TITLE: EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE IN SOUTH AFRICA: TOWARDS AN ETHICO-LEGAL FRAMEWORK TO ASSIST MEDICAL PRACTITIONERS WITH END-OF-LIFE DECISION-MAKING

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DECLARATION

This thesis represents my own original work, produced with supervisory assistance. All the relevant sources that I have used during the course of writing have been fully credited and acknowledged. This thesis has not been submitted for any other academic or examination purposes at this or any other university.

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Date: 31st day of July 2023

This work is dedicated to my husband, Franco for the immeasurable love, support, wisdom, patience, and cooking that made this thesis possible, and my children, Deanna, Alyssa, and Nadia for believing in me and giving endless encouragement.

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ABSTRACT

South Africa is confronted with court challenges from people who fear intractable suffering from terminal illness requesting assisted death. Euthanasia (E) and physician assisted suicide (PAS) are still criminal offences in South Africa. Where they have been legalised internationally, the concept has been 'medicalised' because of the role medical practitioners are asked to fulfil to enable it.

The aim of the study was to investigate South Africa's ethical and legal environment on end-of life choices. In particular E and PAS in foreign countries was examined to propose a sound ethico-legal framework to assist South African doctors and the legislature to deal with end-of-life decision-making going forward.

Well-known philosophical theories and their use in solving bioethical dilemmas, South African case law, and established E/PAS legislation, were canvassed to produce draft South African legislation and recommendations for the management of end-of-life decision-making. The controversial role of medical practitioners in the delivery of E/PAS was analysed. Significantly, the World Medical Association does not presently support E/PAS.

It was found that foreign end-of-life models, which generally utilise medical practitioners and health services to facilitate E/PAS, would not be suitable for South Africa. If South Africa were to opt for legalisation of assisted dying, it is proposed that the process be kept outside of the health care service to ensure that it is never perceived to be an extension of medical care. To achieve this, an alternative end-of-life care model is suggested where nongovernmental organisations manage the procedure.

Ultimately it was concluded that without a strong palliative care system and income equality, legislation of E and PAS is not yet an option for South Africa. Focus and resources should be directed rather at improving universal access to good palliative and health care. An ethico-legal framework to assist South African doctors with end-of-life decision-making is proposed.

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ACRONYMS

AAHPM	American Academy of Hospice and Palliative Medicine
ACDP	African Christian Democratic Party
AHPRA	Australian Health Practitioner Regulation Authority
AMA	American Medical Association
AS	Assisted Suicide
BCE	Before the Christian era
BMA	British Medical Association
CAT scan	Computerised Axial Tomography
CCA	Council of Canadian Academies
CCO	Coordinated Care Organisations
CE	Christian Era
CEJA	Council on Ethical and Judicial Affairs
COHSASA	Council for Health Services Accreditation of Southern Africa
COVID-19	Coronavirus disease 2019
CTOP	Choice on Termination of Pregnancy Act
DWDA	Death with Dignity Act
E	Euthanasia
EAPC	European Association of Palliative Care
ECHR	European Court of Human Rights
EPS	Entidades Promotoras de Salud (Health Promotion Agency)
Exit ADMD	Association pour le Droit deMourir dans la Dignité
FMH	Foederatio Medicorum Helveticorum (Swiss Medical Association)
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association
HPCSA	Health Profession's Council of South Africa
ICU	Intensive care unit
KNMG	Royal Dutch Medical Association
KNMP	Royal Dutch Pharmacists Association
LEIF	LewensEinde Informatie-Forum
MAiD	Medical Aid in Dying
NGO	Nongovernmental Organisations
NHA	National Health Act

NHI	National Health Insurance system
ODE	Organ Donation Euthanasia
OECD	Organisation for Economic Co-operation and Development
OHA	Oregon Health Authority
OHP	Oregon Health Plan
PAE	Physician-Assisted Euthanasia
PAS	Physician-Assisted Suicide
POLST	Physician Orders for Life-Sustaining Treatment
PVS	Permanent Vegetative State
QUT	Queensland University of Technology
SA	South Africa
SALRC	South African Law Reform Commission
SAMA	South African Medical Association
SAMS	Swiss Academy of Medical Sciences
SAVES	South African Voluntary Euthanasia Society
SCEN	Support and Assessment Organisation
TB	Tuberculosis
UCT	University of Cape Town
UK	United Kingdom
USA	United States of America
VAD	Voluntary Assisted Dying
WACHS	WA Country Health Service
WFRtDS	World Federation of Right to Die Societies
WHO	World Health Organisation
WMA	World Medical Association

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CHAPTER 1: EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE IN SOUTH AFRICA: TOWARDS AN ETHICO-LEGAL FRAMEWORK TO ASSIST MEDICAL PRACTITIONERS WITH END-OF-LIFE DECISION-MAKING

1.1. INTRODUCTION

Beyond the disciplines of philosophy, theology and law, there is not a great deal of academic work written on euthanasia in South Africa. This may partly be because it is an anomaly for the majority of South African society who see hastening death as contradictory to their deep-rooted communitarian history[1]. However, the legalisation of euthanasia and physician-assisted suicide (E/PAS) is becoming more popular in foreign countries as an end-of-life option, despite the availability of palliative care. South Africa, too, must confront requests for assisted death through legal challenges brought to court by people who fear intractable suffering from terminal illness, with a view to pressurising South Africa to follow suite. Where euthanasia has been legalised, the concept has been 'medicalised' because of the role medical practitioners are asked to fulfil to facilitate it. Legislation requires doctors to assess a requesting person's eligibility for assisted death and then to perform either the administration of a lethal drug or write the prescription for lethal medication. In this chapter, I briefly present the background from which I argue for an ethico-legal framework that can assist South African doctors with decision-making related to the patient's end of life. I conclude the chapter with an outline of this thesis.

1.1.1 Terminology

The academic literature covers end-of-life challenges related to children ranging from new-borns to adolescents, and other categories of vulnerable people in need of guidance and support. However, each group with its complexities could be a study on its own. Unless otherwise stated, and for the sake of brevity, I focus on adults with full legal capacity who seek end-of-life options.

Throughout this thesis I use the following expressions for 'medical doctor' interchangeably: 'doctor', 'medical practitioner', and 'physician'.

For convenience, the phrases, 'assisted death' and 'hastened death' are used as catch-terms in this thesis to refer to euthanasia, physician-assisted suicide, or both, as well as to 'assistance in suicide'. The word 'death' in 'assisted death' is preferred to that of 'dying', as noted by Shariff[2],

because not everyone I refer to in the thesis will be in their terminal phase of life, although they may request a premature death.

The terms ‘ethics’ and ‘ethical’ may also be switched with ‘moral’ and ‘morality’ to refer to the same concepts, despite some authors making a distinction between the two[3].

1.2. LITERATURE SURVEY

Great strides have been made in medical technology to prolong life, in law so that a human rights culture has developed, and in ethics to encompass issues specific to medicine. Yet termination of a life at someone’s request remains unlawful in South Africa, despite the person experiencing extreme physical or emotional suffering, asking for the ‘right to die’ or begging for their life to be ended when they choose, in a humane and compassionate way. This process of active mercy-killing is known as ‘euthanasia’, a word of Greek origin, which means ‘good death’[4], but the word does not express the important fact that it refers to another person intentionally killing the individual who asks for death. Typically, the attending physician who has a relationship with the terminally ill patient is approached to carry out euthanasia or, alternatively, to prescribe a lethal dose of a medication which will assist the person to end their own life, termed physician-assisted suicide[5].

This literature review provides a summary of the various authorities considered to establish what is required to create an ethical and legal framework to assist doctors dealing with end-of-life decisions of patients and their families. It is therefore necessary to explain the meaning of ‘euthanasia’ and ‘physician-assisted suicide’ within the context of the work presented.

1.2.1. Defining Euthanasia and Physician-assisted suicide

In this thesis I use the definition of euthanasia proposed by the European Association of Palliative Care (EAPC) Ethics Task Force[5]. The members reached agreement on what euthanasia does not encompass and collaborated to formulate a definition that most academics accept of what euthanasia and physician-assisted suicide does entail.

Euthanasia is not the withholding or withdrawing of futile treatment, nor is it palliative or terminal sedation, where sedative medication is administered to relieve intractable suffering in the final days of life. The EAPC task team agreed that where consent is not given by the person

who is assisted to die, the death is medicalised killing, that is murder. Consequently, both 'involuntary euthanasia', which is killing someone against their will, and 'nonvoluntary euthanasia', which refers to killing a person who is unable to consent, such as an unconscious person, are not classified by the EAPC Ethics Task Force as euthanasia. By definition, euthanasia can only be voluntary, so the expression 'voluntary euthanasia' is tautologous, and should be discarded. It implies that there are other forms of euthanasia when there are none. Thus, a person seeking assisted death must be able to consent for themselves, resulting in euthanasia.

Another distinction that is frequently made in the literature is between 'active' and 'passive' euthanasia. The EAPC task force argues that this is also incorrect because euthanasia is 'active' by its nature. Therefore, the term 'passive euthanasia' contradicts itself and cannot exist. The Netherlands has the same understanding of the term and supports this interpretation[6]. In line with this, the meaning of 'euthanasia' and 'physician-assisted suicide' used in this thesis are presented below.

Although the EAPC task force specifies that euthanasia is performed by a medical practitioner, in a very limited number of countries outside of Europe a suitably qualified nurse is also permitted to administer a lethal medication. Accordingly, when discussing those foreign jurisdictions, the broader implication of the word can be assumed.

'Euthanasia' **(E)** is defined as a medical practitioner intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.

The EAPC Ethics Task Force emphasises that the intention is to kill the patient, the procedure is to administer a lethal drug, and the successful outcome is immediate death.

'Physician-assisted suicide' (PAS) refers to a medical practitioner intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request.

More generally, I apply the Worldwide Hospice Palliative Care Alliance's definition of 'assistance in suicide'[7], which is framed as follows.

'Assistance in suicide' is knowingly and intentionally providing a person with the knowledge

or means, or both, required to commit suicide, including counselling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.

1.2.2. Hospice care

Hospices were established specifically to cater for patients' needs at the end of life where palliative care replaces futile life-prolonging treatment**.** As the founder of Hospice, Dame Cicely Saunders' views on what it meant to 'die well' underpinned the moral tradition of hospice. Its mission was to provide care that neither hastened death nor prolonged life. It was positioned between two adverse approaches: high-technological aggressive medical intervention on one hand, and death by euthanasia on the other. The patient and the family were offered compassion and comprehensive care by focussing on all the patient's needs and not just the physical discomfort of a terminal illness[8]. Comprehensive care includes palliative care, symptom control, pain management and preserving 'human potential at life's end', according to Dr Ira Byock, a leading American palliative care physician. This approach is promoted as providing an alternative to physician-assisted suicide and euthanasia[9].

1.2.3. International organisations

The World Health Organisation, in defining palliative care, also supports the view that it is intended to neither hasten nor postpone death[10].

In 1983 the World Medical Association (WMA) released the Declaration of Venice on Terminal Illness. This independent confederation was founded in 1947, after World War II, as an international organisation to represent medical doctors. It is presently made up of 116 constituent Medical Associations[11] who communicate and collaborate with one another to reach consensus on the highest standards of ethical behaviour and care, professional competence and to encourage professional freedom for medical practitioners, amongst other objectives. For this purpose, the WMA provides Declarations, Resolutions and Statements as a guide for the profession[12].

The WMA Declaration of Venice on End of Life Medical Care considered it to be unethical for doctors to intentionally cause death[13]. This stance was adopted despite the arguments in favour of E and PAS and the rights of patients to refuse medical treatment and to request palliative measures to ease suffering that may have side effects which would accelerate the end of life. The WMA Declaration proposed that attention should rather focus on improving the standards

of palliative care. During October 2019, in Tbilisi, Georgia, the WMA's attitude of being firmly opposed to E and PAS was reiterated in a revised and updated publication of the Declaration on Euthanasia and Physician-Assisted Suicide[14]. Some of the reasons for this outlook were reflected in a 2017 WMA news-post related to the Australian Victorian Voluntary Assisted Dying Bill which favoured PAS[15]. The WMA expressed its concern that, if passed into law, the legislation would conflict directly with the ethical obligations of physicians towards their patients, resulting in 'ethical harm' to the profession. The WMA was also concerned that vulnerable people would be placed at risk of abuse and that E and PAS would finally become an ethically acceptable precedent going forward.

Nevertheless, despite opposition and resistance from palliative care associations and world medical organisations, legalisation of E and PAS is gaining momentum.

1.2.4. Foreign jurisdictions

While E and PAS (E/PAS) are illegal in South Africa, one or the other approach towards death, or both, are legalised or tolerated in several countries. The Netherlands[16] allows both E and PAS, Belgium[17] both, Luxembourg[18] both, Colombia[19] both, Canada[20] both, and, since Spain adopted assisted death law in June 2021, Spain now allows both E and PAS[21] (E Countries), although the countries differ slightly in terms of the permissiveness of their laws.

Switzerland accepts PAS under certain conditions[22]. Several jurisdictions permit physicians, or, more infrequently, nurse practitioners, to prescribe and/or administer lethal doses of medications to persons who choose to end their lives because of grave illness[23,24].
Other regions that are in the process of implementing assisted death laws include Australia's provinces of New South Wales[25], Queensland[26], and South Australia[27], where legislation will commence in 2023.

In the United States of America, a number of states have passed laws, but they are more conservative than the E Countries mentioned above. They only allow a physician to prescribe lethal doses of medication, which must then be self-administered by a terminally ill person who has less than six months left to live[28]. As of January 2023, those states include: California[29], Colorado[30], the District of Columbia[31], Maine[32], New Jersey[33], Oregon[34], Vermont[35], Washington State[36], Hawaii[37], and most recently, New Mexico[38]. Montana has a Supreme Court ruling on the question, but no legislation in place[39]. Other states are slowly following suite.

1.2.5. South African Law

South African doctors working in hospice and palliative care units are frequently confronted with the ethical and legal issues surrounding death and dying[40], particularly those with terminally ill patients experiencing excruciating pain and discomfort. Undoubtedly, legislation that addresses end-of-life decision-making would greatly assist the medical profession and the community because it would clarify present legal uncertainty and offer guidance to facilitate the process.

Areas where South Africa needs clarity, as did Canada in the early days of their legislative process, include: effective management of pain and suffering and the role of hospice care; the withholding and withdrawal of treatment; the legal status of advance directives and a durable power of attorney for health care; and assistance with dying[41].

Successful arguments used in favour of E/PAS overseas have been about the right to exercise self-determination and to protect individual dignity, amongst others[42]. However, some of the objections to legalising assisted death are that the government will not make every effort to sustain and improve palliative care if physician-assisted death is accepted; that a 'slippery slope' will develop where, progressively, more people will be allowed to have assisted death for reasons other than intolerable suffering (such as the elderly choosing an early death in order not to be a burden on their families), and that, because life is sacred, there is no justification for intentionally ending it[43].

These opinions were canvassed in 1997 when the South African Law Reform Commission (SALRC) produced a Discussion Paper for public comment on *Euthanasia and the Artificial Preservation of Life*[44]. As a result of their research, the Commission suggested *inter alia* the following points for public consideration: the circumstances in which it would be lawful for a doctor to withdraw life-sustaining treatment of a person in a persistent vegetative state (PVS); the right of a person to refuse life-sustaining treatment even though this refusal may hasten death, including if this refusal is in a written directive; the right of a doctor to alleviate pain and distress according to responsible medical practice by increasing a medicine dosage, even if the secondary effect may shorten the patient's life; and, compliance with a competent patient's well-informed request for the administration or provision of a lethal agent to end life. Following the production of recommendations that specifically excluded administration of a lethal agent at the patient's request, a draft bill was published, namely the End-of-Life

Decisions Act of 1998. No progress was made to enact the legislation[45]. Ultimately, the ethical and legal dilemmas confronting doctors regarding the topic of end-of-life management, including E and PAS as an option, have not been resolved[46].

During 1996 the Constitution of South Africa was promulgated to uphold the values of the State, specifically human dignity, equality and the advancement of human rights and freedoms[47]. Section 2 clearly affirms that this law is supreme and law or conduct inconsistent with the Constitution is invalid. Of importance is chapter two (the Bill of Rights), where the rights to human dignity[48], life[49], and the right to freedom and security of the person[50] reside. This latter right includes the right not to be treated in a cruel, inhuman, or degrading way[51], and the right to bodily and psychological integrity, which itself consists of the right to security in and control over one's body[52]. Consequently, it is the cornerstone for ensuring patients give informed consent or refusal when deciding on any intervention for themselves and could be extended as the right to choose to die.

Nonetheless, the Constitution does not support a right of access to assistance to die at the hand of another person, because the assisting person's action would still be murder under South African criminal law[53]. A few other provisions have relevance for legal argument in favour of permitting E and PAS, such as the rights to privacy and freedom of religion, belief and opinion[54]. However, detailed legal debate on these topics is beyond the scope of this thesis. I do not delve into the intricacies of technical legal argument to justify or refute the right to die and leave that up to the courts to determine.

In 2005 the National Health Act 61 of 2003 came into force with clear wording that people have a right to refuse health services (s6(1)(d)) either 'expressly, impliedly or by conduct' (s7(1)(e)). This statute also empowered people to mandate someone else in writing to consent (or, by implication, refuse consent) on their behalf should they be unable to do so themselves. However, this clear legal wording has not yet translated into the right of people to be assisted to die, should they choose this path, instead of waiting out their last days, weeks or months in distress, for the inevitable end.

South African courts have used legal argument to indicate that there is a place for limiting the right to life, making technical points that work around the right, such as in respect of terminations of pregnancy[55] (an unborn child has no rights until it is born alive[56]), and where hospital policies manage limited resources. This was illustrated in 1998 in the *Soobramoney*

case[57], where Mr Soobramoney, who had kidney failure, was refused chronic renal dialysis, a limited resource at a public hospital, even though he was terminally ill and in desperate need of the treatment to stay alive. He was ineligible according to the admission criteria stipulated for dialysis. The Court confirmed that the State hospital's decision was acceptable for the purposes of managing a scarce resource and upheld it.

Other case law has accepted the ending of life by the withdrawal of ongoing medical treatment, nutrition and hydration. That applies when treatment becomes futile and it is the compassionate decision to withdraw treatment, considering the perceived best interests of the patient. In the case of *Clarke v Hurst*[58], in 1992, Dr Clarke had suffered a stroke and was in a permanent vegetative state. For four years, only brain stem activity was detectable, allowing him to continue breathing and to have a heartbeat, but no higher brain functioning was evident. Previously, while he was still competent, he had prepared an advance directive expressing his wish not to be kept alive artificially. His wife eventually applied to court and was granted an order entitling her to remove the nasogastric tube that fed him artificially, and which was keeping him alive. As this case was decided before the Constitution was in force, the Court applied 'the legal convictions of the community' as the test for unlawfulness. It reasoned that where a person, who was unconscious and experiencing a very low quality of life, had a prognosis without hope of recovery, termed a permanent vegetative state, the withdrawal of nutrition from such a person would be lawful. Dr Clarke's advance directive had no bearing on the judgment, but was mentioned as confirmation that the patient's wishes were consistent with the outcome.

Instances of allowing death by withdrawal of treatment are now relatively uncontroversial. The law has removed the uncertainty around the decision to discontinue a life where only biological functions, namely heartbeat, respiration, digestion and blood circulation, are sustained in the brainstem, while cortical and cerebral functioning of the brain, which give cognitive and intellectual life, are absent[59]. In Clarke's case, the Court accepted the evidence that where the higher brain functions were destroyed, the quality of life was gone, and only the biological functions remained[60]. In this situation, the Court held that the moral or legal convictions of society would not consider withdrawal of treatment to be wrongful where there is no duty to continue with a procedure that proved to be unsuccessful. Such an existence would be akin to a plant or something less[61].

The element of wrongfulness is a fundamental requirement for delictual and criminal liability

in common law. What amounts to wrongful conduct has been developed over time. Judge Thirion explains this in Clarke's case using Maasdorp's translation of Grotius' *Inleidinge* 3.32.3, 5. It states that delict is 'whatever is contrary to reason as indicated by natural law'[62]. Natural law arises from the universal moral standards first proposed by Aristotle (384-322 B.C.E.)[63] and Plato (427-347 B.C.E.)[64]. The term 'natural law' refers to an ethical theory that says people have an intrinsic knowledge of what is right and wrong that governs their reason and behaviour. Thomas Aquinas, a Christian theologian and philosopher, who played a central role in the theory of natural law, describes it as a practical rationality[65].

Wrongfulness was therefore decided at the time of Clarke's case on the basis of the *boni mores* (good morals) of society or, as stated in the case of *Ewels*[66], the legal convictions of the community[67]. In the *Ewels* judgment, Rumpff CJ affirmed that South African law had developed to a stage where wrongful conduct could be associated with an act or omission that 'evoked moral indignation', as well as the legal convictions of society. The opposite would also be valid: if society no longer considered an act or omission to be wrongful, it would no longer be wrongful in law[68].

The legal scholar and author, Boberg[69], similarly reinforced the understanding that a value judgment 'based on considerations of morality and policy' was applied to what was considered wrongful in law, where the competing interests of the parties were balanced against each other, and the law then decided which interest to protect against the other's intrusion.

Legal clarity eases moral discomfort to some extent. Case law elucidates that intentionally causing death is not always considered wrong by society's moral and legal convictions, as illustrated in Clarke's case[58] discussed above.

The Health Professions Council of South Africa (HPCSA) under the jurisdiction of the Health Professions Act[70] accepts the professional withdrawal or withholding of treatment where treatment has become futile, and the end of life is near. The HPCSA has produced a booklet of guidelines to assist health professionals to make ethical decisions in this regard[71].

In contrast to the tolerance shown for withholding and withdrawing medical treatment, the attitude towards E and the request for PAS has been very different. In 2015, Advocate Stransham-Ford in his personal capacity brought an urgent application to court[72] seeking an order to allow him assistance with suicide as he was suffering from terminal cancer. The court

handed down an order in his favour unaware that just a few hours before he had died. For this reason, the order became meaningless and was ultimately reversed by the Supreme Court of Appeal[73]. That left South Africa with no new law to help resolve the legal and ethical dilemmas that surround the topic today.

During 2018, a new action was launched in the South Gauteng Division of the High Court by three plaintiffs, Dr Suzanne Walter, a palliative care specialist suffering from multiple myelosis, Mr Dieter Harck who has a terminal neurological disease, and a Trust seeking a change in the law to allow euthanasia[74]. This action remains to be argued at some future date.

More recently, in June 2019, the case of South African academic Sean Davison, then a 58-year-old professor of biotechnology at the University of the Western Cape (previously found guilty by a New Zealand court for assisting his terminally ill mother to commit suicide), again cast the spotlight on euthanasia and assisted dying[75]. He pleaded guilty to three counts of murder, having assisted three people to die at their requests: a person who was a quadriplegic, another who had suffered a stroke and someone with motor-neurone disease. He was freed in June 2022, after serving a sentence framed as eight years of imprisonment, of which three years were served under house arrest, and five years were suspended for five years[76].

Davison is a co-founder of the activist group Dignity SA, which is a lobbying group to have euthanasia legalised in South Africa, and a past-president of the World Federation of Right-to-Die Societies from 2018 to 2020. The World Federation is made up of 58 organisations from 30 countries around the world[77].

Historically, euthanasia was usually associated with terminal illness, an act performed out of compassion by a second party, where palliative care was ineffective, and the person faced no hope of recovery[78]. Despite this respectable connection, according to Landman[79], a South African ethicist who undertook a limited survey in 2011 to ascertain the attitudes of 120 doctors towards PAS in South Africa, 51% of the doctors were not in support of PAS being legalised and 53% did not back active euthanasia either. Only 37% of medical practitioners were certain that if they had an illness severe enough to warrant early death, they would not end their lives prematurely or ask a colleague to do so.

However, since 2011, there has been growing pressure globally and within South Africa for people to reconsider their stance on E and PAS and to legalise it as an end-of-life option[80].

Assisted death is not only offered to the seriously ill in numerous countries, but the principle of equality tends to support making the option available to all who experience intractable physical and emotional suffering[81]. Should the State finally accept the arguments in favour of legalising E and PAS in South Africa, doctors will be confronted with having to decide where their personal convictions lie and whether to comply with the law or find ways to avoid it.

From an ethical perspective, great controversy remains around assisted death, often because of the spiritual and moral convictions of both doctors and the families of dying patients[78]. In E countries, very ill patients are often the ones who seek E or PAS and the physicians are the people who either prescribe the lethal medication or administer the lethal procedure. Ethical issues consequently arise surrounding the role of the doctor as healer and the doctor-patient relationship[82] at death.

There has been a long religious and philosophical history of opposition to intentional killing, the exception being where killing is a result of self-defence. However, in recent decades the movement to expand reasons for acceptable killing to encompass E and PAS has increased in fervour[83].

1.2.6. Ethical Theories

To cast light on why the euthanasia movement has continued to gain traction, several moral theories and a set of biomedical ethical principles are introduced and presented in this thesis in more detail in Chapter 2, as tools to identify the outlook of society towards assisted death as it has shifted through time. Bearing in mind that medical practitioners are part of the community themselves, it is interesting to observe whether the medical profession has similarly changed its attitude towards the value of an individual's autonomy to choose hastened death in contrast to the doctor's role as healer and to offer comfort.

1.2.6.A Biomedical Principles

McLean, a philosopher, wrote that there is no morally neutral attitude. He said that the presumption is that life is good and that the duty of care for physicians is to sustain life[84]. This accords with Beauchamp and Childress's four biomedical moral principles[85], a helpful and popular tool for ethical decision-making amongst medical practitioners.

Two relevant bioethical principles associated with the quality of medical care are beneficence (the obligation to help others) and non-maleficence (the obligation not to harm). However, it is accepted that futility of treatment removes the responsibility to sustain life where instead it causes prolonged dying. There is no duty to maintain life where preserving life amounts to a greater harm or suffering disproportionate to the good[84]. The other two biomedical principles are acknowledgement of a person's autonomy (respect for the person's decision-making capacity) and justice (the distribution of benefits and risks between all people equally).

Patients argue that the moral principle of respect for autonomy requires physicians and the community at large to allow persons to make decisions not only about the integrity of their bodies and minds as it relates to health care, but also regarding how they wish to end their lives. This stance may be viewed as an extension of the fact that South African law already recognises that a competent person may refuse medical treatment[86] even to their personal detriment However, as Beauchamp and Childress point out, emphasising the importance of autonomy should not ignore the reality that a person remains part of a social context when they exercise a choice that affects others, nor allow reason to simply replace emotion, or let legalism overshadow social practices and responsibilities. Autonomy does not take precedence over all other moral considerations[87].

1.2.6.B Virtue Ethics

The first philosophical theory that will be examined to illuminate the ethical role of the doctor is Virtue Ethics. Aristotle first presented this idea in the fourth century B.C.E. and Aquinas re-ignited interest in it during the thirteenth century[88]. They believed that a person's greatest desire is to live a life of flourishing by attaining true happiness through being morally virtuous, and this could be achieved by exercising prudence. Although other philosophies overtook virtue ethics with time, the doctrine was re-introduced in the 1950s by Anscombe[89]. Virtue was positioned, as the focal point of the theory, in a person's character[90]. A virtue was then proven to exist through commendable habitual action, such as compassion, courage, reasonableness, and tolerance[91].

A virtuous doctor's compassion is used as a persuasive argument in favour of E and PAS for the relief of suffering, for someone who is in terrible anguish at the end of life[92]. The justification for E and PAS is that the person's pain is perceived to be unbearable and the options to remove pain are no longer effective to offer relief. With multiple organ failure, for

example, medication cannot be metabolised for absorption in the body. If a doctor, moved by compassion, were then to assist with E, it would result in a speedy end to suffering, and could be construed as a virtuous gesture, morally motivated. Were the doctor to refuse to assist the suffering patient, he would seem to be lacking in compassion. A counterargument used for E is that a kind and considerate doctor could administer terminal sedation instead, to place the patient in an unconscious state, but this situation too, is not how some people would choose to end their lives[92]. A weakness of this ethical theory is that, although it recognises the importance of a good character, it does not answer the question of what action the doctor ought to take when faced with an ethical dilemma, which makes it seem incomplete[93].

Devettere explains that the three main concepts of virtue ethics are happiness, moral virtue, and prudence. Prudence is described as an intellectual virtue[94]. Of particular interest from this theory is the application of prudential thinking that Devettere promotes for ethical problem-solving in healthcare. The ethical dilemma is viewed from the perspective of each of the moral agents who are involved to reach a solution. The practical decision-making is applied on a case-by-case basis.

1.2.6.C Utilitarianism

John Stuart Mill (1806-1873) promoted the consequentialist philosophy that the correct action is the one that causes the best overall outcome in a situation[95]. The 'greatest good' was to be established in terms of the total intrinsic value of well-being, measured by how much happiness, pleasure, welfare and satisfaction, amongst other attributes, was achieved by an action[96]. With respect to the role of a doctor, an application of the consequentialist argument supports the view that a person should be assisted to die where they have made this request. Suffering irremediably in the terminal phase of life, where death is perceived to have greater value than life, it would end their agony. Mill supported the stance that the law should promote the welfare of people, restricting it only to avoid their distress[97], and thereby ensuring their freedom as far as possible. Commenting on the individuality of a person, Mill suggested that people should evolve according to their own convictions as long as they did not interfere with the assertion of others' independence or unjustifiably cause harm to others[98].

1.2.6.D Deontology

The contemporary philosopher, Immanuel Kant (1724-1804) saw respect for autonomy as

flowing from the recognition of each person's 'intrinsic worth' or 'dignity'[99]. He embraced a deontological philosophical approach, accepting that if a person's autonomy were ignored, that person would be treated simply as a means to fulfil someone else's goals. He proposed that the morally correct approach was for people to be treated as ends in themselves because of their innate value as human beings[100]. He did hold, though, that suicide was a violation of our duty toward ourselves and therefore abhorrent. Yet Kant left open the question of whether there were ethical exceptions to this prohibition, such as with an incurable disease that would cause someone to become mentally ill and injure others[101]. The South African Constitution[52], National Health Act[102] and HPCSA[103] endorse this philosophy by recognising the importance of the autonomy of people and promoting the respect of health professionals for the decisions patients make about their bodily and psychological integrity. Consequently, doctors are required to embrace this ethical perspective and to try to uphold the wishes of their patients within the parameters of the law. A conflict arises when the doctor holds a different personal view to that of the patient, in a situation where the law recognises the right of the doctor to refuse to act, such as with a conscientious objection to perform abortions. Some academics have raised the question whether the exercise of the doctor's right to refuse is itself ethical, considering the obligations that the doctor has towards the patient. But the doctor, too, has autonomy and inherent dignity, and if obliged to perform E/PAS against their will would themselves be used by the patient simply as a means to an end.

Arguments have been made that a doctor's refusal to act in line with their conscience could cause injury. An example is the deferral of the performance of a termination of pregnancy which has time limitations according to the law. A delay could occur between the refusing doctor's ethically required referral to another who is willing to perform the termination and the performance itself, so that the woman is no longer legally permitted to have the abortion and is faced with carrying the pregnancy to term against her will[104]. However, whether a doctor causes harm by refusing to assist a patient to hasten their death with E/PAS is less obvious.

1.2.6.E African Philosophy

Following the liberation of the cultural, social and political life of African people, there has been a revival in acknowledging and applying indigenous values to the South African community. The Western attitude of respect for personal independence, often echoed in the theories and principles described above, is in direct contrast to African philosophy, which promotes communitarianism and '*ubuntu*'. Traditionally '*ubuntu'* referred to a human quality

described as 'humanity' or 'being humane', amongst other similar definitions[105].

Over time the concept of '*ubuntu*' has been linked to an ethic, philosophy, or worldview which is reflected in numerous case reports of the South African Constitutional Court, such as *S v Makwanyane*[106]. Justice Madala draws attention to its influence on the Constitution, particularly the chapter on human rights. Although within the African continent there are diverse cultures, outlooks and beliefs, a commonality across the board is the 'interrelatedness with others'[107]. *Ubuntu* comes from the Nguni language and can also be expressed as 'a person is a person through other persons', or 'humanity' towards others. At a more philosophical level it is described as the belief in 'a universal human interdependence, solidarity and communalism'[108].

Applying this worldview, it could be argued that the approach of a South African doctor towards a patient at the end of life affects the whole community. By treating the patient in line with the beliefs, dignity, and humanity of the society of which they are a part, their own dignity and humanity are also respected.

It is important to appreciate that the philosophy of *Ubuntu* has an underlying influence on the application of the Constitution to everyday life in South African society. This approach to the law should impact on any future deliberations about E/PAS legislation. The draft End of Life Decisions Bill that was proposed by the SALRC in 1998 for parliament's consideration raises the question of whether South African society and medical practitioners would welcome E/PAS as a legitimate option for the alleviation of suffering, and how it would accord with the philosophy of *Ubuntu* to re-establish a sense of humanity and respect for one another. Where a hostile environment has been created for sick people who are vulnerable because the public health system is struggling to maintain a minimum standard of health services nationally, it cannot offer adequate palliative care to everyone who needs it. These issues are expanded upon in the chapters that follow.

The central value of this research is to offer an ethico-legal framework for South Africa to assist doctors in reaching decisions when dealing with patients who express intractable suffering and a wish to have their death hastened.

1.3. AIM OF STUDY

To date South Africa has not had to confront the prospect of E/PAS becoming part of society's

culture. However, there is litigation pending in the Johannesburg High Court which is due to be heard in 2023. As such, there is an urgent need to decide first on the role and attitude of the doctors who would be asked to administer E/PAS in South Africa should it be introduced through case law or legislation, and secondly, what can be done to improve palliative care as soon as possible. The aim of this study is therefore to analyse the ethico-legal environment of E/PAS both overseas and in South Africa with a view to proposing an ethico-legal framework that will assist South African doctors with end-of-life decision-making going forward.

1.4. OUTLINE OF THIS THESIS

In order to discern an ethico-legal framework that South African doctors would find helpful for end-of-life decision-making, the ethical tools that I apply to comparative environments for this purpose are first identified. In **Chapter 2** I present in chronological order some of the commonly known moral philosophies and bioethical principles that I use to show the progression in law and health care of a society's moral transition with regard to the terminal phase of life. In **Chapter 3** I apply these theories to investigate how they have influenced the development of the South African law through the reasoning of judges who have deliberated on cases that dealt with assisted suicide and euthanasia. This chapter also examines the attitude of the judiciary to health care options at the end of life, as reflected in court cases brought by people challenging the law to assert their rights. In **Chapter 4,** as a comparison for South Africa, some of the foreign jurisdictions that permit E or PAS, or both, are introduced as examples of societies that have made the paradigm shift to allow assisted death. I describe the history of the introduction of E/PAS law in each of those countries, discuss their legal frameworks, and the impact on their doctors. A superficial overview of the societal culture in each case is portrayed in an attempt to understand why the law has been accepted, and how it has been received by the health sector. This exercise highlights the differences and similarities between each region's communities and the South African environment. Having established what foreign legal models of E/PAS integration entail, in **Chapter 5** I critically analyse the South African draft E/PAS legislation put forward in the End of Life Decisions Bill proposed by the South African Law Reform Commission 24 years ago. I dissect and re-work the Bill to offer an updated version in light of recent developments. In **Chapter 6** I then propose an alternative framework for the re-worked Bill, and motivate the reasons why I believe the alternative would be better should South Africa choose to promulgate E/PAS law in the future. In this chapter I also focus on the role that South African medical practitioners fulfil in end-of-life management and argue for their protection and support in the event of a societal change in

attitude that encourages assisted death. As a backdrop to E/PAS legislation, in **Chapter 7** I examine the state of palliative care in South Africa from when it was first formally introduced to what is available now. I address the plans for its improvement and describe the ethical guidelines for palliative care that have been written recently for South African Health Professionals. In C**hapter 8** I conclude the thesis by summarising the main points extracted from the body of work. I explain how an ethico-legal setting can be achieved, and offer an ethico-legal framework that would give doctors clear direction on how to manage difficult end-of-life dilemmas in South Africa.

1.5. RESEARCH ETHICS COMMITTEE

This research did not involve the participation of human research participants, or the use of animals. A waiver of ethics review was applied for and approved. See **Annexure 3** for the waiver certificate.

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CHAPTER 2: ETHICS

2.1. INTRODUCTION

Prior to embarking on an ethical analysis in the chapters that follow to assess how different ethical environments affect the law, communities and medical professionals, some explanation must be given of what the term 'ethics' entails. Beauchamp and Childress describe it as a broad, non-specific term that encompasses the different ways to examine and understand what it means to live a moral life[1]. Rachels and Rachels explain that, at its minimum, morality is the intention to guide human behaviour by reason. One must act in accordance with what option has the best reasons for doing something, while assigning the same weight to the interests of each person affected by the decision[2]. Several methods of inquiry are available for examining what it means to live a moral life, but for an examination of medical ethics, it is appropriate to use a normative ethics approach.

Ethical theories are used in an attempt to recognise and justify the norms. Practical or applied ethics, which incorporates medical ethics, is the effort made to interpret general norms to solve specific dilemmas and contexts. The norms are applied in discussion about ethical difficulties, practices and guidelines in professions, organisations and government[3]. Consequently, normative ethics is important for choosing an appropriate ethical environment in which doctors can be assisted when making end-of-life decisions.

General normative ethics tries to answer the question of which broad moral norms should be embraced for the guidance and assessment of conduct, and why. These norms may be in the form of theories, principles or precedents. The collection of norms shared by all who pursue a moral life is called the common morality. The common morality sets the standard by which people are judged as moral or immoral, depending on their conduct. Examples of the common morality include: 'do not kill', 'do not cause others pain and suffering', 'prevent harm'[4].

Below is a selection of the better-known moral philosophies and bioethical principles applied globally. They are presented in chronological order to illustrate how philosophies changed within social environments as mindsets shifted to accommodate new challenges. Ultimately, they influenced the South African legal framework.

2.2. ETHICAL THEORIES

2.2.1. The Ethics of Virtue

The Greek philosopher, Aristotle (384-322 B.C.E.), conceptualised the theory of virtue ethics, of which the following is a brief history.

a) Ancient history

The ancient world's law and custom was generally opposed to suicide. In ancient Greece and Rome, between approximately 500 B.C.E, spanning a vast period to 350 C.E.[5], the discussion surrounding euthanasia began. On a moral level, many people accepted euthanasia and suicide only in extenuating circumstances. Despite this stance, suicide was supported and commended if, in fact, it was based on reasons of poverty, mutilation, sickness, sudden misfortune, habitual vice, or disgrace[6].

Aristotle tolerated euthanasia and suicide depending on the circumstances. For example, he thought that to kill defective infants was not unethical, but did not support suicide if it conflicted with any of the virtues. Thus, killing oneself to avoid the suffering of life was viewed as cowardice because it undermined the virtue of courage. Also, where suicide was against a city's laws, such as in Athens, it would desecrate the virtue of justice by breaking the law. On the other hand, when suicide was an act of courage or love Aristotle did not condemn it as immoral[7].

Some Greek philosophers went as far as to promote suicide. Epicurus (341-270 B.C.E.), who founded his own school of philosophy, Epicureanism in support of hedonism, proposed that the chief good in life was to seek pleasure and avoid pain[8]. At the point that pain engulfed the pleasures of life and there was no longer the hope of pleasure, he saw suicide as an appropriate moral response[7]. Stoicism, a philosophy that was popular throughout the classical period after 300 B.C.E., encouraged living 'according to nature'. Consequently, death was perceived to be 'natural', so hastening its onset at the end of life was advocated as reasonable and virtuous[7].

In contrast, there was a group of philosophers, the Pythagoreans, who did not agree with this way of thinking. Around the fifth century B.C.E., Pythagoras (l.c. c571- c497 B.C.E.) focused on the importance of the immortality of the soul and the emphasis on virtuous living. He identified essential incontrovertible truths in life which he believed one should acknowledge

and live by in order to lead a good life[9]. The Pythagoreans established a deep-rooted tradition in medicine that was attentive to the education and ethical foundation of physicians. They were opposed to euthanasia because they viewed life as a single entity shared by all living things which recycled. With this in mind, intentionally bringing about death was seen as disruptive or damaging to the order of life and, therefore, wrong[10].

The physician, Hippocrates, followed Pythagorean beliefs. Significantly, the Hippocratic Oath named after him remains a reference for moral guidance in medicine to this day, although it is thought not to have been written by Hippocrates himself [11]. It includes a promise by physicians not to give a lethal drug to anyone if asked[12]. Pythagoras ultimately influenced Plato's thinking. Plato (427-347 B.C.E.) was a student of Socrates (c470-399 B.C.E.) who, during the third century B.C.E., became Aristotle's teacher[11].

Aristotle developed his own ethical theory about virtue. He proposed that by living a virtuous life one could attain happiness, the highest purpose for human existence[10]. Aristotle's explanation of a virtue was a trait of character that was valuable to have - for instance courage - expressed as the mean between two extreme vices, one being of excess and one of deficiency. A virtue existed through commendable habitual action such as compassion, courage, reasonableness and tolerance[13]. Being virtuous required practice, starting from childhood where one would be taught right from wrong. Over time this behaviour was expected to lead to 'personal excellence', a virtuous character, applying practical wisdom[14] that would help one to gauge any situation and know how to respond appropriately.

The three main concepts of Aristotle's virtue ethics are summed up by Devettere as happiness, moral virtue, and prudence[15].

Happiness is explained as what everyone aspires to attain, and the best way to achieve happiness is by practising moral virtue, as clarified above. The pursuit of happiness in Aristotle's time, unlike now, was not driven by selfishness. Until the end of the 16th century, most people did not have an individualised idea of existence, but rather embraced a social existence of community made up of personal and political relationships. It was understood that everyone was connected at an existential level. If the existence of someone was undermined, it affected others in the community[16].

