becoming prey to ‘nonvoluntary conduct’ owing to situations where the patient is either severely depressed or misinformed.¹⁰ Hard paternalism would indicate a situation where a physician intervenes in a patient’s decision, even where informed consent has been provided.¹¹

Soft paternalism, therefore, is not considered to lead to the removal of a person’s autonomy as it already has diminished, but hard paternalism does. A soft form of paternalism may thus be implemented where a patient (or family member of a potential deceased donor) is in a state of severe depression, leaving his autonomy already compromised. Such a method may be implemented in a mandated system of donation, where individuals are fully educated and able to make informed decisions before their death and, therefore, not burden family members with the difficult decision of whether or not to donate the organs of their loved ones.

The thesis elaborated on the principle of justice in biomedical ethics.¹² Justice depicts ideals of fairness and equitability.¹³ Distributive justice, which refers to the distribution of resources based on everyone’s needs, was the focus of the discussion. When put into the context of organ donation, it entails the need for every individual suffering from organ

⁹ As discussed in chap 2.

¹⁰ Beauchamp & Childress (n 1 above) 209.

¹¹ As above.

¹² See chap 2.

¹³ As above.

failure to have fair and equal access and an opportunity to access available organs for transplantation. This principle requires an examination of the distribution of organs as well.

6.3. Law and organ donation and transplantation

This study focused on cadaveric donations as the dominant form of donation and transplantation in most developed countries.¹⁴ Two types of procurement systems were highlighted; namely, an opting-in system (where a person has to register as a donor before their death); and the opting-out system (where a person is considered a donor upon their death unless they register against donation prior to death).¹⁵ Despite criticism relating to the presumed-consent models (or opting-out systems), countries such as Spain and Singapore have implemented a soft form of the opting-out systems whereby the deceased's next of kin and/or family members are consulted before proceeding with a donation.¹⁶

The main argument against the opting-out model highlighted in the thesis is that it proposes a violation of the right to individual autonomy in instances where a person did not wish to be a donor.¹⁷ Kurosu goes as far as to associate presumed consent with a violation of a person's voluntary beneficence, in that people are already beneficent to others and are more likely to be so even without an express statement needing to be given.¹⁸

Other authors, however, are in favour of this model as they believe a deceased individual is longer is in need of his organs,¹⁹ whilst others take a utilitarian approach to presumed consent believing it to be for the greater good of society without resulting in significant harm.²⁰ The study determined that, even in a soft opting-in system there still exists a

¹⁴ D Price *Legal and ethical aspects of organ transplantation* (2000) 23.

¹⁵ As discussed in chap 2.

¹⁶ As above.

¹⁷ As above.

¹⁸ As above.

¹⁹ R Veatch *Transplantation ethics* (2000) 144.

²⁰ Sanders & Dukeminier as discussed in chap 2. For a more detailed discussion on the arguments for the presumed consent model, see chap 2.

possibility of violating a person's autonomy where individuals who wish to donate their organs neglect to make their wishes known before their death. The violation would happen in instances where a family member or next of kin of the deceased overrides a decision to donate. In this instance, a utilitarian perspective may be better-suited, that is, adopting a system where the majority is benefitted by an increase in the donor pool.²¹

The NHA makes provision for an opting-in system of donation in South Africa.²² The NHA further provides a definition of death which was concluded to be unsatisfactory for the purposes of organ procurement.²³ It was stated that the definition is too narrow and limited and, as such, may prevent a person from becoming a donor or to donate the organs of a loved one.²⁴ Three different conceptions of death were outlined, namely, the biological criterion ('permanent cessation of the functioning of the organism as a whole'); the physiological criterion (when all brain function has irreversibly ceased); and the legal criterion (the legislative description of death).²⁵ It was recommended that, since organ donation and/or transplantation is a sensitive topic, it may be beneficial to include in the definition of death (for transplantation purposes), the notion of 'personhood' (where a person is viewed as a human being as opposed to being seen as a biological entity, taking into consideration aspects such as a person's awareness for example).²⁶ The thesis examined death as viewed by the courts in *S v Williams* and *Clarke v Hurst*, as well as by foreign case law. Definitions of death provided by the World Health Organisation were considered.²⁷

It is submitted that an appropriate definition for the purposes of organ donation and transplantation may read follows:

A person may be considered to be dead for transplantation purposes when:

²¹ As discussed in chap 2.

²² Sec 62.

²³ Death is defined in sec 1 as 'brain death'.

²⁴ As discussed in chap 2.

²⁵ M Nair-Collins 'Death, brain death, and the limits of science: why the whole-brain concept of death is a flawed public policy' *Journal of Law and Medical Ethics* (2010) 667.

²⁶ As discussed in chap 2.

²⁷ See chap 2.

- a) There is an irreversible cessation of the respiratory and circulatory functions as determined by a physician using cardiopulmonary criteria;
- b) There is an irreversible cessation of all the functions of the brain (whole brain death), including the brain stem and cerebral functions; 'characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses'²⁸ (neurological criteria);
- c) There is an irreversible cessation of all the functions of the brain stem; or
- d) The person is deemed psychologically dead, in line with the moral convictions of society.

A person who is considered brain dead either by way of whole-brain death or brain-stem death shall be deemed to be dead in terms of this section irrespective of whether the biological functions of the person are functionally maintained by artificial means.

A definition of this kind is in line with the legal, physiological and psychological concepts associated with death and takes into account the relevant moral dimensions in order for it to be ethically sound. This definition also considers both brain death and cardiac death for purposes of transplantation, thus further attempting to increase the donor pool. The thesis, thus, showed the importance of the link between ethical norms and legal concepts. Ethical norms are determined by society and should, therefore, be given statutory recognition. In medical law, recognition has been given to certain ethical guidelines, but a lack of clarity on the extent and scope of these norms in the legal arena still exists.

The study further questioned whether a presumed consent system for organ donation could be implemented in South Africa, so overcoming misconceived religious and cultural objections to donation. This is addressed below.

²⁸ Insert from the 'WHO Global glossary of terms and definitions on donation and transplantation' (2009) 6.

6.4. Religion, culture and organ donation and transplantation

Religion and culture play an important role in any society. An understanding of the religious and cultural backgrounds of persons and communities is important in order to comprehend the fears which donor families may have regarding organ donation, particularly in multicultural, multi-ethnic and multi-religious communities such as South Africa.²⁹ Culture, as well, may affect a person's decision to become a donor or donate the organs of their loved ones as it contributes to the 'perception of illness, response to treatment, and the organisation of medical care'.³⁰ The importance of religion and culture in South Africa is underscored by the fact that the rights to practise culture and religion are entrenched in the Constitution.³¹ For these reasons it is clear that religious and cultural factors need to be considered in devising a rights-based approach toward organ donation and transplantation.

Although the thesis concluded that most religions are in support of donation, there is still an enormous shortage of organs available for transplantation worldwide.³² It was further concluded that the underlying issue may be a lack of clarity with regard to how the religious scriptures and cultural beliefs, which were in existence long before donation, would perceive donation and transplantation. There often are conflicting interpretations of these scriptures and beliefs, and this may shed some light on the lack of clarity that exists in religious and cultural attitudes toward this medical procedure.

In light of the above, the study analysed specific religious and cultural beliefs, focusing on those most prevalent in South Africa in an attempt to gain clarity on the reasons for these ambivalent attitudes towards organ donation and transplantation. The study considered the possibility of implementing a presumed consent system of donation in line with the results of this examination.³³

²⁹ As discussed in chap 3.

³⁰ As above.

³¹ Secs 9(1) and 9(4) Constitution of the Republic of South Africa, 1996. The grounds include one's 'race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth'.

³² As discussed in chap 3.

³³ As discussed in chap 3.

6.4.1. Organ donation and Christianity

The Christian faith's most frequently-raised objection to organ donation and transplantation is found with regard to the belief in the resurrection upon the Rapture. The Rapture is the belief that when the time comes, the living and the dead are taken from the earth and will rise to heaven.³⁴ A literal interpretation is that one's body needs to be intact when this event occurs, ie, without any organs missing.³⁵ However, a reluctance to donate organs is contradictory to the altruistic nature of Christianity. Despite the numerous disparities among the different denominations of Christianity, the underlying message of salvation remains the same: 'God loved the world so much that He sent his only son, Jesus Christ, that whoever believes in Him should not perish but have life'.³⁶ His sacrifice is seen as the ultimate act of altruism; it can be stated that the Christian faith is based on altruism which, surely, supports organ donation. It has also been shown that the Pope has no objection to donation and in fact supports it.

Therefore, the objections of adherents to the Christian faith to donation and transplantation are misconceived and misguided. Therefore, adherents to Christianity who use their religion as a reason to object to donation and transplantation are misguided.

6.4.2. Organ donation and Islam

In the Islamic faith, the human body, whether living or dead, is viewed as sacred and a violation of it is prohibited.³⁷ This however conflicts with the principle of saving a life. It was shown above that a principle which may reconcile this dilemma is *al-darurat tubih al-mahzurat*. This translates as 'necessity overrides prohibition' and the concept has been used previously to commend the use of pork insulin and porcine bone grafts.³⁸ Another principle cited in favour of organ procurement is 'the choice of the lesser of two evils'.³⁹ These principles may be seen as a way to condone donation and transplantation in the

³⁴ As discussed in chap 3.

³⁵ As above.

³⁶ John 3:16; as discussed in chap 3.

³⁷ As above.

³⁸ As above.

³⁹ As above.

Islamic faith. Further, as discussed in chapter 3, several Islamic rulings have been made which are interpreted to be in favour of donation.⁴⁰

Muslim custom surrounding death was investigated in this study in order to uncover objections to organ donation and transplantation. It was determined that where medical personnel are not aware of these rituals, their actions may be viewed as disrespectful of the deceased and this, too, could be a hindrance to donation. Therefore, it is imperative that hospital staff be educated about the different religious beliefs in order to prevent this from happening. Nevertheless, generally speaking Islam still is in favour of donation as highlighted above.

Medical personnel and the transplant team, therefore, should be well-versed in these religious rituals so as not to offend the deceased's family, and these rituals should also be taken into consideration in the devising of new legislation dealing with donation and transplantation.

6.4.3. Organ donation and Judaism

It is believed in Judaism that God has ownership of everything; including our bodies which God has loaned to us.⁴¹ Since God owns our bodies, God has the final say in how they are to be governed and this restricts their use to the rules provided in Jewish law.⁴² In chapter 3 of the thesis it was determined that, in terms of Jewish law, we not only have a duty to preserve our own lives, but we also have an obligation to assist others in evading illness, death and injury.⁴³ Sickness, then, is seen by the faith as one of the 'divine punishments for disobedience' and medicine is 'an improper human intervention in God's decision to cause illness or cure it'.⁴⁴ Nevertheless, Rabbis believe that physicians have been granted overt permission from God to cure the sick as supported by two books in

⁴⁰ As above.

⁴¹ As discussed in chap 3.

⁴² As above.

⁴³ As above.

⁴⁴ EN Dorff *Matters of life and death* (2003) as discussed in chap 3.

the Bible: Exodus 21: 19 -20 and Deuteronomy 22:2 ('[a]nd you shall restore the lost property to Him').⁴⁵

The importance placed on the role of physicians in the Jewish community was discussed in chapter 3.⁴⁶ Dorff's view that our duty to God to preserve our bodies can be achieved only where a physician is available was highlighted.⁴⁷ It was further established that Judaism supports donation and transplantation. Cadaveric donation is also a source of objections to transplantation and donation in the Jewish faith. This is due to restrictions in Judaism placed on death. The obligation to assist those in need (*pikuach nefesh*) is used, however, as a principle to override these prohibitions.⁴⁸ The book of Leviticus is cited as a basis for an affirmative duty placed on individuals to intervene directly in an effort to save a person's life, using one's own resources.⁴⁹

It was determined in chapter 3 that there is no religious law or prohibition in Judaism against organ donation. Organ donation is in keeping with the principle of *kavod ha-met* (the dead must be honoured) as, since the principle of *pikuah nefesh* overrides the prohibition against the desecration of a corpse, the use of a cadaver to save a life would in fact be honouring the dead.⁵⁰ This also implies that a deviation from certain customs, such as burying the body after 24 hours, is allowed.⁵¹ Furthermore, in its Committee on Jewish Law and Standards, the Orthodox Movement confirmed that owing to the shortage of organs, failing to arrange for the donation of organs after death should be viewed as a violation of the commandment 'Do not stand idly by the blood of your neighbour',⁵² because it should be seen as a failure to rescue those in need of a transplant.⁵³

⁴⁵ As above.

⁴⁶ Chap 3 discussed the prohibition placed by the Talmud on Jews living in communities where there is no physician available.

⁴⁷ Dorff (n 56 above) as discussed in chap 3.

⁴⁸ R Khalaila 'Religion, altruism, knowledge and attitudes toward organ donation: a survey among a sample of Israeli college students' (2013) 32 *Medicine and Law* 116 as discussed in chap 3.

⁴⁹ S Resnicoff 'Supplying human body parts: A Jewish Law perspective' (2006) 55 *De Paul Law Review* 853, as discussed in chap 3. Leviticus 19:16 states: 'Do not stand idly by your fellow's blood'.

⁵⁰ As discussed in chap 3.

⁵¹ As above.

⁵² Dorff (n 56 above) 227 to 228.

⁵³ Dorff (n 56 above) at 227.

6.4.4. Organ donation and Hinduism

With regard to cadaveric donation, beliefs surrounding death are obstacles to organ donation. It was shown how this is due to the belief in the *Atman* (soul).⁵⁴ Nevertheless, donating one's eyes and body parts still is considered a virtuous act according to Hinduism. Certain scholars are of the opinion that there indeed is no objection to donation in Hinduism, as long as cosmetic considerations are considered, taking into account the fact that the viewing of the deceased's face is of great importance.⁵⁵

6.4.5. Organ donation and Buddhism

The main objection against organ donation from the Buddhist religion relates to the doctrine of reincarnation and the lack of clarity regarding the existence of personhood.⁵⁶ The debate centres around the 'no-self' doctrine, according to which some Buddhists believe that there is no 'self' *per se*.⁵⁷ This raises the question as to what exactly reincarnates should this be the case.⁵⁸

In the context of the present discussion, the doctrine of reincarnation shapes Buddhist practices and beliefs surrounding dying and abortion.⁵⁹ According to this belief, the interruption of the transmigration of the being which is reincarnating, for example through cadaveric organ transplantation or abortion, may have negative karmic implications.⁶⁰ A further problem would be the ideal that, even after death, once a person stops breathing, the spiritual consciousness stays in the body for a few days.⁶¹

Nevertheless, Buddhist principles such as selfless giving and generosity support organ donation.⁶² Despite the arguments of some of the adherents of Buddhism against organ

⁵⁴ See chap 3.

⁵⁵ As above.

⁵⁶ As discussed in chap 3.

⁵⁷ As above.

⁵⁸ As above.

⁵⁹ As above.

⁶⁰ As above.

⁶¹ As above.

⁶² As above.

donation, it in fact is in keeping with the central principle of generosity, and the adaptation of Buddhism to different medical practices further support donation.⁶³

6.4.6. Organ donation and African cultural beliefs

One of the most important concepts to consider when looking at African culture is that of *Ubuntu* (a Nguni maxim which in full is given as *umuntu ngumuntu ngabantu*).⁶⁴ This phrase refers to beneficence in an African cultural context, in that it is believed a person exists through other people. This sense of a communal utilitarianism may be a positive platform from which to argue for a system of organ donation as it can be said to be in line with the concept of *ubuntu*. It may further be argued that *ubuntu* corresponds to the ethical principle of beneficence - to act for the benefit of others. The idea behind this is that the community makes the person, or that personhood only is fully gained through the community.⁶⁵

The role of traditional medicine and healing, similarly, are relevant to this discussion. This is because traditional cultural healthcare practices may deter a person from becoming an organ donor: where Western medicine focuses on chemical, surgical and/or medical interventions, traditional healing places the emphasis not only on the biological and mental malfunctions, but also on the social dysfunction of the patient.⁶⁶ It was argued in chapter 3 that at the very least, in order to harmonise these differences, an opportunity should be afforded for traditional healers and medical doctors to work side-by-side in order to encourage a more positive outlook with regard to donation.⁶⁷ Botha writes that this may be achieved through a regulatory framework 'that ensures the efficacy, safety and quality of traditional health care services' so that they 'can provide a means to allow the Sangoma and the [medical doctor] to work together as partners, without suspicion'.⁶⁸

⁶³ As above.

⁶⁴ As above.

⁶⁵ As above.

⁶⁶ As above.

⁶⁷ As above.

⁶⁸ C Botha 'The sangoma and the MD: The clash of western medical science and traditional medicine in South Africa' (2004) 5(2) *Phronimon* 46.

A move in this direction is included in the Traditional Health Practitioners Act (the THP Act).⁶⁹ Although not fully in force, the Act was formulated with the purpose of regulating the traditional health services sector in South Africa. Integrating traditional healers into the medical practice, or at the very least collaborating with them, may also assist in their education about organ transplantation and donation, which knowledge may be shared with their patients. Educating medical personnel on cultural and traditional beliefs and practises may similarly assist in alleviating the bias and create a rapport between the two systems.

6.4.7. Moment of death in religion and culture

The NHA defines death as 'brain death' in section 1, which is a definition most commonly accepted worldwide. As has been determined, the Catholic faith does not appear to object to this brain-oriented definition of death.⁷⁰ Similarly, in Islam it is left to those in the medical profession to determine signs of death, and Shariah law accepts a brain-oriented definition of death for transplantation purposes.⁷¹

Definitions of death are controversial in Judaism; some scholars focus on an irreversible cessation of the cardiac and respiratory functions; others believe death occurs only once a person is brain-dead.⁷² Khalaila proposes a third approach which may reconcile the two opposite approaches and allow for a brain-related definition of death. Khalaila states that, should the breathing function located in the brain stem no longer be operating so that a person can no longer breathe unaided, this is the ultimate determination of death.⁷³

Hinduism accepts the notion of brain-death as discussed in chapter 3, and Buddhism, although the issue is controversial, may as well. There is no formal determination of death in African culture, and one may suggest the inclusion of traditional healers in the diagnosis of death in order to prevent doubt about the concept of brain-stem death.⁷⁴

⁶⁹ Act 22 of 2007.

⁷⁰ See chap 4.

⁷¹ As above.