The Greek philosophers did not separate virtuous traits from the exercise of reason[17]. Aristotle

deduced that everyone and everything had a purpose, a reason for existence. The purpose was identifiable by studying the real world which offered a rational reason for existing. The reason was to benefit humankind[18].

Aristotle and Aquinas proposed that in order to decide what would lead to moral virtue, one was expected to apply prudence. They saw prudence as an intellectual virtue, which was the dominant virtue for ethical and political decision-making. Prudential reasoning is adjusted to situations and contexts[19] and is presented in more detail later as a suggested tool to be applied by doctors.

b) Christian influence

Once Christianity was established, Saint Augustine of Hippo (354-430 C.E.), who was a respected early medieval philosopher and theologian, proposed placing God's moral law above man's reason. Divine Law was consequently the dominant doctrine, encompassing theological virtues.

Augustine made no allowance for suicide. Ortiz highlights that in Augustine's translated work, *The City of God,* Augustine argued that suicide violated the divine law against killing and the command to love one's neighbour as oneself [6]. It also transgressed the natural law that required one to seek the good of existing. Divine law was reflected in natural and human law. Augustine reasoned that nature recoiled from non-existence because everything had a natural 'desire' to exist. Furthermore, Ortiz explains that Roman law at that time judged the magnitude of the crime of killing to be more serious the closer the relationship of the accused was to the person killed. Augustine believed that the closer the victim was to oneself, the more one threatened the order of society and God's order of the world. This, in turn, undermined personal existence and the relations that emerged from it. He observed that pagans seemed to have a lust to die, a '*libido moriendo*', so he incorporated into Christian morality a principle first articulated by Socrates, that it is better to suffer evil than to commit evil.

Divine Law was replaced during the Renaissance period (1400-1650) with a move back to reason and the establishment of Moral Law. This was a more rules-based approach, which asked the question: 'What beneficial action should be taken in a situation?', instead of 'What character traits make up a good person?'[20] Moral rules were said to have originated from the laws of nature. The doctrine of natural law was founded on trust in the existence of a natural moral

code. It relied on the recognition of some basic, objectively demonstrable, human 'goods' that were believed to have been present before any formal social or political order. Likewise, people were deemed to have natural rights as individuals, free from society or politics[21].

The laws of nature resulted in Natural Law Theory. The theory was an outcome of the Middle Ages. It became well-known through the famous works of the Italian Dominican friar and priest, Saint Thomas Aquinas (1225-1274)[22]. Aquinas proposed that mankind has an inherent awareness of right and wrong that directs their mind and conduct. He called this ethical theory 'practical rationality'[23]. The Theory of Natural Law supported the idea that the correct action was whatever offered the soundest reasons for its application, removing morality from the ambit of religion. It was viewed, significantly, as an independent concept[24].

Natural Law laid the foundation of South African law, as illustrated in the writings of the Dutch statesman and scholar, Grotius (1583-1645)[25], who embraced Aristotle's and Plato's philosophical outlooks[26].

The South African legal case, *Clarke v Hurst*, which concerned the lawfulness of withdrawal of treatment from a person in a vegetative state to allow him to die, reveals the court's application of natural law: the judge refers to Grotius's definition of 'legal damage' (delict) as 'whatever is contrary to reason as indicated by natural law'[27]. This case is analysed in detail in the next chapter.

In the 17th and 18th centuries, with the ongoing development of the doctrine of natural law, a notion of human rights materialised that was a precursor to modern-day understanding[21]. Devettere asserts that the French philosopher, Descartes (1596-1650)[28], who became known as the father of modern philosophy for having famously said: 'I think, therefore I am', drew attention to individualism. It removed the emphasis on communal existence and altered the prevailing perception that everyone was connected at an empirical level.

Some 20th century philosophers, according to Devettere, have tried to redress the excessive focus on individualism that place human rights foremost in modern philosophies and liberal political theories, by trying to recapture the social existence of the past[16]. Human rights were recognised as necessary in order for a person to lead a minimally good life. Several moral doctrines underpin the philosophical development of the prerequisites for contemporary human rights. As a starting point, the writings of Aristotle and the Stoics are associated with the first

suggestions of moral universalism in Europe. The origins of human rights stem from the idea that a universal human community existed with a belief in moral universalism. Over subsequent centuries in Europe, Christianity sustained the confidence in a universal moral community. Aristotle put forward an argument for the presence of a natural moral order that he thought should provide the foundation for all rational systems of justice. He distinguished between 'natural justice' and 'legal justice' by emphasising that natural justice has the same legitimacy everywhere and did not depend on people's acceptance of it[21].

Locke (1632-1704), a British medical researcher and philosopher who lived through a tumultuous political period of conflict between the Crown, the State and the Church, was the chief proponent of the argument that people possessed natural rights. He had read Descartes' work, adapting it to his own philosophy and found it preferable to Aristotle's[29]. Locke put forward that natural rights arose from natural law, and that natural law came from God. He suggested that, by attentively establishing God's will, an authoritative moral code could be identified. He proposed that individuals owed God a duty of self-preservation. To uphold this duty a person had to be free from danger to their life and liberty. The motivation to protect a person's natural rights was the only reason, according to Locke, to form a government. In addition, the boundaries of governmental authority were clearly demarcated: they were to deal specifically with life, liberty and property, where having property was seen by him as a requirement for self-preservation. He stated that government was to ensure the wellbeing of its people exclusively, not to pander to the interests of the Monarch or a ruling faction.

Ultimately, Locke established a precedent that advocated for genuine political leadership based on a foundation of rights which would be a vital constituent of human rights. However, the moral reasoning behind the theoretical core of human rights is given by a German Philosopher in the 18th century, Immanuel Kant, who is reviewed later in this text[21].

c) Present considerations

Following Descartes' introduction of the concept of individualism, over the subsequent centuries various moral theories such as Utilitarianism and Kantianism were formulated, which concentrated on right action and rules. (These philosophies are presented later) Despite their fresh approach, the doctrine of virtue was re-introduced during the 1950s by the British analytic philosopher, Elizabeth Anscombe (1919-2001)[30]. This was in response to her[31,32] impression that the ethical theories being espoused were incorrect and had been a failure. She embraced

Aristotle's earlier work, once more positioning virtue in a person's character as the focal point of philosophical theory[32,33]. Anscombe's effort initiated a great deal of contemporary literature in support of Virtue Theory. It accepted that some virtues apply to everyone regardless of culture or personality, for example courage, generosity and loyalty[34]. She also believed that moral rules were absolute, such as it never being acceptable to intentionally kill innocent people. Many philosophers disagreed and argued that circumstances existed that could justify an exception[35].

Virtue ethics, when applied to the doctor-patient relationship, highlight that the virtues displayed by doctors towards patients, such as integrity, honesty and compassion, result in a connection which generates trust. Baier (1929-2012)[36], a New Zealand feminist philosopher, expressed this trust as an acceptance of letting someone care for them. It involves giving another some degree of discretionary responsibility in deciding their care[37,38]. Trustworthiness is indispensable in medical care where people are placed in vulnerable positions. Consequently, where a law exists that permits euthanasia as an end-of-life choice, consultation with a doctor within this relationship of trust and the presentation of all the options can influence the patient in ways that would not arise if the law were not in place. This point is canvassed further in chapter 5.

Advocates of E and PAS anticipate that a doctor's compassion is at the fore when they respond to a patient's request to relieve unbearable suffering through E or PAS. This could be a strong and credible reason to assume that it is both merciful and ethical to support the patient's wish to die in line with a primary objective of medicine, which is to relieve suffering. However, various writers have warned that a sympathetic and passionate commitment to others can also mislead, resulting in bias, irrationality and flawed judgment[39].

Opponents of hastened death argue that a reasonable alternative to euthanasia is to place a person under deep terminal sedation, essentially rendering them unconscious for the final days of their life. Terminal sedation is contemplated in chapter 6. However, the proponents of E state that to simply prolong death in this manner, against the patient's final wish, is neither rational nor humane[40]. The process of terminal sedation is perceived by some as placing a person into a vegetative state. This may seem very unsatisfactory, but Devettere contends that, morally, it may be the lesser of two evils: to compassionately relieve suffering, rather than to kill. He suggests that terminal sedation should be seen as being the worst that one can do, which is better than encouraging private killings[41]. The only justification for E, then, would be where

suffering could be relieved in no other way than by killing – such as on a battlefield. Indeed, the court in the *Clarke* case held that quality of life in a vegetative state is factually no life at all[42].

According to Rachels and Rachels, virtue ethics has two main strengths: firstly, it motivates people to act morally, and secondly, it encourages caring relationships. These are important in order to live well. Other theories, in contrast, promote impartiality and right action without considering character, which gives the impression that they are incomplete. Rachels and Rachels do offer a frequently expressed weakness of this model, and that is that it does not guide someone in a practical dilemma. It does not assist where either of two conflicting virtues could be exercised, such as being honest as opposed to being kind because a person's feelings may be hurt. Virtues contemplated in isolation, he says, are too non-specific, and therefore unhelpful in resolving an ethical dilemma. Rachels and Rachels recommend that the theory may best be used by combining it with other philosophies so that each is enhanced by the strengths of the other[43]. Some elaboration is provided at the end of this chapter.

The complaint that virtue ethics does not produce codifiable principles, so cannot give guidance for actions because the theory is 'agent-centred', is contradicted by other writers such as Anscombe. An example of turning a virtue into an action-guide is offered by the academic, Hursthouse who writes, 'Do what is honest; do not do what is dishonest'[44]. Hursthouse further points out that the vocabulary of virtue and vice has a fairly short list of virtues but a comparatively long list of vices. The vice terms are far in excess of standard deontological rules. She illustrates her statement by showing that a great deal of good can come out of refraining from actions that are irresponsible, self-indulgent, inconsiderate, intolerant, tactless, indiscreet, disloyal and many others. Applied in this way, virtue ethics has a place in the ethical guidance of doctors.

After the development of Moral Law based on human reason rather than religion, but before Elizabeth Anscombe's commentary, rules were created to clarify what actions were considered to be right. The duty of ethical individuals was to follow the rules, which led to modern theories that focused on right action and obligations[45]. Two of the most popular theories, Utilitarianism and Deontology, are examined next.

2.2.2. Utilitarianism

Utilitarianism is a form of consequentialism. This theory proposes that right action is the one that produces the most favourable consequences[46]. For example, public hospital policies which regulate the use of scarce resources are structured to achieve the best outcomes for the most people[47]. According to the author, Mizzoni[48], utilitarianism has an altruistic foundation which considers what the outcome of an action would be for all involved. Unlike egoism, it is not driven by self-interest. Another distinguishing factor is that it is applied impartially: everyone's happiness is of equal importance[46].

a) History

In the 1600s the early utilitarian thinkers believed it was their obligation to foster happiness among mankind because that was what God intended. The 3rd Earl of Shaftesbury, Anthony Cooper (1671-1713)[49] reasoned that a person's virtue could be measured by how he used his good intentions for the general well-being of all. He evaluated a person's moral standing through their virtues or vices. This led subsequent utilitarian writers, such as Francis Hutcheson (1694-1745)[50], a British moralist, to contemplate the link between moral decision-making and the choice of action that followed. Hutcheson ascribed the utilitarian principle of choice of action to a person's virtue being proportionate to the number of people who are made happy by him or her. However, he mentions a deontological constraint, that a person's dignity, or moral importance, may counteract the quantity of happiness achieved.

Hutcheson taught David Hume (1711-1776), an Enlightenment philosopher who, although neither a utilitarian nor consequentialist, was associated with pondering the role of sympathy in humans. He placed benevolence at the centre of his common-morality theory which had some utilitarian elements[51, 46]. Hume was sceptical of human nature. He perceived that humans were naturally selfish and had very little sympathy for the troubles that others faced, although he accepted that people could surmount these weaknesses with contemplative judgment. Striving for moral excellence in this way would lead to impartial viewpoints that were more socially and publicly sensitive. He lamented the fact that people's severely limited capacity for sympathy and generosity could result in the abuse and neglect of the frail and elderly[52, 46]. However, Hume saw a strong connection between morality and human sociability because of the individual's ability to participate in others' beliefs, feelings and emotions[53].

Classical utilitarianism was fuelled by a need to transform corrupt social and legal practices of 18th century society. Jeremy Bentham (1748-1832)[54], trained in law and influenced by Hume's theory of social utility, promoted the idea that governments should apply the principle of utility to maximise happiness. He proposed this as the standard for correct action given that actions could be controlled through legislation. He saw the development of law as an ongoing process that responded to changes in society over time, its purpose being to promote welfare. Government, on the other hand, was required to keep the restriction of personal freedoms to a minimum. Consequently, Bentham thought that only harmful or dangerous activity should be illegal[55].

The focus of these utilitarian philosophers shifted towards evaluating the consequences of an act, rather than the content of a person's character[46]. The principle of utility, being the production of the most happiness possible in every situation, was a drastic change in thought: it removed abstract moral rules and God from the determination of what ought to be done[56]. Morality was now associated with the pursuit of happiness by engaging in pleasurable activities.

John Stuart Mill (1806-1873)[57] was an English philosopher and political economist. He followed Bentham and admired his thinking, although he criticised some of Bentham's ideas, such as his theory that there were no differences between various types of pleasures or happiness, only the quantity thereof. Mill also attempted to influence the law and social policy using his utilitarian theory. He was a great supporter of women's rights and free speech from the perspective of utility. He reasoned that a right or duty that proved to be harmful, such as refusing women access to education, would preclude a major source of happiness: a right or duty that increased happiness was good. Nonetheless, Mill recognised that virtue was still required for the mind to embrace utility and find general happiness[46].

In his writing, Mill stated that the only legitimate exercise of power against someone's will would be if it were to protect others from harm. What a person chose to do to himself was his own business and should be beyond the reach of the law[57]. Euthanasia would find support in this theory because Utilitarianism weighs up what action would produce the greatest amount of happiness over unhappiness. Where suffering of the individual is so deep and unrelenting that the prospect of death is seen as preferable to continuing with life, and the person requests assistance with death, a utilitarian philosopher would defend euthanasia as being morally right. This would be so because it is viewed to be neither harmful nor dangerous to anyone else, and no one else's business. It would replace the anguish that the person experiences with peace of

mind.

Although the Christian influence was still prevalent at the time of Bentham, being a classical utilitarian, he argued that the principle of utility did not go against religious beliefs: a wise and powerful God who is also benevolent would understand it. E then, could be promoted as moral by such reasoning, but most religious people would differ with Bentham[55].

Koenane[58], a professor of philosophy in South Africa, has suggested that Utilitarianism would support E and be a moral intervention because it would bring happiness to the greatest number of people with terminal illnesses who have no hope of recovery, in contrast to the alternative indignity of their intolerable pain and suffering. However, he acknowledges the moral dilemma that E creates because of the participation of other moral agents: the doctors who share in the act to give the patient their wish to die, other medical staff who may be involved against their will and family members who may not be supportive of the decision. If one weighs up the amount of pleasure generated by the death compared with the unhappiness caused by the process, E may not necessarily result in the greater happiness.

A criticism of Utilitarianism is that it is overly simplistic, so could support any behaviour that leads to greater happiness. The focus of this theory is too narrow in that it overlooks other important factors to consider for a person's wellbeing, such as treating people fairly by applying justice in the specific situation in which they find themselves. An example that Rachels and Rachels offer to illustrate the shortcomings of this philosophy and its perversion of the truth is where riots occur because of a crime in an area and a utilitarian, who has a duty to bring about the best consequences, names someone falsely as the perpetrator to stop the riots[59].

b) Present considerations

Medical Ethics textbook authors, Mason and Laurie, write that modern Utilitarianism is considered by many to support modern ethical medicine. They put forward that it has developed to recognise the significance of rules in ascertaining moral goals and explain that this prevents the 'happiness of many overshadowing the rights of a few'[60]. Peter Singer, an ethicist who has contributed a great deal to contemporary applied ethics, subscribes to a further modification of the theory called 'preference utilitarianism': it permits the assessment of the value of an action according to the level of its consistency with the preferences of all the people affected by it. He explains that in the normal course of life we should adhere to a set of standard moral rules

derived from years of knowledge. This approach results in behaviour that promotes the best balance of consequences, taking into account the interests of all those involved in a situation. By considering everyone's preference for the highest good in an activity, it is unnecessary to assess increasing pleasure or decreasing pain[61].

Singer holds the opinion that the consequentialist ethics of the 'quality of life' measure in medicine has weakened the traditional emphasis on the 'holiness of life'[61]. He argues that certain forms of killing are morally permissible: a disabled new-born who, once killed, can be replaced with a healthy child so that the parents have a better quality of life, or terminally ill people who choose to end their lives so as to escape the poor condition they are in. He also sees no 'inner moral difference' between actively killing a person or allowing someone to die by withholding life-sustaining interventions, because the agent remains morally responsible for both, thereby advocating that E should be permitted[62].

Preference utilitarianism could be helpful as an ethical tool to assist doctors with weighing up end-of-life decisions with patients.

2.2.3. Deontology

In contrast to consequentialists who emphasise maximising the amount of good that results, focusing on the outcome of an action, deontologists concentrate on what a person ought to do in a given situation, and the appropriateness of the act itself. The decision of what the correct action is has priority over the amount of good that could ensue. Choices must be supported by a moral norm, so deontologists subscribe to the belief that some choices are forbidden, regardless of the outcome[63]. An example of a forbidden choice is to lie.

a) History

Mill and Hume, previously mentioned, lived during the Enlightenment Period, where science was the paradigm for knowledge. In the same period, a German academic who was influenced by Hume, Immanuel Kant (1724-1804), was recognised as a persuasive philosopher who became pivotal to modern philosophy[64]. He rejected the theories proposed by both the empiricists, such as Hume, who believed that one's senses created one's reality, and the rationalists who stated that one's reason created one's reality. He came up with his own new theory which borrowed from both points of view: that a person can only have knowledge of

things they experience, because human reason is limited to experience[64]. Kant argued further that moral rules were absolute and moral requirements categorical, based on his opinion that reason dictated morality. Kant attempted to state universal moral principles based on rational explanations that he believed should be applied to everyone equally[21].

Kant promoted the universal ethical principle, also called 'a categorical imperative', which stated that each person's humanity must be respected, and one should only act on rules that could apply to everyone. He believed that rational, morally autonomous people who were all equal would choose to impose a categorical imperative upon themselves. Consequently, acting in accordance with a maxim that bound all human beings would lead to doing the correct thing in a given situation. The requirement of universality of the moral principles, Kant thought, was a necessary expression of moral autonomy and equality between people. He expected consistency in reasoning which a rational person could accept, but limited the application of his theory by insisting that no exceptions could exist beyond the formulated moral rules[21].

Many academics disagreed with his creation of absolute rules that allowed no exception, including Anscombe who, although she accepted his conclusion, believed his reasoning to be flawed. Rachels and Rachels highlight that the Kantian rules were reasonable if they were not required to be absolute. The framework just required the proviso that if a violation of a rule occurred, there would be an explanation for it that everyone would accept[65].

Kant emphasised the importance of treating every individual as an end in themselves, not as a means to an end. Therefore, people were to be respected as having moral worth, acknowledging their autonomy[66]. The intrinsic value of every person was also perceived as innate human dignity[67]. Ironically, Kantian philosophy promoted a focus on the obligations owed to others, whereas the emphasis on autonomy reinforced peoples' rights, focussing on themselves. That failed to address the consequences of the exercise of those rights on society at large[64].

Ultimately, Kant made a huge contribution to the theory of human rights. Contemporary philosophical defences of human rights contain many of Kant's themes, such as the possibility of a universal community of rational individuals who especially value and uphold equality and moral autonomy. Equality and moral autonomy are two ideals that Kant emphasised as key in his philosophy. He offered the power of reason in support of human rights being used as the foundation of self-determination. He endorsed human rights as universal rights that people acquire as autonomous and 'formally equal' human beings[21]. These exist as standards beyond

any legal system, whether the system defends them or not.

When political theories were developed with natural rights at their core, the most important right was the right to life in order to safeguard everyone from being killed. The expansion of the right to life in moral and political philosophy laid a persuasive foundation henceforth for the protection of the lives of innocent people[68]. Consequently, with regards to ending a person's life prematurely, Kant rejected the killing of innocent people out of hand, including committing suicide. This attitude was based on the argument that human beings as rational agents have inherent dignity and therefore intrinsic value[67]. Hence, to cause death is seen as a form of harm that cannot be acceptable under any circumstances. People have an equal duty not to harm themselves. Kant would accordingly not have supported E or PAS. However, he did have questions about possible exceptions to this rule such as where a person was suffering from an incurable disease that would result in him losing control of his mental faculties and injuring others. Devettere highlights the irony of how the rights movement has changed from canvassing for protection of human life in the past, to justifying its extinction now[68].

b) Present considerations

In the last twenty years, contrary to the established religious and philosophical positions of old, there has been a moral shift towards promoting the acceptance of 'reasonable' suicide and E as an extension of the rights to autonomy and dignity highlighted in bioethical and legal fora[68].

Medical practitioners and sometimes nurse practitioners perform E and PAS in foreign jurisdictions such as Canada: it has legislation in place that upholds the individual's right to dignity and self-determination by permitting their choice of a hastened death[69]. The South African Constitution[70] is comparable to the Canadian Constitution[71], whose experts contributed significantly to South Africa's legislative framework[72]. If the legal structure of a country mirrors its public morality, then South Africa reflects a deontological trend that is identifiable in its Bill of Rights. The Bill of Rights legalised the universal rights of every person, guaranteeing state protection thereof. The judiciary interprets them on a case-by-case basis to develop working rights that are less abstract. At the level of judicial interpretation, one sees the influence of other ethical theories, which are elaborated upon in chapter 3.

In line with a deontological approach, the medical practitioner also has the right to refuse to take part in practices that offend their personal morality. They make use of conscientious

objection, despite the doctor-patient relationship, the patient's autonomy, and their dignity. Forcing Medical practitioners to perform E/PAS against their will would cause harm to them, be disrespectful and be treating them simply as a means to an end. Rachels and Rachels elaborate that Kant did not object to someone being treated as a means as long as they consented to it. He objected to a person being treated only as a means, for example through manipulation of them to achieve one's own purpose. To treat someone as an end entails treating them well, respecting them, not causing them harm, and promoting their wellbeing[73].

The deontological emphasis placed on a rational individual's self-determination is evident today, making this theory valuable to the ethico-legal environment in which a doctor could discuss end-of-life decisions. Autonomy is also one of the four pillars of the biomedical ethical principles discussed next.

2.2.4. Biomedical Principles

As the terrain of bioethics developed, ethicists Beauchamp and Childress presented four biomedical moral principles to provide a helpful and popular tool for ethical decision-making amongst medical practitioners[74]. A brief history of the advancement of these bioethical principles follows.

a) History

Callahan[75], a communitarian philosopher, records that during the early seventies attention settled on the domain of medical ethics. He questioned whether it should have as its source the traditions and history of medicine, or rather base its foundation in general ethical theories and principles such as in the fields of deontology or utilitarianism (or a combination) with which philosophers were familiar. These proved to be inadequately broad tools for clinical decision-making, while Principlism as a methodology gained traction with physicians who faced ethical dilemmas.

The work of ethicist William Frankena in the 1960s is noted as an important early inspiration for the development of ethical principles, such as his concept of 'action-guides'[76]. Subsequently, in America from 1974 to 1978 the National Commission for the Protection of Human Subjects of Biomedicine and Behavioral Research was tasked with compiling a report following an investigation into alarming abuse in research. Beauchamp was a member of the

Commission in his capacity as staff philosopher, which ultimately produced The Belmont report. This report's ethical findings had a great impact on almost every area of Bioethics, including research, medical practice, government regulation and moral theories. It led Beauchamp and Childress to produce a book on biomedical ethics during the same period[77].

In 1977, Tom Beauchamp and James Childress sent the first edition of the book '*Principles of Biomedical Ethics*' to press. It described four bioethical principles as an approach to solving dilemmas in clinical ethics[78]. The principles identified are autonomy (respect self-determination), beneficence (do good), nonmaleficence (do no harm), and justice (be fair). 'Principlism' presents a fresh alternative to the other theories, such as virtue ethics, utilitarianism and deontology, that were the main philosophies concerned with medical ethics at the time. Beneficence and nonmaleficence practised in medical care can be traced back to the Hippocratic tradition. It was the abuse of autonomy and justice, which related to fair and equal treatment of patients in health research, besides medical care, that led to their inclusion as principles. People brought legal cases to court to pursue remedies for such abuse which led to laws in support of the field of bioethics[79].

The authors locate their principles in the hierarchical framework of bioethics as follows: specific actions and ethical judgments → moral rules → ethical principles → ethical theories In this context, ethical principles are used to ground ethical rules which defend ethical judgments about the morality of actions. Like Frankena, they refer to principles and rules as 'action-guides[78].

b) Present considerations

A brief discussion of each principle follows.

(i) Autonomy

Beauchamp and Childress emphasise that respect for an individual's choice is not promoted to the exclusion of the social context and the impact a decision or action has on others, nor does it replace emotions with reason, nor are they highlighting legal rights at the expense of communal practices and accountabilities. Respect for autonomy does not have a higher status than the other principles, despite it being well recognised in western common morality. Autonomy encompasses self-governance that is free from the supervisory meddling of others,

as well as from some constraints such as an insufficient understanding that prevents the exercise of appropriate choice[80].

This concept combines Kant's focus on the autonomy of the will driven by reason. Mills' focus is on the autonomy of action, exercising freedom of choice. Beauchamp and Childress, on the other hand, suggest that respect entails giving due regard to the person's contemplated judgment which affects only himself, even when it is thought to be incorrect. The exercise of autonomy necessitates that a person has the freedom to choose, otherwise there is an obligation on society to protect them from harm. The judgment, however, must be based on rational reasons[81].

A weakness with this principle is that even rational people may experience temporary constraints to their sensibilities, for instance from sickness, depression, inexperience, ignorance or coercion[82]. Similarly, emotions such as dependency, trust and love could have comparable results.

The principle of respect for autonomy is used by proponents of E and PAS to endorse self-determination. Such a decision, it is argued, would only affect the individual who made it. However, the strength of the argument is undermined when placed in a social setting because it does impact others, for example those required to facilitate the action, including family and the larger medical community. Some academics recommend that autonomy be interpreted through relationships rather, arguing that identity is shaped by complex social determinants such as race, class, gender and authority structures[83].

South African medical law promotes the ethical value of self-determination, such as through the National Health Act's provision for informed consent, including the right to refuse medical treatment, and the patient's right to participate in every decision related to medical care, regardless of their legal capacity[84]. Furthermore, the medical practitioner's professional ethical guidelines require doctors to uphold the value of respect for patients' autonomy[85].

(ii) Nonmaleficence

The principle of nonmaleficence - to intentionally avoid doing acts that produce harm - will be limited in this thesis to not causing physical harms, including pain, disability, suffering, and death, in line with Beauchamp and Childress's approach[86]. However, avoidance of creating psychological distress remains important. At the end of a person's life, medical practitioners

are confronted with conflicting emotional and ethical dilemmas when upholding the value of nonmaleficence. Death as an outcome after medical involvement may be contemplated as either foreseeable harm or compassionate good. An example of this difficulty is illustrated in the process of withholding or withdrawing medical treatment.

Beauchamp and Childress fiercely support quality-of-life judgments when the experience of life is so reduced that treatment results in more harm than benefit[87]. They put forward that, despite the emotional differences between the processes, there is no moral distinction between withholding and withdrawing medical treatment. However, the literature indicates that medical practitioners differentiate ethically between these two options at the end of life. Withholding therapy, such as by implementing a 'do-not-resuscitate' order, is seen as less ethically challenging than removing parenteral nutrition or switching off a respirator. This is suggested to be because they may not feel causally responsible for the patient's death by withholding treatment and have not created an expectation that they will continue to treat. Withdrawing treatment, however, could lead to discomfort that they have reneged on their contract. Reasoning in support of not withdrawing treatment in progress is that a *prima facie* claim arises to continue therapy once it has been started if the patient has not waived this claim at some earlier stage, even if it would have been ethical to withhold it originally, despite a lack of consent[88]. Beauchamp and Childress point out that either withholding or withdrawing treatment can be justified under certain conditions, resulting in allowing death or causing death, and to draw a distinction between the two processes is flawed reasoning[89]. Moreover, the judiciary and the Health Professions Council have accepted both these steps as morally and legally acceptable[90].

The patient's refusal of ordinary life-saving treatment could be classified as suicide because it is the person's intention to die as a consequence of the decision[91]. Likewise, the doctor's withholding or withdrawing of treatment is a purposeful act or omission, each of which will foreseeably result in death. These practices are essentially accepted by society as reasonable and ethical today. Arguably, in principle the same attitude could apply to E and PAS, as there is no difference in the outcome. Beauchamp and Childress say that if we assume the principles of autonomy and nonmaleficence validate the refusal of treatment, then these ideologies might extend to the support of medical practitioners prescribing barbiturates or performing other types of assistance requested by the terminally ill to hasten death[92]. Quill *et al.,* while expressing their view in support of the Doctrine of Double Effect, which permits the administration of higher dosages of medication that could hasten death in order to alleviate terminal discomfort, state

that a medical practitioner's care of the dying patient is appropriately guided by the patient's level of suffering, their informed consent and the lack of any less harmful alternatives to the treatment offered. This approach is in line with traditional medicine and the expectations of society[93].

The issue is whether a valid request could be recognised in similar circumstances to a valid refusal, particularly when it means that the medical practitioner does not abandon the patient and when it may be a compassionate act, in the patient's best interests. Patients would have freely chosen the cessation of life, to be relieved of pain and suffering. Death, then, is perceived by the patient to be a benefit rather than a setback to their interests, not a harm or a wrong. In contrast, the outcome of a doctor not assisting the patient could result in prolonged pain, discomfort, despair and indignity which would be a harm[94].

Bearing in mind that the principle of nonmaleficence is to do no harm, terminal sedation is another final management solution used in South Africa and offered at the end-of-life to alleviate suffering. This option is offered to people with intractable pain or severe distress, refractory to standard palliative medication. Sedative medications are administered to relieve discomfort by reducing patient consciousness while also forgoing hydration and nutrition[95]. One only becomes eligible for this stage of intervention once other palliative medications for each symptom are no longer effective[96]. In this scenario, doctors are reassured that the compassionate gesture of administering high doses of medication to put the patient into a comatose state, along with withdrawing fluids and nutrition, is ethically and legally acceptable. Although the foreseeable end point is death over a period of days that follow, the intention is to relieve distress and not to kill[97]. By comparison, it is arguable that there is no difference in principle between terminal sedation and E, except in the time it takes for life to end. The end-of-life decisions made by the medical practitioner of withdrawing or withholding treatment, and terminal sedation, often in conjunction with the patient's family, amount to an intentional and active process of achieving death[98]. It may just take longer, which proponents of E put forward as less kind than the alternatives of PAS or E, considering that E and PAS both offer a more rapid progression towards the inevitability of death[99].

The examples above demonstrate that the principle of nonmaleficence is not invariably violated when death ensues from the actions of a medical practitioner.

(iii) Beneficence

The principle of beneficence requires the medical practitioner not only to refrain from causing harm but to ensure a positive outcome or benefit, for a patient[100]. It is similar to utilitarianism in this respect but is not the dominant determinant of the four principles, rather one of the group[101]. A doctor's primary purpose is to promote the welfare of their patients. There is an embedded assumption in the health context for medical personnel to be beneficent, recognising the debt owed by Medical practitioners to patients for allowing them to learn their skills in the first place. This renders them less 'independent' as practitioners than often conveyed in medical ethics codes, in which they are presented as altruistic[102]. Beneficence shown to specific persons stems from unique moral relationships with the individuals, either through contractual relationships or institutional roles. Harms need to be balanced against benefits such that benefits are maximised while harms are diminished[103]. Thus, where medical practitioners are confronted with a request for E or PAS from an incurably ill patient who, because of inexorable suffering, sees fear of life as greater than fear of death, and does not want to be terminally sedated, the principle of beneficence may dictate that upholding the request for E is a benefit owed to that person, rather than a harm. Accordingly, a refusal by the medical practitioner to facilitate someone's demise because of their personal opinions could be criticised as being inappropriate and unprofessional.

Whether the exercise of the doctor's right to refuse is itself ethical, considering the relationship that the doctor has with the patient, has been questioned by various authors[104]. Savulescu states that when the duty to perform is a duty arising from the trust-relationship, it is immoral for a physician to refuse. He expresses the opinion that although values are important, they have different functions in private and public life. They can direct the mind toward what type of health system to deliver, but not influence the care offered by an individual doctor to a patient. 'Value-driven-medicine', as he describes it, has no place in professional performance because ethical relativism creates confusion, injustice, and a loss of service delivery. He believes that the public interest, not private interests, must be served by public servants[105].

It is accepted that ethical physicians will not cause harm to life unless they reach the conclusion from moral deliberation that there are substantial overriding reasons to do so. They would try to prevent harm whenever possible and promote the well-being of the patient. Devettere submits that sometimes a good life cannot be achieved without damaging or even destroying life. He suggests a practical guideline: 'Whenever what we are going to do, or not going to do but could

do, will result in a bad outcome, (that is, will give rise to suffering or damage to life) then we will avoid the behaviour unless there are overriding reasons not to avoid it. And the greater the bad, the stronger the overriding reasons have to be'[106].

(iv) Justice

Aristotle, referencing Plato, stated the principle of proportional equality as 'treat like cases as like'[107]. Namely, treat equals equally, and unequals unequally as the minimum standard of justice. Contemporary academics now offer a more focussed explanation of the concept of justice as fair, equitable treatment of people because of what they are entitled to expect in light of their particular circumstances. Justice is an act or omission that gives people resources and protections to which they have a moral right[108].

The academic, Fagan, puts forth that the primary philosophical foundation of human rights is confidence that a form of justice exists for everyone[21]. He observes that through the language of human rights people have an expectation of how they ought to be treated in contemporary society by each other and international bodies. Human rights should be viewed as moral guarantees of how to lead a minimally good life. So, to the extent that these have not yet been realised by the modern world, Fagan suggests that it reflects a dismal failure to establish a morally compelling order founded on human rights.

In ethical theory, distributive justice encompasses fair and appropriate distribution of benefits and burdens amongst the population, through policies based on just rules and practices. This includes managing society's political and civil rights and responsibilities towards one another[109]. Several principles of justice exist based on different fundamental moral theories, including utilitarianism and communitarianism. John Rawls, an American political philosopher in the liberal tradition, proposed an egalitarian theory of justice that embraces 'fair equality of opportunity'[110]. It has been applied by Norman Daniels, also an American political philosopher and ethicist, to health care models. Daniels promotes the idea that public institutions influencing health care distribution have a positive obligation to ensure that everyone receives the usual range of opportunities available in society by removing barriers that may exist[111]. Rawls offers a 'fair equality of opportunity rule' to overcome shortcomings in the societal infrastructure so that disadvantaged groups do not get overlooked in the distribution of benefits, while, at the same time often carrying greater burdens[111]. Some authors see this concept as important when writing health policy to manage limited health resources[112].

Distributive justice becomes an important ethical principle when considering the consequences of the injustice of not offering the same standard of palliative care to terminally ill people in less well-resourced regions of the country as those who live in city centres. If E and PAS became available as options to society in end-of-life decision-making, the concern would be that the decision to accept E and PAS may be a quick and painless exit in place of offering or improving the range of palliative care interventions available in the area. Medical practitioners may also be under more pressure in rural areas to assist people who elect to have E and PAS, despite their personal convictions, because of fewer numbers of medical practitioners working in outlying districts and the consequent inability to refer to a willing colleague, should they wish to refuse. Where end-of -life options are not available to rural communities because of a lack of resources, the principle of justice is not upheld, and medical practitioners will need to think of the best alternatives to deal with ethical dilemmas.

The authors of the four principles of bioethics acknowledge that despite the many theories, rules and principles that now exist, division, disagreement, and moral vagueness remain inescapable facets of applying moral codes to problems. These difficulties are unlikely to be removed with any one moral theory. To be effectively applied, their four principles need to be analysed and interpreted, then associated with other norms, or else they remain just a form of classification[113].

However, the bioethical principles have been widely used in practical guidelines to assist medical practitioners to assess ethical matters. Demonstrations of their application are seen in the latest Health Professions Council of South Africa (HPCSA) Guidelines for Palliative Care[114] and the World Medical Association Medical Ethics Manual[115], referred to further on in this thesis.

2.2.5. African Philosophy

African philosophy, described as African Humanism by the academic, Gade, promotes communitarianism and *ubuntu*[116], in contrast to modern western thought that focuses primarily on autonomy (Kantianism)[21]. The ethic of communitarianism is at the heart of African values.

South African people have sought to re-acknowledge their traditions and indigenous culture following the cessation of apartheid, which was a cruel system of forced racial segregation and oppression in South Africa from 1948 to 1994[117]. The concept of '*ubuntu*', guided the fight against the inequality and separation of people[118], in stark contrast to the governing South

African morality of the time. *Ubuntu* refers to a way of life that benefits the whole community by living well together through a shared sense of humanity and respect for one another's dignity[118].

a) History

Communitarianism should not seem unfamiliar to the Western European cultures because in the ancient past, Aristotle, for example, understood the importance of the collective over the individual when writing about subjects that would affect the common good. In his work entitled *Politics*, he states that the political community comes before the individual citizen, just as the whole body is more important than its segments. (1253a18–29). He proposed that no citizen belonged exclusively to himself, but also was part of the city (1337a28–9). Where some issue affected the well-being of everyone, he suggested that the individual should be guided by the entire community's shared decision. In these circumstances the person would replace his independent decision-making ability with those of the society[14].

Although there are diverse cultures, worldviews and beliefs within the African continent, a commonality across the board is the acknowledgment of one's interrelatedness with others[119]. The reference to *ubuntu*, discovered in writings as early as 1846, and a concept found in almost all indigenous African languages, is thought to have originated from the Nguni language. *Ubuntu* can also be expressed as 'a person is a person through other persons', or 'humanity towards others'[120]. The academic and philosopher, Mangena, adds that the African conception of the *ubuntu* ethic has a religious foundation, explained by writers as a triadic constitution of community, which includes the living, the living-dead (ancestors), and the yet-to-be-born. Individuals therefore have an on-going fellowship and connectedness with their ancestors[121]. This is a significant point to be considered in the discussion of E and PAS in South Africa because a relationship with the spiritual world influences a large sector of South African society's attitude towards death. Understanding African morality also helps medical professionals to better appreciate their patients' needs.

Another scholar of African philosophy, Metz, suggests further that he has identified two themes frequently present in discussions about the nature of African kinship: 'identity' and 'solidarity'. These contribute to his definition of the theory, where people, as members characterising themselves with the same group, take pride in it or feel shame for its activities as a collective. Additionally, they combine their energy to reach a shared beneficial result[122]. However, Metz

is criticised by Mangena for being influenced by Western philosophical thinking and attempting to negate the religious dimension of *ubuntu* ethics[123].

b) Present considerations

African philosophy acknowledges respect for humankind and the ethical responsibility to care for one another in order that all should benefit, as a virtuous way of living[124]. This, in turn, translates into a collective responsibility to maintain each person's innate worth and protect their right to dignity, comparable to the deontological approach previously discussed. Metz associates himself with the dominant view amongst various scholars, that South African human rights are grounded in human dignity, as expressed by Kant, who postulated that the substance of dignity is upheld by respecting our self-determination[125]. However, in contrast to this notion of valuing dignity through a regard for autonomy, Metz advocates that the source of dignity is in communing with others[126]. Similarly, Dhai, a South African ethicist, draws attention to an interpretation of the principle of autonomy by African philosophers as being a norm of respect that relates to the shared environment, community, the common good, harmony and common sense. This perception of self-determination clearly embraces an inter-connectedness with one another in a way that each person mutually affects the other person's dignity, rights and responsibilities[124]. Thus, in this context, one can appreciate that respect shown by South African Medical practitioners for a patient's beliefs, dignity, and humanity when they are in the terminal phase of life also upholds respect for the community of which the patient is a part, and respect for themselves as participants in the relationship.

The emphasis on placing the community before oneself brings a different perspective to autonomy. Bikopo, in his Master's thesis, described autonomy in the African community as being perceived as a value, besides a human right, where it is exercised by someone for the benefit of the whole group, instead of for selfish reasons[127]. To illustrate, he mentions a certain Ntomba tribe that believes euthanasia of the chief must be carried out when he is near death to prevent the essence or energy of the people being lost through the chief's natural death. Many non-western cultures do not recognise 'life' as belonging to an individual, so a 'right' to request death has no place, except for compassionate reasons[128].

In this framework, Dhai proposes that autonomy as a value of respect may be interpreted as extending into many facets of communal life in an interrelated way, highlighting the interdependence of the rights, obligations and dignity of each person, which ultimately creates

an entitlement of respect for all[124].

Archbishop Emeritus, Desmond Tutu (1931-2021), a highly esteemed African theologian and human rights activist, promoted the African philosophy of harmony, friendliness and community as being the greatest good, particularly during the Truth and Reconciliation Commission[129]. During 2014, he stated publicly that, acknowledging that dying is a part of life, people should be permitted to experience a peaceful death after saying goodbye to their loved ones, and if they chose, preferably to be able to die at home. He mentioned that if a person's quality of life is seriously deteriorating and he wishes to end it, then he should not be forced to live at any cost. For reasons of personal dignity and autonomy some may prefer E or PAS as opposed to palliative care and sedation[130].