⁷² As above.

⁷³ R Khalaila (n 61 above) 117.

⁷⁴ BR Bhengu 'Organ donation and transplantation within the Zulu culture' (2004) 27 *Curationis* 30.

6.4.8. Incorporation of a presumed consent model for donation

It was conclusively determined in the thesis that there is no objection to organ donation and/or transplantation and a brain-oriented definition for death among the leading religions in South Africa and African among culture. The thesis further examined whether a presumed consent model for organ procurement could be reconciled with the different religions and cultures that were studied. The thesis found that such a system would be feasible if the general public is educated thoroughly about donation.⁷⁵ The thesis further found that a mandated choice system for organ procurement would be a realistic stepping stone towards implementing a presumed consent model in the future once the public has been properly educated on the procedures and terms involved with cadaveric donation.⁷⁶

6.5. A human rights-based approach to organ donation and/or transplantation

Having investigated the misconceptions about donation and transplantation that adherents of the different religions and cultures hold, and having established the ethical appropriateness of organ donation, the thesis proposed the implementation of a human rights-based approach (HRBA) to organ donation. The aim was to formulate a system which would not only respect and protect the inherent human rights of those involved in the procedure, but also implement a mandated choice system for donation to increase the donor pool. HRBAs are designed to assist policy-makers in effectively targeting inequalities in different areas where they are the result of social, cultural and/or economic aspects, and prioritising those with the greatest need.⁷⁷ The study focused on individuals suffering from organ failure.

Amartya Sen's capability approach (CA) to poverty reduction was employed and adapted to suit the needs of those suffering from organ failure. A fundamental aspect of the CA is an investigation into the 'well-ness' of a person, or the quality of his living or being.⁷⁸ Sen's model defines this as being a set of interrelated functionings which determine a person's

⁷⁵ See R Li 'Should the rest of the UK follow the lead of Wales and introduce an opt-out system of organ donation?' (2015) 2 *Edinburgh Student Law Review* 69 and BR Bhengu (n 110 above) 27.

⁷⁶ As discussed in chap 3.

⁷⁷ As discussed in chap 4.

⁷⁸ As above.

well-being.⁷⁹ A person's capability would thus be a person's opportunity or freedom to achieve well-being in that sense.⁸⁰ Applying this model to donation implies that individuals who suffer from organ failure and who are unable to receive an organ for transplantation purposes, or who are not in a position to access the necessary facilities for their treatment, would be viewed as having low levels of capabilities.⁸¹ Such individuals lack basic freedom or opportunity to be free from the health symptoms associated with organ failure.⁸² Basic freedoms, therefore, must be present to attain a minimal level of human dignity.⁸³ The CA is reinforced by a HRBA which grants every person inalienable rights to these freedoms.⁸⁴ Inadequate basic freedoms or a denial of certain basic freedoms, therefore, would amount to the non-realisation of the rights to these freedoms.⁸⁵ This ultimately would be a violation of a number of human rights.

One may argue further that, should this be the case, the individual is not given the opportunity to enjoy aspects of their religion in conflict with section 31(1) of the Constitution which guarantees this right. This conclusion was reached in the thesis because, in terms of most religions, the body is seen as a sacred gift from God.⁸⁶ The Islamic faith, for instance, sees the body as sacred and entrusted to man's care.⁸⁷ This implies that humans need to care for it in order to comply with religious precepts. If not afforded this capability, the individual is prevented from enjoying and practicing their religion.

The essential idea behind a HRBA to organ donation is the elevation of basic freedoms to the status of enforceable rights. In the context of organ failure, therefore, a person should be afforded the opportunity, at the very least, to be able to avail himself a chance to pursue transplantation as an option to improve their quality of life. This is regardless of

⁷⁹ As above.

⁸⁰ As above.

⁸¹ As above.

⁸² As above.

⁸³ As above.

⁸⁴ As above.

⁸⁵ As above.

⁸⁶ See chap 3 above.

⁸⁷ As above.

whether they choose this option or not, and also regardless of their financial or other status.⁸⁸

The human rights norms relevant to this study and which were discussed in detail in chapter 4 are the rights to privacy, life, human dignity, health and access to healthcare services.⁸⁹ It was established that the human rights to human dignity and the concept of *ubuntu* are interrelated as held by the court in *S v Makwanyane*.⁹⁰ These concepts were analysed in relation to members of society who need to help one another to survive; not only individually, but also as a group. This is essential for organ donation and transplantation, as donating one's organs or the organs of a loved one contributes to the furtherance of the community's health-related needs and constitutes an act of humaneness.⁹¹

The right to life not only is a fundamental human right⁹² but it reflects the value placed on life in most religions. Christianity and Judaism, for instance, attach great importance to saving a life (as Christ was sent to sacrifice his life for the lives of mankind).⁹³ A similar emphasis on the importance of life exists in African culture, as was shown in chapter 4 of the thesis.

The right to an adequate standard of living was discussed in the thesis because of its relation to the right to life; after all, improving the quality of a patient's life is the main goal of transplantation. Indeed, a person suffering from organ failure experiences symptoms which may make life 'not worth living'.⁹⁴ This right connects with the rights to health and dignity because a person with deteriorating health is prevented from enjoying life to the full. The right to health encompasses the health and well-being of human beings whereas the right of access to healthcare services relates to obligations on the state to provide

⁸⁸ See chap 4.

⁸⁹ As above.

⁹⁰ As above.

⁹¹ As discussed in chap 4.

⁹² As above.

⁹³ As above.

⁹⁴ A person suffering from kidney failure experiences both physical and psychological symptoms, for example, in addition to a loss of income from being on dialysis up to four times a week.

these services to all, including the most vulnerable groups in society.⁹⁵ Individuals suffering from organ failure constitute such a group. The guiding principles of the World Health Organisation (WHO) likewise emphasise the importance of protecting the health of organ donors ‘during the process of selection, donation, and necessary aftercare to ensure that the potential untoward consequences of the donation are unlikely to disadvantage the remainder of the donor’s life’.⁹⁶

The right to bodily integrity, as elaborated in section 12(2)(b) of the Constitution, was canvassed in chapter 4 in relation to organ donation. The right applies to both donor and recipient of organs. It was stressed that both the recipient and donor of organs must provide their free and informed consent to organ donation and transplantation.⁹⁷

The study further suggests that misconceptions regarding donation in culture and religion may obstruct a person’s ability to give informed consent to donation. As it was confirmed that no cultural or religious objections to donation exist, those labouring under the misapprehension that there are such objections and who then base their decisions on this misunderstanding, have not given full and free consent.⁹⁸

The thesis further established that the right to privacy requires that both the donor and recipient of an organ remain anonymous.⁹⁹ However, privacy must allow for clinical results to be transparent and open to scrutiny, as expounded on by the WHO guidelines.¹⁰⁰ The reason for this is to allow public access to data dealing with ‘allocation, transplant activities and outcomes for both recipients and living donors’ in addition to the funding, budget and data on the organisation.¹⁰¹ The right to privacy has also been linked with the right to individual autonomy as discussed briefly in chapter 4.

⁹⁵ As discussed in chap 4.

⁹⁶ As above.

⁹⁷ As above.

⁹⁸ As above.

⁹⁹ The regulations regarding the general control of human bodies, tissue, blood, blood products and gametes, No 35099, 2012 also provide in cl 24 for the anonymity of the donor and recipient as discussed above in chap 2.

¹⁰⁰ As above.

¹⁰¹ Commentary on Guiding Principle 11 – ‘WHO Guiding Principles on human cells, tissue and organ transplantation’, 2010; 8.

The right to equality protects the right of organ donors and recipients not to be discriminated against on any grounds listed in the Constitution.¹⁰² The study linked this right to the bioethical principle of justice as it entails a degree of fairness and equality.¹⁰³ This is particularly necessary when looking at the distribution of organs; the allocation system in place needs to be equitable and fair, and consider all groups in society regardless of social or other status.

The study deliberated upon the main features of a HRBA to organ donation and transplantation. A CA advocates the empowerment of vulnerable groups and, in order to enhance the capabilities of that vulnerable group, they need to participate in policy-making, particularly when dealing with organ donation.¹⁰⁴ This entails the involvement of leaders from the different religious and cultural sectors, as well as the integration or inclusion of traditional healers.

A fundamental aspect of a HRBA is that ‘every human being is a rights-holder and that every human right has a corresponding duty’.¹⁰⁵ A rights-holder is entitled to claim these rights from a duty-bearer who should be able to be held accountable.¹⁰⁶ The overall responsibility rests on the state, and that includes ‘all organs of State such as parliaments, ministries, local authorities, judges and justice authorities, police, teachers or extension workers’.¹⁰⁷

The investigation showed that, in relation to donation and transplantation, there are a number of human rights which potentially may be violated if the system in place is not adequate. In order to be accountable, in a HRBA rights-holders (those suffering from organ failure) and duty-bearers (not only the state but also every individual involved in the procurement and allocation process, such as, *inter alia*, healthcare practitioners and

¹⁰² The equality clause in sec 9 of the Constitution lists these grounds as being – ‘race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth’.

¹⁰³ As discussed in chap 4.

¹⁰⁴ As above.

¹⁰⁵ As above.

¹⁰⁶ As above.

¹⁰⁷ As above.

transplant coordinators)¹⁰⁸ must all work towards the realisation of the human rights of those in need of organs.

Nevertheless, this realisation of rights is not expected to happen immediately. International agreements, such as the International Covenant on Economic, Social and Cultural rights, obligate states parties to take steps towards achieving the full realisation of the rights contained therein, 'to the maximum of its available resources'.¹⁰⁹ The availability of resources, therefore, places a limitation on the realisation of rights.

However, a study in chapter 4 of case law dealing with the realisation of rights in instances where resources are limited, confirmed that the progressive realisation of rights still requires the state to take steps to resolve problems of inadequate resources.¹¹⁰ An example in the context of organ donation is the design and implementation of a new system designed to increase the number of donors (as the scarce resources in this scenario are available organs for transplantation). In this regard, a system of mandated choice could be introduced, incorporated into a HRBA to organ donation.

6.6.A system of mandated choice in a HRBA

A system of mandated choice requires competent adults to make a decision prior to their death as to whether they would like to be organ donors upon their death. In such a case there is no provision for acquiescence, and individuals may also indicate whether they would like a relative or next of kin to have the final say.¹¹¹ The idea behind this is to remove the *veto* power of the next of kin regardless of what decision had been made. Policy-makers should determine how this choice is to be registered. It could be made a requirement for tax claims or returns to be processed, or the renewal of drivers' licenses, and so on. This system would, however, need to be adapted to reach people in all communities and, thus, enhance the HRBA features of participation and inclusion.¹¹²

¹⁰⁸ As above.

¹⁰⁹ Art 2(1) ICESCR.

¹¹⁰ *Soobramoney v Minister of Health (Kwazulu – Natal)* 1998 1 SA 765 at para 43.

¹¹¹ As discussed in chap 4.

¹¹² As above.

However, as discussed in chapter 4, the main problems with such a system would be with regard to its logistics, the maintenance of records, the modification of medical systems, and also that it could lead to an undermining of personal autonomy. Regarding arguments that individual autonomy may be undermined in a mandated choice-system, it was concluded that such a system for organ donation would actually protect individual autonomy as everyone would be given the opportunity to make a decision which could be changed at any point before their death.¹¹³ Such a system would also relieve families of the burden of making decisions regarding organ donation at such a sad and sensitive time.

With regard to the logistics of the mandated choice system and other objections, it was established that systems which are already in place may be utilised; for instance licence registries and tax structures.¹¹⁴ No system is perfect, but the argument is that a mandated choice system, incorporated into a HRBA, should be seen as a positive step towards increasing donation whilst enhancing the rights of the individuals involved.

6.7. Comparative analysis of donation systems

Early on in the thesis it was established that the system currently in place in South Africa is ineffective in increasing the donor pool. In an attempt to find ways of improving or changing the current system the thesis undertook a comparative analysis of systems in place in other countries. The organ donation and transplantation systems (specifically the systems for procurement and allocation) in place in Spain, Singapore, Malaysia and the United States of America (the USA) were examined in chapter 5 of the thesis. From this comparative analysis it was concluded that the regulations and legislation currently in place in South Africa are inadequate as they do not sufficiently provide measures which may assist the donation process, such as the introduction of committees devised specifically to deal with the donation process.¹¹⁵

¹¹³ As above.

¹¹⁴ As above.

¹¹⁵ As above.

From the comparative analysis in chapter 5 it was concluded that legislation adopted solely for donation and transplantation purposes has more often than not had a positive effect on the donor pool.¹¹⁶ As well, it was concluded that discussions surrounding the drafting of new policies for donation and transplantation should include representatives from the main religions in South Africa, as well as cultural leaders as discussed above. This would not only help to spread awareness regarding organ donation and transplantation, but would also promote the education of individuals about donation and transplantation. This would further enhance the participation and empowerment elements of a HRBA to donation. This element could be further boosted through the creation of a national organisation aimed at providing support for regional and local hospitals regarding donation and transplantation, as is the system in place in Spain.¹¹⁷

From the comparative analysis in chapter 5 we further learnt that the involvement of the media could assist greatly in the education of the general public on matters relating to donation. This could be a simple yet effective means of increasing the donor pool.¹¹⁸

The introduction of committees and councils dedicated to matters related to organ donation and transplantation is a further necessary step in a positive direction. In chapter 5 we saw that Malaysia, for instance, has a council which recommends policies and training activities regarding donation and transplantation to another committee which has the power to implement these suggestions.¹¹⁹ This could be an effective addition to a new system.¹²⁰

With regard to the allocation of organs, it is important that the procedures in place be both ethically and clinically sound, as emphasised by the WHO.¹²¹ It is necessary to find a balance between clinical and ethical criteria for organ donation whilst showing sensitivity to individual human rights. In South Africa this standard is not upheld as is seen in the limitations placed on access to dialysis in the state sector, as opposed to the more

¹¹⁶ As above.

¹¹⁷ As above.

¹¹⁸ As above.

¹¹⁹ As above.

¹²⁰ As above.

¹²¹ As above.

structured private sector allocation procedure.¹²² This discrepancy alone reveals a measure of inequality in the system currently in place in South Africa. The procedure to determine which organ is to go the private or public sector is also unregulated which means that there is no way of ensuring accountability.¹²³

Essential in developing a more efficient and fair allocation system would be the creation of a national registry, a proper waiting list and proper procedures. In this regard guidance may be derived from the system adopted in the USA, so that a national waiting list is implemented to bring about proper structure to the organ allocation system. The introduction of an electronic system should be considered in order to curb human error and/or bias.

Important also would be the introduction of a system of reciprocity to further inculcate the values of a HRBA as discussed in chapter 5. This would discourage so-called 'free riders' and promote fairness, ultimately supporting the ethical principle of justice.

6.8. The need for new legislation – national and international standards

It was established throughout the thesis that there is a need for the development and adoption of new legislation in South Africa dealing specifically with organ donation and transplantation. In South Africa as in many other countries, Parliament adopts new legislation when one of three things is present: 'there are gaps (*lacunae*) in the law; the law no longer corresponds to needs in modern society; and there are defects or loopholes in existing legislation'.¹²⁴ It is submitted that this study shows that all three of these are present. There are indeed gaps in the law dealing with organ donation which could greatly improve the donor pool such as, *inter alia*, the absence in the law of provision for committees and bodies which deal solely with donation and transplantation, a proper national waiting list, registry and procedure as discussed previously.¹²⁵ Furthermore,

¹²² As above.

¹²³ As above.

¹²⁴ D Kleyn & F Viljoen *Beginner's guide for law students* (2010) 42.

¹²⁵ Chap 5.

statistics reveal that the procurement system in place currently does not meet the needs of South African society as is seen in the dwindling number of donations.¹²⁶

A logical step would be the implementation of a new system, governed by legislation which deals specifically with organ donation and transplantation. This system should incorporate a human rights-based approach to organ donation and transplantation in order to bring about the realisation of the human rights of individuals suffering from organ failure. The structure of this system must meet human rights standards, including the rights to dignity, life, health and access to healthcare services, privacy, equality and non-discrimination as well as the right to bodily integrity as discussed previously.¹²⁷

6.8.1. The World Health Organisation – international inclusion

The WHO is a specialised organ of the United Nations the main objective of which is the ‘attainment by all peoples of the highest possible level of health’.¹²⁸ In order to achieve this objective, the WHO’s Constitution provides it with certain functions, such as establishing and maintaining collaboration with, *inter alia*, governmental health administrations and professional groups.¹²⁹ The WHO Constitution further provides an administrative and cooperative function whereby it ‘enjoins the Organisation to establish cooperative relations with other organisations, both inter- and non-governmental, international and national, which are concerned with any phase of WHO’s work’.¹³⁰

This could present an opportunity for South Africa to acquire assistance from the WHO to devise a new system for organ donation and transplantation that is in line with international health standards. This could be achieved in collaboration with various non-governmental organisations which deal with organ donation, such as the Organ Donor Foundation and others. The WHO does, indeed, have programmes relating to organ donation and transplantation, and the World Health Assembly released resolution

¹²⁶ See M Slabbert ‘The law as an obstacle in solid organ donations and transplantations’ (2018) 81 *THRHR* 70.

¹²⁷ Chap 4.

¹²⁸ Art 1 Constitution of the World Health Organisation- adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States (*Off. Rec. Wld Hlth Org.*, 2, 100), and entered into force on 7 April 1948.

¹²⁹ Art 2 WHO Constitution.

¹³⁰ D Fidler *International law and public law: materials on and analysis of global health jurisprudence* (2000) 92.

WHA63.22 which urges member states to adhere to the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation.¹³¹

6.9. Concluding remarks

Organ transplantation is a viable, if not necessary, treatment option for individuals suffering from organ failure. With the rising number of people in need of an organ for transplantation and the dwindling number of donors, numerous individuals suffer the symptoms of organ failure with no means of attaining an organ for transplantation. It is evident that the system currently in place in South Africa is ineffective at reconciling the supply and demand for organs in South Africa, and this leads to various human rights violations as has been shown in the thesis. This is a direct result of the shortcomings of the NHA and the regulations thereto.