Dhai points out that, because of its overlap with each of the theories and bioethical principles mentioned above, the tenet of Ubuntu could be the basis for a bioethical theory that is universally applicable in time to come[124]. Mason and Laurie view contemporary medical ethics as made up of a collection of philosophical theories inter-laced together, particularly the deontological and consequentialist theories. They support their stance by explaining that the deontological strand focusses on whether an act is morally right or wrong. Furthermore, people should not be used, but be seen as ends in themselves, with their individual integrity respected. Being sensitive to human feelings requires virtue ethics, exercising wisdom, compassion and fairness towards patients, and a weighing up of the consequences of actions to ensure the best outcome is a utilitarian approach. Finally, a communitarian theory, such as the ethics of *Ubuntu*, places the expression of a person's autonomy within the community so the value is shared[131].

For South Africa, the ethic of *Ubuntu* has been reinforced as an important philosophy for society to embrace, not only by great leaders such as Nelson Mandela[132] and Desmond Tutu[133], but also through a number of Constitutional Court judgments, it having always been part of the cultural heritage of South African people in the past. Judges expanded upon the application of human rights at a practical level through legal cases, such as Justice Mokgoro's commentary in *S v Makwanyane*[134], which is canvassed in the next chapter. Sachs, J, a Constitutional Court Judge, highlighted in another case that *Ubuntu* pervades the whole Constitutional order, combining individual rights with communitarianism. He viewed the Bill of Rights as 'a structured, institutionalised and operational declaration … of the need for human interdependence, respect and concern'[135].

This philosophy will consequently be relevant when the judiciary and government deliberate on whether there is a place for assisted death in the country's future and subsequently, when medical practitioners support patients with end-of -life decisions.

2.3. TOOLS FOR SOLVING ETHICAL DILEMMAS

In the literature several models have been proposed to assist with solving medical ethical problems, based on the ethical theories presented above. Three models are introduced here for medical practitioners to consider.

2.3.1. Prudential decision making

Devettere promotes Aristotle's application of the intellectual virtue of prudence found in prudential thinking for ethical problem-solving in healthcare. Aquinas recognised eight dominant traits of prudence that he extracted from Aristotle's work and other writers. The list is not exhaustive nor in any order of importance, but simply a compilation to better understand prudence as a concept. Prudence involves memory, understanding, learning from the prudent, shrewdness, reasoning, consideration of consequences (foresight), consideration of circumstances (establishing who is performing it, what kind of action, where, by what means, why, how, and when) and caution[136].

To use prudential reasoning, the ethical problem is contemplated from the perspective of each moral agent who is involved in the situation. It is practical decision-making applied on a case-by-case basis. In recent years, two main models have developed: a 'rational choice' model and 'naturalistic decision-making' one[137].

The rational choice approach is described as grounded in psychological studies of problem-solving under laboratory conditions. It utilises a strategy of comparing alternative possible solutions and choosing the one best suited for the problem.

Strengths of the rational choice model include that it is generally effective because of the thoroughness of listing all the advantages and disadvantages. Different ethical options to solve the dilemma are compared, and the one offering the most favourable outcome is ultimately chosen. Due to the process undertaken, the method presents a rational well-thought-out result that the decision-maker can justify to others. Another strength is that a person who has had only

limited exposure to resolving ethical issues can use this method as a starting point to reach a conclusion[138].

Weaknesses of the model are that the rational choice process is laborious and time-consuming. It is less effective at guiding a person in more complex, ambiguous moral situations. The model responds best where rules can be applied, but humans are not always rational or controlled by rules, and create rules as they go along. Devettere elaborates that applying rules to a problem is a mostly detached activity, whereas reaching ethical decisions can be, for all involved, both very personal and emotional[138].

The second model for prudential decision-making is the naturalistic decision-making approach, also called the 'recognition-primed decision model'. It is explained as having developed from observing experienced people in actual situations solve ethical dilemmas successfully, using their insights, intuition and past experience. This model, according to Devettere, supports Aristotle's awareness of prudence and choice. Like the virtue of prudence, the decision-maker's past experience, which led to their expertise, is applied. A rapid assessment is made in the circumstances and recognition of what solution should be implemented occurs almost intuitively. Relying on knowledge from similar past situations, only a few options are weighed up to achieve the intended goal, so the range of all possible favourable and unfavourable outcomes do not need to be canvassed. Because of experience, key patterns and incongruities can be identified, facilitating a compatible solution being visualised that offers the best outcome for happiness as an endpoint. The decision is evaluated in the course of it being implemented, and situational awareness is used to observe any recognisable, as well as unfamiliar, elements with the expectation that a positive response could be followed[139].

The strength of the naturalistic decision-making approach is that it is useful to resolve complex ethical problems.

A weakness is that the success of the model depends on one's experience of a range of ethical dilemmas or knowledge of how actual situations have been approached. A person with such expertise may not be readily available in every environment that calls for ethical decision-making. Furthermore, in completely novel situations, a person must begin once more with deliberation and discussion with others. Usually, some formal reasoning is applied once a provisional decision has been formulated. Deveterre suggests that the primary cause of bad ethical decisions is insufficient awareness of the reality of the situation and a lack of experience

in handling ethical dilemmas well[140].

Lastly, Devettere offers an important moral insight in the use of prudence, described as the 'cognitive virtue of decision-making'. He proposes that the specific perceptions and deliberations of prudence applied to each real situation may have far greater value when seeking what helps to live a good life, than employing the moral generalisations portrayed in moral laws, principles, virtues, rules, and rights. Additionally, he suggests that prudential reasoning used as a priority would improve the widespread interests of everyone[141].

2.3.2. WMA Medical Ethics Manual

The World Medical Association (WMA) refers to the dominant ethical theories discussed above in its Medical Ethics Manual to provide medical professionals with ethical guidance for professional practise[142]. The Association acknowledges that physicians are often unprepared for the ethical complexities of modern medical healthcare. As a result, the Manual offers advice regarding every facet of the professional relationship, including how to approach solving ethical dilemmas.

Three core values in medical ethics to be upheld by the medical profession at all times are promoted by the WMA. Those are compassion, competence and autonomy. Of the three, it says that the clinical and professional autonomy previously enjoyed by medical practitioners and the bodies that decided on the standards of medical education have been moderated the most globally, to ensure greater control over medical practitioners by authorities.

Despite this development, medical practitioners still value their clinical and professional independence as far as possible.

Patient autonomy has also been elevated throughout the world such that patients must be the ultimate decision-makers on matters pertaining to their own health and well-being[143]. A feature of medical practitioners' decreased autonomy is that they have far more accountability to others now, besides their patients. These include third parties such as their healthcare organisations, regulatory boards and the judiciary, compared to the past where accountability was primarily to themselves, their colleagues and their profession. The WMA suggests that ethically, the needs of society must be included in the doctor's responsibilities too, to manage the health system's scarce resources[144].

When confronted with making decisions, the WMA observes that although medical practitioners most often have to reach solutions to dilemmas themselves, it is helpful to be aware of what other medical practitioners have decided in similar situations. This is comparable to the prudential reasoning model of naturalistic decision-making described above. However, there are also medical codes of ethics and policy statements that capture the general consensus regarding how a doctor should respond in certain more common circumstances. The WMA advises that these ought to be followed first, unless there is a good reason for not doing so[145].

Bearing in mind that medical ethics vary between countries, medical associations also differ on certain topics, such as their attitude towards euthanasia. The WMA has attempted to represent all medical practitioners and to offer general standards in medical ethics for doctors worldwide. Ethical policy statements are thus required to have 75% consensus before they are released[146].

Two broad methods of solving ethical problems are described by the WMA: a non-rational, or a rational approach. Examples of the non-rational kind are obedience to rules and instructions, or imitation of a role model, both of which subordinate the decision-maker's opinions to a higher authority. Also listed for use are feelings, where one responds in terms of what seems right at a subjective level, likewise with the implementation of intuition, another trait that can be engaged which is similar to the prudential model previously discussed. The last non-rational approach is to rely on habit, where similar situations that are repeated are treated in the same way[147].

The rational approach is explained as a systematic, reflective use of reason and incorporates the well-known theories of virtue ethics, deontology, consequentialism and principlism. Although this style of problem solving is favoured by the WMA, it admits that no theory has been universally accepted as a perfect tool for application. Some of the reasons are highlighted below[148].

Virtue ethics emphasises the character and behaviour of the decision-maker more than the decision-making process. The assumption is that a moral, virtuous doctor, who is compassionate, ought to make good decisions, but that is not always the case, such as when a novel problem creates uncertainty[149].

Deontology attempts to identify sound rules on which moral decisions can be made in specific circumstances. Disagreements arise, for instance, when trying to establish how extensively

rules should be applied[150].

Consequentialism stresses the importance of implementing the decision that would achieve the best outcome. However, differences of opinion occur when discerning what the best outcome actually is. Utilitarianism focuses on achieving the greatest happiness for the most people, but other measurements may be considered in medical care such as the quality of life or cost effectiveness. A criticism of the theory is that it could support 'the end justifying the means' because ethical principles are not applied, such as sacrificing an individual's rights in order to achieve a social goal[150].

Lastly, Principlism, a popular rational decision-making approach in health care currently, identifies four principles considered paramount when making ethical decisions: autonomy, beneficence, non-maleficence and justice. The principles, along with rules and consequences, are borne in mind while analysing particular situations in order to reach a conclusion about the correct way forward. As explained in earlier paragraphs, a problem with the choice of principles is that they can contradict one another in specific cases, so further analysis is needed before a resolution is reached[149].

The WMA reinforces the notion that a combination of these theories is the best way to approach ethical dilemmas. Intuitively, a person who strives to do their best for professional and compassionate reasons (applying virtue ethics), would probably do this anyway when they have knowledge of all the theories. The WMA sums up that this would be achieved by bearing in mind the well-established ethical rules, identifying appropriate principles that could be relevant, attempting to apply them with good effect, and considering the alternative options along with their predicted outcomes. Finally, the best solution in the circumstances would be chosen for the desired outcome.

The following steps laid out by the WMA guide the process succinctly[149]:

1. Establish whether the problem is an ethical dilemma.
2. Consult authoritative sources of medical ethics found in professional codes and policies, as well as respected colleagues for guidance on how the problem is usually managed.
3. Consider alternative solutions that maintain similar values and principles, and weigh up their predicted consequences.
4. Discuss the possible solution with those whom it will affect.

5. Act on the final decision, being aware of its impact on all who are affected by it.
6. Evaluate the decision and be prepared to make different choices in the future, where required.

2.3.2.1. WMA and Euthanasia

For a number of countries where E and PAS have become legal, the physician's role in the process presents a relatively new ethical challenge. The WMA addresses the topic in its Medical Ethics Manual by first highlighting that the cornerstone of medical ethics is the doctor-patient relationship[151]. With reference to the Declaration of Geneva (the modern Hippocratic Oath)[152], the WMA re-asserts that the health of patients is a doctor's primary concern and that they must maintain the highest respect for human life. Consequently, tension can arise in the relationship between the physician's awareness that a person who requests E or PAS finds their suffering so intolerable that they would rather die, the patient's expectation that the doctor should participate to hasten their death, and the traditional role of the doctor as healer. The law, on the other hand, perceives the physician to be the most suitable person to carry out the killing, which the WMA suggests is because of their medical knowledge and access to drugs[153]. Having said that, the WMA has repeated in its updated and combined 2019 Declaration on Euthanasia and Physician-Assisted Suicide[154] that it remains committed to upholding the greatest respect for human life and is firmly opposed to E and PAS.

In support of all medical practitioners, particularly those who are reluctant to participate in requests for assisted death where it has been legalised, the WMA provides guidance for palliative care in its amended 2022 Declaration of Venice on End of Life Medical Care[155], which is discussed in Chapter 7.

2.3.2.2. WMA and Justice

As part of the ethical approach to medical decision-making at the end of life, it is of value to reiterate the setting in which the doctor functions, specifically the various relationships that need to be maintained, which also affect decision-making. The doctor's relationship with patients, colleagues, allied medical professionals and society at large create 'social contracts'.

The WMA views the profession of medicine today as much more of a social rather than an individual occupation. For instance, there is a dependence on government and corporations for organisation and funding, and reliance on product development and research for a knowledge

base and treatments. Due to the privilege of being allowed to train in hospitals using public patients, being given almost exclusive responsibility for the provision of services, and independence to self-regulate, the doctor undertakes to use those privileges firstly for the benefit of the public and secondarily for themselves[156]. The WMA points out that diseases originate as much from social environments now as from biological origin. For this reason, important ethical commitments in the role of the doctor within society are to promote public health, education, protection from the environment and laws that ensure the well-being of society, including participation in judicial proceedings.

The WMA believes that physicians have a duty to assist in the allocation of scarce resources for everyone, not just for their own patients, and to prevent patients who would not be eligible for certain services, from accessing them. Clearly, such decisions could create ethical conflicts in the choice between society and the individual patient[157]. In South Africa, palliative care is a scarce resource, and is examined in detail in Chapter 7.

This dilemma highlights the ethical principle of justice as an important value in modern medical decision-making. A case in point occurred with the COVID-19 pandemic during 2020. At the peak of the pandemic, the high demand for ventilators and intensive care beds caused a great amount of stress for medical staff in light of institutional policies having been drawn up to restrict these scarce resources on the basis of age[158]. The WMA's Declaration of the Rights of the Patient[159] however, specifically states that, in the event that a choice must be made between potential patients for a medical treatment that is in short supply, all patients are entitled to a fair selection procedure based on medical criteria, made without discrimination.

To facilitate decision-making, four attitudes to justice are introduced by the WMA: i) a libertarian approach, which promotes resources being distributed in line with market principles. Market principles are explained by the WMA to mean 'individual choice conditioned by ability and willingness to pay, with limited charity care for the destitute'; ii) a utilitarian approach, where resources are to be distributed to achieve the greatest benefit for all; iii) an egalitarian approach, when resources are distributed only according to need; and iv) a restorative approach, which requires resources to be distributed such that the historically disadvantaged are favoured[160].

The WMA's Statement on Access to Health Care[161] reinforces that no one should be denied an available medical service because of an inability to pay. Therefore, a libertarian attitude, which

is what South Africa has in the private sector for palliative care focussing on individual patients, would be seen as unjust, unless there were comparable accessible palliative care services in the public sector from which all those in need could benefit. As an alternative, the utilitarian attitude is considered to be the most difficult to implement because it would require a lot of data to confirm what the best outcome would be, and that is not readily available. Contemplating all the options, there is no agreement on which approach is the best to ensure fairness, but the WMA has observed that it depends on the country's socio-political environment and the personal morality of the doctor[162]. Health systems tend to have a few of the approaches to justice present at the same time, as witnessed in South Africa.

The WMA draws attention to the fact that, besides their responsibilities, medical practitioners also have a right to be treated well. Doctors are feeling progressively more frustrated with the difficulties they face as a profession in terms of limited resources, intense government and corporate regulation of health care delivery, media reports that sensationalise questionable medical conduct or errors, and the challenges levelled at their authority and skills by patients and providers[163]. A more recent development that could be perceived to be a form of interference in the profession is making E and PAS the responsibility of doctors.

The Medical Ethics Manual's last words remind the medical profession that with the future being unpredictable, medical ethics needs to remain versatile, although it is hoped that the basic principles do not change. Specifically, the values of compassion, competence and autonomy should be upheld[164].

2.3.3. HPCSA General Ethical Guidelines for the Health Professions

The Health Professions Council of South Africa (HPCSA) has published 17 booklets of ethical guidelines on different topics to assist medical practitioners with ethical decision-making[165]. In its first booklet an approach to solving ethical dilemmas is presented[166]. The HPCSA's guidance is also adapted from the WMA Medical Ethics Manual, showing its support for the proposed methods of ethical reasoning.

Four main steps are used to reach a solution for an ethical dilemma:

1. Formulate the problem: confirm that it is an ethical issue and check whether there is a clearer way to understand it.
2. Gather information: clinical, personal, social data. Consult authoritative sources and

colleagues, seeing how others have dealt with similar situations.

3. Consider options: examine alternative solutions in light of the principles and values they uphold.
4. Make a moral assessment: weigh up the ethical content of each option by asking:
   a. What are the likely consequences of each option?
   b. What are the most important values, duties and rights? Which weighs the heaviest?
   c. What are the weaknesses of the Medical practitioner's personal view concerning the correct option?
   d. How would the Medical practitioner personally want to be treated under similar circumstances?
   e. How does the Medical practitioner think that the patient would want to be treated in a particular circumstance?
5. Discuss the proposed solution with those whom it will affect.
6. Act on the decision with sensitivity to those affected thereby.
7. Evaluate the decision and be prepared to change the approach in future.

The model is a conservative and thorough blend of the various methods described above, incorporating both the 'rational' and 'irrational' approach mentioned in the WMA Medical Ethics Manual. It also introduces some prudential thinking by ensuring input from experienced colleagues and allowing for a measure of personal intuition to be considered. The final steps of implementation with cross-checks listed (5-7) ensure that, as far as possible, an ethical solution has been cautiously applied, and where necessary, will be adjusted to improve on it in the future.

2.4. CONCLUSION

In this chapter I have given a chronological overview of the five most common ethical theories and principles that have influenced both western and African communities, thus catering for the ethical environment in which present-day South African society exists. Doctors will draw on these theories when grappling with ethical dilemmas in end-of-life decision-making. Each theory has its uses for the medical practitioner when faced with a difficult moral dilemma, but ultimately all have been shown to impact on the practical process of decision-making, which is encouraged. Accordingly, a few models for finding solutions to ethical dilemmas have been offered. In the two legal chapters that follow, the theories will be used to examine how a progressive shift in people's moral outlook over time affects the law because the philosophy of a society translates into that society's public morality. The way subsequent changes in the law

impact on the microcosms of communities will then be considered, specifically with regard to people's attitude towards the terminal phase of life and the available health care options that are offered to patients. These factors, in turn, will **influence** the ethico-legal environment in which medical doctors will function when helping patients to make the best possible end-of-life decisions for their circumstances.

In the next chapter I discuss how South African law related to suicide and death has developed through the years in line with the public morality it mirrors.

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CHAPTER 3: SOUTH AFRICAN CASE LAW

3.1 INTRODUCTION

Well-known ethical theories and bioethical principles were examined in the previous chapter. The object was to consider what ethico-legal tools are available to medical practitioners when confronted by patients and their loved ones asking difficult ethical questions about end-of-life decisions.

Bearing in mind that these theories and principles influence both society and the legal paradigm in which society functions, this chapter traces the thread of philosophical theories through the history of South African case law. The historical context in which legal rules and judicial systems arose offers both an understanding of the law and the particular social, political and economic aspects of the society at the time[1].

Specifically considered is the way they influenced judicial decision-making on euthanasia and assisted suicide, with a view to assessing judicial support for E and PAS when deliberating potential new law, such as legalising E and PAS. Possible legislation is relevant because it has an influence on suggestions for an ethico-legal framework which is proposed in chapter 8.

What the South African government's current approach will be towards legalising E and PAS depends on the attitude of society about its rights, obligations, and its perception of the health system, together with the role of the medical practitioner within the community. The political sector, being a microcosm of the people, in turn proposes and promotes community interests at government level to adapt the law accordingly. However, the law should be informed by ethics, not politics, and should not be used as a political tool.

At present, there is a gap in the national legal infrastructure for palliative health care where minimal legal directives exist to support medical professionals in a number of challenging areas. These include applying the doctrine of double effect, withholding and withdrawing treatment, surrogate decision-making for incompetent patients, and advance directives. Because no explicit statute is available yet to direct end of life decisions, case law is the exclusive guide.

The South African judicial system uses the doctrine of precedent to steer and develop the law. This doctrine entails case-based reasoning, similar to that of the applied ethic of casuistry,

which was influential during the medieval period and in early modern philosophy. Casuists believed that fitting moral judgments could be reached by applying the historical record of similar cases with a thorough knowledge of particular sets of circumstances. They viewed principles as flexible, not universal, and trusted the patterns of repeated cases to formulate authoritative and enduring sources of knowledge.

Beauchamp and Childress describe ethics as emerging from the communal agreement formed around cases that are then applied to fresh matters by analogy. Over time, society gains confidence in its settled moral conclusions, and these evolve into generalisations that reflect the community's moral insights about different situations[2].

Comparably, the rulings from important legal cases have become authority for new matters that arise, slowly adjusting the legal standards of concepts such as justice, equality, and the measures for negligence and murder. This evolution of a set of legal and moral norms developed by ongoing reflection is witnessed through the chronology of case law traversed in this chapter. Ultimately, the Constitutional Court used similar wording to describe the task that lies ahead of it in interpreting and giving content to South Africa's body of rights[3].

An opinion piece in the British Medical Journal in 2019 drew attention to the need for differentiation between legal rights and their implementation. Dr Fritz, the author, argues that the question of whether to allow someone the choice of when to die prematurely and just how this should be facilitated, including whether it would affect the doctor-patient relationship, are separate matters and should be managed separately. She proposes that a way forward to respect everyone's rights and roles is to, firstly, accept the court as the best forum to reach the decision of whether someone meets the criteria for PAS, having screened the cases and listened to evidence, where necessary. Then, a dedicated team of licensed practitioners could carry out the court order, made up of people who are willing to participate in the process. This would prevent the unsatisfactory outcome of two medical factions being created: those who refuse to assist on one hand and those who are willing to assist on the other, if it was legislated that the medical profession exclusively should fulfil this role[4].

In this thesis I support the view that a person having a legal choice on when to end their life, and the role a second party must play to assist with that process, are two separate questions to be dealt with individually. I focus primarily on the second question by means of case law and arguments relating to the role of the assisting party, in particular the role of the doctor.

An analysis of the philosophical and legal approach to the court cases follow, building towards an ethico-legal framework to guide doctors in reaching sound decisions for patients who require terminal care.

3.1.1. The Common Law

The first question of whether someone has a 'right' to end their life is not controversial. In South Africa, at common law, it is not a crime to attempt or commit suicide[5]. However, the second inquiry, whether a person who assists, encourages, or facilitates the act may be convicted of murder, attempted murder or culpable homicide, is dependent on the facts of each case. The reason therefor is that the person who assists affects the life of another person[6].

South African criminal law is made up of legislation, common law and case law. Our common law incorporates both Roman and Roman-Dutch law, which has been referred to in more recent South African case law. Thus, the common law and case law overlap to some extent. The crime of murder is defined as the 'unlawful and intentional causing of the death of another human being', from the case of *Ndlovu* decided in 1945[7]. However, as Professor Snyman in his Criminal Law text-book states, this definition is an over-simplification. He explains that there are numerous ways to cause death, with different degrees of moral reprehensibility attached[8]. This emerges from the case law discussed below.

This history of South African law specifically related to suicide was succinctly explained by Chief Justice (CJ) Steyn when he dealt with a legal query as a result of the case of Grotjohn, described in further detail below[9]. Steyn, CJ illustrated how Roman law supported the proposition that, although suicide was not punishable, an individual who had assisted the deceased could be found guilty of a crime, depending on the facts. Despite this confirmation, the ancient Roman-Dutch writers had a narrower, more disapproving view. An example is Matthaeus, in his work *De Criminibus*[10, 11]. Matthaeus identified the Roman legal approach as based on Stoic philosophy, which differed from his Christian view which emphasised the sanctity of all life. His Calvinist morality led him to perceive that suicide was a crime, a rebellion against the Creator, so hanging a corpse for public viewing, then placing the body under the gallows instead of providing a proper burial, was a fitting punishment. Huber agrees with Matthaeus and motivates this stance on the basis that anyone who does not spare himself would spare another much less.

Damhouder and Van Leeuwen include in their records the practise of insulting the corpse and confiscation of their property, which was deemed appropriate at the time, to act as a deterrent. Other early writers saw the criminality of attempted suicide being because no one is master of their own body and body parts. Thus, attempted suicide and being an accomplice to suicide were indictable offences[12].

In the same judgment, Judge of Appeal (JA) Rumpff also offered some comments, adding that it seemed clear that in the ancient world suicide was considered a moral transgression against nature. It was an act in violation of the duty to self-development or self-perfection. Where there was a realization that the individual belonged not only to himself but also to the community, jurists argued that suicide was an offense to their fellow human beings, towards whom they owed duties[13]. The attitude in early Roman-Dutch law appeared to be religious and duty-bound to protect society from harm.

Even during the earliest Roman years, writers distinguished between the different states of mind that led to suicide and what punishment would be suitable. As long as the reason for death was fatigue of life, unbearable pain, despair because of guilt, or some similar cause, the offender would still be entitled to an heir, compared to if he ended his life to avoid a debt or some other prosecution. The Romans reasoned that suicide was then an admission of guilt, deserving of punishment and loss of his estate[14].

The kinder approach of accepting that emotional problems as a motive for ending life deserved to be dealt with less harshly, did eventually carry over into the Roman-Dutch period, according to the jurist, Moorman. By 1732, the confiscation of property as a sanction for suicide, was no longer followed[15].

Steyn, CJ concluded that, subsequent to earlier centuries, punishment for suicide, which in reality affected only the families of the deceased, ended[16]. The legal morals of society during the 17th and 18th century enlightenment period had shifted from respect for natural law based on religious roots, to a more liberal way of thinking, which emphasised reason, individualism, and scepticism.

In the 1900s, South African law recorded cases where tolerance of the accomplice to a suicide left them unpunished, as long as the deceased had acted independently at the time of death. However, the line between what was independent action on the part of the deceased and what

amounted to assistance, remained blurred, and cases tended to contradict one another.

3.1.1.1. *Peverett,* 1940 (suicide pact / attempted murder)

For example, in the 1940 case of *Peverett*[17], a couple entered into a suicide pact where the accused made the necessary arrangements to introduce exhaust fumes into a car in order for them to gas themselves once seated inside. His partner climbed into the car willingly, but only Peverett turned on the ignition. Before death ensued, they were saved, although his companion was already unconscious. Peverett was held responsible for trying to kill his partner because she had not participated in the preparation. He was convicted of attempted murder and fined £30. The judge reasoned that the accused's involvement went beyond preparation to include an intention to kill. He supported this analysis by explaining that Peverett had contemplated and expected that, as a consequence of his actions, his partner would die.

3.1.1.2. *Makali,* 1950 (principle)

Around 1950, with the matter of *R v Makali,* the Court reinforced the principle that to hasten someone's death is also a crime, even if the perpetrator's intention was not to kill. The specific facts related to a robbery, where the deceased was wounded on his arm with a knife, but not fatally, yet died from a heart attack following the frightening experience of his home invasion[18].

The judiciary highlighted this legal rule when it considered the issue in later years. Specifically, it's findings were applied in a passive euthanasia incident in 1975[19], and then again in 1992 when *Makali* was referred to while debating the question of whether it was lawful to withhold or withdraw treatment from a patient[20]. These cases are examined later in this chapter.

3.1.1.3. *McCoy,* 1953 (principle)

The case of *McCoy* is authority for the principle that a person cannot consent to injury when the act is itself unlawful. Although the facts are not presented here because they do not relate to the theme of assisted suicide or euthanasia, the case is important because the principle has been applied in such cases. *McCoy* indicates chronologically when the principle was first highlighted in South African law.

3.1.1.4. *Davidow*, unreported, 1955 (murder / euthanasia)

Despite not having been reported, this case appears to be the first instance where someone was prosecuted for carrying out euthanasia. The mother of the accused suffered from a terminal illness which left her in great pain and unable to move. She became very depressed and requested that she be helped to die. The deceased's son attempted to obtain assistance from his friend to give her a lethal injection, but this was refused. Finally, while under severe emotional stress, the accused fatally shot his mother in her hospital bed. He was charged with murder. However, a jury found him not guilty although the act was unlawful, based on the finding that his emotional state had caused him to no longer have a blameworthy state of mind[21].

3.1.1.5. *Nbakwa*, 1956 (assisted suicide)

In Southern Rhodesia, in 1956, the legal tide turned in a different direction to that of *Peverett*'s case, when a charge of incitement to commit suicide arose in the action of *S v Nbakwa*[22]. Judge Beadle was asked to apply his mind to what constituted attempted murder. He reasoned that providing a person with the means to commit suicide and persuading her to carry out her own suggestion only amounted to preparation, but not attempted murder. He held that, on the assumption that suicide is not a crime, incitement to commit suicide could also not be a crime because the incitement was simply accessory to the suicide itself. The facts of the case were briefly that the deceased was the mother of the accused man. His child had died of natural causes, but he blamed his mother for her death. The mother then told her son to kill her. After some days the son finally tied some rope to a rafter and told his mother to hang herself. He placed a block of wood under the noose for her to stand on and helped her into a sitting position on her bed because she was ill. The mother then managed to complete the act by kicking away the wooden block.

3.1.1.6. *Gordon*, 1962 (suicide pact)

Next, the *Gordon* case[23], in 1962, presented the courts with one more opportunity to consider what constituted murder, in circumstances where a couple had also entered into a suicide pact. They chose to die by ingesting a quantity of tablets supplied by both of them. The accused had divided the tablets equally between them and, once each had swallowed their share, he finally woke up to find his partner dead next to him, while he had survived. The Court found that the deceased had voluntarily and independently consumed the tablets, so the accused was not

responsible for her death. He was, therefore, not guilty of murder, because suicide is not a crime and a person who only incited or encouraged the suicide was not thought to have committed an offence, according to the Natal Provincial Court's reasoning.

3.1.1.7. *Robinson*, 1968 (murder / voluntary assassination)

Eventually, the Appeal Court, in 1968, heard an unusual set of facts in *S v Robinson*[24] which, as Holmes JA observed, introduced a novel twist in the history of the country's development of the common law surrounding murder. The Court had to determine whether the intentional and unlawful killing of another human being, at his own request, reduced the assassin's moral blameworthiness and so established extenuating circumstances. Judge Holmes described the details as a 'grim and sombre drama of despair and mercenary death. Uniquely macabre because the deceased arranged his own murder, in circumstances of dire financial distress'[25].

The deceased had requested that he be lethally shot in order to be free of his financial problems, but also so that his wife could receive his life insurance pay-out. A moment before his death, the deceased told the accused that he had changed his mind but the accused, who was already holding a gun, went ahead with their plan anyway. The accused explained that he did so because the deceased had reversed his decision on two previous occasions and this time specifically stated that no matter what happened, the accused must complete the murder. The Court held that, because the accused had shot the deceased after he had retracted his consent, he acted outside of a common purpose. However, the fact that the deceased both requested his own death and tempted the murderers with financial gain did disclose extenuating circumstances that reduced the accused's moral blameworthiness, but did not change the verdict of guilty of murder. The Appeal Court accordingly replaced the accused's death sentence, handed down by the Court of first hearing, with a lesser sentence of imprisonment for 15 years.

3.1.1.8. *Grotjohn*, 1970 (assisted suicide)

More controversially, following *Gordon*'s 1962 assisted suicide case, another set of facts were presented during 1969, in the matter of *Grotjohn*[26], which was first heard in the Natal Provincial Court. Grotjohn was accused of murdering his wife because during an argument he had encouraged his wife, who was paralysed and suffering from manic depression, to shoot herself, after she had threatened to do so. At her request, he had loaded his rifle with a cartridge in her presence and then handed it to her, telling her that she should go ahead and shoot herself because

she was a burden to him. The Provincial Court held that the deceased had acted independently. Furthermore, incitement to commit suicide, in the circumstances, was not a crime. It, therefore, found Grotjohn not guilty of murder.

This outcome caused concern for the Minister of Justice and, in 1970, led him to ask the Appeal Court for clarification of the law. The Court, per Steyn CJ, confirmed that neither suicide nor attempted suicide are crimes. However, encouragement, help or enabling someone to carry out the act could be construed as an offense, depending on the details of the particular case. This was regardless of the fact that the final act was the deceased's independent and voluntary accomplishment. He elaborated further that, if a direct causal link existed between the action of the accomplice who intended that death should ensue, and the other's demise, then he was guilty of a crime[13].

In a later case it was stated that a conviction of murder arises because, had the assistance to the suicide not been given, the death would not have occurred[27]. Legal academics explain that awareness of the unlawfulness thereof is part of an intention to kill, regardless of whether death only occurs much later (*dolus eventualis*)[28]. Unlike many other legal systems, in South Africa, no distinction is made between types of murder, but when deciding on appropriate punishment, extenuating circumstances are considered[29].

3.1.1.9. *De Bellocq*, (1968) reported 1975 (murder / 'mercy killing')

A case in point, *S v de Bellocq*, occurred in 1968, but was only published in 1975[30]. The Judge of the Transvaal Division had to decide what constituted 'mercy-killing'. The particulars were that a young, newly married French woman gave birth to a premature baby boy who initially appeared to be fine. However, over time he did not thrive and could only be fed via a feeding tube. He was kept in the nursing home despite the mother being discharged. Finally, after three weeks and the transferral of the baby to a hospital, a diagnosis of toxoplasmosis was made. The hospital could do no more to assist the family, so the baby was then sent home. His mother, having been a fourth-year medical student, understood that he was permanently, extremely, mentally underdeveloped. Consequently, he would never be able to eat properly or progress through other growth milestones, resulting in his eventual death from health problems. Impulsively, in a moment of anguish, she decided to end her son's life by drowning him while giving him his bath. Mrs De Bellocq readily admitted that it was her intention to kill her baby. The Court accepted that she was in a fragile emotional state post-natally and lacked the support

of her family or close friends to assist or advise her, being in a foreign country with her husband only. These factors counted as extenuating circumstances when considering her crime. Judge President (JP) De Wet reiterated that, despite these mitigating reasons, it could not be said that the accused's emotional state reduced her intention to kill. In addition, regardless of whether a person is severely intellectually impaired or seriously ill, the state does not allow anyone to be killed. Therefore, Mrs de Bellocq had to be found guilty in law of murder.

Significantly, De Wet JP, showed the state's capacity to exercise compassion in the leniency of sentencing. He saw no value in sentencing the accused to a term of imprisonment nor a suspended sentence, because it would be difficult to decide what conditions to impose on her. The accused was ultimately discharged on the condition that she entered into an agreement with the Court that she would re-appear in Court within the following six months should she be called up for sentencing, which never happened.

This trend by the judiciary to show mercy in cases where killing had occurred in exceptional, tragic circumstances, was illustrated once more in *Hartmann*, in 1975[31].

3.1.1.10. *Hartmann* 1975 (murder / 'mercy killing')

Hartmann's case is the only one in South Africa where a doctor is accused of 'mercy-killing'. A doctor found himself in the situation where his father was terminally ill and suffering intensely from great pain. His father was originally diagnosed with prostate cancer, but this had spread eventually to his bones and lungs. Dr Hartmann organised for his father to be admitted privately to the hospital where he worked so that he could continue to manage his care himself. An intravenous infusion was set up to administer medication, but over time his father deteriorated and could no longer swallow. He was only semi-awake and dependent on others for every need, including being fed through an intravenous portal. Pain control was the greatest challenge.

One evening, when the father appeared to be extremely near death, Dr Hartmann was keeping vigil and asked the night nursing sister to draw up a ½ gram of morphine for his father. The sister carried out the instructions but felt unwilling to dispense it because the dosage was a large one. An hour later the doctor requested that a second ½ gram of morphine be prepared, which he administered himself. Eventually, 1½ hours later, around 11pm, Dr Hartmann requested 150 milligrams of pentothal, an anaesthetic agent, which he injected into his father's intravenous

line. Pentothal can have a fatal effect, and within minutes his father died. In the course of evidence, Dr Hartmann confirmed that he had asked his father whether he wanted the drug and he had nodded. Under the circumstances, this consent was of no significance because, as the judge reported, that was no defence to the charge of murder. However, the evidence showed that it was also unlikely that this communication would have amounted to consent because of the late stage of his father's deterioration and probable lack of consciousness from medication. An autopsy established that the cancer was rife, and death would have probably ensued within hours. Nevertheless, the blood level of pentothal found in the deceased's system verified the suspicion that this drug was the immediate cause of death.

Judge (J) Van Winsen stated that, despite the fact that the father was on his deathbed, the law is clear that to hasten a person's death still amounts to murder. Regarding the purported consent to receive Pentothal, the judge said that the Appellate Division had ruled more than once that even though the deceased wished to be killed it did not exclude the criminal responsibility of the perpetrator. In these particular circumstances, the action of the accused had clearly been motivated by compassion for the deceased's grave suffering. Nonetheless, this type of 'mercy killing' had been a topic of intense public debate over a long period and was still not resolved. Van Winsen, J mentioned that some held the view that the law was too harsh and unsympathetic, especially where a doctor is confronted with the impossible dilemma of 'whether or not to actively assist or refrain from preventing his already doomed and suffering patient's demise'[32]. At the time of this case, the judge informed the Court that South African law was comparable to the stance of most other western countries, such as the UK and USA, where attempts to change legislation had been unsuccessful. He acknowledged that there were also strongly held opinions, both in religious and sectarian communities, that 'to allow mercy-killing, even with suitable safeguards in place, would pave the way for abuses which would be damaging for the community'. Van Winsen, J said that he had mentioned these aspects to reinforce that it was the legislature only that could change the law, not the judiciary. Hartmann was found guilty of murder[33].

It was in sentencing that the Court could reflect the attitude of society with regard to mercy killing. The Judge expressed the Court's view and reasoning by weighing up mitigating factors that could make the crime less reprehensible. It took into consideration that Hartmann had believed he was acting in the patient's best interests. Evidence had indicated the close relationship between him and his father. It was common cause that he cared for his father greatly, to such an extent that he had transferred him into his own care so that he could be in

attendance. He was witness to the magnitude of his father's suffering, the father's extreme misery because of unremitting pain, loss of bodily functions and total dependence on others for his simplest needs. The Court acknowledged that it would be almost certain that the stress brought to bear on a doctor when his patient is at the terminal point of a fatal illness with unrelenting pain must be immense. Their relationship as father and son would heighten the emotional trauma for the accused.

Judge Van Winsen gave the Court insight into the state of affairs by describing a situation where a patient's quality of life no longer had any value to the patient, because of the misery of pain and physical incapacity, aggravated by the effects of powerful drugs administered to release him from discomfort. He asserted that the evidence presented convincingly supported the fact that the deceased had reached this end-phase. The judge then drew attention to the moral quandary with which a doctor would be confronted at the terminal stage of the patient's life. It arises from a conflict of ethical principles: whether to save life or relieve pain and suffering. He said that the relationship between the doctor and patient would influence the extent of the predicament in each case, but a close affectionate familial bond would certainly make the conflict worse. Van Winsen, J assumed that this internal turmoil temporarily clouded Hartmann's judgment and allowed his emotional reasoning to override conventional medical practice. The judge was satisfied that when Hartmann commenced these actions, he knew that he was breaking the law but made peace with his conscience. For this reason, the State's criticism of Hartmann was that his compassion did not respect legal boundaries[34].

When deliberating on an appropriate sentence, this case, too, was placed in a different category to other offences related to murder, in line with the previous case of *De Bellocq* described above. The Court weighed up the need to prevent the offender from repeating his crime, but also to deter the public from similar behaviour in the future. Judge Van Winsen was not concerned that Hartmann was a threat to other patients, nor that doctors in general would take similar action in the future because of their known professional commitment to preserve life. He applied a quotation from Holmes, JA's judgment in *S v V*, 1972 (3) SA 611 (AD) at 614, which stated that: 'Punishment should fit the criminal as well as the crime, be fair to the accused and to the society and be blended with a measure of mercy'.

Accordingly, the Judge decided to hand down a suspended sentence. Hartmann was sentenced to one year of imprisonment, detained until the rising of the Court, and the balance of the sentence was suspended for one year, on condition that he did not commit an offence involving

the intentional infliction of bodily injury during this time[35].

Despite the mercy and leniency shown by the Court, the then Medical and Dental Council sanctioned Dr Hartmann for unprofessional conduct. He was struck off the medical roll, so was unable to practice for a period of time, after which he was reinstated. It is noteworthy that, despite the stance of the Council, Hartmann received public support and sympathy from the press. This open response offers a window of insight into the gradual shift that was occurring of society's legal morals towards tolerance of compassionate killing[36].

3.1.1.11. *McBride*, 1979 (murder / 'mercy killing')

The sad circumstances of this crime[37] were that the accused, Mr McBride, who had loved his wife dearly, watched while his wife nursed both her mother and her sister through painful terminal cancer until their deaths. She too, became unwell and they both assumed it was cancer. His wife became progressively worse over the years but refused any medical assessment or intervention. Along with her failing health, their financial position also became precarious, which caused the accused even greater anguish. He had apparently frequently promised her, in order to comfort her, that he would not allow her to suffer in the final phase of her life[38].

One day the wife phoned her husband at work and requested him to come home urgently because she was very ill. He sat with her through the night as he had often done, and decided that this was the right time to end her life by shooting her, and then to end his own life. He managed to kill his wife, but before he achieved his own suicide, he was arrested for murder. A post-mortem of the wife's body revealed that she had not, in fact, suffered from cancer.

In prison he pursued his attempt to end his own life, but, again, was thwarted[39]. Three psychiatrists appointed by the Court to examine Mr McBride agreed that the accused had been suffering from endogenous depression at the time of the killing. They found that, although he was aware that his action had been unlawful, he had, owing to his poor mental health, experienced diminished responsibility under the circumstances to prevent him from carrying out the killing. The accused was portrayed as incapable of sensibly weighing up the after-effects of his actions, because he had what was described as 'clouded thinking disturbed by mental anguish'. One of the psychiatrists added that it was not uncommon for a person suffering from endogenous depression to believe that he was being altruistic by taking the life of another person, particularly of someone whom he loved[40].

Although he had appeared to be mentally well at the trial, Mr McBride stated that, should he be presented with similar circumstances, he would do the same thing again. After a great deal of deliberation, the Judge found Mr McBride not guilty by reason of mental illness, but he was to be detained in a mental hospital or prison as a State President's patient[41].