The study revealed that religious and cultural misconceptions toward donation and transplantation further contribute to the shortage of organs available for transplantation. Adherents of the different religions and cultures in South Africa mistakenly believe that their religions and cultures prohibit or frown upon organ donation. A new system that is implemented should, therefore, not only protect the human rights of organ donors and recipients, but must assist in increasing the donor pool by dispelling religious and cultural misconceptions regarding organ donation. Such a system would need to consider and be sensitive to cultural and religious beliefs surrounding death. Educational programmes and public awareness campaigns will have to be launched to educate the public and so dispel the misconceptions they may hold in this regard.

In these circumstances it is predicted that the donor pool will increase as the public would be made aware not only of the process involved with donation, but also of a newly organised system geared toward respect for religious and cultural rights. Doubt surrounding donation will be cleared up. This favourable outcome will be brought about

¹³¹ WHA63.22, 21 May 2010. The relevant sections of the guiding principles were discussed in previous chapters.

by implementing a human rights-based approach to donation, which incorporates a system of mandated choice.

Bibliography

Books

- Ackermann, L (2012) *Human dignity: lodestar for equality in South Africa* Cape Town: Juta & Co.
- Asher, J (2010) *The right to health – a resource manual for NGOs* Leiden: Martinus Nijhoff.
- Beauchamp, T & Childress, J (1994) 4th Edition *Principles of biomedical ethics* Oxford: Oxford University Press.
- Beauchamp, T & Childress, J (2009) 6th Edition *Principles of biomedical ethics* New York: Oxford University Press.
- Boesen, JK & Martin, T (2007) *Applying a rights-based approach: an inspirational guide for civil society* Denmark: The Danish Institute for Human Rights.
- Carstens, P A & Pearmain, D (2007) *Foundational principles of South African medical law* Durban: LexisNexis.
- Cornell, D & Muvangua, N (eds) *Ubuntu and the law* New York: Fordham University Press.
- Currie, I & de Waal, J (2013) *The Bill of Rights handbook* Cape Town: Juta & Co.
- Devenish, GE (1998) *A commentary on the South African Constitution* Durban: Butterworth Publishers (Pty) Ltd.
- Dixon, M (2013) *Textbook on international law* Seventh edition. Oxford, United Kingdom: Oxford University Press.
- Dobrin, A (2002) *Religious ethics: a sourcebook* New York: Arthur Dobrin.
- Dorff, EN (2003) *Matters of life and death: a Jewish approach to modern medical ethics* Philadelphia: The Jewish Publication Society.
- Dworkin, G (1988) *The theory and practice of autonomy* United Kingdom: Cambridge University Press.
- Kleyn, D & Viljoen, F (2010) *Beginner's guide for law students* Cape Town: Juta & Co.
- Feinberg, J (1987) *Harm to others: The moral limits of criminal law* New York: Oxford University Press.

- Fidler, DP (2000) *International law and public law: material on and analysis of global health jurisprudence* New York: Transnational publishers Inc.
- Foster, C (2011) *Human dignity in bioethics and law* United Kingdom: Hart Publishing.
- Frankfurt, H (1999) *Necessity, volition and love* England: Cambridge University Press.
- Hart, HLA (1994) *The concept of law* New York: Oxford University Press.
- Hallaq, W (2009) *An Introduction to Islamic law* New York: Cambridge University Press.
- Helen, K & Geir, U (2012) *UN human rights treaty bodies: law and legitimacy* New York: Cambridge University Press.
- Hughes J 'Buddhist bioethics' in Ashcroft, RE, Dawson, A, Draper, H & McMillan, J (eds) (2007) *Principles of healthcare ethics* England: John Wiley & Sons Ltd.
- Kant, I, Wood, AW & Schneewind, JB (2002) *Groundwork of the metaphysics of morals* New Haven: Yale University Press.
- Mason, JK (2003) *Law and medical ethics* United Kingdom: Lexisnexis Uk.
- Oshana, M (2006) *Personal autonomy in society* England: Ashgate Publishing Limited.
- Pieterse, M (2014) *Can rights cure? The impact of human rights litigation on South Africa's health system* Pretoria: Pretoria University Law Press.
- Price, D (2000) *Legal and ethical aspects of organ transplantation* Cambridge: Cambridge University Press.
- Raz, J (1986) *The morality of freedom* New York: Oxford University Press.
- Rhona, KM (2003) *Textbook on international human rights* England: Oxford University Press.
- Schicktanz, S, Wiesemann, C & Wohlke, S (eds) (2010) *Teaching ethics in organ transplantation and tissue donation* Umschlaggestaltung: Jutta Pabst.
- Spielman, B (ed) (1997) *Organ and tissue donation: ethical, legal and policy issues* Carbondale: Southern Illinois University Press.
- Stoecklin, D & Bonvin, J (eds) (2015) *Children's rights and the capability approach: challenges and prospects* New York: Springer.
- Symonides, J (2002) *Human rights: concept and standards* England: Ashgate.

- Thornberry, P (2001) *International law and the rights of minorities* New York: Oxford University Press.
- Thornberry, P (1991) *International law and the rights of minorities* New York: Oxford University Press.
- Veatch, R (2000) *Transplantation ethics* Washington, DC: Georgetown University Press.
- Viljoen, F (2007) *International human rights law in Africa* Great Britain: Oxford University Press.
- Woolman, S (2013) *The selfless constitution: experimentalism and flourishing as foundations of South Africa's basic law* Cape Town: Juta & CO Ltd.

Chapters in books

- Hughes, J (2007) 'Buddhist bioethics' in Ashcroft, RE *et al* (eds) *Principles of healthcare ethics* England: John Wiley & Sons Ltd.
- Mokgoro, Y (2012) 'Ubuntu and the law' in Cornell, D & Muvangua, N (eds) *Ubuntu and the law* New York: Fordham University Press.

Journal articles

- Anand, P 'Capabilities and health' (2005) 31 *Journal of Medical Ethics* 299.
- Badrolhisam, N & Zakaria, Z 'Knowledge, religious beliefs and perception towards organ donation from death row prisoners from the perspective of patients and non-patients in Malaysia: a preliminary study' (2012) 2 *International Journal of Humanities and Social Science* 197.
- Baker, R 'Bioethics and human rights: a historical Perspective' (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 241.
- Bannister, P 'Regulating 'tradition' – South African *Izangoma* and the Traditional Health Practitioners Act 2004' (2008) 27(1) *Cambridge Journal of Anthropology* 25.

- Beauchamp, T 'The promise of the beneficence model for medical ethics' (1990) 6 *Journal of Contemporary Health Law and Policy* 145.
- Becker, A, de Wet, A & van Vollenhoven, W 'Human rights literacy: moving towards rights-based education and transformative action through understandings of dignity, equality and freedom' (2015) 35 *South African Journal of Education* 1.
- Becker, C 'Buddhist views of suicide and euthanasia' (1990) 40 *University of Hawaii Press* 543.
- Berger, K 'Informed consent: information or knowledge?' (2003) 22 *Medicine and Law* 743.
- Berges, S 'Why the capability approach is justified' (2007) 24 *Journal of Applied Philosophy* 16.
- Bhengu, BR 'Organ donation and transplantation within the Zulu culture' (2004) 27 *Curationis* 24.
- Blank, R 'End-of-life decision making across cultures' (2011) *Journal of Law, Medicine and Ethics* 201.
- Blondeau, D, Godin, G, Gagnea, C & Martineau, I 'Do ethical principles explain moral norm? A test for consent to organ donation.' (2007) 9 *Journal of Applied Biobehavioral Research* 230.
- Bogopa, D 'Health and ancestors: the case of South Africa and beyond' (2010) 10 *Indo-Pacific Journal of Phenomenology* 1.
- Bonnie, RJ, Wright, S & Dineen KK 'Legal authority to preserve organs in cases of uncontrolled cardiac death: preserving family choice' (2008) 36 *Journal of Law, Medicine and Ethics* 741.
- Borry, P, van Reusel, W, Roels, L & Schotsmans, P 'Donation after uncontrolled cardiac death (Udcd): a review of the debate from a European perspective' (2008) 36 *Journal of Law, Medicine and Ethics* 752.
- Botha, C 'The sangoma and the MD: the clash of western medical science and traditional medicine in South Africa' (2004) 5(2) *Phronimon* 39.
- Brindle, W 'Biblical evidence for the imminence of the Rapture' (2001) 158 *Bibliotheca Sacra* 75.

- Britz, R & le Roux-Kemp, A 'Voluntary informed consent and good clinical practice for clinical research in South Africa: ethical and legal perspectives' (2012) 12 *South African Medical Journal* 746.
- Budiani – Saberi, D & Columb, S 'A human rights approach to human trafficking for organ removal' (2013) 16 *Medicine, Healthcare and Philosophy* 897.
- Chenwi, L 'Unpacking 'progressive realisation', its relation to resources, minimum core and reasonableness, and some methodological considerations for assessing compliance' (2013) *De Jure* 742.
- Chin, J & AV Campbell 'Transplant tourism or international transplant medicine? A case for making the distinction' (2012) 12 *American Journal of Transplantation* 1700.
- Chin, JL, Kwok, THX 'Ethical challenges in the deceased organ donation programme: Asian perspectives' (2014) XI *Indian Journal of Medical Ethics* 139.
- Choi, E *et al* 'Brain death revisited: the case for a national standard' (2008) 36 *Journal of Law, Medicine and Ethics* 824.
- Chouhan, P and Draper, H 'Modified mandated choice for organ procurement' (2003) 29 *Journal of Medical Ethics* 157.
- Coertzen, P 'Constitution, charter and religions in South Africa' (2014) 14 *African Human Rights Law Journal* 126.
- Cotter, H 'Increasing consent for organ donation: mandated choice, individual autonomy, and informed consent' (2011) 21 *Health Matrix* 599.
- Curtice, M & Exworthy, T 'FREDA: a human rights-based approach to healthcare' (2010) 34 *The Psychiatrist* 1.
- Daar, AS & P Marshall 'Culture and psychology in organ transplantation' (1998) 19 *World Health Forum* 125.
- Darwall, S 'The value of autonomy and autonomy of the will' (2006) 116 *Ethics* 263.
- Dhali, A 'An introduction to informed consent: ethico-legal requirements' (2008) 63 *SADJ* 18.
- Dukeminier, J & Sanders, D 'Organ transplantation: a proposal for routine salvaging of cadaver organs' (1968) 279 *New England Journal of Medicine* 413.
- Dunphy, JE 'The story of organ transplantation' (1969) 21 *The Hastings Law Journal* 67.

- Dupre, C 'Unlocking human dignity: towards a theory for the 21st Century' (2009) 2 *European Human Rights Law Review* 190.
- Dworkin, G 'Paternalism' (1972) 56 *The Monist* 64.
- Dworkin, G 'The nature of autonomy' (2015) *Nordic Journal of Studies in Educational Policy* 7.
- Ekstrom, LW 'Alienation, autonomy and the self' (2005) 29 *Midwest Studies in Philosophy* 45.
- Escobar, M, Cubillos, L & Iunes, R 'Looking for evidence of the impact of introducing a Human Rights-Based approach in health: the SaluDerecho experience' (2015) 17 *Health and Human Rights Journal* 58.
- Essex, K 'The Rapture and the book of Revelation' (2002) 13 *The Master's Seminary Journal* 219.
- Fitzgibbons, S 'Cadaveric organ donation and consent: a comparative analysis of the United States, Japan, Singapore, and China' (2000) 6:73 *International Law Students Association Journal of International and Comparative Law* 73.
- Fordham, H 'Coerced donation of body tissues: can we live with *McFall v Shimp*?' (1979) 40 *Ohio State Journal* 409.
- French, R 'What is Buddhist Law? Opening Ideas' (2015) 63 *Buffalo Law Review* 833.
- French, R 'On Buddhism and Natural Law' (2014) 8 *Journal of Comparative Law* 153.
- Gatrad, AR 'Muslims customs surrounding death, bereavement, postmortem examinations and organ transplants' (1994) 309 *British Medical Journal* 521.
- Gill, M 'Presumed consent, autonomy, and organ donation' (2004) 29 *Journal of Medicine and Philosophy* 37.
- Gillon, R '*Primum non nocere*' and the principle of nonmaleficence' (1985) 291 *British Medical Journal* 130.
- Gruskin, S, Bogecho, D & Ferguson, L 'Rights-based approaches' to health policies and programs: articulations, ambiguities, and assessment' (2010) 31 *Journal of Public Health Policy* 129.
- Glannon, W 'Free riding and organ donation' (2009) 35 (10) *Journal of Medical Ethics* 590.

- Gutmann, T & Land, W 'Ethics regarding living-donor organ transplantation' (1999) 384 *Langbeck's Archives of Surgery* 515.
- Haeck, M, Hoogslag, GE, Rodrigo, SF, Atsma, DE, Klautz, RJ, van der Wall, EE, Schali, AJ & Verwey, HF 'Treatment options in end-stage heart failure: where to go from here?' (2012) 20 *Netherlands Heart Journal* 167.
- Heyns, C & Kaguongo, W 'Constitutional human rights law in Africa' (2006) 22 *South African Journal of Human Rights* 673.
- Himonga, C 'The right to health in an African cultural context: the role of *Ubuntu* in the realisation of the right to health with specific reference to South Africa' (2013) 57, 2 *Journal of African Law* 165.
- Hoffenberg, R 'Christiaan Barnard: his first transplants and their impact on concepts of death' (2001) 323 *British Medical Journal* 1478.
- Howard, RJ 'We have an obligation to provide organs for transplantation after we die' (2006) 6 *American Journal of Transplantation* 1786.
- Hunt, P, Yamin, AE & Bustreo, F 'Making the case: what is the evidence of impact of applying human rights-based approaches to health?' (2015) 1.
- Irving, M, Tong, A, Jan, S, Cass, A, Rose, J, Chadban, S, Allen, RD, Craig, JC, Wong, G & Howard, K 'Factors that influence the decision to be an organ donor: a systematic review of the qualitative research' (2012) 27 *Nephrology Dialysis Transplantation* 2526.
- Kapoor, C 'The removal of organs from cadavers: a utilitarian perspective' (1994) *Jurisprudence Review* 104.
- Kassim, PNJ 'Organ transplantation in Malaysia: a need for a comprehensive legal regime' (2005) 24 *Medicine and Law* 173.
- Kelly, E 'International organ trafficking crisis: solutions addressing the heart of the matter' (2013) 54 *Boston College International & Comparative Law Review* 1317.
- Keown, D 'Buddhism, brain death, and organ transplantation' (2010) 17 *Journal of Buddhist Ethics* 1.
- Kerridge, IH, Saul, P, Lowe, M, McPhee, J & Williams, D 'Death, dying and donation: organ transplantation and the diagnosis of death' (2002) 28 *Journal of Medical Ethics* 89.

- Khalaila, R 'Religion, altruism, knowledge and attitudes toward organ donation: a survey among a sample of Israeli college students' (2013) 32 *Medicine and Law* 115.
- Khalil, K 'A sight of relief: invalidating cadaveric corneal donation laws via the free exercise clause' (2003) 6 *DePaul Journal of Health Care Law* 159.
- Kirby, N 'Access to healthcare services as a human right' (2010) 29 *Medicine and Law* 487.
- Komrad, M 'A defence of medical paternalism: maximizing patients' autonomy' (1983) 9 *Journal of Medical Ethics* 38.
- Kurosu, M 'Ethical issues of presumed consent in the use of patient materials for medical research and the organ donation for transplantation' (2008) 3 *Journal of Philosophy and Ethics in Health Care and Medicine* 64.
- Kwek, T, Lew, TW, Tan, HL & Kong, S 'The transplantable organ shortage in Singapore – has implementation of presumed consent to organ donation made a difference?' (2009) 38 *Annals Academy of Medicine* 346.
- Lee, M 'The problem of 'thick in status, thin in content' in Beauchamp and Childress' principlism' (2010) 36 *Journal of Medical Ethics* 525.
- Li, R 'Should the rest of the UK follow the lead of Wales and introduce an opt-out system of organ donation?' (2015) 2 *Edinburgh Student Law Review* 65.
- Lobas, M 'Living organ donations: how can society ethically increase the supply of organs' (2006) 30 *Seton Hall Legislative Journal* 475.
- Lombard, J 'The definition of death' (2012) 63 *Hibernian Law Journal* 63.
- London, L 'What is a human rights-based approach to health and does it matter?' (2008) *Health and Human Rights Journal* 65.
- Lwin, MO, Williams, JD & Lan, LL 'Social Marketing Initiatives: National Kidney Foundation's Organ Donation Programs in Singapore' (2002) 21 (1) *Journal of Public Policy and Marketing* 66.
- Mannan, H 'Deaths as defined by Hinduism' (1996) 15 *Saint Louis University Public Law Review* 423.
- Matesanz, R 'A decade of continuous improvement in cadaveric organ donation: the Spanish model' (2001) 5 *Nefrologia* 59.

- Matesanz, R, Dominguez-Gil, B, Coll, E, de la Rosa, G, & Marazuela, R 'Spanish experience as a leading country: what kind of measures were taken?' (2011) 24 *Transplant International* 333.
- McKinstry, B 'Paternalism and the doctor-patient relationship in general practice' (1992) 42 *British Journal of General Practice* 340.
- McQuoid-Mason, D 'Human tissue and organ transplant provisions: chapter 8 of the National Health Act and its regulations, in effect from March 2012 – what doctors must know' (2012) 1012(9) *South African Medical Journal* 733.
- Miranda, B, Luca, MF, de Felipe, C, Gonzales-Posada, JM & Matesanz, R 'Organ donation in Spain' (1999) 14 *Nephrology Dialysis Transplantation: official publication of the European Dialysis and Transplant Association-European Dialysis and Transplantation Association-European Renal Association* 14.suppl_3 15.
- Mnyongani, F 'De-linking *ubuntu*: towards a unique South African Jurisprudence' (2010) 31 (1) *Obiter* 134.
- Muller, E 'Organ donation and transplantation in South Africa – an update' (2013) 31 *Continuing Medical Education Journal* 221.
- Murphy, C 'Distributive justice, modern significance' (1972) 17 *American Journal of Jurisprudence* 153.
- Naidoo, P 'Informed consent in South Africa' (2003) 41 *The South African Radiographer* 8.
- Naidoo, S 'Obtaining informed consent for surgery' (2014) 27 *Current Allergy & Clinical Immunology* 112.
- Nair-Collins, M 'Death, brain death, and the limits of science: why the whole-brain concept of death is a flawed public policy' *Journal of Law and Medical Ethics* (2010) 667.
- Narayanan, V 'Diglossic Hinduism: liberation and lentils' (2000) 68 *Journal of American Academy of Religion* 761.
- Neal, M 'Respect for human dignity as a 'substantive basic norm'' (2014) 10 *International Journal of Law in Context* 26.
- Oliver, M, Woywodt, A, Ahmed, A & Saif, I 'Organ donation, transplantation and religion' (2010) *Nephrology Dialysis Transplantation* 437.