3.1.1.12. *Hibbert*, 1979 (assisted suicide)

The evidence in *S v Hibbert*, in 1979[27], was that the deceased, who had just ended a secret extra-marital relationship, was the wife of the accused. On the fateful day, the wife was upset, drunk, depressed and argumentative when her husband arrived home. During a confrontation with one another, the deceased said that she might as well commit suicide. The accused asked her how she planned to do it and helped by listing some possibilities. The wife opted to shoot herself, so the accused then took her to retrieve a gun, loaded it and handed it to her so she could follow through with her threat. When the deceased actually fatally shot herself in the head, her husband was immediately distraught and remorseful. The Court held that no new intervening incident (*novus actus interveniens*) had occurred to interrupt the chain of events between the husband handing his wife a loaded gun and her killing herself [42]. The husband was therefore found guilty of murder with extenuating circumstances because the State proved a direct causal link between his conduct and the deceased's death. The Court clarified, though, that the finding that the accused had an intention to kill was based on his reckless disregard for a foreseeable consequence, and not on him having intended the outcome of death[43].

The extenuating circumstances borne in mind by the Court were that the husband had shown no intention or desire to kill; he had been filled with shock and regret at the consequences of his actions, and that the deceased had carried out the final act herself, ending her life. Judge Shearer, when contemplating a fitting sentence, took cognisance of the fact that the husband had suffered greatly as a result of the circumstances of his wife's death the previous year. It was accepted by the Court that he had been considerably provoked and was angry. The Judge then emphasised the seriousness of the crime but reasoned that no purpose would be served by sending the husband to prison. In view of this, the sentence passed was four years' imprisonment, suspended for five years, on the condition that he was not convicted of committing an offence involving assault during the period of suspension[44].

3.1.1.13. *Mayer*, 1985 (murder / suicide pact)

This Zimbabwean High Court case of *Mayer*[45] is noted because it applied similar sentencing to that of the case of *Hartmann*, namely that the person guilty of murder was shown the full mercy of the Court because of extenuating circumstances. The reasons for this sentence were as follows: a husband and wife entered into a suicide pact because they believed that they would not cope financially once the husband was retired by his employer in a few months' time. While his wife was asleep, the husband fatally shot her but, in then attempting to shoot himself, he only successfully caused blindness. During sentencing, the Court reasoned that the accused was not criminally minded, therefore the public did not need to be protected from him, nor was there a likelihood that he needed to be deterred from repeating this crime. He had also already undergone a devastating disability, besides the loss of his wife. Based on legislation, the Court was not able to prescribe a wholly suspended sentence, so it repeated the words used in Hartmann, that the accused be detained until the rising of the Court[46].

3.1.1.14. *Williams*, 1986 (withdrawal of treatment)

In 1984, a situation arose where a Cape hospital was confronted with a woman who had received a serious gunshot wound to her neck during an armed robbery. The facts of *S v Williams*[47] describe that the damage was to two main blood vessels. By the time she was admitted she was unconscious, had lost a lot of blood and did not move the limbs on her right side. The medical staff eventually transferred the patient from George to Tygerberg Hospital's intensive care unit. A CAT scan (computerised axial tomography) showed that the brain tissue on her left side was dead. Although she could still breathe spontaneously, a ventilator was set up to assist her with breathing. The following day, according to her doctor, Buchmann, no more brain activity was detected because the woman's brainstem was dead. Despite this, the ventilator kept the patient's heart and lungs functioning for a further 48 hours. At this point, after consulting two neurosurgeons about the case and performing a thorough neurological examination, Dr Buchmann disconnected the ventilator. Ten minutes post disconnection, the electrocardiogram machine to which the patient was attached recorded that no cardiac activity was present.

A trial court convicted the accused of murder, but an appeal was raised using the argument that the ventilator was a *novus actus interveniens* and it was the removal of the ventilator by the doctor that resulted in the patient's demise, not the gunshot wound to her neck. Chief Justice

Rabie dealt with the appeal in 1986. The question placed before the Court to decide on the accused's role in causing the termination of the deceased's life, was what, from a legal point of view, constituted death: brainstem death or the cessation of a heartbeat and breathing. If death was a consequence of Dr Buchmann removing the machinery that kept the patient alive, then the argument was that he had not caused the termination and the accused was no longer guilty as charged. Dr Buchmann testified that, according to medical science, death occurred with brainstem death, so death would have set in before the ventilator was connected to the patient. He asserted that the ventilator had simply kept the heart and lungs working artificially[48].

Chief Justice Rabie approached the question of death by applying the legal and moral convictions of society: he contended that death was not just mechanical, as observed by medical science, but rather had both moral and religious considerations in addition, in which the community believed[49]. Those embraced the idea that death occurred once the heartbeat and breathing ceased. Consequently, the judge accepted that the patient died once the ventilator was removed, and all signs of life ended in the minutes following. He recognised that life had been artificially sustained because she could no longer breathe independently. The disconnection of the ventilator was then not an intervening act that hastened death, but rather the termination of a failed attempt to preserve life that had been cut short when she was originally fatally wounded by the bullet. The doctor just allowed the progression of death by removing the machinery. Reference was also made to British case law, namely *R v Malcherek R v Steel* [1981] 2 All ER 422, in which the situations in each case were comparable to this one. They confirmed that the action by a doctor to remove artificial support where the patient was, despite their best efforts, no longer responding to treatment, would not be unlawful[50].

Different views of when death occurs biologically were not canvassed, so the Appeal Court chose not to deal with that query any further. There remained no clarity, either in the common law or the South African law, on at what moment death manifested until the National Health Act 61 of 2003 came into being. The Act now includes a definition of death as 'brain death'[51]. This elucidation of the law is important as it has many legal repercussions besides criminal liability, such as on decisions surrounding organ donation[52].

3.1.1.15. *Marengo*, 1991 (murder / involuntary euthanasia)

This murder of a father by a daughter was a tragic consequence of the daughter having felt trapped while subsisting in an extremely lonely and stressful environment. The accused, Miss

Marengo[53], was an only child, who was unmarried and 45 years old. She had nursed her 81-year-old terminally ill father without assistance for two years because her father refused to accept help from anyone else. Marengo had also cared for her mother who had been very controlling, before her mother's demise. Because of her commitment to her parents' care, the accused had experienced no social life and was without friends. Her depression and anxiety progressively increased over time until, according to the experts, she suffered a disintegration of her personality. Psychiatric evidence led in Court explained that at this crisis point her appreciation of wrongfulness was diminished by her mixed emotions of altruism, self-preservation and failure of moral judgment. This is when the fateful event occurred, in the early hours of the morning. The accused finally killed her dying father. She admitted that it was intentional and that she knew the act was unlawful, but had wanted to end his suffering.

In sentencing, the Court took into account all the extenuating factors. It determined that punishment as a deterrent was unnecessary, and community service unsuitable, too, considering that she had endured excessive emotional strain at the time, never to be repeated. A sentence of three years' imprisonment, totally suspended for five on condition that she did not commit another offence during this period, and that she be supervised by a social worker, was considered fitting[54].

3.1.1.16 *Clarke*, 1992 (withdrawal of treatment, principle)

A novel set of facts was presented six years after the Williams 'ventilator disconnection' case, in 1992, in the court application of *Clarke v Hurst*[55]. Judge Thirion, who was presiding over the Durban High Court, was confronted with a perplexing moral dilemma. The wife of a patient with severe brain damage had requested that she be allowed to give instructions to the medical staff to stop providing him with nutrition through his feeding tube so that he be allowed to die.

The facts were as follows: an application was brought by the wife of a doctor who had suffered a heart attack four years previously and who was now unconscious. She had asked the Court to appoint her as her husband's *curatrix personae*, giving her authority to make decisions on his behalf that would be in his best interests. Decisions included the withholding of consent for medical or surgical treatment and authorising the discontinuance of treatment, including nutrition and hydration. In essence, she asked that the exercise of her authority should be lawful, despite the prospect of hastening her husband's death, which would be a crime[56].

At the moment of Dr Clarke's heart attack, he had been successfully resuscitated, but only after a prolonged phase without oxygen to his brain, a situation that caused him to suffer extensive brain damage, including an inability to swallow, resulting in him being in a permanent vegetative state. From this point on his heart rate and respiration continued to function at a biological level, unsupported by medical machinery, but he remained deeply comatose with no prospect of recovery. A naso-gastric feeding tube had been inserted to facilitate provision of nutrition and hydration, while a tracheostomy site at the base of his throat allowed for staff to suction out secretions that accumulated as a consequence of his inability to swallow. Suctioning occurred up to five times a day to prevent choking. During Dr Clarke's earlier years, he had expressed a clear wish not to be kept alive by artificial means if there was no hope of recovery. He was a life member of the SA Voluntary Euthanasia Society and had prepared a 'living will' to record his choices related to the end of life. A representative for the husband was appointed by the Court. This *curator ad litem* supported the wife's application based on the preferences Dr Clarke had expressed independently while he had been healthy and of sound mind. The Court granted the wife her order.

Judge Thirion applied the following reasoning and principles to the facts. The starting point was a discussion about surrogate decision-making and that the role of a *curator personae* is to uphold the patient's best interests, even if a pronouncement goes against the patient's known wishes. The Court would not simply weigh up the suffering person's interest in wanting personal freedom from non-consensual therapy against the State's interest to protect life or the belief in the sanctity of life. It would also not necessarily support that another's right to self-determination and privacy always outweighed society's interest in preserving life.

These sentiments expressed by the Judge shed light on the social milieu of the '90s. The sacredness of life remained important to the judiciary as well as to the public, but the right to self-determination and privacy had become topical, too. Within four years the emphasis would shift to a focus on individual rights being a dominant theme with the introduction of a Constitution. Thirion, J reminded the Court that assisting with a suicide is a crime, depending on the circumstances, and could result in a conviction of murder or culpable homicide[57].

The Court's attention then turned to what the medical fraternity meant by 'a persistent vegetative state'. Doctors thoroughly explained the extent of physical and neurological shortfalls in the injured patient, including the resultant negligible biological and intellectual life that remained. Medical experts agreed that the cortex, which gave the intellectual functioning

and cognitive awareness sections to the brain, was extensively damaged and beyond repair, so no improvement was possible. Consequently, the vegetative part of the brain continued to work, such as respiration, heart rate, muscle reflexes, digestive and excretory systems, but no cognitive function was present. No behavioural evidence of self-awareness or meaningful response to the environment could be elicited. Only involuntary and unconscious actions remained. Brain scans indicated large empty spaces filled with fluid in place of brain tissue. Electrical activity in the brain was slow and haphazard. Four years had already passed during which Dr Clarke had continued to be nursed at Addington Hospital.

The following information is relevant for an understanding of the rationalisation of how death can be construed as preferable to life. When asked to comment on the patient's quality of life, the expert neurologist, Mr Staub, reported that the patient displayed no intellectual experience, could not think and would not even be aware of his biological existence. He proposed that if quality of life depends on one's capacity to think and engage with the exterior environment, living an independent life and enjoying the usual experiences it offers, then Dr Clarke had none of that actuality. There was no sign of any level of awareness except for biological continuation[58]. Professor Bill, also a specialist neurologist, clarified that legally, there was no doubt that the patient was alive and death not imminent, although the life expectancy was uncertain[59]. The consultant physician, Ms Dumeniet, added that once the naso-gastric tube was removed the patient was most likely to progress towards death slowly until the heart ceased, over a two-to-three-week period, but without knowing either pain or discomfort. She confirmed that the cessation of nutrition and hydration would definitely hasten the patient's demise[60].

These two facts - that the patient was not near death biologically, although arguably in a protracted terminal phase of life, and that withdrawal of artificial feeding and hydration would hasten death - unmistakably supported the present and acknowledged intention to speed up his death. If the patient's quality of life was so low that it amounted to a life that barely existed, described as biological only[61, 47], not worth living, and would only end after three weeks of withholding nutrition, it is arguable that a lethal injection administered at the time of the removal of sustenance would offer a more compassionate, sensible end. Some literature suggests that, instead of using terminal sedation, which is also associated with the withdrawal of hydration and nutrition, a more immediate death by the administration of a lethal injection would possibly be a kinder, more humane, and morally acceptable termination of life[62].

Thirion, J., having created a comprehensive picture of the patient's prognosis, then focussed on

the legal questions. The first question was whether the *curatrix* would be acting unlawfully and wrongfully if she gave instructions to withdraw nutrition and hydration from her husband with the intention to facilitate his death. The Court held that the answer depended on the common law principle of the *boni mores* or 'good morals' of society.

The objective test for 'wrongfulness', a distinct element of criminal liability in the common law, encompasses what the public perceives as fair and just in a situation – their legal convictions[63].

The issue for the Court to decide in this case was whether society would think it reasonable under the circumstances to withhold nourishment and hydration. Thirion, J relied on Snyman, who, amongst a number of legal authors with similar views, advocated that, in order to establish if an act was unlawful, it must be ascertained whether the act violated the good morals or legal convictions of the community. Furthermore, he mentioned that grounds of justification, a well-known practical means of determining wrongfulness when applied, could exclude wrongfulness. Its limitations though, were that it does not cover the whole area of lawful and unlawful behaviour[64]. Examples of grounds of justification are self-defence, consent (where assisted death is legislated) and necessity[65], none of which were relevant to this case.

Drawing from the case of *Minister van Polisie v Ewels* 1975 (3) SA 590 (A) at 597, Chief Justice Rumpff was quoted as saying that it seemed as if South Africa had reached a stage in the development of its law where an omission is treated as wrongful conduct when, based on the circumstances of the case, both a sense of moral indignation and the legal convictions of society demanded that the omission be classified as unlawful behaviour. Judge Thirion proposed that the converse should also hold true: if society's legal convictions do not require that either an omission or commission be treated as wrongful, it would not be wrongful in law. He included morality as a factor shaping the public's legal opinions, and suggested that 'the law is but a translation of society's fundamental values into policies and prescripts for regulating its members' conduct …'. Accordingly, the Court had to bear in mind the prevailing values of society when determining the limits of wrongfulness[47, 66].

The Court maintained that the answer to whether withdrawal of nutrition was reasonable and therefore lawful, depended on the patient's remaining quality of life. It relied completely on the fact that Dr Clarke's brain had totally lost the capability to generate a corporeal or cognitive reality at a level that compared to human animation. In this situation, applying the legal

convictions of the people, continuing to feed this patient would fulfil no rationale to sustain life as it was commonly experienced. Feeding was not sensible because it served no purpose. The wife, then, in her capacity as the *curatrix*, would not be acting wrongfully, but rather would proceed reasonably and justifiably, if she authorised the discontinuation of artificial feeding of her husband, even if this instruction would hasten death.

Judge Thirion approved of the medical advancement that had occurred to sustain life but accepted that this also presented unusual ethical dilemmas. A shift in public attitudes towards a fresh approach to the process of dying was needed. He confirmed that community's legal opinions had come to accept the hastening of death in certain contexts. Administering drugs to relieve pain that may accelerate death is considered lawful, for instance, based on the British criminal case of *R v Adams*, 1957[67], or the removal of a ventilator only supplying mechanical life, as happened in *S v Williams* in 1986[68].

He drew a distinction between the act of withholding nutrition compared to physically suffocating the patient, suggesting that society's sense of propriety dictated that the natural order of death should occur as far as possible. For that reason, a person had no right to interfere with this process because that would be wrongful. Meddling, he stated, alters both the course and the cause of death[69].

The Judge's sentiments gave the impression that he believed that it was not acceptable to interfere with nature. He used an executioner and his prisoner as an example of an unnatural death: if a person killed the prisoner before the execution, it would be wrongful because the perpetrator was not entitled to 'meddle', regardless of the motive. The act would interfere with the purpose of the execution rather than the manner of death. He drew a comparison between a doctor who, while foreseeing the possibility of hastening death, was treating pain, compared with the doctor who prescribed an overdose of drugs to end a life. The doctor's intention and behaviour in the latter circumstances would be unlawful, he explained, because it went beyond the scope of his 'legitimate function'[70].

Despite the Judge's effort to distinguish these examples from the present case, he must have appreciated that they were somewhat vague, because he finally admitted that, 'The distinction between what is wrong and what is right cannot always be drawn according to logic. Logic does not dictate the formation of society's legal or moral convictions'[71]. This certainly seems to be true.

The Court held that there is no legal distinction between an act and an omission that causes death when establishing criminal liability. If the naso-gastric tube had not been inserted, legal liability for the omission would depend on whether there was a duty to insert it. Therefore, the question arose whether there was a duty not to remove the artificial feeding apparatus once in place. Judge Thirion said a duty could not arise if the life-sustaining measures implemented had failed. There would be no value in continuing the process, therefore the *curatrix* did not have a duty to persist with the nutrition[72]. The feeding-tube *in situ* was clearly sustaining life by allowing the patient to be fed. It was just that the person's 'life', as the world understood it, was factually meaningless.

The Court then focussed on the *curatrix's* duty to have the best interests of the patient in mind with every decision that affected him, even if those interests did not match his wishes. The Judge opined that he could not readily imagine a situation in which someone would be better off if he did not exist at all, except for the examples of a permanent vegetative state or suffering unbearable pain. In the specific circumstances of this case, the patient had passed the point where he would have any interest in the decision taken. Although the Court would, as a general rule, choose to preserve life, the Court held that discontinuing feeding was not against the patient's interests. This was because the Court did not support the maintenance of life at all costs, irrespective of its quality. Moreover, the decision did align with the patient's expressed wishes in his Living Will, written while he was in good health[73]. The words that Judge Thirion chose to use, 'being in unbearable pain' are also those used by people who seek to justify their request for euthanasia.

At the end of the judgment, to endorse the principles that were held by the Court, there was a final note stating that, as a matter of policy, bearing in mind factors such as reasonableness, fairness and justice, death would not, in law, be caused by the removal of the artificial feeding regime[74].

The Court exercised its discretion despite the opposition of the Attorney-General who thought this was beyond the Court's power. The Court stated that it could only make an order on facts that provided certainty that there was no reasonable possibility that the applicant, on acting on the order, was committing a crime against the patient. Judge Thirion confirmed that no court was competent to sanction the commission of a crime or wrongful act[75].

It is interesting to ponder that the case of Clarke may be similar in morally relevant respects to

that of Hartmann. In both cases a close family member was exercising the utmost kindness when deciding on behalf of their suffering relative that they would finally be at peace if they were helped towards death. Removal of Dr Clarke's naso-gastric feeding tube was an active intervention to shorten the patient's existence. Likewise, Dr Hartmann's administration of a lethal dose of morphine to his father was an active intervention to shorten the patient's terminal phase prior to death. It just had a more rapid result that the death of Dr Clarke.

A frank comparison, noting the similarities, should support a change in the law or at least assist with altering the mindset of those who feel that E could never be embraced. In both cases the Courts accepted that these were acts of deep compassion, not warranting punishment. In fact, in the matter of Clarke, by assisting in Dr Clarke's death, the Court was itself an accomplice.

3.1.1.17. *Smorenburg*, 1992 (attempted murder / euthanasia)

This case is the only other occasion, besides Hartmann's, where a medical professional was accused of performing or attempting to perform euthanasia within the hospital environment. Friedman JP, in the Cape High Court, acknowledged at the start of the judgment that this case brought into sharp focus the difficult circumstances with which medical staff are confronted in the face of their patients' intense human suffering during the terminal phase of life. On a daily basis the staff are thrown into ethical conflicts, to make choices between their moral duty to preserve life and an instinctive desire as fellow humans to alleviate pain, misery and anguish. This is particularly so when their patients' no longer have any quality of life, and no hope of improvement exists. He noted that it makes criminals of people who would normally never see the inside of a court, a feature that is comparable to other euthanasia cases throughout the world[76].

The facts were that a 32-year-old nursing sister, Sister Smorenburg, attempted to end the lives of two terminally ill patients in her care, in a general surgical ward. She injected them with large doses of insulin, hoping to put an end to their suffering. One patient died a few hours after administration, while the second patient died within a half hour of receiving the insulin[77]. Her evidence was that their misery had affected her greatly because she was overwhelmed by caring for the seriously ill and geriatric population, so much so, that she had contemplated leaving nursing as a profession shortly before the incidents. Sister Smorenburg's skills had been homed in casualty, which allowed her to save lives and see the positive results of her nursing care[78].

The Court found her guilty of attempted murder and sentenced her to three months' imprisonment, suspended for a year on condition that she did not practise as a nurse until or unless she was re-registered[79]. The Court accepted as mitigating factors that the accused had no previous convictions and had shown sincere remorse. Sister Smorenburg had been an outstanding nurse previously, and was viewed as compassionate, kind and attentive to her patients. Despite this, she had immediately resigned from the hospital and de-registered with the Nursing Council after her actions. At the time of the patients' deaths, she had admitted her crime to the matron on duty. The Court believed that the accused had been battling with great emotional distress, which led to an ethical dilemma in which she perceived that she was carrying out the wishes of her patients to end their prolonged anguish. Evidence described the accused as believing that the patients were experiencing grave suffering and indignity, and that the insulin injection would lead to their painless death[80].

Curiously, Friedman, JP remarked that there had been no evidence that the patients felt even the slightest pain or suffering from her actions. No judge appears to have taken this aspect into account in previous cases. He did observe, though, that more training was required to equip nurses with the coping mechanisms for managing patients at the end of their life[81].

Some background to the facts was that Sister Smorenburg mentioned in her testimony that the subject of euthanasia had been discussed in the tearoom on occasion. She held the opinion that if the process was properly regulated and administered through a panel of experts, it would be a good law to have in place so that people could die with dignity, free from protracted suffering. Smorenburg also shared that during late 1989, while she was struggling to make peace with the difficult progression towards death that some of her patients were experiencing, she had read an article about nurses in Austria who had used insulin to bring a painless end to their patients' lives[82]. These snippets of information had influenced her mind. The accused told the Court how, after the deeds had been completed, she felt some relief but, in her words, knew what she had done was both against the law and against God's teachings[83]. The ambivalence she felt may have indicated regret, but also highlighted the conflict of conscience that can be generated through actively facilitating the process of death.

Sister Smorenburg admitted that, following her resignation, she sought help from a psychologist. Although at the time of the incidents she had believed that carrying out euthanasia was the correct thing to do, she now appreciated that she had been wrong. The accused apparently still supported the concept of euthanasia but acknowledged that it required

regulation[84].

The blurring of roles between being a caregiver and an executioner could plausibly create moral confusion, both for the medical practitioner and, as it has been suggested by a few writers, for society, although data from first world countries does not support this view[85]. It is unknown whether, in a different and diverse culture such as South Africa's, moral confusion may yet occur. If so, that could be a reason for not allowing the task of assisted death to be performed by the medical sector, despite their withholding and withdrawing treatment when appropriate.

Summary of pre-Constitutional era

The pre-Constitutional phase of South African cases from 1940 to 1993, spanning 50 years, illustrate the following points. Principles were extracted from South African sources of ancient law and society's legal and moral convictions of the day. Judges were open about their spiritually based beliefs which supported their decisions that were often also moral dilemmas. Suicide was not punishable, but actively helping someone else to commit suicide amounted to a crime if a causal nexus was proved to exist. The theory of natural law applied by the early judges is evident. The courts always exercised a measure of mercy where the emotional anguish of the accused was apparent as an extenuating factor. This clemency was displayed through lighter penalties than would have been expected for the crime of murder. On a few occasions the sentencing amounted to no punishment, which illustrated a tolerance for and understanding by the Court of compassionate killing. Furthermore, there was actually support from the Court for withdrawal of treatment in circumstances where the patient was confirmed to be alive but in a permanently vegetative state with no prospect of improvement in health or quality of life.

A summary of the pre-Constitutional cases is presented in Table 1.

3.1.2. Constitutional era

Interim Constitution, commenced 27 April 1994, repealed 1997.

On the 27th of April 1994, a new legal standard to ensure the protection of human rights in South Africa was introduced in an interim Constitution.

Table 1. South African cases that consider 'mercy killing', assisted suicide and withdrawal of treatment

Year	Case Name	Type	Charge	Verdict	Sentence
1940	R v Peverett	**Suicide pact.** Couple attempted to gas themselves in car but survived.	Attempted murder	Convicted of attempted murder	Fined £30
1955	R v Davidow (unreported)	**'Mercy killing'.** Son shot terminal mother who requested because pain unbearable.	Murder	Not guilty. Emotional state = not blameworthy state of mind	
1956	S v Nbakwa	**Assisted suicide**. Prepared noose for hanging with block to stand on.	Incitement to commit suicide	Not guilty, because suicide not a crime	
1962	S v Gordon	**Suicide pact.** Couple ingested tablets, accused lived, partner died.	Murder	Not guilty, because suicide not a crime	
1968	S v Robinson	**Voluntary assassination**. Requested shooting to avoid debt.	Murder	Guilty, with extenuating circumstances	15 years, (reduced sentence)
1969	S v Grotjohn (unreported)	**Assisted suicide**. Gave wife loaded gun to kill herself.	Murder	Not guilty, incitement to commit suicide not a crime	
1975	S v De Bellocq (From 1968)	**'Mercy killing'**. Physically & mentally impaired baby drowned.	Murder	Guilty, with extenuating circumstances	Discharged from court, to re-appear in 6 mo's. Not called.
1975	S v Hartmann	**'Mercy killing'**. Son gave dying father lethal injection.	Murder	Guilty, with extenuating circumstances	1 year, detained to rising of court, suspended for 1 year
1979	S v McBride	**'Mercy killing'**. Shot wife who thought she had cancer.	Murder	Not guilty, by reason of mental illness	Detained as a state president's patient
1979	S v Hibbert	**Assisted suicide**. Gave wife loaded gun on request.	Murder	Guilty, with extenuating circumstances	4 years in prison, suspended for 5, if no more convictions
1986	S v William	Gunshot, then death **Withdrawal of ventilator**	Murder (for gunshot)	Guilty. Appeal brought based on 'new intervening act'	Appeal rejected. Guilty sentence confirmed
1991	S v Marengo	'**Mercy killing'**. Terminal father shot by daughter.	Murder	Guilty, with extenuating circumstances	3 years in prison, totally suspended for 5, & supervision by social worker
1992	Clarke v Hurst	**Withdrawal of nutrition** and hydration	Request: appointment of curator to stop food	Order granted. Naso-gastric tube removed.	N/A
1992	S v Smorenberg	**'Mercy killing'**. Nurse injected insulin into terminal patients.	Murder. Plea of guilty entered.	Guilty. Attempted murder.	3 months in prison, suspended for 1 year under Nursing Act conditions

Table 1. South African cases that consider 'mercy killing', assisted suicide and withdrawal of treatment

Year	Case Name	Type	Charge	Verdict	Sentence
2003, Constitution	S v Nkwanyana	**'Mercy killing'**. Shot friend with mental illness.	Murder + 2 gun charges. Plea of guilty entered.	Was in jail 2 years awaiting trial. Guilty, extenuating circs.	5 years in prison, suspended for 5.
2019	S v Davison	**'Mercy killing'.** Suffocation, lethal medication	3 counts of murder. Plea of guilty entered.	Guilty, extenuating circs. Second conviction.	8 years in prison, suspended for 5, 3 under house arrest.

Ethical theories identified:

- 1940 – 1980s: Natural law applied, arising from universal moral standards first proposed by Aristotle. (as stated in *Clarke v Hurst NO and Others* 1992(4) SA 630 (D) at 650H – 651C)
- 1940 – 1980s: Christian influence of natural law, too, and what the moral/legal convictions of the community were at the time. (1970 Grotjohn case; 1986, J Rabie.)
- 1968 – 2000s: Virtue ethics applied, as acts of compassion and mercy in sentencing.
- 1992 – onwards: Shift towards principles of autonomy and privacy

Once a final Constitution was adopted in 1996, the interim statute was repealed. New important cases arose on the topic of the right to life. These have a bearing on the prospects of South Africa promulgating E and PAS legislation in the future. They are now analysed, in addition to the criminal cases presented.

It is noteworthy that, along with a legal paradigm shift, moral emphasis also shifted from a natural law foundation that had become associated with Christian values and the exercise of virtues such as mercy and compassion, to that of a more deontological focus, incorporating self-determination, dignity, and equality. The Constitutional Court refers to humanism and *ubuntu* philosophy to guide their reasoning, as indicated in the cases that follow.

3.1.2.1. *Makwanyane*, 1995 (principles; rights to life, dignity, not to be subjected to cruel, inhuman, or degrading treatment)

S v Makwanyane[86] was the first Constitutional Court case to be heard at the new stage of South African law during February 1995, although the judgment was only handed down in June of that year. The matter dealt with the constitutionality of legislation that allowed the death penalty as a punishment for serious crime. It is pertinent for this thesis because the focus is on an agent of the State putting a prisoner to death.

As a component of addressing the constitutional challenge, the Court discussed the approach to the interpretation of constitutional rights generally, and the meaning of '*ubuntu'*. Each Judge participated in the final presentation of a thoroughly reasoned judgment handed down by President (P) Chaskalson.

According to Justice (J) Sachs, the history of Constitutionalism arose out of the Age of Enlightenment. This new concept brought with it the end to governments wielding indiscriminate power, and a new beginning that followed principles and procedures that upheld the inherent values people had by virtue of their humanity. It was also associated with the belief that no one had a God-given right to rule over other people as the monarchy had done in the past. He went on to elaborate that a second constitutional surge happened after World War II in reaction to leaders witnessing a complete disregard for humanity and the gross abuse of power by some governments during the war. This led the rights to dignity and life being firmly entrenchment in the Constitution. Justice Sachs then pointed out, speaking of South Africa, that the authors of our Constitution brought in values such as equality, freedom and tolerance. They

rejected all hateful law and practices, observing that people treated inhumanely had a diminished respect for life[87].

The challenge in *S v Makwanyane* was that capital punishment directly violated the interim Constitution's right to life (s9), right to dignity (s10) and the right not to be subjected to cruel, inhuman or degrading treatment (s11(2))[88]. Accordingly, it was argued that the law needed to be struck down as invalid[89].

On the question of whether society viewed the death penalty to be cruel and inhuman treatment, President Chaskalson, on behalf of the Court, held that, although public opinion had some influence, it was not significant anymore, compared to the duty of the courts to interpret the Constitution and to enforce its provisions in a completely neutral manner. The Constitution, as a new legal order, had replaced the parliamentary sovereignty of old that had to answer to the public because of the mandate it had been given by the people. If this were not so, the opinions of society would be decisive, and the Constitutional Court would have no need to adjudicate[90].

Both the right to life and the right to dignity were considered by the Court to be the two most important rights and the source from which the other personal rights developed. Consequently, they were also to be the highest in value for the community, if it intended to have an infrastructure founded on the recognition of human rights. The State was to demonstrate their worth in all it did[91].

Justice Langa drew attention to the violent recent past of South African history at that time and made the point that respect for both life and inherent dignity had been the chief fatalities. He voiced his expectation that the new Constitution indicated a dramatic change in the system of governance where democratic principles and the values of freedom and equality would take precedence. However, Langa, J directed the government to lead by example, to reflect a culture of respect for human life and dignity, as encapsulated in the concept of '*ubuntu*'. *Ubuntu* is described in the judgment as being an attitude of the African community to highly value life and a person's inherent dignity. It also appreciates that another's life is at least as precious as one's own. Justice Langa admitted that treatment that is cruel, inhuman, and degrading, as well as violent crimes against members of society are the antithesis of *ubuntu.* He said that in South Africa life had become cheap and worthless[92].

Sadly, the government has fallen far short of this standard of *ubuntu* in the current experience

of the South African people. Besides the prolific state corruption uncovered by Chief Justice Zondo's Commission of Inquiry[93], President of the Constitutional Court since the 10th of March 2022, several incidents have arisen that proved the opposite of government respect for human life and dignity to be true. For example, the lives of striking miners were lost during a confrontation with police at Marikana, North West Province, on the 16th of August, 2012. It was labelled as a massacre after police killed 34 workers, and seriously injured 78 others, while the miners had gathered peacefully on public land[94].

Four years later, during 2016, the Gauteng Health Department decided to transfer approximately 1 500 vulnerable mental health care users from a private facility, Life Esidimeni, a long-term psychiatric care hospital, to other non-governmental organisations (NGOs) and psychiatric facilities, against the advice and in the face of objections from medical personnel and other stakeholders. The intention was to reduce costs and place these people within communities, but the concern of society was for their safety, ongoing care and protection of dignity because families and other interested parties had either not been consulted or were ignored. Within months of the transfer of many patients, it was established in the media that patients had been lost and numerous people had died. The handling of these people had caused them great suffering, starvation, and dehydration, aside from emotional distress. More than 94 people were reported to have died but others still remained unaccounted for[95]. Former Deputy Chief Justice Moseneke, reading his Arbitration Award against the State in this affair, observed that the government's decision had 'caused so much pain and suffering, stress, trauma and morbidity'. He added that, in his opinion, it was 'a very serious breach of the constitutional obligations by the State and its servants'. The Constitution, and the philosophy of *ubuntu*, had evidently made no impact at the time of these crimes. In 2022, six years later, the Esidimeni inquest remained ongoing. Human dignity is meaningless when life is treated as worthless.

Following this embarrassment, in September 2019 there was national civil unrest where 12 people were killed and others injured following attacks primarily on African foreign nationals and their businesses. The anti-migrant sentiment and domestic disturbances have been increasing progressively since around 2008 because of local unemployment and limited economic opportunities. Unfortunately, it is not appreciated that the migrants and refugees too, have left their homes because of natural disasters, food insecurity and political instability[96].

Then, in July 2021, violence and looting broke out again across different areas of South Africa, especially in the big cities, primarily fuelled by politics[97]. The State failed to quell the unrest

and had to seek assistance from the South African Defence Force, as well as private security companies[98].

South African communities remain far removed from an *ubuntu* mindset right now, where daily life for many remains a struggle for survival in the wake of dire poverty, unemployment, violence, sickness and death. Twenty-eight years later, life is still under-valued.

At paragraph [120] of the *Makwanyane* judgment, Chaskalson, P listed the causes of violent crime in South Africa during that period: 'homelessness, unemployment, poverty and the frustration consequent upon such conditions'. He added that the police and prosecuting authorities had been unable to cope. The Attorney-General's evidence was that many serious crimes remained unsolved, and that only approximately a third of the total were prosecuted. Currently, 28 years on, the problems with life-threatening crime remain a serious concern[99].

Didcott, J reinforced President Chaskalson's stance on avoiding any discussion around the negation of the essential content of a right in this judgment, suggesting that another case in the future may be more suitable for the exercise. Likewise, he included postponing an interpretation of what a definition of the right to life would incorporate for a different case in the future[100].

Now the country has that opportunity once more, in the pending case of *Walter & Others v Minister of Health & Others*[101]. This action is likely to bring clarity to exactly what the right to life entails because it is a request to legalise euthanasia.

In *Makwanyane*'s case, Justice Madala highlighted the primacy of the Constitution when Parliament legislates in the future. He stated that public opinion could not be canvassed to assist decisions of the courts because the provisions of the Constitution had to be interpreted using legal argument. All law then, would be judged according to the Constitutional standard and if it was not aligned, would be struck down[102].

Mahomed, J articulated a similar train of thought to Justice Madala's, elaborating on the different role Parliament has to that of the Judiciary. He said a crucial difference was that Parliament applies political discretion using the political preferences of the electorate, and, he acknowledged, public opinion does have a legitimate place to comment on a public concern. However, he stated that the judicial process is entirely different, utilising provisions of the Constitution, foreign law, local precedent, text and context, as well as other interpretative tools

to balance divergent interests through a judicious assessment of all the elements, ultimately to reach agreement on what the Constitution permits and prohibits[103].

Justice Mahomed, in summary, concluded that the Constitutional Court would make value judgments objectively, using the ordinary meaning of words used in the Constitution; consistency with the other rights in the Bill of Rights; constitutional philosophy and humanism expressed in the pre- and post-ambles of the Constitution; harmony with the national ethos identified by the Constitution; historical background to the objectives and structures of the Constitution; proportionality (applying the limitation clause), and consistency with constitutional perceptions evolving within South Africa and the world with which the country shares emerging values[104].

This judicially revised pragmatic ethos is based on human reason and experience, in contrast to the elements of spiritual faith that contributed to the morality of judges observed in earlier legal cases like Grotjohn[105]. 'Humanism' is defined in various ways in the Merriam-Webster dictionary[106]. Some meanings that may fit appropriately here are '1(b). the revival of an individualistic and critical spirit, and emphasis on secular concerns characteristic of the Renaissance; 2. devotion to human welfare: humanitarianism; 3. a doctrine, attitude, or way of life centred on human interests or values, especially: a philosophy that usually rejects supernaturalism and stresses an individual's dignity and worth and capacity for self-realisation through reason: secular humanism'. This philosophy of humanism in the present day replaces the religious dogma and natural law of the past.

Justice Mokgoro possibly offers a broader foundation for applying Mahomed, J's 'humanism', in the philosophy of *ubuntu,* by expanding on Justice Langa's explanation of this ethic. She emphasised the importance of group solidarity for survival within the community, besides the central ideals of compassion, respect, human dignity, conformity to basic norms and collective unity. Mokgoro, J said that essentially, *ubuntu* encompasses personhood, humanity and morality, encapsulated in the words *umuntu, ngumuntu ngabantu* (a person is a person through other persons[107]). She added that this is not different from other cultures that hold respect for life and humankind in high regard, but South Africa had traumatised the human spirit by negating each person's identity and dignity[108].

In fact, the philosopher, Tschaepe, combines the *ubuntu* ethic with secular humanism by proposing that *ubuntu* provides the humanistic moral rule that brings about the obligation the

person has to the community to uphold virtues, which in turn will sustain the harmony of the community[109].

Justice Mokgoro reiterated how important the value of human dignity is and the need to protect it as an inherent right, intrinsic to life itself, which *ubuntu* upholds[110]. She stated that the government, as the representative of the public, lays down the guidelines for society's moral standards through law[111]. While interpreting the rights, the Constitutional Court is charged with the task of promoting the values written in the Constitution that bring about an open and democratic society, based on freedom and equality[112].

Bearing this in mind, with the awareness of the evidence in the media of an ongoing struggle to find respect for human life, both the government and the people it governs do not seem to be ready to manage far-reaching legislation that allows for the negation of life by euthanasia at this stage of South Africa's democracy. Having said this, despite the social problems or because of them, it is to be noted that, in 1996, the updated Choice on Termination of Pregnancy Act (CTOP Act)[113] was promulgated, with much broader provisions to allow for an abortion than in the past, such as allowing it up to the 21st week of gestation where the continued pregnancy would significantly affect the social or economic position of the woman.

It remains to be seen what the outcome of the legal challenge to define the right to life will be.

Justice O'Regan, in her contribution to President Chaskalson's judgment, honed in on the wording: 'everyone has the right to life'. She shared her observation that the formulation of South Africa's right to life, in its all-encompassing broadness, differs from other countries' words for their right to life, including the international human rights conventions. These entities use phrasing with a proviso inserted, such as that 'no one may be deprived of life arbitrarily', or 'without the due process of law', which, she said, made them less helpful to the Court for shedding light on interpreting South Africa's right[114]. O'Regan, J proposed that applying the purposive or teleological approach to analyse the right guided one to consider what rationale the framers of the Constitution had in mind. In certain situations, this could require a generous reading to be given to the Bill of Rights, while at other times a narrower construal might be appropriate. Her conclusion was that even though a right may be allocated minimal content as a start, in time to come these ideas could be expanded upon when new legal cases were heard[115].

Justice O'Regan's point would certainly be relevant for the understanding of the right to life in

circumstances where there is a request to terminate life in the future.

O'Regan, J expanded the discussion by contemplating that the entitlement to life was not just incorporated into the Bill of Rights to ensure existence. Similar to the reasoning seen in the case of *Clarke v Hurst*[55], she maintained that life as 'mere organic matter' was not what the Constitution envisaged, but rather a life to be lived engaging with the community and participating in humankind. This meaning of life assimilated dignity as part of its core. Justice O'Regan conceptualised the right to life as one being respected as a human being with dignity, and without dignity, she admitted, life would be markedly reduced. Justice O'Regan was of the opinion that dignity, recognised as a separate right, indicated that the drafters appreciated that people have intrinsic worth. She quoted the right in the interim Constitution as 'Every person shall have the right to respect for and protection of his or her dignity'[116].

In fact, the wording of the right to dignity in the final Constitution confirmed Justice O'Regan's original interpretation, because it was altered in its final form to state that 'Everyone has **inherent** dignity and the right to have their dignity respected and protected'.

Justice Sachs, like Madala, J and Mogoro, J, also emphasised the need to include African resources when clarifying the values set out in the Bill of Rights. He agreed with colleagues on how Constitutional questions should be interpreted, but specifically mentioned that, regardless of their individual opinions on a topic, the answer to the question must be a purely legal one. For example, an execution would extinguish the right to life, so could not be permitted, whether one held the view that the punishment was just or not. He referred to Justice Mahomed's remarks about life not being able to be limited incrementally, only its enjoyment restricted, and death was the same: irreversible and permanent[117]. Mahomed, J had also shared his personal opinion that, by the State carrying out an execution, not only would the dignity of the individual be assaulted, but possibly, as a result, in a caring community, everyone's dignity would be diminished[118].

This important moral insight resonates well within the context of *ubuntu* philosophy. Arguably, it could be applicable to euthanasia law, too, but the assault would be on the dignity of the agent who carries out the procedure, not on the requester, whose dignity would have been extinguished.

Sachs, J noted, similarly to O'Regan, J, that other countries' constitutional frameworks have

worded their right to life clearly to allow for deprivation under certain circumstances. In comparison, the framers of the South African Constitution specifically opted for a right that was in no way qualified by other language, indicating that life will actually be protected. He suggested that, in the future, when required, proportionality would be read into the definition to balance competing interests[119].

The result of the evidence led, alongside the contributions made by the Justices, was that the Constitutional Court found the death penalty to have violated the right to life, the right to dignity and the right not to be subjected to cruel and inhuman or degrading treatment. It was accordingly in conflict with the provisions of the Constitution Act 200 of 1993 and therefore no longer valid in law. The whole bench agreed.

The Constitution, commenced 04 February 1997

3.1.2.2. *Soobramoney,* 1998 (principles; right not to be refused emergency treatment; right to life; right of access to health care services)

During the first year of the commencement of the 1996 final Constitution[120], the *Soobramoney* case[121] was heard. It is relevant for this thesis because, besides considering what 'emergency treatment' entails, it examines the right of people to access health care services, the status of government hospital policy, and it contemplates the end of life.

Briefly, the facts of the case were that a 41-year-old diabetic man, Mr. Soobramoney, suffering from serious cardiac and vascular problems, including chronic renal failure, sought the court's urgent assistance to gain access to renal dialysis at the provincial hospital in order to prolong his life. Without dialysis he had no prospect of survival. As the hospital had limited resources it could not admit everyone who needed dialysis but had a set of criteria to select those who would benefit the most from it. All acute kidney failure patients were eligible, but of those who were chronic, primarily the ones awaiting kidney transplants qualified, as they had been found to be suitable for the transplant list because of not having any major cardiac and vascular disease. Mr Soobramoney, unfortunately, was not an appropriate candidate for a transplant. He brought an urgent application to the High Court, hoping to use the Bill of Rights, s27(3), 'No one may be refused emergency treatment', and s11, 'Everyone has the right to life', to persuade the Court to provide him with dialysis treatment and to stop the State from refusing him admission to the renal unit. The application was dismissed, so he appealed to the Constitutional

Court[122].

The Constitutional Court held that Mr Soobramoney's request for dialysis as a consequence of a chronic condition did not fall within the ambit of supplying emergency services, or immediate remedial treatment in terms of s27(3), and should be refused[123].

Using the ordinary meaning of the words to understand s27(3) in a practical way, President Chaskalson, highlighting that it was expressed in negative terms, proposed that the intention behind the right was to prevent obstacles from arising that could delay medical attention in a situation of a sudden, unexpected event that required immediate assistance[124].

The Court then turned its focus to analyse the content of s27(1), being access to health care services and other necessary amenities, and s27(2), ensuring reasonable legislative and other steps are taken within the government's available resources to progress towards fulfilling these rights. It determined that the patient's demand to receive hospital dialysis more appropriately fell within this ambit, as opposed to s27(3)[125]. Chaskalson, P elucidated that the obligations imposed on the State in respect of s27's rights of access to health care, food, water and social security depended on the means available for these purposes. However, because of a lack of resources, these rights were limited. In addition, since there was such a great demand for these needs as a result of dire poverty, high unemployment, inadequate social services and a prevalent lack of access to clean water and satisfactory health services, an unqualified promise to meet these expectations could also not be given. This was the context in which the Court had to interpret the right to access health services[126].

Chaskalson, P emphasised the point that, in order to manage its inadequate resources, the government would sometimes need to use an expansive approach towards the general requirements of the community, rather than attending to the individual desires of a minority[127]. He confirmed that the State had a constitutional duty to meet the commitments imposed on it by s27. Nonetheless, in these circumstances, he said, it was not proved that the government had been in breach of its obligations by not providing everyone who required dialysis with treatment[128].

This finding is significant in its support for the State. The long-term repercussions are that the arguments could equally relate to the need for palliative care at the end of life and chronic diseases, often associated with the elderly. The Esidimeni failure mentioned in the previous

paragraphs was a consequence of the government not being able to provide care for the mental health needs of a vulnerable minority.

Justice Madala, while agreeing with President Chaskalson's judgment, provided further points of contemplation: he referred to the State's interest in preserving and protecting life in the face of the patient's existence being at stake because of a refusal to waste scarce resources on a futile exercise. He mentioned how the conflict is brought into sharp focus when, on the one hand the Constitution upholds the right to access health services, while on the other, decisions must be made on how to distribute the limited resources of the Department of Health in an equitable way. He acknowledged the fact that doctors must find themselves facing these distressing dilemmas every day[129].

Madala, J reiterated what Chaskalson P had said, that not all rights are absolute and therefore can be limited. They are a gold standard to be aspired towards and this would take time to accomplish. Section 27(2) allows for this in the wording that says reasonable measures should be taken within the State's available resources to achieve progressive realisation of the rights listed in s27.

The impression given is that, with time, if available resources increase, so will the progressive realisation of the right of access to health care, amongst other rights. However, should the available resources decrease, then the achievement of the right would be hindered. At this stage of South Africa's democracy, the debt owed by the Department of Health because of litigation across the provinces is catastrophic[130]. Health facilities are in disrepair and, in some cases, have been maliciously damaged by dissatisfied workers[131]. These are important facts for the discussion of allowing euthanasia as an additional medical service in the future, as well as the need for good palliative care for people who would not choose euthanasia. Sadly, South Africa is failing dismally at offering end-of-life care, whether in state hospitals or through other entities such as hospice[132, 133], discussed in chapter 6.

Justice Sachs, assenting to Chaskalson, P's judgment, elaborated on the fact that other countries with open and democratic societies also restricted their scarce health resources as part of general human rights management, similar to South Africa. He quoted from case law that expressed the problem in these circumstances as follows: if governments were unable to give any benefit to anyone without having to give it to everyone, no one would be able to receive anything. However, he said, interdependence is part of everyday life and cannot be avoided when

managing limited reserves. He suggested that a broad constitutional framework needed to be drawn up to deal with the special problems associated with scarcity and sharing the right of access. It should give guidance on how to adjudicate fairly between competing parties' valid entitlements for maximum enjoyment of the right, to prevent shortages being seen as placing a limitation on these rights[134].

Sachs, J's final comments related to the right to life. He observed that now, more frequently, people have the opportunity to choose when they will die, compared to the past when it depended on fate. Whether their dilemma is about committing to more medical interventions, or 'scarce artificial life-prolonging resources' to prolong what life remains, or whether it is to refuse further treatment, Sachs, J, quoted from foreign case law[135]. He highlighted the sentiment that courts needed a framework to establish which end-of-life decisions are appropriate to engage with, and which are not. He turned his attention to Mr Soobramoney's request and declared that, regardless of how the right to life is eventually defined, the right could never be extended constitutionally to incorporate a right to evade death forever. With reference to the same foreign case, Justice Sachs cited Stevens, J who expressed the thought that 'dying is part of life, its completion rather than its opposite'[136].

Using this reasoning for an argument in support of euthanasia: if death is an aspect of the right to life - simply its completion - then perhaps a person should be allowed to have someone assist them to complete it, just as someone assists them in birth, to start life.

Justice Sachs summed up his opinion by asserting that courts are not the proper place to resolve distressing personal and medical dilemmas. He shared the opinion that South Africa's judicial infrastructure could not be substituted for the difficult private conflict endured between the patient, the caregivers and the family[137].

I disagree with this view. The fact that the Bill of Rights includes a right to life and a separate right to dignity bestows a duty on the Constitutional Court to clarify the parameters of each right for the benefit of the people. Often the Court, as a neutral third party, is better placed to pass judgment on a difficult situation objectively, free from all the emotional encumbrances and relationship ties that exist between all the parties.

This is a particularly important role for the Court where the interests of society are at stake, and also the well-being of the individual. The question surrounding legalising E creates this tension.

An example of where the Court has been of great assistance to the medical fraternity is where Jehovah's Witness parents have withheld their consent in an attempt to prevent life-saving blood transfusions from being administered to their children. The Court overrode the refusals with orders that were in the best interests of the children, upholding the child's right to life[138].

It is noteworthy that, philosophically, the rights of the individual, in the circumstances of Mr Soobramoney, were secondary to the needs of society as a whole. The utilitarian philosophy applied by the State of choosing an option that ensures the greatest good for as many people as possible is often found in the structure of public policies that manage scarce resources.

A spate of cases followed Soobramoney's matter and, although they were unrelated to death, they contributed to developing an understanding of what the right to life entails and how to interpret the law using constitutional principles. The case law is listed below to give a brief overview.

3.1.2.3. 1998: *Christian Lawyers Association of SA and Others v Minister of Health and Others*[139]

A foetus is not recognised as a legal person in law, so does not have a constitutional right to life.

The Christian Lawyers Association challenged the constitutionality of the Choice on Termination of Pregnancy Act, arguing that a foetus had a right to life in terms of s11 of the Bill of Rights. The Court held that it was not its function to answer this question based on religious or philosophical arguments, nor did it depend on medical or scientific evidence, but only on a legal interpretation. The South African law has not accorded a foetus personhood, so it is not recognised as a legal *persona* in the Constitution.

3.1.2.4. 2001: *Mohamed and Another v President of SA and Others*[140]

The Government has a constitutional obligation to protect life.

Mohamed faced extradition to a country for a trial on an offence that carried the death penalty. The Government was held to be constitutionally bound to secure an undertaking that the death penalty in that country would not be imposed, or if imposed, not carried out, following the

reasoning in the case of *Makwanyane* discussed above.

3.1.2.5. 2001: *Carmichele v Minister of Safety and Security*[141]

The Courts have a duty to develop the common law in accordance with the spirit, purport, and objects of the Bill of Rights, in line with s39(2) of the Constitution. It is also to promote the values of society, based on human dignity, equality and freedom.

The Court warned that while exercising its authority to re-shape the law, the Judiciary should remember that the main vehicle for law reform is the Legislature. Judges may make modest, necessary changes to update the common law, though, in order to keep it aligned with contemporary society[142].

The Court ruled further that where the common law is deficient in promoting the objectives of s39(2) then, depending on the circumstances, the common law must be advanced. It explained that the investigation has two stages: (1) an enquiry regarding whether the common law requires development to meet the objectives of s39(2), and, if so, (2) an enquiry into how the development should be achieved[143]. Judges Ackermann and Goldstone. advised that the process requires a close interaction between the High Courts, Supreme Court, and the Constitutional Court, so that the final court may have the benefit of the skill and knowledge of the other courts, specifically regarding whether the common law should be developed or not[144].

The Justices held that the State and its organs have a duty to protect members of society. A wrongful action must be decided by applying the constitutional 'proportionality' test. This, they explained, involves balancing the interests of individuals against the conflicting interests of the public, in accordance with the spirit, purport and objects of the Bill of Rights. Factors have to be weighed in the context of a State that is grounded in human dignity, equality and freedom[145]. Further, they elaborated that ideas such as 'policy decisions and value judgments' that echo 'the wishes … and the perceptions … of the people' and 'society's notions of what justice demands' may need to be exchanged, augmented, and enhanced with suitable standards from the Constitution's objective and value-based infrastructure [146].

This case is important for the forthcoming case of *Walters and Others*[101] because it seeks to develop the common law related to the crime of murder.

3.1.2.6. 2002: *Ex Parte Minister of Safety and Security: In Re S v Walters*[147]

A right can only be justifiably limited if there is a persuasive public interest that requires it.

This matter dealt with the constitutionality of a statutory provision relating to the use of force when carrying out an arrest. A quotation from Kriegler, J is of relevance: '… the right to life, to human dignity and to bodily integrity are individually essential and collectively foundational to the value system prescribed by the Constitution. Compromise them and the society to which we aspire becomes illusory. It therefore follows that any significant limitation of any of these rights would for its justification demand a very compelling countervailing public interest'[148].

The quotation resonates when weighing up whether the public interest for PAS and E is convincing enough to justify a limitation of rights, and if so, whether our society's values would change for better or for worse.

3.1.2.7. *Nkwanyana*, 2003 (murder / voluntary euthanasia)

The facts of the case of *Nkwanyana*[149] are significant because the problem was unique for the Provincial High Court. Heidi Picker, the deceased, was suffering from a severe psychiatric disorder, specifically anorexia nervosa, associated with major depression. Despite a range of medical treatments and interventions involving numerous admissions to psychiatric institutions, she still wanted to end her life to be rid of her misery and had made several attempts to kill herself, without success. Eventually, the deceased befriended the accused who worked as a building cleaner at a shopping centre. After a period of around five years of friendship in which she had told him her history, she asked him to assist her to plan her death. The deceased explained that she had emotional problems and wanted to end the unbearable suffering in her head. He initially refused, realising the wrongfulness and far-reaching consequences of this action but, following ongoing persistence, badgering and emotional pressure from the deceased, he agreed to help her end her life. He explained that he had felt deeply sorry for her, witnessing her unrelenting torture and intense sadness. The deceased planned the details of her demise and arranged for the accused to meet her. They drove together for the accused to purchase a firearm illegally with money the deceased had given him for this purpose. They then proceeded with their pact at a cemetery carpark. When she was ready, he shot her in her car and walked away, throwing the gun into grass along the footpath.

Once arrested, the accused remained in prison for two years awaiting trial. At the hearing he pleaded guilty to all the charges against him. Judge Makhanya accepted that this case had extraordinary and extenuating circumstances which he applied in mitigation of the sentence. He was satisfied on evidence that the accused was not a danger to society and the exceptional situation justified a lesser sentence than prescribed in law. The accused was found guilty of murder and two other charges related to the gun, but sentenced to five years' imprisonment, suspended for five years.

This case draws attention to the unbearable suffering that people with mental health disorders sometimes experience. Yet, the deceased would not have qualified for euthanasia or assisted dying based on South Africa's draft End of Life Bill, discussed in chapter 5. A few foreign jurisdictions, such as Belgium[150], have permitted PAS or E for severe psychiatric illnesses. However, it has taken time for doctors, who must diagnose the disorder as permanent to justify hastened death, to accept. Canada is presently in the process of updating its law to accommodate this category of suffering[151].

3.1.2.8. *Stransham-Ford*, 2015 (euthanasia request)

South Africa's first and only civil case requesting permission for euthanasia or physician assisted suicide, *Stransham-Ford*[152], was heard on an urgent basis in the Pretoria High Court during 2015. This matter was brought on an urgent basis by the applicant, Advocate Stransham-Ford. He requested that a doctor be authorised to end his life using lethal medication, because the applicant was suffering intolerably from terminal cancer and on his deathbed. Indirectly, it was an attempt to initiate a change in the legislation in order to make way for the legalisation of PAS and E. The applicant requested that the common law relating to murder and culpable homicide be developed in terms of s 39(2) of the Constitution[153].

Unfortunately, on 30th April 2015, the morning the judgment was to be handed down, the applicant passed away a few hours before the Court was in progress. Advocate Stransham-Ford's death was unknown to all the counsel appearing, including to Judge Fabricius, which resulted in the Judge making his findings an order of Court in favour of allowing E and PAS. The order was immediately seen as a legal success and made headlines, despite the order for a personal claim no longer being applicable or legally valid[154].

The wording of paragraphs 1.4 to 1.6 of the Court Order is relevant for this thesis. It stated:

‘1.4 Applicant is entitled to be assisted by a qualified medical doctor, who is willing to do so, to end his life, either by administration of a lethal agent or by providing applicant with the necessary lethal agent to administer to himself.

1.5 No medical doctor is obliged to accede to the request of applicant.

1.6 The medical doctor who accedes to the request of applicant shall not be acting unlawfully, and hence shall not be subject to disciplinary proceedings by the third respondent for assisting applicant’[155].

Publication of the far-reaching judgment immediately led some foreign jurisdictions to assume that South African law surrounding E and PAS had changed[156]. In New Zealand, in mid-May of 2015, Lecretia Seales, who was suffering from a brain tumour, cited the Stransham-Ford judgment as an international legal precedent in support of her appeal to the Wellington High Court, which ultimately failed[157].

As a consequence of the wide publicity and general confusion which followed both locally and abroad, the South African government and other parties took the matter to the Supreme Court of Appeal in order to gain legal clarity.

3.1.2.9. *Estate Late Stransham-Ford*, 2016 (principles)

During November 2016, the case of *Estate Late Stransham-Ford*[158] was re-visited in order for a five-judge bench of the Supreme Court of Appeal (SCA) to reconsider the judgment handed down by Judge Fabricius. The Ministers of Justice and of Health, the Health Professions Council of South Africa (HPCSA) and the National Director of Public Prosecutions, were appellants, and there were five other parties with the status of *amicus curiae* (‘friends of the Court’) to assist the Court by presenting their arguments and insights on the matter.

Fabricius, J’s order was overturned by the whole bench, but in doing so, the SCA gave a thorough judgment on how to approach the topic in the future.

Judge of Appeal (JA) Wallis, speaking on behalf of the Court, who were in full agreement, gave three specific reasons for the Court’s decision to set aside the order. Firstly, the cause of action ceased to exist on the death of the applicant which occurred a few hours before the order was read in open Court. The claim was personal, so did not pass on to the applicant’s estate, and the estate had no further interest in pursuing it. Secondly, bearing in mind that the subject is a contentious one, there had been no full and proper opportunity to scrutinise the current law, nor

the chance to consult either the local or international authorities, or to apply the constitutional rules required to interpret the Bill of Rights while developing the common law. Thirdly, the Court held that the findings were made on a flawed and restricted set of facts, without complying with the Court's procedural rules and without giving all interested parties a fair opportunity to present their opinions in argument.

In summary, the Court declared that the urgent and rushed circumstances of the case did not allow for a full canvassing of all the complex and emotive arguments surrounding such a drastic change to the law. This had made it unsuitable for Judge Fabricius to attempt to develop the common law related to the crimes of murder and culpable homicide[159].

Wallis, JA acknowledged that with the progress of medical science, people lived longer. However, that also prolonged the death process, which was sometimes found to be painful and burdensome. The situation had led to a global debate regarding whether it should be permitted for people to either be assisted to end their lives themselves or be assisted by a doctor who could terminate their lives for them at their request.

Judge Wallis stated that, for the purpose of clarity, the definitions the Court used were: physician assisted suicide (PAS) to refer to circumstances where a person would be able to obtain a prescription for lethal medication they could ingest to terminate their lives themselves; and physician assisted euthanasia (PAE), where a medical practitioner would be given permission to end the person's life, at their request. The latter is also known as voluntary euthanasia. He explained that these situations did not include either refusal of medical interventions, or withdrawal of treatment, which are considered lawful actions in South Africa. This is not the case globally, where some countries classify these decisions as passive euthanasia and illegal behaviour.

The Court did acknowledge that there are opinions that the distinction made between different procedures to end life is sophistry[160]. In my opinion, however, the abbreviations used by Wallis, JA are confusing because they are too similar to differentiate between the doctor's different roles in each procedure. This is why I suggest the alternative acronyms of E and PAS in chapter 1, which I continue to use for clarity.

After giving a detailed explanation of why the Fabricius Court Order was invalid, the Court turned its attention to providing a brief outline of the status of South African law surrounding

euthanasia and assisted suicide. It confirmed that the law is clear that suicide and attempted suicide by an individual are not against the law. Furthermore, where a person chooses to refuse treatment, with full mental and legal capacity, this is recognised as an exercise of personal autonomy which is constitutionally protected and not labelled a suicide. The use of medical equipment such as ventilators and artificial feeding was included here.

On the other hand, the Court said that where the patient is unable to exercise free will because of age or any incapacity, the Court may be called upon to assist with a court order, as observed in the *Clarke* case[55], discussed earlier. It acknowledged that medical practitioners are entitled to make decisions with families regarding withdrawal of treatment for patients incapable of communicating their wishes when there is neither a palliative nor a therapeutic purpose to the medical intervention being offered.

In addition, while managing palliative care, doctors do not commit an offence if medication is prescribed that may have a side-effect of shortening the patient's lifespan. Wallis, JA specifically emphasised that all four of the experts called upon to give evidence on the effectiveness of palliative care impressed upon the Court that huge advances had been made in the realm of palliative care, both in training doctors in its administration, as well as with the hospice movement that exists in the country. That evidence had not been contradicted[161].

The Court then emphasised that the South African position on 'mercy killing' is that it constitutes the crime of murder, as indicated in past case law[162]. Significantly, none of the cases referred to in support of the applicant's original request in the Pretoria High Court were situations where the deceased person had solicited their own death. However, Wallis, JA acknowledged that the cases did indicate that the motives for the killings materially affected sentencing, in that a lesser sentence was considered to be appropriate[163].

Wallis, JA went on to succinctly express the crux of the issue in the *Stransham-Ford* matter: the legal question was whether the law relating to consent as a defence to a charge of murder should become acceptable for 'mercy killings' in future. This would have required an expansion of the principle affirmed in the *Peverett*[17] and *Robinson*[164] cases, discussed earlier in this chapter, but the Court pointed out that neither of these cases, nor the principle, had even been mentioned at the first hearing. The Court went further to state that, where there is a challenge to a common law principle, it should be approached directly, and be articulated clearly in terms of the scope and ambit of the interrogation.

With regard to the attitude of other countries, Wallis JA noted that at the time of this hearing only four countries in the world had legalised euthanasia, illustrating the need for a court to give the topic far more consideration than had occurred thus far[165].

Attention was then given to the alternative order sought by Advocate Stransham-Ford, to assist him to commit suicide using a lethal medication prescribed by a doctor. As the Court observed, without a court order in place, this act would have caused the medical practitioner involved to be criminally liable. The case of *Grotjohn*[105] had originally been relied upon by the deceased's counsel. Accordingly, Wallis, JA quoted extensively from this case, emphasising Steyn CJ's point that the final, independent act of a deceased to end their life was not invariably an interruption in the cause of events leading up to the death.

This is particularly true where another person has actively assisted in, and, in fact, participated in, the ultimate termination of the deceased's existence by giving them the means to that end. Chief Justice Steyn described the assistant's mindset as foreseeing a possible outcome and having the desire to bring about that intended goal, or at least, relying on the fact that the assistance would result in the outcome hoped for. The assistant's intention to kill would be present. Consequently, it would be in conflict with accepted legal principles and justice to allow the assistant to be protected from prosecution by hiding behind the deceased's final accomplishment. The assistant could be found guilty of murder, attempted murder or culpable homicide, but it would depend on the facts of the specific case under consideration[166].

Significantly, Wallis, JA drew attention to the fact that the Court in *Grotjohn's* matter did not reach the conclusion that a crime is always committed when there is encouragement, help or enablement of an individual who wants to commit suicide. Thus, he reasoned, it could not be asserted, based on the findings in *Grotjohn*, that PAS in all situations was unlawful. The principles articulated would have to be applied to present-day facts. Current legal standards should be used, such as s 39(2) of the Constitution, and foreign law, to assist with interpretation. Wallis, JA added, regarding the unlawfulness of PAS, that it was not predictable at this stage which way the law would ultimately develop[167].

Final observations of the Court concerning the local law were that, in the event that the moment arrived where the common law might justifiably be advanced to include PAS, the Court would have to determine whether the principles relating to either causation, or intention, or rather unlawfulness, needed to be modified. Also, the bench could weigh up the option of a special

defence for medical professionals. However, the Stransham-Ford case had not been suitable for this purpose[168].

A comprehensive summary of foreign law related to E and PAS followed in the judgment. Wallis, JA remarked that he was aware of only four countries at that time that had embraced E: the Netherlands, Belgium, Luxembourg, and Canada. In fact, he asserted that, in these countries, any form of not prolonging life or assisting to end life actively or passively, was treated as the same conceptually. The explanation for this was that these actions were classified in the domain of a private relationship between doctor and patient, monitored by adhering to specific requirements and following regulations, including reporting, to avoid misuse.

An important observation made for the purpose of this thesis was that, invariably, medical professionals were involved in overseeing the process. An exception to this trend was Canada, where assisted suicide in the final phase could be provided by someone other than a doctor[169].

Another point noted by Wallis, JA that is relevant to South Africa's pending legal challenge in favour of PAS, is that three countries and an American state had adjusted their law as a direct result of court cases that had initiated the first step, as opposed to drafting legislation from the outset to satisfy public sentiment. Mention was made of Colombia, the Netherlands, the American state of Montana, and Canada, where each utilised different legal arguments to achieve the same goal. Similarly, he observed that there is no consistency between countries regarding which human rights are guaranteed and thus used as the tools to motivate for the legalisation of E and PAS. Each country, based on its own perspective and situation, had emphasised a number of different rights which had been effective for their internal purposes[170].

With regard to the development of the South African common law, the Court reinforced the fact that this body of law affects everyone and not just individuals. Accordingly, if the criminal law were to be expanded to include E and PAS, it would be necessary to contemplate how this would impact on the whole medical profession. In this regard, Wallis, JA put forward some probing questions to ponder, such as: whether the patients' rights justify a change in the criminal law that would directly affect doctors. He also asked whether the right to health care would then incorporate an entitlement to the administration, or possible delivery to people for their own ingestion, of fatal doses of medication, or explicitly exclude it.

Lastly, Judge of Appeal Wallis put forward the question of what repercussions such a law would

have upon palliative care, if the argument was accepted that the right to dignity is infringed because that patient could not choose when and how to die[171].

Part of the process of establishing whether the common law could be advanced required an examination of the law in light of s 36 of the Constitution - an enquiry, the SCA pointed out, that the High Court had failed to address. Furthermore, Wallis, JA commented that all the foreign jurisprudence to which he had referred made it clear that governments had a valid interest in restricting the use of E and PAS, including other means of assisting with suicide. He affirmed that it was evident that in South Africa too, some restriction would be reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom. To establish how much restraint would be acceptable, he elaborated on what elements to enquire about under s 36. These aspects would be: contemplation of the nature of the right that is encroached upon by the current law; the importance of the purpose of the limitation; the nature and extent of this limitation; the relationship between the limitation and its purpose, and the less restrictive means to achieve the purpose[172].

Wallis, JA drew attention to the point that, even the Canadian case[173] to which Judge Fabricius referred as authority for his decision in the High Court, curtailed the criminal law relating to suicide only to the extent necessary to prevent interference with a right. The Supreme Court of Canada had held that the prohibition of aiding and abetting suicide cast the net too wide, so unjustifiably encroached on a guaranteed right. Wallis, JA added a further word of caution that, because the law had been applied differently within foreign jurisdictions across countries, counsel needed to be cautious in future when attempting to import the same arguments for South Africa. The Court criticised Fabricius J for not considering the very different environment of South Africa when this foreign law was approved for local purposes.

The following important factors to bear in mind when debating how the law should be adapted going forward were listed by Wallis JA: the availability of medical services, particularly palliative care; our society's cultural multiplicity and belief systems; the responsibility to protect vulnerable groups such as the frail and destitute, and the significance associated with undertaking such protection[174].

The last question that the Court proposed for future consideration was what format the remedy should take if South African law were to be altered. On the assumption that a right was found to be infringed, the Court apparently favoured the Canadian approach of declaring an

incompatibility of the law, and a suspension of the order so that Parliament could correct the shortcomings with legislation over a period of time. This method met with approval in the case of *Carmichele*[142], which was mentioned earlier in this chapter. It would also allow an opportunity for public comment, an important and necessary contribution from society when dealing with the details of regulation and supervision of PAS and E, a contentious and emotive subject[175].

The Court used the opportunity to voice its concern about the prospect of a change in the law to allow E and PAS. It created a clear picture of the local environment at that time, and drew a contrast between South Africa and the foreign jurisdictions where advanced health infrastructures existed, along with their wide-spread palliative care facilities. Wallis, JA mentioned that, understandably, South Africa has many different challenges compared to those experienced overseas because, amongst other variances, those countries have far greater wealth. He pointed out that, for instance, it is the voluntary organisations and the private health sector that provide most of the palliative care in South Africa, resulting in the majority of people not benefitting from this service. The gulf between the rich and poor within a diverse society highlights the inequality. Examples of difficulties include a lack of regulatory oversight in many areas which results in rules, procedures and protocols not being enforced. Wallis, JA suggested that before a court could be assured that the known risks associated with PAS and E were preventable by applying legal controls, it had to be convinced that a functional regulatory framework could be established, not just imagined from behind a desk[176].

Significantly, in evidence brought by the Health Professions Council of South Africa, Ms Mayeza, a palliative-care social worker employed at Chris Hani Baragwanath Academic Hospital, gave valuable insight into the attitude of the communities she served and for whom she cared. Judge Wallis repeated her words, that the lives of the elderly and frail were respected and appreciated, therefore family members and the neighbours helped care for them. Within their communitarian culture, Ms Mayeza described life as a gift that should be protected. Accordingly, allowing PAS and E would be contrary to their belief system and, bearing in mind their difficult socioeconomic circumstances, Ms Mayeza thought that such a change in the law could present a tangible risk to the well-being of their more vulnerable people[177].

The Court brought attention to the stark reality of the South African landscape in 2017. Presently, almost six years on, it remains unchanged and the situation, in truth, is possibly worse-off now, following the ravages of the COVID-19 pandemic and government failures in

the recent past, referred to earlier.

3.1.2.10. *Davison,* 2019 (murder / voluntary euthanasia)

The most recent criminal court case pertaining to euthanasia was in June 2019. The accused was Sean Davison, a professor of biotechnology, who had assisted in the deaths of three people, at their request, and with the knowledge of their families. He was already a well-known personality, having been in the public eye in the past, and known amongst pro-euthanasia activism groups.

During 2013, a quadriplegic, Dr. Anrich Burger who was a medical doctor, was the first to be helped to die. Then, in 2015, Justin Varian, who suffered from motor-neurone disease, was second, and lastly, in the same year, there was Richard Holland to whom he administered a lethal dose of drugs. Sean Davison pleaded guilty to all charges and was sentenced to 8 years imprisonment, suspended for 5 years, of which 3 years would be under house arrest (with permission to attend work, church or to see a doctor)[178].

This was not Sean Davison's first prosecution in which he was convicted of assisting people to die. Previously, during 2010 in New Zealand, he had helped his mother, who had been deteriorating from terminal cancer, to ingest a lethal dose of morphine after she had attempted a failed hunger strike to end her life herself. Davison then published his diary, giving details of what he had done and the turmoil he had gone through emotionally. On being convicted of incitement to commit suicide, Professor Davison was also sentenced to house-arrest for five-months there[179].

Following his experience with euthanasia in New Zealand, Professor Davison co-founded an activist group in South Africa called Dignity SA and, from 2018 until 2021, was the president of the World Federation of Right to Die Societies. Dignity SA has been involved in both the *Stransham-Ford* court case[180] and now, in the pending matter of *Walter, Harck and Others* in the South Gauteng High Court, discussed next.

3.1.2.11. *Walter, Harck,* 2022, pending (request for euthanasia)

In the course of 2017, another civil case, *Walter, Harck and Others*[101] was subsequently launched in the South Gauteng High Court, Johannesburg. It involves three parties: two

individuals and a Trust. The plaintiffs are Dr Suzanne Walter, previously a palliative care specialist who was diagnosed with multiple myeloma, an advancing cancer, and Mr Diethelm Harck, who suffers from motor-neurone disease, a progressive neuro-degenerative disorder affecting his muscles. It will eventually cause him to stop breathing unless he is assisted to breathe using a portable mechanical ventilator. According to the pleadings, the Trust is cited as a party with a view to supporting the cause, the process, or the organisations that hope to develop the law. It can continue with litigation even in the event that the other parties die before the case reaches its final hearing.

The plaintiffs seek an order, firstly to change the common law so that it will permit E and PAS for those terminally ill people who wish to choose to use it. Alternatively, the State is asked to enact legislation, or amend the Health Professions Act[181], so that doctors would not be removed from the professional register if they assist with suicides. The plaintiffs also make personal requests in the proposed order, that they may receive PAS or E in the interim period, should they reach a stage in their terminal phase of life where dying becomes preferable to living, as expressed in the words of Mr Harck. He and Dr Walter gave their oral evidence using the internet during February 2021 under special circumstances, because Mr Harck is losing his ability to speak with clarity, requiring his wife to interpret his sentences for him. Dr Walter is also relatively frail and dependent on pain management for her comfort.

The legal teams for the parties are all likely to ensure that they fulfil the standard of performance laid out for them in the judgment of the Late Stransham-Ford by Wallis, JA, to facilitate a successful and fair canvassing of the important issues that were of concern to the Appeal Court.

Beauchamp and Childress describe how, through a series of medical legal cases over time, medical ethics can be changed by the court while it develops a new framework of substantive rules. The rules are shaped by problems needing solutions for the case at hand. Consensus gradually emerges in law and ethics to create a framework of decision-making[182]. Gostin takes this thought further by observing that 'the judiciary has not only transformed the practice of medicine and the rights of patients, but also has shaped societal values'[183]. This exercise is illustrated in *S v Makwanyane*, where the judicial officers held that Constitutional values were far more important than public opinion on the question of the death penalty. The controversial subject of E and PAS will likely test to its maximum the tension between popular sentiment, legal interpretation, and ethics.

Summary of Constitutional era to date

The case law selected that provides insight into mercy killing, suicide and, more indirectly, the right to life and to choose when to die, indicates that the philosophical background to this fresh new period in South African law appears to be comparable to a deontological ethic. This is so in so far as respect for a person's inherent worth, or dignity, is brought to the fore (*S v Makwanyane*[184]), and in facilitating self-determination through respecting people's autonomy and privacy (confirming the validity of the CTOP Act[185]). However, the ethical perspective is modified by the Constitutional Court's emphasis on approaching legal interpretation through an *ubuntu* and humanist morality, which was elucidated in the discussion of the *Makwanyane* case.

A blend of cultural sensitivity will hopefully, in the future, ensure that there is a balance between the benefits to the individual and, with its social interests, the benefits to the South African community. This is recognised as an important factor for the Court to bear in mind given the *Late Stransham-Ford* Appeal case[158].

The utilitarian attitude articulated in the *Soobramoney* case[121] has found acceptance through the Constitution's wording of the state's management of scarce resources in s27's rights to health care. People who can benefit most from scarce resources are eligible and will hopefully gain access. This has resonance with policymaking by organs of the State: they have a duty to ensure that, as far as possible, the principle of justice is applied to limited assets so that they will be fairly distributed.

Considering the legal framework, individual rights are emphasised in contrast to the dominant State authority of the past. Notably, legal rights and moral human rights are viewed as two separate categories for the purpose of their application. Legal rights exist in legal codes such as the SA Constitution and are protected by the law, as well as limited by the body that has that jurisdiction. In contrast, moral rights may be perceived to be moral claims because they are not legally enforceable until assimilated into national or international law. They exist for everyone independently of a country's legal framework. Even when the law does not recognise them as worth protecting, they are morally valid[186].

The academic writer, Fagan[186] expresses the view that the doctrine of human rights is now the leading moral doctrine for appraising a society's moral standing. This ethical dogma has

attempted to put forward the first level of human rights needed to start to live at an acceptable standard for a minimal good quality of life. Various international declarations and legal conventions have assisted with this process, but the three most influential are the Universal Declaration of Human Rights[187] which was the first document of influence in 1948, followed by the European Convention on Human Rights[188] which became effective from September 1953. The International Covenant on Civil and Political Rights was formulated in 1966[189]. Fagan suggests that together they create an international Bill of Rights which helps frame national public moral norms going forward.

A summary of the Constitutional cases is presented in Table 2.

3.2. CONCLUSION

This chapter analysed the attitude of the South African judiciary towards legal cases that address assisted suicides, mercy killing, and more indirectly, the right to life and the right to choose when to die. I have also attempted to follow the changes in ethical philosophies reflected through time in the minds of the judges and society that could have influenced judicial decisions. Along with the legal paradigm shift, moral emphasis moved from a natural law foundation that had become associated with Christian values and the exercise of virtues such as mercy and compassion, to focus on human rights, such as self-determination, dignity and equality, found in the ethics of humanism and *ubuntu*.

This exercise has shed light on how the courts may respond to similar challenges in the future and what they deem to be of importance for the well-being of South African society. Of particular interest will be how the High Court addresses the current case for the development of the common law to allow for assisted death. Whether doctors will be confronted with the request to provide a service for E and PAS in the future remains unknown. However, the impact on the medical fraternity could be onerous.

In the next chapter the role of medical practitioners is observed while gaining an overview of the law and social environment of foreign countries that have incorporated E and PAS into their national legal infrastructure.

Table 2. South African Constitutional cases that consider the right to life

Year	Case Name	Issue	Provisions assessed	Finding
1995	S v Makwanyane	Challenge to death penalty	Life, dignity, not to be subjected to cruel & inhuman treatment	Death penalty violates rights and extinguishes right to life. Struck down
1998	Soobramoney v Minister of Health & Others	Emergency dialysis sought	Life, not to be refused emergency treatment, access to health services	Scarce resources justify eligibility criteria for access. Emergency treatment defined as acute danger of harm. Right to life not involved.
1998	Christian Lawyers Assoc & Others v Minister of Health & Others	Constitutionality of Choice on Termination of Pregnancy Act	Whether right to life exists for foetus	A foetus is not a legal person, no constitutional right to life
2001	Mohamed & Ano v President of SA & Others	Extradition to face death penalty	Protection of right to life	Government has a constitutional obligation to protect life.
2001	Carmichele v Minister of Safety & Security	Rapist out on bail despite request not to release him by victim	State's duty to protect society's rights	Courts have a duty to develop the common law according to the spirit, purport and objects of constitution. Proportionality test applied.
2002	Ex parte Min of Safety: In Re S v Walters	Constitutionality of statutory provision re arrest with force	Limitation of right to life, dignity, bodily integrity	Right can be justifiably limited only when compelling public interest demands it
2015	Stransham-Ford v Minister of Justice (High Court)	High Court Request for euthanasia	Development of common law. Dignity, no cruel & inhuman treatment	Order granted.
2016	Min. of Justice v Estate Late Stransham-Ford (SCA)	Supreme Court of Appeal Order permitting euthanasia	Development of common law to allow E revised.	Order invalid and reversed.

Ethical theories identified:

- 1940 – 1980s: Natural law applied, arising from universal moral stds first proposed by Aristotle. (as stated in *Clarke v Hurst NO and Others* 1992(4) SA 630 (D) at 650H – 651C)
- 1940 – 1980s: Christian influence of natural law, too, and what the moral/legal convictions of the community were at the time. (1970 Grotjohn case ; 1986, J Rabie.)
- 1968 – 2000s: Virtue ethics applied, as acts of compassion and mercy in sentencing.
- 1992 – onwards: shift towards principles of autonomy and privacy
- 1994 – onwards: humanism, ubuntu philosophy, deontological focus of self-determination, dignity, equality
- 1996 – onwards: scarce resources managed in line with utilitarian philosophy
- 2018 – onwards: suggest primary focus on principles of justice, equality and consequentialism/utilitarianism, autonomy still present, but diluted in community

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16. *Ex parte Minister van Justisie: In re S v Grotjohn* 1970 (2) SA 355 (A) at 362H
17. *Rex v Peverett* 1940 AD 213
18. *R v Makali* 1950 (1) SA 340 (N)
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CHAPTER 4: COMPARATIVE LAW

4.1 INTRODUCTION

In the previous chapter I examined South African case law which dealt with assisted suicide, mercy killing, the right to life and requests to hasten death. Simultaneously, I contemplated the ethical philosophies that underlay judicial reasoning. The object was to identify whether trends existed which could be applied to future euthanasia cases. One of the reasons for doing so was to compare the similarities and differences between South Africa and foreign jurisdictions. In this way I sought to predict what medical practitioners in South Africa might confront when assisting patients with end-of-life decision-making should the law be amended to allow E and PAS.

Several countries have permitted euthanasia under varying levels of restriction. The Netherlands[1], Belgium[2], Luxembourg[3], Canada[4], Colombia[5], and others have embraced PAS. Switzerland[6] and several states in the United States of America, including Oregon[7], were amongst the first to do so. Every year one reads about activist groups in various countries seeking to change existing laws to include either E or PAS. The United Kingdom[8], and a few European countries such as France[9] and Spain[10] are some examples. This triggers a great deal of resistance, and extensive debate, every time, with limited success. South Africa has reached this stage of its constitutional development.

Although legal arguments have been persuasive in legalising E and PAS in foreign jurisdictions, it is important to note that each country is markedly different. Where there have been a variety of approaches to achieving this status based on the law of that land, very different social settings also exist in each of those countries, compared to South Africa.

I discuss several countries that have and are developing E and PAS law and, in the case of Switzerland, its well-established practice, with a view to comparing them to the South African environment.

A. Euthanasia and Assisted Suicide permitted

4.1.1. Netherlands

4.1.1.1. History of legal development

The Netherlands offered the most comprehensive body of information related to E and PAS. Its government websites ensured that accessible facts were available to the public for scrutiny and educational purposes. The websites were available in English, amongst other languages, and were extremely helpful. For this reason, I have referred to the processes used in the Netherlands in more detail than other countries.

The Dutch Penal Code (*Wetboek van Strafrecht*[1]) is clear that, in line with Articles 293(3) and 294(4), E and PAS are criminal offences. Article 293 states that anyone who takes the life of another at his explicit and earnest request will be punished by imprisonment to a maximum of 12 years or a fine, while Article 294, similarly, warns that anyone who incites or assists another to commit suicide, or procures for another the means to commit suicide, will be punished by imprisonment for a maximum of three years or a fine, if the suicide is successful[12]. The law, therefore, does not create a right to have E or PAS, neither is there an obligation upon a doctor to perform it[13].

A. Early years

Weyers[14] recorded that from the time that Dutch doctors were recognised as proficient to practise, having passed their state exams as stipulated in the *Law of Medical Practice* in 1865, the doctor-patient relationship was of a paternalistic and hierarchical nature. This law facilitated the creation of a professional body and standardisation of practice. In addition, *A Medical Disciplinary Law* was promulgated in 1928.

In the early years, the government apparently only intervened when the public was threatened in some way. Otherwise, the doctors acted almost independently. She explained that the Dutch Medical Association, which had come into existence as early as 1850, also exercised some oversight authority, but the sanction was exclusion from the Association, which was not a powerful deterrent for medical misconduct.