- Oosthuizen, H & Verschoor, T 'Ethical principles becoming statutory requirements' (2008) 50 *South African Family Practice* 36.
- Pace, N 'Transplantation: ethical and legal considerations' (2006) 7 *Anaesthesia and Intensive Care Medicine* 185.
- Pathikonda, M & Munoz, S 'Acute liver failure' (2010) *Annals of Hepatology: Official Journal of the Mexican Association of Hepatology* 7.
- Pepper, M 'Partial relief from the regulatory vacuum involving human tissues through enactment of chapter 8 of the National Health Act and regulations thereto' (2012) 9 *South African Medical Journal* 736.
- Provost, J 'Canonical aspects of the treatment of the dead' (1999) 59 *The Jurist* 203.
- Quigley, M, Brazier, M, Chadwick, R, Michel, MN & Paredes, D *et al* 'The organ crisis and the Spanish model: theoretical versus pragmatic considerations' (2008) 34 (4) *Journal of Medical Ethics* 223.
- Randhawa, G 'Death and organ donation: meeting the needs of multiethnic and multifaith populations' (2012) 108 *British Journal of Anaesthesia* 108.
- Resnicoff, S 'Supplying human body parts: a Jewish Law perspective' (2006) 55 *De Paul Law Review* 851.
- Robertson, CT 'From free riders to fairness: a cooperative system for organ transplantation' (2007) 48 (1) *Jurimetrics* 1.
- Rodriguez, S 'No means no, but silence means yes? the policy and constitutionality of the recent state proposals for opt-out organ donation laws' (2011) 7 *Florida International University Law Review* 149.
- Roig, E, Perez-Villa, F, Cuppoletti, A, Castillo, M, Hernandez, N, Morales, M & Betriu, A 'Specialised care program for end-stage heart failure patients. Initial experience in a heart failure unit' (2006) 59 *Revista Espanola de Cardiologia* 109,
- Ross, E 'The intersection of cultural practices and ethics in a rights-based society' (2008) 51(3) *International Social Work* 384.
- Ross, L 'Solid organ donation between strangers' (2002) 30 *Journal of Law, Medicine & Ethics* 440.
- Rudra, A & Murty, OP 'Attitude to organ donation and autopsy in different religious denominations' (2014) 31 *Journal of Forensic Medicine & Toxicology* 47.

- Sanders, D & J Jr, Dukeminier 'Medical advance and legal lag: hemodialysis and kidney transplantation' (1967) *UCLA Law Review* 357.
- Sarma, D 'Hindu ethics' (2008) 36 *Journal of Law, Medicine and Ethics* 51.
- Saunders, B 'Opt-out organ donation without presumptions' (2012) 38 *Journal of Medical Ethics* 70.
- Schmidt, V & Lim, CH 'Organ transplantation in Singapore: history, problems and policies' (2004) 59 *Social Science and Medicine* 2173.
- Sen, A 'Human rights and capabilities' (2005) 6 *Journal of Human Development* 151.
- Shepherd, L, O'Carroll, RE & Ferauson, E 'An international comparison of deceased and living organ donation/transplant rates in opt – in and opt – out systems: a panel study' (2014) 12 *BMC Medicine* 131.
- Siemionow, M, Rampazzo, A & Gharb, BB 'Cultural differences in views on transplantation, including composite tissue allotransplantation' (2011) 66 *Annals of Plastic Surgery* 410.
- Silberhorn, T 'Germany's experience in supporting and implementing human rights-based approaches to health, plus challenges and successes in demonstrating impact on health outcomes' (2015) 17(2) *Health and Human Rights Journal* 21.
- Singer, P 'Famine, affluence and morality' (1972) 1 *Philosophy and Public Affairs* 229.
- Slabbert, M 'One heart, two patients: who gets a donor organ?' (2009) 20 *Stellenbosch Law Review* 124.
- Slabbert, M 'Ethics, justice and the sale of kidneys for transplantation purposes' (2010) 13 *Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad* 2.
- Slabbert, M 'The law as an obstacle in solid organ donations and transplantations' (2018) 21 *Tydskrif vir Hedendaagse Romeins-Hollandse Reg* 70.
- Slabbert, M & Venter, B 'Organ procurement in Israel' (2015) 8(2) *South African Journal of Bioethics and Law* 44.
- Slabbert, M, Mnyongani, F & Goolam, N 'Law, religion and organ transplants' (2011) 76 (2) *Koers* 261.
- Spellman, D 'Encouragement is not enough: the benefits of instituting a mandated choice organ procurement system' (2006) 56 *Syracuse Law Review* 353,

- Spital, A 'Donor benefit is the key to justified living organ donation' (2004) 13 *Cambridge Quarterly of Healthcare Ethics* 105.
- Steinbuch, R 'Kidneys, cash, and kashrut: a legal, economic and religious analysis of selling kidneys' (2009) 45 *Houston Law Review* 1529.
- Steinmann, AC 'The core meaning of human dignity' (2016) 19 *PER: Potchefstroomse Elektroniese Regsblad* 1.
- Taylor, JS 'Autonomy and organ sales, revisited' (2009) *Journal of Medicine and Philosophy* 632.
- Taylor, RS 'Kantian personal autonomy' (2005) 33 *Political Theory* 602.
- Thomas, R *et al* 'Assessing the impact of a human rights-based approach across a spectrum of change for women's, children's, and adolescents' health' (2015) 17 *Health and Human Rights Journal* 1.
- Thornton, R 'The transmission of knowledge in South African traditional healing' (2009) 71(1) *Africa: Journal of the International African Institute* 17.
- Troug, R 'The ethics of donation by living donors' (2005) 353 *New England Journal of Medicine* 444.
- Oliver, M *et al* 'Organ donation, transplantation and religion' (2010) 26 *Nephrology Dialysis Transplantation* 437.
- Udombana, N 'Life, dignity, and the pursuit of happiness: human rights and living standards in Africa' (2008) 27 *University of Tasmania Law Review* 47.
- Van der Bank, C 'The right to privacy – South African and comparative perspectives' (2012) 1 *European Journal of Business and Social Sciences* 77.
- Van Oosten, FFW 'The liability of doctors and hospitals for medical malpractice' (1991) 80 *South African Medical Journal* 23.
- Venter, B 'A selection of constitutional perspectives on human kidney sales' (2013) 16 *PER: Potchefstroomse Elektroniese Regsblad* 355.
- Walker, M 'Amartya Sen's capability approach and education' (2005) 13 *Journal of Educational Action Research* 103.
- Welbourn, H 'A principlist approach to presumed consent for organ donation' (2014) 9(1) *Clinical Ethics* 10.

- White, L 'The traffic in heads: bodies, borders and the articulation of regional histories' (1997) 23(2) *Journal of Southern African Studies* 325.
- Wicks, E 'The meaning of 'life': dignity and the right to life in international human rights treaties' (2012) 12 *Human Rights Law Review* 199.
- Williams, C 'Combating the problems of human rights abuses and inadequate organ supply through presumed donative consent' (1994) 26 *Case Western Reserve Journal of International Law* 315.
- Wong, LP 'Factors limiting deceased donation: focus groups' perspectives from culturally diverse community' (2010) 42 *Transplantation Proceedings* 1439.
- Yamani, AZ 'The eternal *Sharia*' (1980) 12 *New York University Journal of International Law and Politics* 205.
- Robson, NZ, Razack, AH & Dublin, N 'Organ transplants: ethical, social and religious issues in a multicultural society' (2010) 22 *Asia-Pacific Journal of Public Health* 271.

Theses and dissertations

- De Vries, L 'The ethics in genetics -the legitimacy and application of stem cell research' Unpublished LLM thesis, University of Pretoria, 2005.
- Fourie, EJ 'An analysis of the doctrine of presumed consent and the principles of required response and requires request in organ procurement' Unpublished LLM thesis, University of Pretoria, 2005.
- Labuschagne, B 'An analysis of organ transplantation in South Africa with specific reference to organ procurement' Unpublished LLM thesis, University of Pretoria, 2013.
- Pearmain, D 'A critical analysis of the law of health service delivery in South Africa' Unpublished LLD thesis, University of Pretoria 2004.
- Prinsen, L 'An analysis of the proposed regulatory framework for the procurement and distribution of stem cells' Unpublished LLM thesis, University of Pretoria, 2010.
- Swanepoel, M 'Embryonic stem cell research and cloning: a proposed legislative framework in context of legal status and personhood' Unpublished LLM thesis, University of Pretoria, 2006.

- Venter, B 'A selection of constitutional perspectives on human kidney sales' Unpublished LLM thesis, University of South Africa, 2012.