Consistent with this perception of the medical role, supervision of the doctor's end-of-life

management was minimal. *The Burial Act* permitted a burial or cremation once permission had been granted by the Registrar of Births, Deaths and Marriages. This permission, in turn, would only be granted after the family's doctor had certified that a person had died from natural causes. In the event that the doctor was uncertain that the death was natural, the death certificate could not be issued, and the prosecuting authorities had to ultimately give permission for the disposal of the corpse after an investigation. This process generally still existed at the time of this thesis. Weyers pointed out that because of the pivotal role of the doctor, they assisted in uncovering possible crimes. Thus, if the doctor was the one to have committed the offence, the system had the chance to fail. Accordingly, Weyers asserted that there were suspicions of non-reporting of suspected unnatural deaths that were a consequence of medical interventions. However, there were also no indications that the government saw this failure to report as a problem at the time. This was despite the fact that, based on research done in the 1980s, it likely existed, and euthanasia was being performed in the 1970s.

B. The 1970s.

Ten Have and Welie[15] suggested that the public interest in euthanasia in the Netherlands had arisen during 1969 because a Leiden professor of psychiatry wrote a widely published book, *Medical Power and Medical Ethics*[16], criticising the medical profession for wielding too much power over life and death. Professor van den Berg believed that, with the advancement of medical technology, doctors stopped considering whether or not the patient really benefitted from these interventions. He proposed that the focus should shift from simply maintaining biological life to supporting a relevant personal existence for each person. The book generated a lot of interest.

Other writers developed the theme by publishing data showing how, for the terminally ill person, their final moments of life had become a sterile, medically managed event, leaving the impression that they were no longer entitled to control it. Elisabeth Kübler-Ross, another influential Swiss American psychiatrist, similarly appealed in her books for more counselling and emotional assistance to be offered to the dying person. Her popular book *On Death and Dying*[17], was first published in 1969.

Thus, the euthanasia movement began as a protest against the medicalisation of death and dying, which was thought to have separated a natural process from the human condition. In this atmosphere, Dutch society highlighted an individual's right to autonomy, to exercise their free

will, as the highest moral principle associated with life and death. It became the foundation for euthanasia.

The first pertinent court case in the Netherlands was in 1973 where a doctor was sentenced to one week of imprisonment, suspended, for giving her mother, who was paralysed and suffering unbearably, a lethal injection. Ten Have and Welie elucidated that, from this point in time, the Association for Voluntary Euthanasia came into existence and public deliberations gained strength. However, over the following decades, arguments changed direction. Where the starting point had focussed on medical-ethical issues surrounding the physician-patient relationship and the quandary of whether or not to allow euthanasia, it was replaced with the socio-ethical and political questions related to regulating the practice of euthanasia. This arose because, although euthanasia was always a criminal offence, the frankness of doctors about their practice of it, and blatant legal tolerance, without the regulation of euthanasia, led to a concern surrounding just how many deaths occurred as a result of requests and how many did not.

C. The 1980s

Through the 1980s some significant court cases were heard. One, in particular, in 1984 was the *Alkmaar* case[18], finally decided in the Court of the Hague. It arose when a 95-year-old, terminally ill woman, who had repeatedly requested that her doctor end her life, became unconscious a week before her death. In one waking moment she asked again that the doctor end her agony and he finally honoured her request. This case was unusual because the doctor successfully pleaded that he was faced with a situation of necessity (*force majeure*) occasioned by a conflict of duties: a duty toward the patient to bring an end to hopeless suffering and a duty to uphold the law and preserve the woman's life. Professor Gevers[19] explained that medical practitioners would not be prosecuted if they could show that they carefully weighed the contradicting duties, then reached a conclusion that could be objectively justified in the unique circumstances of the case. The Supreme Court held that a court should consider whether a dying person may soon be unable to pass away in a manner desirable to a human being, with dignity.

Guidelines were set down in 1981 by the Criminal Court in Rotterdam. They required that the person should be experiencing unbearable permanent physical or mental suffering; the patient's decision to die must be voluntary, informed, and irrevocable, in circumstances where no other solution to improve the situation was acceptable to the patient. The person had to have a

terminal illness, which also encompassed problems such as paraplegia. The Court specified that a medical practitioner had to be involved in the decision and at least one other professional. The doctor had the responsibility to prescribe the lethal drug. In addition, the time and manner of death was not to cause avoidable distress to others.

The doctor in the *Alkmaar* case argued that he had complied with the Rotterdam guidelines, but the first Appeal Court did not accept that this was the only option available to the patient. It also held that the people who had been involved in the end-of-life decisions had not been objective, so the Court convicted the doctor. Following the second appeal to the Court in the Hague, the doctor was finally acquitted: the Court accepted the doctor's defence of necessity[20], which falls under the umbrella term '*overmacht'* (meaning a force that someone is not expected to resist[21], found in Article 40 of the Dutch Criminal Code)[13].

During the same period, the Royal Netherlands Medical Association, widely supported by almost all Dutch doctors, published its own guidelines for doctors who found themselves in similar positions to that of *Alkmaar*'s case. Weyers[22] remarked that the favourable stance taken by the Association towards the legalisation of E greatly influenced the courts to be progressive. The Medical Association had managed to convince Dutch society that doctors could be trusted to be accountable when they performed E. The expectation then was that doctors could be truthful when completing death certificates for euthanasia. These guidelines were comparable to the criteria originally proposed by the Court in Rotterdam, now converted into professional standards.

However, an awareness grew that doctors still carried out euthanasia without consent. Published medical research and case studies exposed this fact[19].

When the judgment in the case of the Late Stransham-Ford[23] was handed down, the Supreme Court of Appeal referred extensively to relevant foreign legal material. I have been guided by that judgment in the presentation of the foreign law that follows in this Chapter.

D. The 1990s

Eventually, in 1990, the Minister of Justice and the Secretary for Public Health appointed a committee of doctors and lawyers to investigate and prepare a report covering the nature and frequency of the practice. The intention was to plan a way forward in the management of

euthanasia. It was presented in 1991 as the Remmelink report[15].

The Remmelink Report highlighted how doctors regularly made end-of-life decisions for their patients. This ranged from withholding and withdrawing treatment or increasing drug dosages for pain medication, to assisting in suicide or euthanasia, comparable to the original criticisms levelled at them. Of 49 000 cases, only a relative few patients opted for assisted suicide (400), while approximately 5% chose euthanasia. Patients tended to be suffering mostly from cancers, complaining primarily of either pain or loss of dignity, and had only a very short time left to live.

The authors drew attention to the fact that the Report identified that around 1000 patients died annually, not having specifically requested death, although a quarter had mentioned it over time. The Committee did not believe that this fact should cause anxiety but suggested, rather, that it should be classified under 'providing assistance to the dying'. The Committee's justification was that those patients had experienced unbearable suffering, and, in line with routine clinical practice, their lives were thought to be 'given up'. It elaborated that, in the face of progressive organ failure, to actively terminate life was 'indisputably' ordinary medical practice. The doctors had empathetically responded to the patient's plight, fulfilling the dying person's purported desire. It was assumed that, had the doctor not intervened, the patient's demise would still have occurred soon, possibly within a week[24].

Ten Have and Welie observed that, surprisingly, the disclosures uncovered in the Report had very little negative impact on the public. Instead, it increased encouragement for the termination of life of incompetent patients who could not consent to euthanasia themselves. The authors viewed the Remmelink Report as reflecting another important shift in ethical reasoning. The earliest arguments in support of active euthanasia had stemmed from a need to recognise self-determination because suffering could only be interpreted subjectively. By then, Dutch societyaccepted that the medical community could make decisions about death on behalf of patients incapable of expressing their anguish or giving their consent. The moral endorsement of euthanasia had altered from being about the patient's independence - the bioethical principle of autonomy - to the alleviation of suffering, the bioethical principle of beneficence.

By 1993, ten Have and Welie commented that evidence showed that Dutch culture displayed a marked repositioning in outlook towards death, the terminal phase of life, suffering, old age, dependency, and their continuing need for nursing care. They mentioned that prominent Dutch

ethicists claimed that any differences between active and passive euthanasia were meaningless, because doctors were accountable for the person's demise in both cases. However, ten Have and Welie point out that this attitude failed to consider the doctor's intentions, which could not be ignored. The authors expressed similar sentiments to those in the South African *Clarke* case[25], that, when medically futile treatment was withdrawn which led to the patient's death, it was not the doctor who brought about the end, but rather the underlying illness or generally frail condition which did so. Consequently, there was no moral blame, nor a moral duty, for the doctor to continue with medical interventions.

Under the *Burial and Cremation Act* in June 1994, legal provisions regulating euthanasia were finally enacted. Through these regulations the doctor was compelled to notify the coroner and submit a report whenever either E or PAS was performed. The information was then forwarded to, and also reviewed by, a public prosecutor who decided whether or not the doctor had complied[13]. Ten Have and Welie reflected on how strange the circumstances were to have a Criminal Code in place that outlawed both assisted suicide and euthanasia, and other law that compelled the perpetrators of such an offence to report their activities. They pointed out that the law actually guided the perpetrator on how to carry out the 'crime', then instructed them on what official documentation to fill in afterwards.

E. Legislation from 2002

Finally, in 2001, long-overdue legislation was promulgated to ratify the practice of E, through *The Law on Termination of Life on Request (Review Procedure) Act.* It came into force in 2002. Under Article 20, it clarified the application of Articles 293 and 294 by inserting the provision that the crimes of E and PAS were not punishable as long as they were performed by a doctor who had fulfilled two specified conditions, as indicated in the following translation:

'2. The act referred to … shall not be an offence *if it is committed by a physician who fulfils the due care criteria set out in Article 2* of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and *if the physician notifies the municipal pathologist of this act in accordance with the provisions of Article 7*, paragraph 2 of the Burial and Cremation Act'[1]. (Italics added to highlight two conditions)

The first condition of this provision entailed that the doctor complied with the requirements of due care laid out in Article 2 of the Dutch law. The Dutch Regional Euthanasia Review

Committees' government website[26] listed the following requirements and explained them:

1) **The doctor must have been satisfied that the patient made a voluntary and well-considered request.** The patient must have had the capacity to make their request themselves, and do so without undue influence from others. Their wishes were paramount. Family and staff members could be involved, but their approval or consent was not required. It was noteworthy that the doctor and patient did not need to be in a treatment relationship, nor did the patient's request have to be persistent, just well-considered - two misconceptions found in some literature[27]. The patient must have been capable of understanding all information pertaining to the situation and prognosis, including options available and consequences of the decision. No parent or legal representative could make the request on behalf of the patient. It was not mandatory for the request to be in writing, but an advance directive could add clarity where there was doubt. Minors had to be at least 12 years old when making the request for E or PAS. From 12 to 16 years of age, parental consent was necessary. Those who were 16 to 17 years old could make their own decision, but parents remained involved in the discussions[28].

2) **The doctor must have been persuaded that the patient's suffering had no prospect of improvement and was unbearable**. The website expanded on these terms: 'no prospect of improvement' meant that the disorder was incurable, with no way to alleviate symptoms. This was a reasonably objective test for a doctor, who had to weigh up what improvement could be achieved with a medical intervention, and what burden the treatment or palliation would create for the patient. The concept of 'unbearable suffering', however, was a subjective assessment expressed by the patient: it differed between individuals based on their personality, future prospects, as well as their physical and mental resilience. A doctor was obliged to try and experience the suffering as intensely and tangibly as the patient described it in order to convince the Committee that it was present[29].

3) **The doctor must have informed the patient of the situation**. The patient must have had a full understanding, having received complete information surrounding the disease, including diagnosis, prognosis, and the range of treatment options available[30].

4) **Both the doctor and the patient must have been satisfied that there was no other reasonable solution to the situation**. They must have agreed that ending life was the

only realistic way in which the patient's anguish could be relieved. If the patient refused available treatment, the Committee expected the doctor to include the reasons for a refusal in the report. Those details were to satisfy the Committee that the choice was made rationally, because palliative care was seen as a crucial feature of end-of-life management. Patients were entitled to refuse treatment based on side-effects overshadowing the good care that palliation may have provided, or the patient may not have wanted to endure the fear associated with losing dignity over time, for example[31].

5) **The doctor must have consulted at least one other medical practitioner who had no connection to the case, and who had given a written independent opinion that the attending doctor had met the due care standards**. The government suggested that it was customary and acceptable to ask a doctor from the SCEN Organisation (Euthanasia in the Netherlands Support and Assessment Programme) to assist because of the organisation's independent position. If possible, the doctor should have visited the patient in person and been able to communicate effectively to gain accurate insight into the patient's condition and frame of mind. The alternative was to consult medical records, the advance directive and speak to the appropriate people who were able to offer additional insight. In the independent report, the doctor needed to state the relationship they had with the patient and referring doctor, and the referring doctor had to check that this independent report confirmed that the due care criteria were met. Where a long period of time had elapsed between the independent assessment and the compliance to end a life, the independent practitioner may have had to make contact with the patient again, either telephonically or by re-visiting the patient, depending on the time frame, to establish whether conditions had changed[32].

6) **The ending of life had to have been performed with due medical care**. The government website described two features of due care which had to be met for the standard to be correct: first the appropriate substances and dosages must have been administered, following the approved procedure. Secondly, only the doctor could terminate the patient's life. No other person, such as a nurse, may have proceeded instead. The procedure of euthanasia was normally achieved by intravenous administration of specified medications given in lethal doses. Assisted suicide involved the patient independently ingesting a fatal dose of drugs. The doctor was required to remain present or within the vicinity throughout the process, until the patient died, to ensure that there were no complications. Where a difficulty did arise, such as vomiting, or an excessive

time lapse occurred before death succeeded, the doctor may well have had to intervene to finally terminate the patient's life. This possibility should have been discussed with the patient and family before the actual termination happened. No deadly drugs may have been left with a patient because it posed a danger to the patient and others who were present.

When assessing whether the doctor had followed the due care criteria, the Review Committees relied upon the *Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide of August 2012*[33]. The guidelines were published by the Royal Dutch Medical Association (KNMG) and the Royal Dutch Pharmacists Association (KNMP) and are discussed in more detail later in this chapter. They advised doctors and pharmacists on the list of acceptable drugs that could be administered, as well as dosages and methods of administration. All this information had to be stated in the doctor's report once the procedure was completed.

The government website's final advice related to the standard of due care for euthanasia. It stated that the doctor had to ensure that the patient was in a deep coma before any muscle relaxant was administered. They emphasised that the patient must not be aware of the effects of the muscle relaxant. Suggestions for checking unconsciousness included testing for a corneal or eyelash reflex or using pain stimulation[34].

The second condition of the legal provision instructed the doctor to report the incident to the regional coroner (municipal pathologist) using a detailed form found under Article 7 of the *Burial and Cremation Act*. The coroner then sent the form and report for assessment to one of five Regional Review Committees. This committee evaluated whether the doctor had conformed with the pre-requisites of careful practice. If they were satisfied that the doctor had fulfilled all the steps, the doctor was exempt from prosecution and the file was closed. However, if the Commission had concerns about the lack of due care, the file would be sent on to the prosecutorial authority and Medical Inspectorate for further investigation and possible punishment[35]. The Commission gave feedback to the reporting doctor within six weeks.

Regional Euthanasia Review Committees were made up of members from different disciplines. A minimum of three members made up a quorum, so that a decision by a simple majority was decisive. The committee must have at least included a lawyer, who was the chairperson, a doctor, and a moral philosopher (ethicist). They were appointed by the Ministers of Justice and Health for a period of six years, with one opportunity for re-appointment. Consistency between

different Commissions was maintained through meetings with government officials at least twice a year. The publication of a joint annual report reflecting their findings was obligatory. The report presented anonymised information on the number and nature of cases assessed, as well as the opinions reached, delivering evidence of the work done to the public and allowing scrutiny. These commentaries were useful in that they added to the general body of knowledge about E and PAS, showing trends and offering medical evidence of how regulation seemed to be working in The Netherlands[13].

In 2018, for example, Regional Review Committees Report recorded a slight decrease in the number of E reports received, from 6 585 notifications in 2017 to 6 126 in 2018. That accounted for 4% of total deaths in 2018, compared to 4,4% in 2017. Six cases in 2018 were judged to be not in accordance with due criteria and standards, compared to 12 in 2017. Apparently, the societal deliberations in 2018 focussed particularly on the interpretation of requests from patients with advanced dementia and those with psychiatric disorders. However, both of these groups made up only a small percentage (1%) of euthanasia requests owing to 'hopeless and unbearable suffering'. The vast majority of requests (90,6%) arose from incurable or untreatable disease such as cancer[36] .

F. Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide, 2012

In 2012, guidelines framed by the Royal Dutch Medical Association (KNMG), in collaboration with the Royal Dutch Pharmacists Association (KNMP), relating to the Practice of Euthanasia and Physician-Assisted Suicide[33], were published. They were intended to support doctors and pharmacists in the administration of safe and effective E and PAS. The document's introduction drew attention to how serious and emotional the events of E and PAS were for both patients, and the families involved. It also highlighted how intensely it affected the doctors and pharmacists who participated in the process. They emphasised that doctors and pharmacists did not perform E or PAS frequently, and that each had individual responsibilities besides their joint responsibilities that had to be managed.

The guidelines came into being as a result of an expert group of medical specialist disciplines, such as anaesthesiologists, intensive care specialists and others. They collaborated together via email and met on a number of occasions during the course of a year, to create draft guidelines. Subsequently, by invitation, stakeholders and representatives of medical practitioners met at a conference to discuss the draft document and give further input. Once the guidelines had been

displayed on the websites of KNMG and the KNMP for final comments from the medical fraternity, they were adopted by the Federation Board of the KNMG and the Executive Committee of KNMP.

Some pertinent points in the guidelines add clarity to the due care procedures. A pharmacist could refuse, on principle, to participate in the preparation of the lethal agents to be administered by a doctor. However, they were asked to notify doctors in their catchment area of this fact.

To conduct euthanasia, doctors were advised to insert the intravenous needle into the patient's arm the day before the procedure, to avoid a struggle on the day if veins were difficult to find. They also were to have an extra complete emergency set and medication available in case the initial equipment failed in some way. The period of time between the start of an intravenous infusion to induce a coma, followed by administration of a neuromuscular blocker, and finally death, was fairly rapid - between five and fifteen minutes in total. The patient was to be warned that the intravenous infusion could be painful when it started to flow in, but local anaesthetic should first be inserted in order to prevent this.

In contrast, where a person was ingesting their own medication to commit suicide, a doctor had to remain present for the full duration until death, which could take from 30 minutes to several hours. This delay and waiting phase could create some uncomfortable situations. Due to the unpredictability of the time lapse between the oral ingestion of medication and death finally setting in, this was not the favoured method for ending life. The guidelines suggested that the doctor should reach an agreement with the patient and family involved: after a maximum of two hours of waiting, under those circumstances euthanasia should be administered intravenously so that there was a clear end point. Consequently, it was advised that all patients routinely had a needle inserted in advance, before they drank their medication, in case the alternative method of death became necessary. Nausea and vomiting from the oral medication were also hazards that might be alleviated by starting the patient on an ant-emetic drug the day before the suicide. The patient ought to be warned that the medication could have a foul taste and that they must sit up in bed when drinking the concoction so they did not run the risk of collapsing from drowsiness before reaching the bed.

Important tables of information were included about the various drugs of choice for the different procedures. They also contained brief notes on their efficacy and interactions, and the forms of

administration suggested.

After the procedure was completed, doctors were advised that the empty vials, syringes and the emergency set had to be stored for a municipal forensic pathologist's visit. This allowed for an inspection and verification of what was used. Those items were sent back to the pharmacist for disposal. The doctor and pharmacist were then each asked to fill out a questionnaire to assess the advice given in the guidelines and return it to the KNMP Drug Information Centre.

G. The Euthanasia Code of 2018

The Euthanasia Code[37], first published in 2015 and updated in 2018, was another useful document prepared by the Regional Euthanasia Review Committees. It offered comprehensive information on all matters that the Committees considered important when carrying out their statutory duties dealing with the review of doctors' notifications of E and PAS procedures. A particular focus was on how the due care criteria were interpreted.

The information in the document was mainly for the benefit of all doctors who performed euthanasia. It was also made available to the public in order to add to a general body of knowledge for educational purposes. According to the introductory paragraph, a survey was carried out in 2016 to ascertain how many doctors who performed E and PAS were familiar with the Code, and what they thought of it. It was established that, of the group that had actually performed E, 80% were unaware of its existence. Consequently, the authors undertook to ensure improvement of doctors' knowledge of the legislation surrounding E and PAS. The revised Code included references to the applicable law from the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, as well as other relevant statutory provisions, and a few helpful practical sources for further information. A number of Supreme Court judgments have assisted in the interpretation of the law, supplementing the Act's requirements.

(i) Due care criteria.

In outlining the due care criteria in the Act[38], the Code mentioned that the Act was silent about the patient's life expectancy: there was no restriction that E could only be carried out in the terminal phase of life or that the patient's condition had to be life-threatening.

A doctor was not obliged to respond to a patient's request for E. However, doctors needed to

inform their patients at an early stage that they were unwilling to perform E so that the patient could approach another doctor. A referral to either a colleague who was willing to administer a lethal injection, or to the End-of-Life Clinic, was suggested as helpful to the patient.
(ii) Notification and Review.

With regards to the law around Notification and Review[39], the doctor had to notify the municipal pathologist and, at the post-mortem, hand over the specific form required. In addition, the pathologist needed the detailed doctor's report, including any advance directive, medical records and letters from specialists related to the case, and the independent physician's report. This file would then be sent on to the Committee by the pathologist. Once the file had been reviewed and the Committee was satisfied that E was performed with due care, the file was closed, and the doctor informed of the verdict in writing. If some of the due care criteria were not fulfilled, and the Committee had concerns, the finding and file would be sent to the Public Prosecution Service for their decision on what further steps should be taken.

(iii) Committee Procedures.

Committee Procedures[40] included monthly meetings where each of the five regional review committees discussed their notifications. Two categories existed: straightforward notifications (80%) and notifications that raised questions (20%). Straightforward notifications were managed digitally and were generally not discussed at the monthly meeting unless there was an aspect that needed to be canvassed. Doctors might be invited to meetings to address queries in person, or to answer in writing. Reports of these encounters were prepared, and the doctor could comment on the report. If the Regional Committee's opinion was not swayed, it sent the report to the other committees for final deliberation and an outcome. The committees strove for consistency in findings to enhance legal certainty and uniformity. Within six weeks the doctor should have received the committee's decision. Anonymised judgments were published on the website.

(iv) Medical Profession's Guidelines.

The Medical Profession's Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide, brought up earlier, were specifically used by the committees to assist in their decisions.

(v) Statutory standard applied.

The Code offered further details relating to the statutory standard of the due care criteria[41]. In the notes about unbearable suffering, the following insightful points were made. The 1984 Supreme Court judgment in the *Schoonheim*[42] case (also referred to earlier as *Alkmaar*'s case) recognised that suffering could comprise the fear of an increasing degradation of the quality of life, or the outlook that death would be without dignity. The writers acknowledged that the weight of suffering was not usually made up of only one concern, but had many facets, such as the realisation that there was no chance of recovery. Doctors were told to examine all aspects to appreciate what made the patient's suffering unbearable and incapable of improvement. Consequently, patients had to be conscious of their suffering, in contrast to the circumstances of palliative sedation or a coma, where the patient would not be aware. Nevertheless, besides what the patient articulated, the doctor was asked to remain sensitive to non-verbal cues that indicated the level of anguish experienced. The Code stated that, in principle, where the patient was not aware of their suffering, euthanasia was not allowed to be carried out, regardless of whether the family found this distressing or undignified.

The parliamentary history of the Act required that a medical dimension to the suffering should exist. According to the Code writers, case law from the hearing of Brongersma[43] in 2002 supported the approach that the source of suffering should emanate from one or more recognised medical disease or condition, which included psychiatric disorders. Therefore a 'completed life' did not meet the 'unbearable suffering' standard for euthanasia. A medical basis for unbearable suffering fell within the scope and expertise of the doctor's experience and training, whereas assessing a 'completed life' (or being 'tired of life'[44]) did not.

An example given by the writers to illustrate a group of medical conditions which were not life-threatening but cumulatively could cause unbearable suffering, were multiple geriatric syndromes, such as sight and hearing impairment, osteoporosis, osteoarthritis, balance problems and cognitive deterioration.

(vi) Support and Assessment Organisation (SCEN).

With regard to the use of a SCEN physician[45] for an independent assessment requested by a doctor prepared to perform euthanasia, the Code gave a few details of the organisation's

background. The SCEN doctors fell under the KNMG which wrote guidelines in 2011 for the Support and Assessment Programme associated with these doctors. They were placed in regions under the observation of the Regional Committees. One of the aims of the guidelines was to ensure that SCEN doctors offered quality peer supervision to the euthanasia doctors. A situation could have arisen where a couple requested euthanasia together, called a 'double euthanasia'. The Committee then expected the couple's doctor to consult two independent physicians, one for each patient, separately, to ensure that neither was bringing undue influence to bear over the other to end their life. A medical expert could have been consulted where there was a concern about the patient's mental capacity to consent, but this was not a requirement for every patient. The committees met annually with the KNMG and SCEN to discuss the standard of the independent reports to ensure quality control.

(vii) Advance Directives.

Advance directives were specifically discussed in the Code[46], in line with section 2(2) of the Act. It stated that even with an advance directive in hand, the due care criteria ought to be met, with attention paid to the special circumstances of the case. It allowed persons of 16 years and older, who were competent to make decisions, to draw up an advance directive to request euthanasia. The content of the advance directive was to give as much clarity as possible regarding the circumstances that the patient would consider to be unbearable suffering justifying the termination of life. As Janssen[13] reiterated, it also had to include a name, date and signature of the patient for authenticity.

The advance directive did not have to be updated regularly either, but if it had been reviewed recently, or orally confirmed, the Committee would find it easier to accept that it conformed to the standard of due care. The Code suggested that every time the patient consulted the doctor about the contents of the advance directive, the information should have been captured in the medical records of the patient. The patient's consistent repetition would reinforce the fact that the advance directive was a true reflection of the patient's will if the situation ever arose that the person could no longer express themselves.

In 2020, another revised edition[47] of the Euthanasia Code 2018 was distributed. It followed Supreme Court judgments in that year about a euthanasia notification concerning a patient with advanced dementia. Subsequent amendments to the Code allowed that, if, at a future date, the person was no longer able to communicate their wishes because of advanced dementia,

intellectual disabilities, aphasia and palliative sedation or coma, the doctor could accept the advance directive in accordance with section 2(1)(a) of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*[1]. This provision gave the document the same status as an oral request for euthanasia.

A specific addition to the due care criteria for patients who had dementia was that irrational or unpredictable behaviour could be expected from the person: it was acknowledged that they could become agitated or distressed while the euthanasia procedure was being carried out. Management advice for such circumstances was that the medical standard of premedication may be necessary to make the procedure as comfortable as possible.

(viii) Specific conditions.

A range of specific conditions were covered individually in the Code. Doctors were offered advice on what the Committee would accept as a suitable standard of care for those circumstances. Examples provided in the Code's list were psychiatric disorders, dementia, intellectual disability, aphasia, coma and reduced consciousness, among others[48].

(ix) Euthanasia verses palliative sedation.

The Code also characterised euthanasia and palliative sedation[49] as two distinct ways of managing unbearable suffering at the end of life. Thus, refusing palliative sedation was not an obstacle to euthanasia. It acknowledged that people had different preferences: some wanted to remain conscious until the end of their lives, so preferred euthanasia; others chose palliative sedation with the expectation that they would receive it when it was anticipated that they had less than two weeks to live. It was also possible for patients to request conditional euthanasia, where, once palliative sedation was commenced, in the event that they still showed signs of suffering, or if they did not pass away within a short time frame, euthanasia could be initiated.

(x) 'Completed Life'.

According to the Code, during 2016 the Schnabel Committee investigated the condition described as 'completed life' and whether assisted suicide should be permitted for those who requested it[50]. The phrases 'completed life' or 'finished with life' were recorded in the legislative history of the Act, most often in connection with elderly people. This group were

described as not having been diagnosed with a medical condition associated with intense suffering, but had reached the conclusion that the value of their lives had deteriorated to such an extent that they no longer wished to live. At that time, euthanasia was not permitted if a person did not meet the legally accepted criterion of having an underlying medical disorder which caused their unbearable suffering.

Following the Schnabel Committee's work, which resulted in the 'Completed Life' Assisted Suicide Act, the KNMG prepared a substantial and thoughtful response[51]. The Act was aimed at the healthy elderly who had an existing, well-considered wish to die because they felt their lives had become meaningless. The response stated that the doctors were aware that the problem was both complex and tragic. There was no easy solution when 'completed life' should ideally have positive connotations. However, they objected to the government drawing a distinction between 'healthy' and 'sick' people who wanted to end their lives. They asserted that the distinction was theoretical and not a true indication of the reality witnessed by the Dutch community and its doctors. They considered the euthanasia law in place to be adequate, transparent, verifiable, and safe. It was widely supported by society, without the need to draft additional parallel legislation for different circumstances. It was suggested that new law might in fact undermine the existing law, which already catered for intolerable suffering relating to geriatric syndromes. The doctors mentioned their fear that a 'slippery slope' could develop and indicated that they remained cautious and aware of that possibility. The members found the proposal to be completely unacceptable at an ethical level.

The KNMG, in essence, reprimanded the government for deviating from disciplinary and judicial proceedings, including ignoring the position held by the Regional Euthanasia Review Committees and the existing professional standards that had been set. The members also said that they found it extraordinary that the multifaceted challenges associated with investigating a 'completed life' request were subject to a far easier assessment and framework for granting assisted suicide, than where there was an obvious underlying medical cause that required an extensive rigorous assessment. The Association made the point that it was more important to find solutions to the problems the aging population were experiencing so as to improve their quality of life, rather than offering them death as a resolution. It highlighted the concern among members of the adverse consequences to society if such a law were implemented. Examples given included making the elderly feel unsafe or having them believe that they were a burden to the community, essentially stigmatising the advanced years of their life.

An important difference between the South African population and the Dutch, is that the Netherlands had a negative birth rate: in 2019 it was recorded as 1.57. That was comparable to other European countries in the same area: Belgium, for example, was at 1.57 and Germany at 1.54[52]. This trend began in the 1970s when families tended to have no more than 2 children. If the trend continues for another twenty years, a different society might exist where many people in their old age would likely not have parents, children or even siblings to take a personal interest in their wellbeing. The problem of isolation and loneliness would become much worse if not addressed. South Africa, on the other hand, had a birth rate of 2.48 for the same time frame, a level The Netherlands last approximated (2.36) in 1971. This reflected a time lag of almost fifty years behind European trends[52].

(xi) Organ and tissue donation after euthanasia.

Although the Act does not prohibit the donation of organs and tissue following euthanasia, it stipulated that the prospect of donations should not affect observing the standard of due care criteria in any way[53]. Donations and euthanasia were treated as completely separate situations. However, the impact that donation arrangements would have on the euthanasia process was that, to facilitate tissue donation, the body would need to be transferred to a hospital post death. Likewise, for organ donations, the person would be admitted to a hospital in anticipation of the organ donation rather than being allowed the norm of dying at home.

The whole process required cooperation between the organ transplant team and the euthanasia doctor. It accordingly involved detailed planning, including informing the family about what would happen. Guidelines prepared by the Dutch Foundation for Transplants[54] were available from transplant coordinators at university hospitals to assist doctors with decision-making. A website on this topic provided further support[55].

Lastly, the Code ended with a 'Useful references' section that identified a few websites which doctors could consult for further information. The Committees' Website featured 'complaints regulations' so that doctors could post their issues experienced with the regulators and in this manner give feedback to the government, too.

The wealth of information on the management of E and PAS that was available in the literature made it evident that the Dutch writers of the various guidelines did not shy away from the truth of the many scenarios that could arise in practice. They appeared to be rigorous and thorough

in recording all advice and evidence pertinent to facilitating the smooth running of this area of medical service.

Conclusion of history

From the starting point of when Dutch society formed activist groups to lobby for autonomy over how to end their lives rather than allowing medical doctors to wield control, the factual situation developed paradoxically. Ten Have and Welie, in their 1996 article[24], observed the irony of what transpired socially. The patient's clear and personal request for euthanasia was no longer the determining reason for it to be granted. Instead, the doctor had to agree that the circumstances were as unbearable as described, and that the suffering so intolerable, that the patient would benefit from being dead rather than alive. In other words, the patient's 'autonomous request' depended on the doctor concluding that the idea was rational, from a medical viewpoint, for it to be fulfilled.

The authors point out that the result of the euthanasia debate actually gave doctors even greater power by providing them with authority to make the ultimate decision whether to allow euthanasia or not. The doctors also influenced the moral justification for euthanasia by having to assess and pass opinions on the extent of the person's physical and existential suffering. Ten Have and Welie pondered, along with other academics, whether doctors were really capable of making judgments about an individual's anguish and whether they even had a right to do so. However, if not the doctors, then the question remained who the alternative was. Family members may have been too subjective, and the legal fraternity too removed.

In 2009 Rietjens, *et al.*[56] found that there were larger discrepancies than anticipated between general practitioners (GPs), medical specialists and review committee members, about the assessment of more complex 'unbearable' suffering of patients. Hypothetical vignettes were put to them for consideration. All three groups showed similar results when measuring the physical suffering, primarily of those with limited life-expectancy. However, the GPs, unlike the other two groups, tended to under-estimate psychosocial and existential suffering. The researchers surmised that this was because GPs had less exposure to the extremes of physical and mental anguish, compared to either the specialists who worked in the hospital intensive care units, or the review committees who read all the reports dealing with the topic. GPs also likely relied more on their knowledge of their patients and their backgrounds, which would normally suffice in other assessments.

The conclusion reached by the authors, ten Have and Welie, about the history of euthanasia, was that, although there was no proof to indicate that the medical profession had evolved much over time, what appeared to be the problem originally identified by society, transformed into society's ultimate solution. The law had given doctors, not patients, increased power and control over the end of life.

Furthermore, de Bellaigue, a journalist who investigated the subject of E in the Netherlands, wrote an article in *The Guardian* in 2019, that 93% of those requesting E by far preferred to be actively euthanised by the doctor than to take the fatal drugs themselves. He pointed out that, for a society that fiercely protected its autonomy, it was a contradictory twist[57]. This attitude by patients has been corroborated in literature from other countries[58].

With the 2002 Act in place, the doctors were not the only safeguard against abuses: the review committees were functioning, but oversight was exercised after the fact and depended on honest reporting by the doctors.

Weyers[59] talked about formal social control of E (as opposed to legal control) being implemented by the Dutch to encourage increased reporting rates. Examples of ways they achieved social control included: initiating research to establish the prevalence of E; creating a reporting procedure at a national level; establishing an infrastructure that offered consultation and information for doctors who were contemplating administering E; and by starting regional review committees to form a safeguard between the reporting doctor and the judiciary. Weyers held the view in 2006 that this plan was quite successful, although not without its flaws. Weyers said that the Netherlands at that time had the most comprehensive system of government social control in the world. That may well still be the case.

4.1.1.2. Dutch social and cultural environment

To appreciate how the euthanasia law came into being, it is important to understand the ethos of the Dutch community. Morality, it was said, was grounded in the reality of social behaviour and culture[35]. Weyers described the Netherlands as unique in its legal mind-shift based on four grounds: 1) the judiciary used the prosecution of doctors to examine the limitations of the law; 2) judges were open to the possibility of legalising E; 3) the Dutch Medical Association was prepared to split from other medical associations in support of E; and 4) Dutch political parties

continued to seek common ground long before the coalition government legally ratified E[59]. However, it remained true that it was the characteristics of the Dutch people that made this outcome possible. Weyers viewed their outlook on death, medical technology, and individualism (discussed by other authors mentioned earlier in this chapter), as being significant cultural features that had an influence. She presented another Dutch writer's perspective, too, Kennedy[60], who believed that the disintegration of taboos around death happened faster in the Netherlands than in the rest of the Western world. Examples of taboos were keeping the fact that a terminally ill patient was dying a secret from them and deeming conversations about death to be offensive or 'dirty'. A similar response was observed in the Netherlands regarding recreational drug use and sex. Kennedy proposed that the speed with which the Dutch society overcame these taboos was because, culturally, the Dutch elevated truth-telling to a high virtue, to be practiced and encouraged.

As people became more prosperous, and secularisation increased along with globalisation, traditional communities changed their attitudes and became unsettled in their beliefs. They considered such taboos to be part of an outdated mindset and, additionally, irrational and oppressive. Instead, the prospect of imminent death was viewed as an opportunity to make decisions about what treatment to embrace or refuse, and how to manage the last phase of medical and religious support according to personal preferences. The Netherlands has since become one of the most secular societies in Western Europe[61].

Another cause for reflection in Dutch society was the expansive development of medical technology after World War II. Doctors acquired the ability to extend life with sophisticated medical interventions. Dutch academics harshly condemned the level of influence the medical profession wielded over people's lives. As alluded to earlier in this chapter (on the history of the 1970s), they called upon the Dutch community to object to it.

This initiated medical-ethical conversations about the level of the patient's participation in the management of their final phase of life. It also led to questions being asked such as, if doctors accepted a person's refusal of treatment knowing it would lead to death, why should the act of doctors facilitating death on request be outlawed in the face of intolerable suffering?

Weyers[62] reported that consensus in the Netherlands was reached relatively quickly. The fast and uncomplicated transition could be explained by the cultural attitudes of the Dutch people, which were evident in their healthcare infrastructure. She mentioned their wide support of

public impartiality and unity in sharing financial responsibilities. They had an egalitarian outlook. Consequently, the Netherlands was a sophisticated welfare state. People made income-related payments to the government, while co-payments were in limited use. Almost every person had health insurance. Their contributions were calculated according to their income, and entitlements were obtained depending on the individual's need.

The Netherlands had a healthcare system that was a universal social health insurance model which combined public and private insurance. It was compulsory for all residents to purchase statutory health insurance from private insurers, who were obliged to accept all applicants. The financing of the model was mostly a public contribution, through tax revenue, premiums and government grants. In addition, the national government set the health care priorities and monitored access, the quality of care, and costs. Standard benefits of the universal health insurance covered hospital, medical practitioner, home nursing, and mental health care, including prescription medication. Adults had to pay premiums, annual deductibles, and co-insurance or co-payments on specific services and medicines. However, children's health needs were covered until they were 18 years old[63].

The Dutch healthcare system incorporated home care as a fundamental part of its organisation. Weyers[64] gave details of the medical care structure managed by GPs. Three chief features existed: 1) 'listing', which meant that each Dutch resident was registered with a GP; 2) 'gatekeeping', where specialists or the hospital required GPs to refer a person for focused attention. Patients had no automatic right of admission without a letter from the GP; and 3) 'family orientation', which denoted that a GP generally fulfilled the role of doctor for the whole family.

As part of the service offered, GPs managed their responsibilities to patients by making house calls. As a result, the Netherlands had a high number of births and deaths at home. This was consistent with the Dutch understanding of the concepts of medicine, science, and a belief in 'thriftiness'. Weyers supported these opinions with evidence from De Vries's writing[65] who asserted that the Dutch did not feel the need to be brave. This was shown by the fact that GPs attended approximately 40% of deaths that occurred at home. His theory of why this culture had arisen was that the Dutch faced 'nuclearisation' of families during the 17th and 18th centuries - earlier than other countries in contrast, when other countries' families became nuclear, industrialisation was taking place. The family was considered the underpin of the Dutch social structure[61], and so Dutch families resisted the institutionalisation of birth and

death. De Vries proposed that this era brought an increase in people seeking professional assistance for birth, sickness, and death because family members had attended to those processes in times gone by.

Weyers added that in many countries one of the public reactions to medical advancement was a shift in views surrounding the sanctity of life. The attitude developed that although life was significant, deference for life was not boundless. The patient's sense of their quality of life became an important part of the medical discussion. Accordingly, besides the doctor exercising ethical self-discipline with regards to the assessment of a person being eligible for E and reporting it, secondary control came from the patient's engagement with the doctor, as described by Van der Heide[66], an end-of life specialist. Third party control was maintained through discussions with other doctors and nursing staff, and ultimately official government regulation too.

A final important feature of Dutch culture that opened the door to permitting E, according to Weyers[61], was individualism. She suggested that the early Dutch community moved from a social structure of collectivism, where people were connected to each other by strong bonds and the place in which they lived, to one of individualism. The society was very homogenous, with 83% being Dutch. They described themselves as disciplined and conservative, private people who did not show emotion. Self-control was seen as a good quality. Consequently, they strove to reach consensus when making decisions, even if it took time[67]. Referring to international comparative research, she stated that the Netherlands was a country with a high tolerance for individual choice, such as with recreational drug consumption and divorce. Its value-orientation was described as 'post-materialistic, centring on autonomy over one's bodily and psychological integrity'. Their self-determination encompassed acceptance of suicide, abortion, homosexuality, and euthanasia.

4.1.1.3. Comparison with South Africa

While the Dutch society emphasised a philosophy of individualism and an appreciation of the virtues of honesty, self-discipline, and integrity, it had a tolerance of everyone's freedom of choice, including how they wished to die. Yet they strove for consensus with decision-making. Despite the bioethical principle of autonomy being held high, they embraced the principle of justice by having an egalitarian outlook that supported shared financial contributions.

In summary, Weyers captured the following characteristics of the Dutch in support of her analysis of why they accepted E so readily: they trusted their community, and people participated in civil society, so fewer governmental regulations and social controls were deemed necessary. Since the Dutch were individualistic, respect for their privacy and freedom was important to them. They regarded their personal opinions highly and, because the attitude towards life being sacred had diminished, they believed that E was justifiable.