International instruments

- The Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin, ETS No. 186, 2002.
- The African Charter on Human and Peoples' Rights adopted 27 June 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58, 1982.
- The Constitution of the World Health Organisation adopted 19-22 June 1946; signed on 22 July 1946, entered into force on 7 April 1948.
- The International Covenant on Civil and Political Rights, United Nations Treaty Series, vol. 999, entered into force 23 March 1976, U.N. Doc A/6316.
- The International Covenant on Economic Social and Cultural Rights, United Nations Treaty Series, vol. 993, entered into force 3 January 1976, A/RES/2200A(XXI).
- The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the application of Biology and Medicine: Convention on Human Rights and Biomedicine, ETS No. 164, 1997.
- The Statute of the International Court of Justice, 18 April 1946.
- The Universal Declaration of Human Rights, 217 A (III), 10 December 1948, U.N Doc A/810.
- The Vienna Convention on the Law of Treaties, United Nations Treaty Series, vol. 1155, entered into force 27 January 1980.

Legislation

South African

- Children's Act 38 of 2005.

- Constitution of the Republic of South Africa, 1996.
- Mental Health Care Act 17 of 2002.
- National Health Act 61 of 2003.
- National Health Bill, 2014.
- Traditional Health Practitioners Act 22 of 2007.

Foreign

- Spanish Law 30/1979, 27 October, on Organ Extraction and Transplantation.
- The Constitution of the Federal Republic of Nigeria, 1999
- Constitution of the Republic of Singapore, 1965.
- Constitution of Spain, 1978.
- Federal Constitution of Malaysia, 2010.
- Human Organ Transplant (Amendment) Act 2004 – Cap.131A (Singapore).
- Medical (Therapy, Education and Research) Act 23 of 1972 (Singapore).
- National Organ, Tissue and Cell Transplantation Policy, 2007 (Malaysia).
- National Organ Transplant Act, 1984 (USA).

Case law

South African

- *AZAPO v President of the Republic of South Africa* 1996 4 SA 671 (CC).
- *Bernstein v Bester* 1996 2 SA 751 (CC).
- *Bhe v Magistrate, Khayelitsha; Shibi v Sithole, South African Human Rights Commission v President of the Republic of South Africa* 2005 BCLR (CC).
- *Castell v De Greef* 1994 4 SA 408 (C).
- *Clarke v Hurst NO and Others* 1992 4 SA 630 (D).
- *Dikoko v Mokhatla* 2007 1 BCLR.
- *Ferreira v Levin* 1996 1 SA 984 (CC).
- *Government of the Republic of South Africa and Others v Grootboom* 2001 1 SA.
- *Hoffman v South African Airways* 2001 1 SA 1 (CC).

- *In re Certification of the Constitution of the Republic of South Africa Constitution Act 1996* 1996 10 BCLR 1253 (CC).
- *Khumalo and others v Holomisa* 2002 5 SA 401 (CC).
- *Port Elizabeth Municipality v Various Occupiers* 2005 1 SA.
- *President of the Republic of South Africa and others v Modderklip Boerdery (Pty) Ltd and others* 2005 8 BCLR 786 (CC).
- *Richter and Another v Estate Hammann* 1976 3 All SA 497 (C).
- *Soobramoney v Minister of Health (Kwazulu – Natal)* 1998 1 SA 765.
- *Stoffberg v Elliott* 1923 CPD 148.
- *S v Makwanyane* 1995 3 SA 391.
- *S v Williams* 1986 4 SA 1188 (A).
- *The Investigating Directorate: Serious Economic Offences and others v Hyundai Motor Distributors (PTY) Ltd and others* 2001 1 SA 545 (CC).
- *Treatment Action Campaign v Minister of Health* 2002 5 SA 721 (CC)

Foreign

- *Airedale NHS Trust v Bland* 1993 1 ALL ER 821 (HL).
- *Glenister v President of the RSA and Others; Helen Suzman Foundation as Amicus Curiae* 2011 3 SA 347 (CC).
- *DPP V Pete* 1991 LRC (Const) 553.
- *Kohn v United States F. Supp.* 568.
- *Mail Newspapers v Express Newspapers* (1987) Fleet Street Reports 90.
- *McFall v Shimp* No.78 – 17711. 10 Pa. D. & C. 3d 90 (1078).
- *Re A* (1992) 3 Med LR 303.
- *Salgo v Leland Stanford etc Bd.Trustees*, 154 Cal. App. 2d 560.
- *Schloendorff v Society of New York Hospital* 211 N.Y. 125, 105 NE 92 (1914).

Case law from international bodies

- *Social and Economic Rights Action Centre (SERAC) and the Centre for Economic and Social Rights (CESR) v Nigeria* (2001) AHRLR 60 (ACHPR 2001).

Internet

- 'About HPCSA' <www.hpcsa.co.za/About> (accessed on 05/08/2015).
- 'Care about Rights? What is a human rights-based approach?' <<http://careaboutrights.scottishhumanrights.com/whatisahumanrightsbasedapproach.html>> (accessed on 31/07/2017).
- Guruswamy, R 'Religions in Singapore' <http://worksingapore.com/articles/live_7.php> (accessed on 20/11/2014).
- Keown, D 'Buddhism and medical ethics: principles and practice' (2002) <<https://www.buddhismuskunde.uni-hamburg.de/pdf/4-publikationen/buddhismus-in-geschichte-und-gegenwart/bd7-k03keown.pdf>> (accessed on 01/05/2016).
- McLean, S 'Human rights and bioethics' <<http://www.unesco.org/new/fileadmin/MULTIMEDIA/HQ/SHS/pdf/Bioethics-Human-Rights-McLean.pdf>> (accessed on 12/05/2015).
- 'Office of the Mufti' <<http://www.muis.gov.sg/cms/oomweb/fatwa.aspx?id=14698>> (accessed on 09/02/2015).
- 'OHCHR - Human rights and poverty reduction – a conceptual framework' (2004) <<http://www.ohchr.org/Documents/Publications/PovertyReductionen.pdf>> (accessed on 27/06/2017).
- 'Organ Donor Foundation – waiting list statistics' - <https://www.odf.org.za/2013-06-11-09-17-45/statistics.html> (accessed 15/09/2015).
- Organizacion Nacional De Trasplantes – 'Transplants' <<http://www.ont.es/informacion/Paginas/Trasplante.aspx>> accessed on 03/05/17.
- 'Porcine Graft' - <<http://medical-dictionary.thefreedictionary.com/porcine+graft>> (accessed 12/03/2016).
- 'Singapore Muslims to be included in Human Organ Transplant Act (HOTA)' <<http://www.hospitals.sg/story/singapore-muslims-be-included-human-organ-transplant-act-hota>> (accessed on 09/02/2015).
- 'Talmud' - <<http://www.biblestudytools.com/dictionary/talmud/>> (accessed on 22/03/2016).

- The Islamic Supreme Council of America – ‘Understanding Islam - what is a fatwa?’ <<http://www.islamicsupremecouncil.org/understanding-islam/legal-rulings/44-what-is-a-fatwa.html>> (accessed on 27/10/2017).
- ‘Thoracic surgery Defined’ - <<http://surgery.about.com/od/glossaryofsurgicalterms/g/ThoracicSurgery.htm>> (accessed on 05/09/2015).
- UNOS – United Network for Organ Sharing <www.unos.org/about/index.php> (accessed on 12/05.2015).
- U.S Department of Health and Human Services- ‘The need is real: data’ <<http://www.organdonor.gov/about/data.html>> (accessed 09/02/2015).
- World Health Organization - ‘Global glossary of terms and definitions on donation and transplantation’ <<http://www.who.int/transplantation/activities/GlobalGlossaryonDonationTransplantation.pdf>> (accessed on 30/07/2014).

Other documentation

South Africa

- Donnelly, J ‘Human dignity and human rights.’ Commissioned by and prepared for the Geneva Academy of International Humanitarian Law and Human Rights in the framework of the Swiss Initiative to commemorate the 60th Anniversary of the Universal Declaration of Human Rights. June 2009.
- Health Care Professions Council of South Africa – guidelines for good practice in the health care professions ‘Confidentiality: protecting and providing information’ (2007) 2nd Edition.
- Health Care Professions Council of South Africa ‘Seeking patients’ informed consent: the ethical considerations’ (2007) 2nd Ed.
- South African Human Rights Commission Report ‘Public Inquiry: Access to Health care services’ (2008).

Foreign

- Dharmananda, V 'Informed consent to medical treatment – processes, practices and beliefs' (1992) *Law Reform Commission of Australia* 10.
- 'Guideline for the Malaysian Medical Council – Brain death' MMC Guideline 008/2006; 7. < <http://www.moh.gov.my/images/gallery/orga/Brain%20Death%20-%20Malaysian%20Medical%20Council.pdf>> (accessed on 23/05/2018).
- *Holy Bible, English Standard Version (ESV)*, Crossway Bibles, a publishing ministry of Good News Publishers, 2007.
- Nuffield Council on Bioethics Working Party Report, *Human Tissue: Ethical and Legal Issues*, Nuffield Council of Bioethics, London.
- World Health Organisation - Guiding Principles on Human Cell, Tissue and Organ Transplantation – As endorsed by the sixty-third World Health Assembly in May 2010, in Resolution WHA63.22. - http://www.who.int/transplantation/Guiding_PrinciplesTransplantation_WHA63.22en.pdf> (accessed on 23/05/2018).
- World Health Organisation Traditional Medicine Strategy 2014 – 2023. http://www.searo.who.int/entity/health_situation_trends/who_trm_strategy_2014-2023.pdf?ua=1> (accessed on 23/05/2018).