Weyers mentioned that the ethical behaviour (self-control) exercised by doctors to report E, besides the other controls presented above in place to monitor it, led to the Netherlands being the country where the most E cases were investigated. Likewise, it was the country with the most prosecutions of doctors for E, too. Weyers suggested that this public control of E, although not yet ideal and subject to ongoing revision to improve it, had no comparison in the rest of the world.

In contrast, South Africa expressed itself as identifying with a communitarian philosophy and embracing humanism when interpreting human rights, although its society is a mix of rural and western traditions[68]. The right to self-determination in South Africa is strong, but not unlimited. South African case law reinforced that the well-being of society as a whole had to be balanced against the well-being of the individual[69], particularly when the distribution of wealth among the population remained extremely unequal.

Other fundamental differences are that birth and death remain primarily an institutionalised encounter in South Africa, as many homes are unsuitable for home-based care, as more fully canvassed in Chapter 7. South African society did not have a great deal of trust in its government, and particularly in the health sector, owing to scandals that were alluded to in the previous chapter. Consequently, a law that permitted medically assisted death might undermine trust further and could be challenging to regulate.

The Netherlands has a universal health care model that may be attractive for South Africa’s needs in the future. There appeared to be some similarity between the Dutch national government’s oversight, and the South African national Department of Health’s responsibilities, particularly in the public sector. But the private sector insurance base in South Africa is, at the time of this thesis, too small to cater for the majority of South Africa's people who receive an insufficient income to support it. The Netherlands is a markedly different society in mindset and social infrastructure to that of South Africa. Thus, caution should be

exercised in imagining or adopting their legal model for euthanasia into South Africa's infrastructure.

4.1.2. Belgium

4.1.2.1. Introduction

Belgium is discussed next as a comparison to the Netherlands and South Africa, because of its interesting health care model. While it allowed euthanasia to be legalised, as explained below, it preserved and enhanced palliative care.

Geographically, the Kingdom of Belgium has the Netherlands on its northern border, Germany to the east, Luxembourg on the south-eastern side, France on the south-west, and the North Sea forming the north-western border. There are three clear independent regions and communities: Flanders in the north is where the Dutch-speaking population reside, French-speaking Wallonia is in the south and the Brussels-capital region is bilingual. A small German community is situated in the Eastern region. Belgium is politically structured as a federal state with a constitutional monarchy, and has three official languages, Dutch, French and German[70].
Culturally, the north is comparable to the temperament of the Netherlands: forthright about euthanasia, having carried out a fair amount of research related to it, and highly valuing autonomy and the quality of life. The south is more reliant on their doctors for guidance, accepting the value of palliative care rather than the need for E. Authors explained that the Belgian society has more of a tradition of liberalism and secular humanism, despite the country being predominantly Roman-Catholic[71].

Consistent with similarities to the Netherlands, Flanders has a higher reporting rate to euthanasia committees than other regions. The Belgian Control Commission's report for 2016 -17 shared that Flanders had 78% of E cases, compared to Wallonia's 22%. People who chose to be euthanised in their homes amounted to 45%, while 39% of euthanasias occurred in hospitals. The remainder were managed in nursing homes and retirement facilities[72]. Professor Cohen-Almagor[73] described Flanders as having many doctors who were organised into consultation teams that managed euthanasia requests (*Leifartsen*), whereas there were far fewer teams in the south. The French region in the south preferred palliative sedation; thus, E cases were less frequent and, accordingly, fewer recorded. Regional differences were attributed to distinct local cultures.

4.1.2.2. History of legal development

Bilsen, *et al.*[74] described the transition to legalisation in Belgium as relatively fast and tumultuous, compared with the Netherlands. The Netherlands had embarked on a decades long research process, discussions with various interest groups, and judicial findings on the topic espoused from prosecutions. However, the first Belgian French and Dutch Foundations - established independently of one another to promote the legalisation of euthanasia - began as early as 1981. In the same year the Foundation of Continuing Care Community, an end-of-life palliative care group, was established. With the influence of Roman Catholics managing hospitals in Belgium, palliative care began to develop more formally from that time onwards, while only sporadic attempts at lawmaking had occurred for euthanasia. Just five years before the Euthanasia legislation came into force, euthanasia discussions gained momentum in parliament and other forums[75]. Gysels, *et al.*[76] stated that palliative care had become very popular and played a key role in the various public debates that had preceded the decision to formalise the E process. Because of this, both the euthanasia and palliative care programs developed in parallel, creating a model of 'integrated palliative care'. This unique concept embraced the provision of palliative care with the ultimate option to choose euthanasia as the final exit.

Bernheim and Distelmans, who were founders of Belgian palliative care, and other authors, believed that offering E to people would be unethical if palliative care services were lacking or inadequate. They hoped that by combining E with palliative care, it would prevent a 'slippery slope' from developing because the standard of medical care would be maintained[75]. They were in favour of giving Belgian society choices regarding the end-of-life[71].

The debates were not acrimonious. Both the E group and the palliative group acknowledged a place for the other's option at the end-of-life. In fact, the university hospital staff who were proponents of E also worked at the palliative day-care centres that had been set up through these hospitals. Likewise, the Catholic hospitals that had patients who preferred to choose E to end their lives were referred to the university hospitals. People promoting euthanasia argued that, like medical futility, the situation could arise at times where palliative futility was evident.

Opponents of euthanasia, on the other hand, accepted that in some cases it would be ethically acceptable to allow euthanasia. Certain of the Catholic palliative caregivers agreed that regulating euthanasia legally amounted to a lesser evil than the secrecy that had surrounded

covert killing and the problem of palliative futility, where some problems could not be adequately treated to relieve patients of their intractable symptoms. By 1999, in Europe, Belgium was only second to the United Kingdom in the number of beds per capita available for palliative care[75].

During the 1990s, people were aware that euthanasia was being performed illegally, but it was tolerated. Research from Flanders throughout that decade confirmed that doctors commonly dealt with end-of-life decisions. Cohen-Almagor[73] gives a statistic of 5% of all deaths having resulted from fatal drug doses in general medical practice, and of these, deaths that had occurred without an explicit request were three times more frequent than those who asked for euthanasia. One study[77] described the Flanders medical approach to euthanasia in 1998 as below the medical standard of care and variable between doctors. Uninformed doctors had used unsuitable drugs at inappropriate doses that would not necessarily have achieved quick, comfortable, assured deaths.

Bernheim, *et al*. recorded that when the Euthanasia law was passed, two other Acts, one on Patients' Rights, the other advancing a 'right to palliative care' came into being at the same time. This move reinforced the institution of palliative care, also massively inflating public funding. These palliative care regulations made it mandatory to have a palliative care team in every hospital and palliative home care available throughout the country. Research provided evidence that Belgium continued to offer excellent palliative care, despite euthanasia becoming openly accessible[75].

Like the infrastructure designed by the Netherlands to ensure oversight of the E process, the Belgian Parliament put in place a Control and Evaluation Commission to which E cases had to be reported. Parliament stipulated that four of its 16 members were required to be palliative care workers, the other members comprised of lawyers, ethicists, and doctors. The Commission was to publish a report on its findings every two years. Also comparable to the Dutch history, the Belgian Medical Disciplinary Board drew up joint guidelines for E and palliative care that supported the law, while stressing the provision of palliative care before a final decision on E was reached. This was reinforced by the Flemish Scientific Association of General Practitioners.

Careful not to cause conflict between the palliative care workers, the Flemish Palliative Care Federation embraced a mixed position, deferring to the patients' end-of-life decisions to ensure

their wishes were honoured above all other sentiments. It asserted that both E and palliative care could be recognised as end-of-life choices, not as alternatives, because they were not incompatible with one another conceptually. Caregivers were allowed to exercise their ethical principles by being honest with respect to their limits of service, but this was to be conveyed early enough for other arrangements to be made. The Flemish Palliative Care Federation was the first professional palliative care centre in the world to recognise 'integral palliative care', a label accepted and used by the General Practitioners' Flemish Scientific Association, too.

For a long time, the Federation of Palliative Care in Flanders was the only palliative care institution world-wide to have embraced euthanasia[71]. In 2016, the International Association for Hospice and Palliative Care finally published a position paper on E and PAS to clarify their stance. They stated that they did not want to be responsible for overseeing or administering E, and any staff member who did not wish to participate had to be allowed to refuse[78].

As a consequence of this social environment, health profession organisations did not overtly resist the legalisation of euthanasia. In fact, Bernheim, *et al.*[75] recorded that the ethics committee of the national Caritas group of Catholic healthcare institutions, which managed 70% of Belgian hospitals, formulated guidelines to assist with introducing the law into the hospitals. The main limitation they inserted in the guidelines was that only terminally ill patients would be eligible for E and that it was compulsory to consult a local palliative team as part of end-of-life decision-making. What evolved was a mutually beneficial and synergistic relationship between the two professional camps. Most values held by both groups were the same. Legalising E had been associated with the expansion of palliative care at a professional and ethical level because E was accepted as a medical act, also from a civic and economic point of view. Authors suggested that this success was achieved because of shared caregivers, political reciprocity, and institutionalised cultural, religious, philosophical, and ethical diversity. Paradoxically, offering satisfactory palliative care to society made legalising E politically and ethically tolerable.

During 2001, euthanasia legislation was proposed in parliament to decriminalize it and finally regulate the practice instead of it taking place in secret. A survey of public opinion indicated that three-quarters of the population appeared to support this significant legal and social shift. In May 2002, following on the heels of the Netherlands, the '*Loi relative à l'euthanasie*'[2] (Law on Euthanasia) came into force, along with the Patient's Rights Act[79] and Palliative Care Act[80]. Belgium was the second country in the world to introduce E legislation. E was only available

for people who resided in Belgium[73].

The definition of E in the Belgian Euthanasia Act (translated from French) is 'an act, performed by a third party, which intentionally put an end to the life of a person at the latter's request'[81]. Clearly, consent is necessary for euthanasia to be lawful. There is no reference to PAS, and it is not considered to be part of Belgium's legal framework. Nonetheless, the Belgian Control Commission records cases if notified, and it is accepted as a practice[82].

Many physicians said that they would have preferred patients to opt for PAS so that they could commit suicide themselves, rather than depending on the doctors: that would have truly reflected patient autonomy. Other doctors, in contrast, preferred to perform E because fewer complications arose. It was suggested that this was also a material factor in patients' minds, adamant that the doctor had to carry out the process. That was even so in the face of an instruction to the patient to simply turn a stopcock on a parenteral intravenous line to allow the inflow of the lethal medication themselves. The psychological aspect to performing E was evidently complex, both for the patient and for the doctor[71].

According to a 2015 European Institute of Bioethics report on Belgium's integrated palliative care model, which looked at whether palliative care was distorted by including euthanasia as one of its end-of-life options, although euthanasia began as an exceptional procedure strictly controlled by the law, premature death became the norm in an environment of progressively weakening and uncertain restrictions over time. People's autonomy and freedom of choice remained of primary importance leading to the original requirements of the E law no longer being applied[83].

4.1.2.2.1. Euthanasia Legislation.

The Belgian Euthanasia Act specifically provides that a doctor who performs E does not commit an offence if the conditions set out in the Act are met[84]. Likewise, the Act states that a pharmacist who dispenses medication for the E process will also not commit an offence. However, the pharmacist has to prepare the medication and hand it to the doctor personally[85]. Interestingly, like the Netherlands, the Belgian Act does not require a person requesting death to be a citizen or resident of Belgium, but, practically, it is unlikely that a non-resident could be given E. The reason is that the doctor is required to have a relationship with the patient and know them well[86].

The conditions justifying E, listed in Article 3.1 of the Act, were originally as follows. They were amended over time:

- The person had to be an adult (18 years and older), or an emancipated minor. According to Cohen-Almagor's research[73], emancipated minors included 16- to 17-year-olds, who were almost adults. This provision was eventually amended in 2014 to include a broader group of minors, discussed later in this chapter.
- The request was made voluntarily, thoughtfully, and repeatedly, and was not a result of external pressure.
- The patient had a hopeless medical condition.
- This condition was associated with constant and unbearable physical or psychological suffering that could not be alleviated, and which resulted from a serious and incurable accidental or pathological condition.

According to the Control and Evaluation Commission, the majority of doctors, and the public accepted that the 'unbearable suffering' term meant more explicitly suffering that was no longer 'tolerated' by the person[71].

Safeguards in place are that the euthanasia process must comply with all conditions and procedures prescribed by the Act. Such conditions and procedures include that the patient is given a complete understanding of the condition, prognosis, and any alternative medical interventions that are possible. Palliative care is discussed, and together they must reach the conclusion that E is the only option left (Art. 2.1). The doctor must be satisfied that the physical or psychological suffering is unrelenting, and the request for a hastened death repeated in several interviews over a reasonable time period (Art. 2.2). Discussions are meant to include the care team, if one exists (Art. 2.4), as well as relatives, should the patient want that, or others that the patient requests (Art. 2.5, 2.6).

An independent second doctor, or a psychiatrist, or a medical specialist who is familiar with the patient's condition, is required to carry out an assessment of the patient, too. Having read the medical files and determined the seriousness and incurability of the condition, a report has to be written by them, either in support of E or giving reasons to oppose it (Art. 2.3). The report is non-binding[87].

The patient's request must have been repeated more than once[88], and finally put in writing and signed by the person who is asking for E. If this is not possible, a designated person who is an adult can help, giving reasons for the assistance in the written document. An amendment to the Act provides that once the request has been processed by the doctor, psychological support should be offered to all persons concerned (Art.4). The request can be revoked at any stage, and the doctor then hands the patient's request back to them from the file (Art. 4). All interviews and requests for E from the patient should be noted in the medical file, as well as the medical steps taken (Art. 5).

Where the patient is not in the terminal phase of life, such as with quadriplegia or other neurological disorders, different safeguards are in place to ensure no mistake with E occurs. At least one month should elapse between the written request and E to allow for reflection by the patient (Art.3.2).

If the patient is not yet at the end stage of life, a second consultation will be required later in the progression towards E (Art. 3.1) on the same basis as the first independent consultation mentioned above. Thus, three doctors participate in the assessment of a person who is not in their terminal phase of life.

Where the patient is irreversibly unconscious but has prepared a written advance directive asking for E, the doctor can proceed based on that text. The Euthanasia Act has specifications for advance directives, such as the need for two witnesses to be present at the time of preparing the document, one having no material interest in the person's death. Originally, the advance directive needed to be updated every five years, but this was amended in the Act, as discussed further below, when it was challenged in court (Art. 4.1).

Studies showed that once legislation had been passed in Belgium, the number of deaths, both with consent and without requests, decreased[74]. Also, the euthanasia requests did not increase but remained consistent with trends prior to the law. Doctors tended to involve family members and staff more frequently in end-of-life discussions. The reason for the decrease was suspected to be because doctors feared prosecution after the government regulated the practice of euthanasia. After a long period of complete silence, the Belgian judiciary had initiated criminal investigations into medical deaths. It was also suggested that the change in the doctors' behaviour was because by that time they were ready to improve the quality of the patient's life, respecting their dignity, by actively including them and their families in discussions. The

increasing emphasis on self-determination was another factor: once discussions were underway for patients to express how they wished to spend their last days, that mitigated against the doctor's independent use of lethal drugs without consent. A final reason proposed by the researchers for the decrease in E cases was that palliative sedation became a favoured alternative to E. It was also actively recommended by those who opposed E.

A study five years post legalization of E in Belgium indicated that 2% of all deaths were related to E and PAS[89]. Of these, 1.8% were without requests. Typically, patients younger than 80 years old who had cancer requested E to die at home. Patients euthanised without request tended to be over 80 years old, in hospitals, either in a coma or suffering from dementia. In some cases, family members had been consulted, but not all. Reasons given by this group for euthanasia without consent were that life was not to be needlessly prolonged, or the patient's life had become a burden to their family. Often, the nurses administered the lethal medication without the doctor present. The authors voiced concern that this represented a vulnerable group of patients who were at risk of receiving E without request. They needed to be better managed and encouraged to complete advance directives while still able to do so, instead of allowing others to decide how their lives should end. The authors suggested that this could reduce deaths by E without consent.

In 2012, a study[76] that compared culture and end of life care in six countries found that Belgium had markedly lower cases of E (1 917) than the Netherlands (10 319) within the first five years of their legislation. This was possibly due to the active palliative care model that was incorporated into the culture. A notable feature of Belgium's health system was that general practitioners tended to work by themselves and developed enduring, trust-based associations with their patients. Patients could choose their own doctors, in contrast to the Netherlands' system of zoning, so care was personalised.

Compliance with drug use guidelines for E had improved substantially by 2013. However, doctors felt that they needed more training on E procedures to avoid adverse events, specifically on the effects and side-effects of opioids and sedatives. Authors suggested that the medical community, for example through the National Disciplinary Board of Physicians, ought to take the lead in giving guidance to peers[90, 71].

In February 2014, the law was amended to allow minors, with no age limit, but capable of discernment and conscious at the time of the request, the choice to be euthanised if suffering

from a terminal illness[91]. This law was contentious, both at a national and international level. Nevertheless, it was approved in the Belgian Senate by 50 votes to 17. A written objection[92] was published at the time, signed by 58 members of the Council of Europe, stating, amongst other objections, such as whether the child truly had the ability to understand the consequences of such a decision, that the law 'promotes the unacceptable belief that a life can be unworthy of life, which challenges the very basis of civilised society'.

The amendment stipulated that doctors had first to confirm that the child was in a hopeless situation with persistent unbearable suffering, that could not be relieved, and would result in death imminently, owing to a serious, incurable, accidental or medical condition. The request needed to be written, and psychiatrists had to establish that there was no coercion or influence from others. Parents had to agree with the decision, and so could stop the process if they did not give their consent[91].

Although there were no cases of minors having been euthanised for a year following the new law, the Federal Commission for Euthanasia Control and Evaluation, in its report of 2018, stated that during the period from January 2016 to December 2017 there were three cases of child euthanasia, which it had accepted as lawful. Explanations for the deaths by lethal injection consisted of a 9-year-old with a brain tumour, an 11-year-old cystic fibrosis sufferer, and a 17-year-old with muscular dystrophy. One of the Commission members, Luc Proot, shared that he had been overwhelmed by the physical and mental suffering described, and believed the E was appropriate. To add perspective, the 2018 report confirmed that there were 4 334 adult deaths by request for the same period, of whom 64% had cancer[93].

Verhofstadt, *et al*.[94] investigated unbearable suffering related to psychiatric disorders in a paper released in 2017. They said that Belgium and Luxembourg were the only countries with the 'unbearable suffering' provision specifically stating the source and type of suffering. It used the following words (translated): 'physical and/or psychological suffering that cannot be alleviated and results from a serious and incurable disease, caused by accident or illness'. However, the research highlighted that suffering remained difficult for doctors to assess without Belgian guidelines that listed the characteristics people perceived as unbearable, although the Dutch Psychiatric Association's guidelines were of some assistance to them. The Belgian Federal Commission for Euthanasia Control and Evaluation recorded in its previous reports that it struggled to reach consensus on how to understand and evaluate the doctors' euthanasia reports, when they specifically relied on intolerable mental anguish to meet the 'unbearable

suffering' criterion. Hopelessness remained a dominant reason for people with psychiatric conditions to seek euthanasia. The research at the time showed that the E process, including finding a doctor who would perform it, added to their suffering. Socioeconomic and financial problems were also highlighted as factors. Such psychological suffering was described in some South African legal cases on assisted suicide[95]. The researchers emphasised that societal failures should never be seen to be resolvable with euthanasia[94]. This is wise advice for South Africa too.

The Flemish Psychiatrists Association (Vlaamse Vereniging voor Psychiatrie) put forward guidelines in 2017 to assist in assessments of persons who requested E while suffering from mental disorders. The Belgian Ordre des Médecins, in 2019 did the same. Both organisations suggested some additional safeguards to avoid mistakes. Examples of these were that, where a treatment existed which had a reasonable prospect of success, despite the patient refusing treatment, the person would not be eligible for E. A lengthy timeframe ought to be allowed for patient follow-up during the assessment phase. Discussions with other doctors, possibly from the patient's past, were recommended, and if the patient refused this, then they were not eligible for E. An independent psychiatrist also had to assess the patient. They considered requiring two of the three independent doctors to be a psychiatrist and, two of the three doctors had to agree with the final decision[87].

Much was written in the media by concerned individuals who monitored the vigilance with which the E law was policed. Their concerns were focused on their fear of a slippery slope developing[96,97]. However, the research articles often included in their commentary that slippery slopes had not yet arisen in either of the two European countries[75,76] Belgium had similar legislation in place to the Netherlands, with a comparable tolerance for the range of disorders that justifed E. At that stage, Belgium also rejected the 'tired of life' criterion as a reason for E[98].

Literature drew attention to how, in the Netherlands and Belgium, the medical mindset continued to move towards a 'hastened death' culture, which was viewed in a positive light. To illustrate the point, a startlingly controversial article was published in 2020 by a group of Dutch and Belgian researchers. They supported what they regarded as 'altruism' in what they termed 'organ donation euthanasia' (ODE). They promoted the advantages of harvesting organs while patients were under anaesthesia only, rather than waiting for circulatory cessation (indicating that the person was dead prior to organ removal) from a lethal injection first[99]. This was already

canvassed in 2012 to increase the number of available organs for donation, by Wilkinson and Savulescu[100]. The benefit of the technique was that it increased the number of good quality organs that became available. The seven authors, who were associated with medical centres in the Netherlands and Belgium, explained that it was the organ donors themselves who, whilst undergoing euthanasia, had suggested the idea in order to improve the quality of the organs they donated. In addition, the researchers submitted that the procedure could be justified on the basis that the doctors were fulfilling the patient's last wish to perform an act of altruism. In so doing, the doctors were respecting the patient's autonomy, and, at the same time, reducing the suffering of patients on the transplant list who received organs[99]. The requests for ODE motivated the researchers, Bollen *et al.*, to investigate the medical, legal, and ethical arguments for ODE. Although they canvassed the novel idea, Bollen *et al* conceded that the psychological consequences for all involved in the practice could not be underestimated. ODE thus remains illegal in the Netherlands and Belgium, viewed ethically as a 'step too far'.

The article is an example of how ethical boundaries surrounding death continue to be challenged. One can only imagine the discussion of which organs should be removed first to keep as many organs viable for as long as possible. In essence, the surgeon could end up performing a dissection of the entire body – and most parts would have value - presumably finally ending the person's life by removing the heart and lungs[100]. The publication was alarming in its confirmation that an individual could be so objectified that death was simply a means to an end.

In light of the fact that the person was not asking to die in order to donate organs but wanted to die in spite of what happened to the organs, it was questionable whether the act could genuinely be called altruism. Likewise, the doctors were not simply being obliging. They too, stood to gain personally from the ODE by fulfilling their own motivations, gaining access to increased transplant surgeries, and possibly furthering their own research. None of these was necessarily wrong in itself, but the objection is to labelling the process in a way that made it more palatable for discussion. (The use of euphemisms is examined further in chapters 5 and 6).

One is reminded that the WMA's 1964 Declaration of Helsinki[101] was written for doctors to safeguard respect for human beings who participate in research, in the aftermath of past atrocities performed on people in the name of research[102].

A case in point that reflected the vulnerability of people under the care of doctors within a

permissive society was the following death that occurred in May 2022 in Belgium. A 23-year-old woman with intractable mental illness was euthanised. She was a survivor of a terror attack in Belgium during 2016[103], but had a prior history of serious mental illness and was struggling to manage the trauma she had experienced. The young woman had refused to engage a therapist who was specialised in treating victims of terror attacks. Instead, she opted to contact a Life End Information Forum that ultimately led to her euthanasia, surrounded by her family. Two psychiatrists had confirmed that she met the criterion of medical futility for a lawful death, amongst other requirements that needed to be met. Were the E legislation not in place, a lethal injection to facilitate a hastened death would not have been accessible to her as an option, and a therapist might have been given the opportunity to try to help her. Sadly, the woman had only just reached adulthood.

As mentioned by others, the measurement for how advanced a society is, is how it treats its most vulnerable inhabitants. E/PAS law was intended to be crafted to protect the vulnerable population[104]. One is left with a sense that the medical and social infrastructure failed her. It is disconcerting to contemplate how rational E/PAS law can appear to be.

In an analysis of the 2020 Belgian euthanasia report, summarized by the Euthanasia Prevention Coalition of the European Institute of Bioethics[105], E cases in 2019 amounted to 2 656, a 12.6% increase from the previous year. However, the report pointed out that it could not be certain of how many deaths were actually facilitated by doctors, because the system relied on self-reporting.

Organ-donation associated with E occurred in 18 deaths. Those cases were either diseases of the nervous system, or a mental or behavioral disorder. They would have been managed in hospitals for that purpose. Of the total number of deaths, 57 suffered from psychiatric conditions, such as mood disorders, personality or behavioral disorders, neurotic problems, somataform disorders, schitzophrenias, delusional disorders and autism. Their conclusion was that ‘once medicalized killing becomes legal, there soon develops many more reasons to kill. Belgium is the prime example of a country that is continuously expanding the scope of its euthanasia regime’. This translation was provided by the Euthanasia Prevention Coalition, so may reflect a biased opinion[105].

In 2021, the European Institute of Bioethics published a study about doctors euthanising babies who were considered to have no hope of a future free from unbearable suffering[106]. Doctors

and parents would have reached that conclusion together. The uproar was that these E cases fell outside of the Belgian legal framework which only allowed E of children who could consciously request E for themselves. The Netherlands has the Gröningen Protocol for neonatal euthanasia to cater for such situations. It was drawn up as a guideline in 2002[107]. However, at the time of this thesis, Belgium had not addressed the topic at all. The researchers highlighted the need for Belgium to develop a similar framework to guide doctors going forward.

The 2020 amendments to the Belgian E law were challenged legally in 2021, but were confirmed constitutional by the Belgian Constitutional Court[108]. The amendments provided that '*no written or unwritten clause can prevent a doctor from performing euthanasia*'[109]. Certain retirement homes and hospitals wanted to be allowed to refuse permission for E to be administered on their premises: they favoured palliative care exclusively, but the Court refused to hear argument on that issue. Another point of contention was that doctors who opposed E on the grounds of conscience or because criteria for E were not met, wished to refer the patient to a centre specialising in E. The Court found that the law respected both the freedom of conscience as well as the patient's right to choose E, so a legal requirement to refer the patient was indeed appropriate. Lastly, the change from a five-year renewal period for advance directives, to one of unlimited validity, was disputed because it was considered too risky in case someone had changed their mind without updating their document. The Court held that there was nothing preventing a person continuing to update their advance directive every five years, and the risk of someone forgetting to do so could happen equally during a five-year time-period, so the Court rejected this objection, too.

Overall, the E law and its reporting structure in Belgium are similar to The Netherlands. Nonetheless, the impression created in the English literature was that Belgium is constantly aware of a concerning discrepancy between the true E figures and those reported, owing to under-reporting by doctors[105]. This presents an inherent flaw in the model, where checks are made only after the fact by the Commission[110], and then only on self-reported cases. Belgium is also less organized in terms of guidelines, so relies on the Dutch information that is readily available. The advantage of the Belgian approach, though, is that it embraces and actively promotes palliative care.

4.1.2.3. Social and cultural environment

To understand the achievement of the integrated health care system, some information on

Belgium's social infrastructure is offered.

Belgium was ranked in the literature as a country with one of the lowest levels of income inequality worldwide, along with specified Scandinavian countries[111]. Being multilingual and multicultural, it has a complicated federal political system. Because the political parties and other bodies are divided between Dutch and French-speaking, the country is used to a coalition government. They describe themselves as able to compromise, so that where one side gains an advantage, the other side is compensated.

Although some literature contradicted the perceived synergy between E and palliative care in Belgium, the model was generally deemed a success. The integration in Belgium of palliative care with E was thought to have been achieved because the majority of the Belgian public had a progressive social attitude and great trust in their health care system[71]. The model was acknowledged not to be perfect, but the improvement process was ongoing. As it was applied in the different regions, it was scrutinised and adjusted to improve it. Bernheim *et al* reflected that, if public confidence in health care management had been low, the prospect of E would have been frightening. The confidence rate in Belgium was 91.2%, second to Iceland, which had the highest rating in Europe. Luxembourg, also tolerant of E legislation, was third[71]. By way of comparison, in 2020 the OECD (Organisation for Economic Cooperation and Development) report reflected that 92% of Belgian citizens expressed satisfaction with public healthcare services, compared to an overall percentage in OECD countries of 71%[112].

Another important facet of Belgian life was that it had a predominantly Catholic tradition, so medical care was said to be more religion-based than secular. Despite this, the acceptance of E seemed to indicate that religious beliefs, generally, had not prevented patients from requesting E, nor doctors from providing this service. Some doctors described their experience with the patient and family at the appointed time of E administration, as being an intensely spiritual and existential moment. There was sadness but also peace and a relief that suffering had come to an end. A Jesuit priest and Belgian palliative care physician, Dr Marc Desmet, when interviewed, was asked whether his beliefs were a barrier to performing E. His response was that in Christian tradition, a person's compassion and conscience overrode doctrine. He did not perform E personally, but referred and accompanied his patient, as far as his conscience allowed, to someone who was prepared to administer the lethal drugs. The authors reiterated that all caregivers were driven by the same empathy and compassion for patients, including respect for their autonomy[71].

4.1.2.4. Comparison with South Africa

In summary, Flanders has a very homogenous Dutch-speaking society[111] that mirrors the mind-set described in the Netherlands. They appreciate their right to personal determination, and self-control is held in high regard. Self-reporting is the means of E regulation as reflected in the levels of E practiced and reported. The southern region, on the other hand, is French-speaking, more continental in mind-set, where Roman-Catholic traditions modified their choices and behaviour. Its preference for palliative sedation at the end-of-life, instead of E, may be attributable to this influence.

Like Belgium, South Africa has a diverse society, but it no longer functions with a coalition government as it did at the start of its new democracy in 1994. This may be because South Africans have fresh memories of their dark and painful apartheid history, and do not want to continue to feel controlled by one another. They sought instead to try to create a better future by working with their own majority representatives in parliament, who could ensure that their interests would be met. The constitutional platform from which the government gained support may have contributed to increased hope for a better future, particularly given that their human rights were legally assured.

Comparing their health care systems exposed a stark difference between Belgium and South Africa. South Africa does not have a strong palliative care infrastructure at the time of this thesis, either in the public or the private sectors. Both spheres of care are under-equipped for the demands they have to meet. Importantly, as writers have said of Belgium, it would be unethical to offer euthanasia in South Africa without offering an attractive alternative in palliative care. This issue is discussed further in Chapter 7.

4.1.3. Luxembourg

4.1.3.1. Introduction

Luxembourg is discussed only briefly because it has E and PAS laws in place which are comparable to its neighbours. However, it also has an oversight system for managing advance directives which is helpful with regard to a person's end-of-life decision-making.

In March 2009, following Belgium's example, it was the next country to enact a law permitting

euthanasia[3] and a law to entrench palliative care throughout the country[113]. The year before, the Grand Duke had opposed the legislation on religious grounds. Nevertheless, under the prime minister at the time, the Constitution was amended so that the Grand Duke's powers to sanction laws was removed and limited to only passing laws going forward[114].

Luxembourg is one of the smallest sovereign states in the world, triangular in shape, with Belgium to the west, Germany to the east, and France to the south. As a result of its position, the greatest influence on its traditions has been from the French and German cultures. The political structure of this Grand Duchy is a democracy, with a hereditary constitutional monarchy[115].

Native Luxembourgers fluently spoke French, German and Luxembourgish, (Lëtzebuergesch, originally a mixture of German, primarily, and French), fluently. These three administrative languages are all used concurrently out of economic necessity and historical tradition. Legislation is written in French, so French legal text is accepted as authentic. Other government information tends to be in all three languages and people can respond in their language of choice[116].

4.1.3.2. Legislation

When the Chamber of Deputies enacted the legislation regulating euthanasia and assisted suicide, it was similar in structure to that of Belgium, embracing palliative care as a recognized alternative to E. However, like the Netherlands, the legislation explicitly covers both E and PAS. Luxembourg defines euthanasia as 'a medical procedure by which a doctor intentionally ends the life of another person at the express and voluntary request of the latter'. Assisted suicide is defined as involving the same conditions, but the person is helped to end their own life, and specifically provided with the means to do it[117].

The government states that their legal provisions are applied strictly. In 2019, a Luxembourg news article reported that only 71 people were reported to have requested E, and 51 people PAS, over 10 years since the law was passed[118]. To illustrate the rate per year more clearly, in 2018, of a total population of 607 913[119], 8 individuals chose euthanasia. (The total death rate in that year was 7.137 per 1000 people[120]). Doctors have formal procedures and conditions to meet in order to administer E, comparable to the Dutch and Belgian doctors. Only then would the procedure be accepted as lawful. They are not obliged to perform E, but then must inform

the person, or the appointed proxy of an unconscious patient with an advance directive, within 24 hours, giving reasons for the refusal, so that the person or loved ones can make alternative arrangements[121].

E is available for adults who are conscious and legally competent to request it (Art. 2.1.1). Older minors of 16 to 18 years may also ask to be euthanised but require their parents' permission[122]. Besides this exception, minors are not permitted to be euthanised, nor may their parents, guardians or trustees make a request on their behalf. This category includes persons under legal guardianship or protection, and those legally incapable of giving consent[121].

The person must have an incurable medical condition. It is irrelevant what caused the problem, but it needs to be associated with unbearable physical or mental suffering that has no hope of improving (Art. 2.1.3). The request should be directly from the person, repeated more than once and is required to be in writing (Art. 2.1.4). All their personal details have to be mentioned, a date included, and their signature. If the person is physically incapable of writing for themselves, someone with legal capacity can write on their behalf. That person has to explain the circumstances, in the presence of the person's doctor, whose details also have to be recorded in the document,[121].

A National Control and Assessment Committee was established to oversee the implementation of the E and PAS legislation along similar lines to the Netherlands and Belgium[123]. It has nine members of mixed disciplines, amongst whom are doctors, lawyers, a magistrate, a representative of the Medical College and two people who have an interest in patients' rights. The Committee must file a report every two years presenting statistics and the work that has been done, including any recommendations to improve the system (Art.9)[124].

4.1.3.2.1. Advance Directives

In anticipation of a time when a person might not be able to express their end-of-life wishes owing to an irreversible state of unconsciousness as assessed by medical science at that time, Luxembourg encourages people who are of legal age and capacity to exercise their choice in advance. They promote the preparation of an 'end-of-life arrangement', comparable to an advance directive[125] in other jurisdictions. The *'Law of 16 March 2009 relating to palliative care, advance directives and end-of-life support'* gives legal instructions on how to prepare an advance directive[126]. The government website provides forms that can be filled in, either by the

person themselves[127], or by someone else on their behalf, if they are physically disabled[128]. A 'person of trust', who is legally capable of representing the person, could be appointed as their proxy to speak on their behalf concerning their last wishes. Information regarding the circumstances and conditions under which the person would require E to be performed are recorded. That may incorporate instructions for burial or cremation.

The document is dated and signed by the individual. Where the person is physically disabled, a legally capable person may write the advance directive on their behalf, explaining the reason for the assistance. It is then also signed by two witnesses besides the writer. Additionally, a medical certificate is required to confirm that the person has a permanent physical disability[126]. The advance directive can be amended or withdrawn at any time, but it must be recorded (Art. 5.4). The last known wishes of a patient take precedence, so if a doctor is aware of the patient's change of mind about E after the written evidence of their wishes, E may not be performed.

The advance directive is to be legally documented with the National Control and Assessment Committee, along with any alterations made over time. From the date of filing, the Assessment Committee has the responsibility to contact the person every five years to check that the advance directive is still valid[127]. There is consequently no time limit on the person's advance directive. When requested, the Committee informs the doctor responsible for the terminally ill patient whether there is an advance directive in place. If so, the doctor is given access to the document to confirm its details.

Any Luxembourgers who wish to make end-of-life arrangements, even if they reside overseas and have a general practitioner in Luxembourg with whom they have had a long relationship, is entitled to do so by completing a form supplied on the government website. This form will be inserted in their medical file and lodged with the National Control and Assessment Committee[127].

4.1.3.2.2. Latest developments

An amendment to the E law was that in 2019 a decision was taken at the government council to categorise E and PAS as natural deaths instead of suicides. This is significant for life insurance claims[129].

4.1.3.3. Social and cultural environment

The original number of Luxembourgers decreased over the years because of their low fertility rate, while the overall population slowly increased as a consequence of immigrants who settled there. The population consisted of around 634 000 people, living on 2 586 km^2 in 2022. Almost half of the inhabitants are foreign-born residents such as Portuguese (14.8%), French (7.6%) Italians (3.7%), Belgians (3%) and Germans (2%), and more recently those from Slavic and Nordic areas. The major social division is between local Luxembourgers and the resident foreigners[130].

Although Luxembourgish is spoken at home, German is the primary language taught at elementary school, then French becomes dominant in secondary school. German is the main language used for print media, but television media is predominantly Luxembourgish. English is also widely spoken by 80% of the population, and specifically used in the international institutions, the business sector, and the financial sector. In addition, other languages, such as Portuguese and Italian are frequently heard. French, spoken by 98% of the population, is more commonly used to communicate in the trade and hospitality sectors, an example being the menus in restaurants, and street signs[116, 115].

The country thrives on its many financial institutions and has developed a very stable economy with a high standard of living since its early success in the steel industry from mining iron-ore. The social welfare programs are seen as one of the world's most generous systems and unemployment is low, 2.1%. Comparable to other European countries, Luxembourg has a free and universal national health insurance system[131]. The country is one of the highest investors in its medical infrastructure compared to other OECD countries and has many doctors and nurses who offer good health coverage[116]. Various Ministries have been established for the family, the disabled and senior citizens to ensure facilities and information exist online specifically for their needs. The government offers extensive assistance and care at home covered by insurance and the national health fund[132].

Religion in Luxembourg has been mainly Roman Catholic (90%) and the Constitution protects freedom to practice all faiths. In 2015, the country re-assessed the relationship between church and state and signed an agreement between the government and the religious communities to restructure their relationship so that it reflects social reality. In public schools a 'common values' education was to commence and church property rights were to be reformed[133].

The presence of a faith-based society may explain the low E and PAS choices made in the past. There was also some criticism by a euthanasia activist group in the Luxembourg media that people had not been adequately informed about their options to choose E and PAS, which was thought to be another reason for the low numbers[114]. As society changes it will be interesting to see whether Luxembourg's numbers increase, or whether excellent senior care and palliative care would be enough for people to die without suffering.

4.1.3.4. Comparison with South Africa

Luxembourg has an extremely high standard of living with an infrastructure that is ranked as one of the top countries in the world for happiness, the quality of life and employment[131]. South Africa, with its radical inequality between rich and poor, and its weakened infrastructure because of corruption and politics, has very little in common with Luxembourg except its multiplicity of languages. South Africans aspire to reaching this state of satisfaction with life and prosperity in the future, but it remains a long way off.

4.1.4.a. Québec

4.1.4.a.1. Introduction

Québec, the largest province in Canada, was the first region outside of Europe to adopt euthanasia legislation in June 2014. Québec was initially a French Colony, then later was under British administration, before it became part of the Canadian Federation in 1867. Its vast area of land is made up of lakes and thousands of kilometres of forests. Most of the population are found living between Montreal and Québec City in the St Lawrence Lowlands, the most fertile area. The province is governed by its National Assembly that represents the people and also has a symbolic representative of the British King, a lieutenant-governor, appointed by the federal authorities. The National Assembly is empowered to make provincial law, and matters related to health care fall within this domain. Québec's judicial system has a foundation of the French Civil Code, while the rest of Canada uses Common Law. Consequently, the Québec courts apply Québec law and federal law[134].

4.1.4.a.2. Legislation

At the time that Bill 52 was passed in Québec in 2014 legalising euthanasia, the Canadian

Federal Criminal Code did not allow a physician to terminate a patient's life at their request. Mishara and Weisstub suggested that this was arguably the reason for Québec referring to euthanasia as 'medical aid in dying', so that it would sound like medical treatment, a part of health care, falling under provincial jurisdiction[135]. This opinion was confirmed to be true in the Canadian government's Final Report of the Expert Panel on MAID and Mental Illness, published in May 2022[87].

In 2015, the Canadian court case of *Canada vs Carter*[136] changed the Federal Criminal Code to make way for the legalisation of euthanasia throughout the country, explained in more detail later. Consequently, Québec's end-of-life law came into force on December 10th, 2015.

The purpose of the End-of-Life Care Act[137] is to ensure that people's rights are respected and that their dignity and self-determination are valued through the care offered to them at the end-of-life. It includes palliative care, as Belgium and Luxembourg have done. The Act therefore creates a framework and infrastructure for end-of-life care that is accessible to everyone, offering a continuum of quality medical attention suitable for different needs to relieve suffering.

Québec has many social institutions including hospitals, community centres and long-term care facilities for the elderly[134]. All institutions that provide health and social services are required by law to offer 'end-of-life care' in line with the End-of-Life Care Act[138]. End-of-life care, by definition, means delivering palliative care and medical aid in dying (MAiD), depending on the patient's choice[139]. Palliative care, as explained in the Act, entails an interdisciplinary team administering total and active care to patients who are suffering from a disease with reserved prognosis, with the intention of relieving their suffering, while neither preventing nor accelerating death, but preserving the highest quality of life attainable. It also includes supporting the patient's close family members as much as possible[140]. MAiD is defined as care involving a physician administering medications or substances to an end-of-life patient, at the patient's request, to stop their suffering by hastening death[141]. Besides the provisions for palliative care and MAID, the Act also covers the option of continuous palliative sedation which falls under palliative care.

Continuous palliative sedation is described as administering medications or substances to an end-of-life patient to relieve suffering by causing a state of unconsciousness until death ensues[142]. Those who opt for this end-of-life care must have the process fully explained to them.

This entails discussing the expected duration of the process and emphasising that the sedation is irreversible. Patients are obliged to give written consent in support of this choice, too, and the doctor must be satisfied that there has been no coercion[143].

Each institution is expected to have a policy or clinical program in place for end-of-life care which incorporates all specialised attention and the options available under the Act[144]. Inspections may be carried out by the government to ensure compliance with the Act[145]. Local community institutions are instructed to plan for offering end-of-life care in family homes, too[146]. The Act stipulates that every terminally ill patient who is in a care institution must be given a private room for the final days before death[147].

The Civil Code of Québec does permit a child of 14 and older to refuse life-sustaining care or withdraw consent to further medical care[148]. E, however, is not an option for a minor. In the case of a younger minor or adult incapable of giving consent, this law allows the person who represents them to refuse care on their behalf as well, after full information has been given related to their illness[148].

Section 26 of the Act lays out the law related to the performance of MAiD. It is silent about PAS, therefore one could conclude that it may be prohibited[149]. The six criteria that need to be met are much more limiting than the law of the European countries discussed earlier in the chapter. Specifically, (i) the person requesting E must be an insured person, so a resident of Québec. (ii) Only conscious adults of full capacity may request E. (iii) Originally they must have been at the end of life, (iv) suffering from a serious and incurable illness, and (v) be in an advanced state of irreversible decline in capability.

The stipulation that the patient had to be ‘at the end of life’, as well as the federal MAID eligibility requirement of ‘reasonable foreseeability of natural death’ was successfully challenged in the Québec Superior Court. In the case of *Truchon v Canada (AG)*[150], on September 11, 2019, it was declared unconstitutional. Those criteria are now no longer a pre-requisite for E. Although the ruling only affects Québec, the Canadian Government formulated Bill C-7 in response to it in order to update the federal law. However, during the time that the Canadian Parliament was taking to amend the law, which was expected to be completed by January 2023, Québecois inhabitants could seek judicial permission to receive MAID even if their death was not foreseeable[87]. Further explanation is given below under Canada’s legislation.

The last criterion that should be met is that (vi) the person's state of decline should cause constant and unbearable physical or psychological suffering, which cannot be relieved in a way that the patient finds tolerable. There is a government form that the patient must personally complete, date, and sign in the presence of a health or social services professional, who then countersigns. A third party can assist someone who is physically incapable of completing it themselves, in line with the Act's provisions[151]. The Act requires the doctor to administer MAID personally and to remain with the patient until death ensues[152].

On completion of either the E process or continuous palliative sedation, doctors need to inform the professional body they are affiliated to, such as the council of physicians, dentists and pharmacists of which they are members, or its committee, within 10 days. The committee appointed assesses the quality of care that was provided. If no council has been formed for the institution, the head of medical services is responsible to fulfil the functions assigned under the Act. Private health practitioners inform the Collége des Médecins du Québec, which prepares an annual report providing statistics for each year[153].

A Commission on end-of-life care has been established by the Act, comparable to the European model discussed for the Benelux countries. It has 11 members from various disciplines and has a mandate to advise the Minister, evaluate the implementation of the legislation and oversee the compliance and functioning of the end-of-life care offered, among other tasks. Therefore, the institutions that receive end-of-life information from doctors send it on to the Commission, when requested. A five-yearly report on end-of-life care from the Commission has to be submitted to the Minister. The Commission also receives notifications directly from doctors within 10 days of them administering MAID, along with the documents stipulated in the regulations to be submitted for oversight purposes[154].

The Commission checks that doctors have met their own practice requirements specified in section 29. Those are: to ensure that the patient fulfilled the criteria set out for MAiD in the Act; that the consent was given freely and after full information was given about the prognosis and other possible medical alternatives with the consequences; that the level of suffering was verified and the wish for MAiD was persistent. Discussions about the patient's request with other staff members and the family must have been recorded, as well as discussions with others who the patient may have wished to see. The second doctor's assessment that confirmed the patient met the criteria for MAiD is inspected, including ensuring the doctor's independence from both the patient and family doctor. Where a patient had become incapable of giving

consent after a request had been made in writing with witnesses, and it was within 90 days of the request, the doctor could still perform MAiD. If two thirds of the Commission are not satisfied that the doctor complied with the Act, the summary of conclusions is sent to either the Collége des Médecins or the institution of the doctor for them to take appropriate steps[155].

A doctor is entitled to refuse to perform E based on personal convictions, as well as other health professionals who do not wish to participate, but they must ensure that continuity of care is given to the person by others, according to their ethical code[156].

4.1.4.a.2.1. Advance Directives

Finally, to uphold an individual's wishes related to their care, the Act has also established an advance directives scheme. The Minister has a form that can be completed by someone with full legal capacity. It is formal and witnessed by two people. The purpose of the advance directive is to specify whether or not they consent to appropriate care for their state of health in the event that they are not in a position to communicate for themselves anymore. However, in that document a person may not request MAiD. An appointed third party can then speak on their behalf when the time comes to make decisions for the patient[157]. This document can be recorded in the advance directives register which is maintained by the Minister or can be handed to the doctor to file in their medical record. In the event of a marked change in the patient's health, the Act's provisions require the doctor to check with the patient whether their advance directive still aligns with their future wishes. Where the patient is unconscious, the doctor must check with the advance directive register whether the patient filed a form so it can be inserted into the medical file. The Act stipulates that an advance directive carries the same weight as verbal consent in Québec[158].

4.1.4.a.2.2. Latest Developments.

The latest development in 2021 has been to consider whether people who are struggling with mental health disorders as their primary problem, and perceive it to be intolerable suffering, could request MAiD in Québec. The Québec government formed a Select Committee of members of the National Assembly to analyse and make recommendations in this regard and they reached the conclusion that people with mental health disorders should remain excluded. Consequently, no safeguards, protocols or guidance were discussed to manage this area of distress. In the meantime, Canada also appointed an expert panel on MAiD and mental illness,

not to decide whether to allow it, but to recommend safeguards that uphold autonomy, equity, and safety of vulnerable groups. Their report was published in May 2022 and is referred to when presenting Canada's status on euthanasia[87] below.

4.1.4.a.3. Social and cultural environment

Although Québec is factually a province of Canada, some see it as a nation in the sense of it being the base of the French-speaking community in North America and Québécois people of non-French origins[134]. When the Canadian Constitution came into being Québec refused to approve it, and Canada, in turn, failed to recognise Québec as an independent state. The Constitution did, however, assure them of the right to a school system under Roman Catholic control, sole jurisdiction over property and civil rights, and their French system of civil law[159]. From 2016's census, 79% of the inhabitants had French as their mother tongue and 8.9% English. The community was made up mostly of Canadians, French, and Irish, with a visible ethnic minority of mainly Arabs, Africans, and Latin Americans, as well as 2.3% Aboriginal. In 2011 almost 88% of the community claimed a religious affiliation, compared with Canada having slightly less at 76%[134].

The indigenous people living within the region of Québec are the Nunavik Inuit and James Bay Cree, who are the largest group of First Nations people in Canada. Their health care needs are met through mutual agreements entered into with the government. Health funding is shared between the federal and provincial governments and managed by the First Nations and Inuit authorities within the provincial health infrastructure. Specific Québec legislation[160] also protects the rights of residents so that they receive fair and equitable health services, including specific health care that they choose to have, where applicable[161].

4.1.4.a.4. Comparison with South Africa.

Québec does seem to function almost as an independent state. It has a provincial charter of human rights, and the social infrastructure offers separate income security and family allowance systems. Like the European countries analysed above, the Québecois philosophy, expressed in section 1 of the End-of-Life Care Act, is to value the community's dignity and autonomy through the care offered to them at the end of life, and to ensure respect for people's rights to access quality care. This is possible because social benefit programs were already established in 1965. As mentioned earlier, Québec has around 800 social institutions which form a complex

network within society, and also embrace a rich cultural appreciation of the arts[134].

In South Africa, of nine provinces, the chances of one province excelling at setting an example of a functional infrastructure for health services is possibly the Western Cape because of fairly disciplined and supportive management at a government level, compared to elsewhere in the country[162]. However, it still falls squarely under national legal control and has very limited provincial powers to function independently. The philosophy of a Constitutional era that upholds human rights is still to become entrenched but the vision of respect for dignity and equality are an important focus in society. A future national health insurance system (NHI) is planned[163] and hopes to provide a more equitable health service for the majority of people in time to come, but at the date of this thesis the two-tier system of a struggling public healthcare sector and separate private sector that caters to those who can afford it, is still entrenched.

4.1.4.b. Canada

4.1.4.b.1. Introduction

Contemplating its relatively recent euthanasia legislation, (MAiD - Medical Assistance in Dying[164] - following Québec's example), Canada has an important contribution to make as a comparison to South Africa. The reason for this comment is that Canada has a complex diverse society, the original population being the Indigenous Peoples who have suffered a great deal under past colonialism. These communities are striving to regain their respect and dignity and to protect the traditions and culture that make their identities unique[165]. For this reason, they do not necessarily have the same views about death as those of the non-indigenous public. As in South Africa, it is acknowledged that bridges need to be built to overcome differences. There is a need to ensure that all Canadians benefit from the same range of health services which the government chooses to make available[166].

The health system in Canada is a universal model[167], (described in more detail in 4.1.4.b.4. 'Social and cultural environment' below) to which South Africa also aspires. Useful information can be found in reading the literature about both the planning and the challenges Canada confronted during the first five years of the implementation of MAiD, some facts of which are referred to further on.

Canada is the second largest country in the world after Russia in terms of area. It is sparsely populated because of its terrain, with a population of 37 808 000. It has ten provinces and three territories, therefore 13 political regions in total. The three territories are Northwest Territories, Nunavet and Yukon. Because of Canada's complex physical topography of mountains, trees and lakes, a strong sense of regionalism has developed as a result of the various disjointed first settlements that emerged[168].

Canada is multicultural and bilingual. French and English are the dominant languages. Although the United States of America is Canada's neighbour and its popular culture is the same as America's, writers describe the heart of Canada as philosophically very different, more aligned with Britain. This reflects its history and the continuing influence of the British crown, even today. Modern Canadians are said to have an appreciation for community rather than individualism. They prefer an orderly central government and, in international affairs, fulfil the role of peacemaker rather than warrior. Canada was a founding member of the United Nations. In legal and official matters, Canada takes after Britain in regions where English is the dominant language. On the other hand, Québec is almost entirely French-speaking and consequently reflects its French character in law, religion, education and architecture[168].

The Native American peoples of Canada are discussed in more detail below, but are called collectively the First Nations. They add their rich cultural heritage to those of the non-indigenous Canadians. Another group of indigenous people who are semi-autonomous are the Inuits. They occupy Nunavut, the newest territory in Canada[169].

The political model of Canada is a constitutional monarchy. A governor-general is appointed to represent the British crown, but, practically, Canada is an independent federal state: following the passing of the Canada Act (the Constitution Act) in 1982, Britain has no control over it[170].

4.1.4.b.2. History of euthanasia law

During February 2015, Canada was confronted with its leading legal case that ultimately triggered a change in the law to allow euthanasia. In the matter of *Carter v Canada*[171], the Supreme Court of Appeal held that the sections of the Federal Criminal Code dealing with the crimes of murder and the aiding of suicides would need to be amended to allow for medical assistance in dying. This was to align the criminal law with the Canadian Charter of Rights and

Freedoms. The government was given a time period of 18 months until June 2016 to promulgate new law. Parliament cooperated by passing federal legislation to permit MAiD for Canadian adults who met the stipulated criteria[172]. The Criminal Code now excludes both doctors and nurse practitioners who provide, or help to provide, MAiD, from prosecution for culpable homicide or assisting suicides. It also lays down the criteria for eligibility for MAiD, and the procedural safeguards to administer MAiD lawfully[164].

Section 241.1 of the Criminal Code is amended to read that 'MAiD' is an umbrella term which includes:

- the administration by a medical practitioner or nurse practitioner of a substance that will cause a person's death at their request; and
- the prescription or provision by a medical practitioner or nurse practitioner of a substance that a person can self-administer to cause their own death.

Others who are listed as permitted to help with MAiD without fear of prosecution include pharmacists, family members or other people the patient asks to help, and health care providers who assist the physicians or nurse practitioners to provide MAiD[4].

The federal criminal law related to MAiD applies to the entire country, but the provinces and territories retain the power to manage it within their jurisdictions as they see fit. This includes legislating and formulating policies to regulate the health professionals who perform MAiD, and to implement MAiD within the established health infrastructure. The regions are not permitted to allow anything that is contrary to the Criminal Code[173].

After five years of the new MAiD Act being in force, section 10 of the Act required that a formal review of the legislation and the state of palliative care be done in order to monitor how it was being managed and received[172]. This has been done and public comments were published in a 2021 report, discussed further below.

The central purpose of Canada's end-of-life regime, like the Benelux countries, was to provide Canadian citizens with the option of having a medically assisted death if they were suffering intolerably.

The law originally stipulated that someone would qualify for MAiD if the following criteria were met: that the person 1) is 18 years old or above; 2) has capacity to make decisions about their health; 3) is eligible for health services funded by the federal government, province or territory; 4) can make a voluntary request for MAiD without coercion; 5) can give informed consent after having been informed of the means that are available to relieve suffering, including palliative care; 6) has a 'grievous and irremediable medical condition', meaning: i) a serious and incurable disease, illness, or disability; ii) an advanced state of irreversible decline in capability; iii) experiencing enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable and iv) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time they have remaining[172].

When the MAiD legislation was promulgated, the government was additionally tasked to investigate and write reports on three other complex problems associated with E: requests for E by mature minors, advance requests, and requests from people with a mental disorder as their only underlying medical problem. Ultimately, the Council of Canadian Academies (CCA) fulfilled the role and published its report in December 2018[174].

Regulations also needed to be prepared to set up a federal monitoring system so that data could be collected to provide information on how the legislation was impacting society. Publishing facts and figures was seen as important to encourage transparency and public accountability, too, considering the serious consequences should the law be broken. This was completed in November of 2018[4].

It became mandatory for doctors, nurse practitioners and pharmacists to report how many requests they received and how many prescriptions were dispensed for MAiD. The first annual report on Medical Assistance in Dying compiled from data capturing was distributed during 2020[4]. It reflected statistics for 2019, but in the meantime four interim reports had been circulated based on voluntary information gathered from the provinces and territories. During 2019, 2% of all deaths (5 631 cases) in Canada were from MAiD. The report included information about palliative care offered and received, and disability support among those who had received MAiD[175].

Predictably, since the legalisation of MAiD, litigation has been initiated to challenge the law. In British Columbia[176] and Québec[177], the cases concerned the fact that the eligibility criteria were not aligned with the *Canadian Charter of Rights and Freedoms*, because they were too narrow. The criticism was that 'natural death had to be reasonably foreseeable', according to the law, yet the plaintiff in British Columbia suffered from Spinal Muscular Atrophy, a progressive degenerative disease. Québec's challenge in the case of *Truchon and Gladu* was similar: it was an objection to the criterion that a person should be at the end of life when both plaintiffs suffered from serious handicaps - one had cerebral palsy since birth, the other had paralysis and severe scoliosis because of poliomyelitis. Their challenges were successful and limited to Québec, but the Canadian federal government accepted that this was a valid reason to amend the MAiD law.

In Ontario[178] a complaint was that the MAiD law violates the *Charter*. The reason put forward was that its safeguards were not adequate to protect Canadians who were presented with the option of MAiD, rather than having been offered better support services to create an improved quality of life. Ontario's plaintiff was of the opinion that the long-term health funding was insufficient for his needs, as he had a chronic neurological disease and was dependent on full-time help. His circumstances were reassessed and he was offered another health-plan which he rejected. No outcome appears to have been reached at the time of this thesis.

Based on the reviews Canada received about expanding MAiD, as well as the annual reports submitted to monitor its acceptance and implementation, Bill C-7: *An Act to amend the Criminal Code (medical assistance in dying)* was introduced in Parliament by the Minister of Justice and the Attorney General during October of 2020. The reason for this Bill was that, as previously alluded to, Canada planned that five years after the legislation was enacted, it would be revised to correspond with the public's changing needs. Those needs were discerned from comments and criticisms received from the communities and stakeholders who had an interest in the MAiD law[173].

Accordingly, in March 2020 a report was published reflecting all the work that had been done to gain clarity around public sentiment[166]. Overall, 73% of those who responded (300 140 people) believed that the safeguards in place were sufficient to prevent misuse and abuse of MAiD. They were supportive of the law being expanded to include additional safeguards for non-terminal patients being eligible for assisted death. They also supported advance directives

that allowed E for people who had become unconscious, and for those who had lost decision-making capacity, such as with Alzheimer's disease.

Responses to questionnaires received from the public, in which they could leave a comment, amounted to 31.9% of the submissions. These were grouped into eight popular themes. The majority supported the right for people to choose when to die, regardless of the circumstances, but MAiD for mental illness and mature minors were controversial. To give insight into the minority public views on E, some excerpts from the feedback are listed below:

- People emphasised the importance of human life and its intrinsic value. They had the view that its sanctity should be upheld, so were opposed to MAiD. Numerous Canadians agreed with the sentiment that as life was a gift from God, only God could give it or take it away. Many also expressed the concern that MAiD was a means by which the government could reduce its financial commitments by encouraging a way to hasten the deaths of the sick, elderly or disabled who became a financial drain on the state.

- The 'slippery slope' was another perceived threat that was frequently mentioned. MAiD was seen to have opened the door to the government allowing death for all cases convenient for their purposes. Overall this sub-group's sentiments were that neither the government nor medical staff ought to determine when life should end because life was precious.

- A widespread call was received for improved financial contributions and provision of long-term, palliative, and mental health care. Requests included more social assistance, disability assistance and counselling so that fewer people sought MAiD as an outlet for their poor quality of life.

- A lot of respondents considered that it was immoral for the state to coerce doctors, nurses and other health care professionals to administer MAiD. People believed that the staff were placed in situations where they were obliged to end a person's life, unwillingly. The comments showed further that people were worried about the mental wellbeing of health care staff who would be performing MAiD, specifically mentioning that their cultural, religious and personal ethics should be appreciated.

- Some respondents made the point that publicly funded hospitals should not be allowed to refuse to offer these services where there is a public need.

In addition to the feedback gathered from society, the two Ministries of Health and Justice, and the Ministry of Employment, Workforce Development and Disability Inclusion, jointly organised meetings with a range of stakeholders and specialists around the country. The object was to give them the opportunity to provide the government with their opinions on MAiD. These included, amongst others, medical personnel, health regulatory bodies, other key health participants, legal professionals, the disability community and civic organisations with specific interests. Separate meetings were held with indigenous practitioners and community leaders to focus on their particular experiences and needs regarding MAiD.

Pertinent excerpts from themes extracted at these roundtable meetings[166] are shared below because they could relate to a South African context, too:

- Access to, and practitioner willingness to participate in, MAiD were discussed. It was noted that both the requests for MAiD and the availability of doctors and nurse practitioners to administer MAiD affected access to it. Some concern was expressed that if the eligibility criteria for MAiD were broadened, such as including mental health disorders, which would further increase demand, access to MAiD could decrease. The government at all levels would need to adapt to these additional difficulties.

  The indigenous peoples and practitioners referred to their own problems with implementing MAiD. That was based on the past suffering they had experienced and intergenerational damage that had occurred as a consequence of their history. Many people spoke of ongoing harm that they were subjected to within the healthcare system. Examples included being subjected to procedures without their consent, discrimination, and minimal availability of what they described as culturally safe care. Leaders also expressed the view that if MAiD's scope was broadened to encompass other problems besides those associated with the end-of-life, this could result in individuals within their communities choosing MAiD for the wrong reasons. Examples highlighted were limited opportunities to receive alternative high quality services such as palliative care programs, pain management regimes, and supportive mental health care services. Even peripheral reasons unrelated to the health infrastructure, such as a lack of housing, could motivate MAiD. Some participants suggested that the most effective safeguards for their communities would be to guarantee the provision of suitable, medical and mental health care that was also perceived to be culturally safe. Healthcare providers needed training on what this entailed in the context of MAiD.

Importantly, a number of indigenous members emphasised that there were differences in how their people thought about death and dying. Guidance from Elders and spiritual leaders was necessary for MAiD to be performed in a culturally appropriate and sensitive manner.

Indigenous leaders reminded the government that, in the northern and remote communities, individuals wishing to access MAiD could face more barriers to entry than those living centrally. These would need to be addressed. For instance, stakeholders mentioned the fact that different languages were spoken. This obstacle, too, limited certain groups from having discussions about the process of MAiD and making a`

- When interrogating the topic of access to alternative treatments, supports and services, many attendees brought up the importance of providing a better quality of health care and social support within the palliative care and disability facilities available. This improvement, they said, would protect society from opting for MAiD, not because their suffering could not be alleviated, but because of a lack of means to alleviate it. The same sentiments were voiced for mental health and suicide prevention management.

- Another notable discussion point was the oversight of MAiD. Stakeholders spoke of there being room to improve the Canadian oversight system because the federal monitoring administration did not fulfil its role effectively. Suggestions were that it should be more transparent, like the system in the Netherlands. Specifically, Canadian participants appreciated the fact that deliberations of the Dutch review committees were publicly available. Practitioners at the meeting proposed incorporating the retrospective case reviews for people to read in reports. Reports compiled as a result of aggregate reporting were apparently not detailed enough. On the other hand, Québec's Commission was referred to as a good example of what the other regions in Canada ought to try to achieve[166].

4.1.4.b.3.1. Revised Legislation

After this phase of assessing how MAiD had been incorporated into society, having investigated three additional categories of potential MAiD candidates, and with the report received from the CCA in 2018 in hand, Parliament passed revised legislation on 17th March 2021. Significant amendments were made regarding eligibility for MAiD, which acquired immediate legal force[179]. The regulatory framework also required adjustment for monitoring MAiD, so new

draft *Regulations for the monitoring of Medical Assistance in Dying* were published for public comment in May 2022.

One of the consequences of the successful litigation in Québec that challenged the 'end-of-life' and the 'foreseeability of natural death' criteria was that this was no longer a legal requirement for access to MAiD in Canada.

A future amendment to include mental disorders is pending, and is elaborated upon under 'Latest Developments' below. The eligibility requirements for MAiD that took effect from 17th March, 2021 were modified as follows, and remain correct at the date of this thesis[164]. A person must -

- be at least 18 years of age or older, and have decision-making capacity;
- be eligible for publicly funded health-care services;
- make a voluntary request, free from external pressure;
- give informed consent to receive MAiD, having heard all information needed to make that decision;
- have a serious and incurable illness, disease or disability (excluding a mental illness until 17 March, 2023).
- be in an advanced state of decline in capability that is irreversible;
- have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.

4.1.4.b.3.2. Revised Safeguards

Having broadened the reach of MAiD, additional safeguards were proposed to cater for the situation where MAiD was offered to those whose natural death was **not** reasonably foreseeable. The chances of error were thought to be higher in such instances, where E could be performed for the wrong reasons, such as loneliness or a lack of adequate support. Consequently, two sets of safeguards would exist side-by-side - the improved original set continuing for those whose natural death was fairly imminent, and the other for the new group just described. At the date of this thesis, the suggested additional safeguards had been implemented[164].

(i) Natural death reasonably foreseeable

Where death is reasonably foreseeable, four safeguards are in place: i) a written request must be made, but instead of two independent witnesses signing the request for MAiD, which has sometimes been an access barrier to MAiD, one signature from an independent witness is enough. The witness may be from the paid staff who provide professional care to the person, as long as they are not the patient's beneficiaries; ii) all eligibility criteria must be confirmed by two independent practitioners; iii) patients are to be told that they may withdraw their request at any time, by any means; iv) immediately before the administration of MAiD, the person should be given the opportunity to withdraw consent. They are then required to confirm their consent to receive it, unless they already have an 'advance consent arrangement' in place.

This new arrangement of advance consent means that, even where a person loses capacity to confirm their original consent in their terminal phase of life, MAiD will still be administered if the person waives the re-consent procedure. Persons can waive it if all other criteria are met, including indicating their preferred date for MAiD. The doctor must have warned them that they could lose their capacity to consent before the administration of MAiD. A written advance consent is required, which must be handed to the doctor reflecting the patient's waiver of the final consent. It should include the doctor's agreement to perform MAiD regardless of the lack of confirmation by the patient on the preferred date (or an elected earlier date). This advance consent arrangement can also be used for a failed or complicated 'practitioner assisted MAiD' (PAS) situation in Canada.

Another change which received huge support during the roundtable meetings, was to remove the 10-day reflection period. Practitioners explained that most often the patient had already given the decision a lot of thought when making their request. The subsequent 10-day delay caused a number of terminal patients to refuse pain medication in order to remain lucid. They sought to ensure their capacity to consent before making the second request just before death. This prolonged, rather than shortened their suffering.

(ii) Natural death **not** reasonably foreseeable

In the circumstances where death is not reasonably foreseeable, the new safeguards are based on those already mentioned in the previous paragraph: safeguard i) is the same, requiring a written request; safeguard ii) is also similar, but of the two independent practitioners evaluating

the case, one is required to be a specialist of the condition in which the person has intolerable suffering; safeguard iii) is new: at least a 90 day period of assessment must be implemented following the MAiD request. This time frame can be shortened if loss of capacity is a concern and the assessments have been concluded; safeguard iv) is an additional requirement to ensure consent is given with full knowledge - that the person must be informed of and offered a range of support services such as counselling, mental health services, disability support, community services and palliative care; safeguard v) further reinforces the requirement at (iv), namely that practitioners must be satisfied that the patient has discussed and considered all reasonable options available to improve their state of suffering; safeguard vi) requires that, just before the administration of MAiD, the person has to be given the opportunity to withdraw their request or confirm their consent to E.

Finally, by 2021, within five years of initiating a MAiD regime, Canadian society had successfully broadened the reach of MAiD to encompass those who were suffering but were not yet nearing the end of their life. This was comparable to the Benelux countries - Belgium, the Netherlands and Luxembourg.

4.1.4.b.3.3. Latest Developments

The newest topic of focus was whether mental illness alone could justify eligibility for MAiD. The Ministry of Health formed a panel to examine if there were situations in which it would be reasonable to allow E under such circumstances. This panel published its final report on 13th May, 2022[87] and explained that it had been faced with two challenges. The first was clarifying the meaning of 'mental illness'. They chose to use the medical term 'mental disorder' so that conceptually it had a standardised definition in the Canadian medical literature. Secondly, they found that the major concerns they had examined, suggestions for safeguards, and protocols and guidance they offered, could apply to other clinical situations. These concerns were incurability, irreversibility, capacity, suicidality, and/or the impact of structural vulnerabilities. With regard to incurability and irreversibility for the purpose of MAiD, the method used by Dutch and Belgian psychiatrists was thought to be appropriate for Canada too. Psychiatrists looked at the history of the progression of medical interventions given to the patient, as well as their responses thereto over time.

The panel acknowledged that the capacity to make decisions is generally assumed to be present in all adults, including those with mental disorders. They recorded that life events could subtly

influence decisions, but this was no different for other medical disorders. Where the practitioner's assessment was so difficult that a person's capacity to consent remained uncertain, the MAiD intervention should not be allowed.

In contemplating the concern of suicidality, the panel members were aware that the patient's mental disorder could lead to thoughts, plans and actions around killing themselves as part of the medical problem. However, despite the strong association noted between completed suicide and mental disorders, the panel found that the mere presence of a mental disorder did not invariably mean the person was at risk of suicide, nor did the vast majority of people complete suicide. Where suicidal thoughts were suspected, the usual medical standard would apply: the person's capacity to give informed consent or to refuse care would be assessed, consideration would be given to whether suicide interventions should be introduced, and any other interventions that could possibly be of assistance were proposed. The panel respected that, according to ethical and legal standards of medical practice, medical practitioners did not stop people from making life-terminating decisions where there was no sudden crisis, nor were they entitled to interfere with a person's autonomy. They encouraged the preservation of life by using therapeutic methods.

The discussion about a person's structural vulnerability related to demographic attributes such as gender, socioeconomic status and race, as well as the person's position in the socio-cultural and political environment of Canada. The panel's research confirmed the difficulties people experienced being associated with some of the negative perceptions of the demographics of which they formed a part. For instance, a lack of employment opportunities and insecure housing were some of the common social problems witnessed. Status within a socio-cultural group affected self-esteem and the manner in which people interacted with, and were treated in, the health care environment. The unease expressed by the panel in this regard was that death could appear to be their only option to escape such troubles. This was a concern previously alluded to by several of the historically marginalised groups at the roundtable meetings, as mentioned above.

Another recognised difficulty with mental disorders to which the panel drew attention was the doctor's lack of appreciation of the extent of suffering when no symptoms were externally visible. The severity could be underestimated, leading to MAiD being refused, and could even result in alternative treatments being forced upon the person. A doctor was reminded to contemplate whether systemic inequality had a bearing on the patient's suffering.

In conclusion of their report, the panel made nineteen recommendations which could be met without increasing the number of safeguards already in place. Along with the existing legal requirements for MAiD and other medical standards and practices, these could be interpreted and applied to mental disorders.

Following the publication of the report, the Canadian government agreed to allow MAiD based on a mental disorder where this was the only medical condition from which the person was suffering, and the eligibility criteria were met. However, that would have been from 17th March, 2023 only, once amended regulations were in place to protect the safety of vulnerable people. The extended period also permitted the various health professional bodies to update their protocols and guidelines. However, in February 2023 the date to permit MAiD for mental disorders was postponed again until 17 March 2024 because key resources still required development[179].

Latest MAiD Report for Canada, 2021

In the meantime, the third annual report on MAiD in Canada was published, giving statistics for 2021 based on the data the government had received under the regulations of the time[180]. Some of the information is presented here to offer insight into how the MAiD law has been embraced by society.

The report has indicated that there were 10 064 MAiD deaths, which amounted to 3.3% of all deaths in Canada for 2021. This number showed an increased rate of 32.4% compared to 2020, where every province has seen a steady growth rate for MAiD each year. Accordingly, the total number of MAiD deaths reported since the law came into force in 2016, including 2021, was 31 664.

The profile of those who received MAiD in 2021 reflected that men were slightly more in number (52.3%) than women (47.7%), and the average age was 76.3 years. This was similar to the two previous years' records. Most frequently cancer (65.6%) was the reason given for the request, then cardiovascular conditions (18.7%), followed by chronic respiratory conditions (12.4%) and neurological conditions (12.4%). Of the total number of MAiD deaths in 2021, 2.2% (219 people) were deaths where a natural death was not reasonably foreseeable. For this category, the average age of individuals was 70.1, and the most frequently named underlying

medical condition was neurological (45.7%), while other conditions (37.9%) and multiple comorbidities (21.0%) made up the rest.

The majority of those who used MAiD (80.7%) had received palliative care in 2021. However, of those who did not receive it, most people (88%) had been in a position to access palliative care, comparable to past years. Also, disability support services had been required by 43.0% of persons who opted for MAiD, and the majority (87.4%) had received it.

Regarding intolerable physical or psychological suffering in 2021, the most common reason expressed for suffering was a loss of the ability to engage in meaningful activities (86.3%) and loss of the ability to perform activities of daily living (83.4%), similar to previous reports.
The practitioners who provided MAiD were made up of physicians (94.4%) and nurse practitioners (5.6%). The total number of practitioners had increased in 2021 to 1 577, from 1 345 in 2020. Family physicians were the primary providers of this service (68.2%), as was seen in previous MAiD reports. Where possible, people preferred to die in private residences (44.2%), as in 2020. Alternative venues used were hospitals (28.6%), palliative care facilities (6.1%), residential care establishments and other settings 1.5%.

The written requests received in 2021 amounted to 12 286, of which 487 people (4.0%) were found to be ineligible. The main reason for ineligibility was that they were considered not capable of making decisions about their health. Of 231 individuals (1,9%) who withdrew their requests, the withdrawals were often because they had changed their minds (62.3%), or because palliative care was found to be sufficient (38.5%). It was reported that 28 withdrawals (12.1%) occurred just before the administration of MAiD, at the moment when they had to provide their final consent. Lastly, the number of persons who died having made the request but before receiving MAiD numbered 1 618 (13.2%)[180].

In November 2022 the previous MAiD Regulations were updated to provide for additional data collection in order for the Government to gain better insight into how the expanded eligibility is being implemented in Canada. They came into force in January 2023[181].

4.1.4.b.4. Social and cultural environment

Canada has three distinct groups of Indigenous peoples: the First Nations (more than 600 communities with 50 indigenous languages), the Inuits and the Métis (Indigenous Peoples).

Each have their own cultures and traditions, including traditional healing which they are trying to retain[169]. Sadly, similar to South Africa's history, harmful practices, policies and laws were introduced by the federal government as a consequence of colonisation. This caused disproportionate poverty, a scarcity of clean drinking water, inadequate housing and insufficient access to education and health care for the indigenous groups, compared to the non-indigenous communities. It is acknowledged that the Indigenous Peoples have their own outlook and perception of death within their traditions that need to be respected with the introduction of MAiD. According to the government's Expert Panel Report on MAiD and Mental Illness in May 2022, these conversations had not yet happened between the government and the Indigenous Peoples' groups[87]. Some Indigenous leaders and communities have already expressed their apprehension about the possibility that it could be easier to obtain help to die than to obtain the resources they needed to live a good quality of life. This is a sobering thought for our South African context, as well.

The history of denial of the people's Indigenous rights also tells a story of side-lining, control and management under discriminatory laws that disempowered them. This has resulted in great impoverishment and disparity[182], comparable to the damage caused during South Africa's apartheid era.

Canada now has an ongoing process of reconciliation and renewal of relationships with the Indigenous Peoples. The need for transformation between the government and the Indigenous population has been recognised. The object is to acknowledge and respect their rights, dignity and well-being by correcting the injustices of the past. It is described as a 'troubled relationship' that must be improved. The Government is cognisant of the Indigenous Peoples' wish to self-govern in the future and knows it must plan accordingly, ensuring their self-sufficiency and opportunity for self-determination[182].

The Canadian health system, Canada Medicare, is universal, decentralized and publicly funded. It was first set up through legislation in the early sixties, but then *The Canada Health Act* of 1984 took over, laying out the national standards for medically necessary hospital, diagnostic, and physician services. The health system's funding and its administration are managed mostly at a provincial or territorial level. As seen with Québec, each province has its own insurance plan and each receives some federal financial assistance, on a per-capita basis. Although services and benefits differ between regions, all citizens and permanent residents can access medically necessary hospital and practitioner services for free. Excluded services, such as outpatient drug

prescriptions and dental care, must be paid by the individual. As a result of this, approximately two-thirds of Canadians have private insurance, while certain targeted groups are supported to some extent with further financial coverage[167].

The Canadian Constitution regulates the arrangement of the health care system to a large extent. Roles and responsibilities are divided amongst federal, provincial and territorial governments. The administration and delivery of health care services is mainly the concern of the provinces and territories. This comprises deciding on priorities specific to that region and managing the budget and resources for health provision. At the federal government level, involvement in health care is primarily through the supply of financing. Federal support is attached to conditions laid down in the *Canada Health Act*, such as the imposition of national standards for health care insurance plans, to which it contributes towards the costs. The Act sets down broad national principles only. An example is the stipulation that the provincial or territorial health care insurance plans for those who are eligible, including Indigenous Peoples, should cover the medically necessary insurable services related to hospitals, physicians and surgical dental services[183].

At the provincial level, the operational details of the health infrastructure are controlled. Standards are set for service delivery such as timeliness, and the quality of care. They can enact their own legislation to regulate health care professionals, for example. The provinces and territories also have discretion with regard to other services they choose to offer, and on the terms and conditions they set. As a result, health care provision varies between regions[183].

The Indigenous Peoples are provided with health care through shared responsibility of the federal, provincial and territorial levels of government. As residents of a province or territory, they have access to the area's insured health services. Amenities are supplemented by Indigenous Services Canada, a government department that has the task of creating policies to improve access to high quality facilities for the First Nations, Inuit and Métis peoples. This entity assists with funding or offers services directly to these groups. It also finances non-insured health care benefits to those who are eligible.

4.1.4.b.5. Comparison with South Africa

Comparatively, South Africa, like Canada, has an abundant variety of cultures and ethnicities, languages and religions, together with a mainly young population[184]. Canada has the *Canada*

Health Act, just as South Africa has the *National Health Act* 61 of 2003, which applies to all South Africans. It is aligned with the constitutional right for everyone to have access to health services[185] and the right not to be refused emergency medical treatment[186]. Primary health care delivery is a priority for the Department of Health. This is illustrated by the provision of free basic health care services for children, according to a provision in the Constitution and the National Health Act[187]. However, racial bias that remains from the years of apartheid has impacted hugely on the health system. Medical care mirrors the economic disparity that still exists between the rich and the poor, as well as the effects of past segregation and unequal government health funding[188]. A two-tiered health system exists side-by-side: the state-funded public sector for those with no or minimal income, which includes approximately 71% of the population, and the private sector for around 27% of people who can afford it[189].

The public health service is highly developed in the cities and big towns where many larger hospitals are linked to university medical schools. However, these hospitals and out-patient clinics are used by the majority of the population. They tend to be stretched to capacity, in many provinces coping with more patients than they can deal with efficiently. They are also challenged by limited resources, with patients being subjected to long waiting periods, both in outpatient clinics[190] and for elective surgery that can be delayed for up to two years[191]. Access to medical services remains markedly substandard in historically Black areas[192, 188].

The expensive private health sector serves a minority who generally bring in incomes high enough to allow for some level of medical insurance cover. This group of people still tend to be mostly white, employed in stable jobs and affluent[188].

Government social support programmes do exist for people whose income is below a certain minimum, such as South African pensioners and people raising children without adequate financial provision[193]. The amounts are minimal for their needs but increased modestly during the COVID outbreak.

The Encyclopaedia Britannica suggests that two of the most significant problems that continue to influence social circumstances in South Africa are high unemployment rates and disparity in income between Blacks and Whites[188]. However, disease profiles are not mentioned, such as tuberculosis (TB), which is one of the leading causes of death in South Africa[194] killing thousands each year. Diabetes is another among illnesses that affect one's ability to work. During 2018, StatsSA processed 454 014 deaths of which TB related deaths were 6%, followed

by diabetes, cerebrovascular diseases, other types of heart disease, and human immunodeficiency virus (HIV), to name a few. The highest rate of death was in the 65-to-69-year age group. For the white population the leading causes of death fell into the malignant neoplasms of the digestive organs[195]. This is significant because cancer-based illness appears to generate the most requests for E in countries that permit E.

The profile of requesters for E and the activists campaigning for it have been described by other writers in similar terms: white, educated, middle-class people[57,58]. In South Africa, when the activist group, Dignity SA, hosted a world conference for the Federation of Right to Die Societies in Cape Town during 2018[196] the stark reality was that, despite the venue being in a diverse, multi-cultural Cape Town, there were almost no representatives from other racial or ethnic groups. The vast majority of attendees, (more than 95%) were white[197].

With regards to E and PAS, like the First Nation People of Canada, the South African black community has not been at the forefront of campaigning for medical assistance in dying, possibly because it is perceived to be alien to their culture and beliefs[198]. However, as illustrated in Canada, it is important to first have discussions with all the communities that would be affected by far-reaching new law. It is important to understand whether it is law they would be comfortable with and if so, what safeguards would need to be in place to protect the vulnerable.

4.1.5. Western Australia

4.1.5.1 Introduction

Western Australia has been chosen for discussion because Australia most recently introduced E legislation in its provinces. Some are still building their infrastructure before the law comes into force. Consequently, like Canada, the provinces have studied other models of legislation and created a model that was intended to suit their own society's needs.

Western Australia is one of six states in Australia. Australia is the smallest, flattest and driest continent, apart from Antarctica, but one of the largest countries on earth. It is positioned between the Pacific and Indian oceans. From the air it appears to be a huge ochre desert. It is extremely sparsely inhabited between states, for thousands of kilometres. An isolated and independent country, Australia is relatively prosperous and has a broad range of cultures. This is as a result of immigration which is re-shaping the Anglo-Celtic slant portrayed in Australian

society. Its isolation is a noticeable feature that explains the unique plant and animal life but is also displayed in the social distribution beyond the cities. Minority rights, multiculturalism and race-related issues have become a central focus of current politics in Australia[199].

The country has a form of federal government, made up of a national government for the Commonwealth of Australia and individual State governments for New South Wales, Victoria, Queensland, South Australia, Western Australia and Tasmania. Each state has its own constitution and a government with a limited degree of independence. Two internal territories also exist which are self-governing: the Northern Territory and the Australian Capital Territory. These include the capital city of Canberra.

Australia's constitution divides powers between the Federal Government and the States. The Federal Government generally oversees defence, foreign policy, immigration, customs and excise, and the post office. The States have powers and responsibilities for the administration of justice, education, health and internal transport[199].

Western Australia's executive government is a cabinet structure where the majority party appoints the State Premier, comparable to South Africa. It consists of a bicameral parliament that is based in Perth, and a local government of 140 elected councils. A hierarchical judicial system exists of lower courts, high courts and specialised family courts - similar to South Africa's judiciary. However, the highest court in the State is the Supreme Court of Western Australia. Where a matter remains unresolved there, it is sent to the High Court of Australia for determination[200].

4.1.5.2 Legislation

With regards to E and PAS, all of Australia's six states have now passed legislation to allow voluntary assisted dying. So far, Victoria and Western Australia's (including Tasmania), laws have come into effect, and are enforceable from 23 October 2022. Queensland's legislation took effect on 1 January 2023, and South Australia's on 31 January 2023. New South Wales's law will come into force on 28 November 2023.

Academics acknowledge that the law dealing with end-of-life decision-making, dying and death is complex. It varies between the States and Territories as each region tries to find the right approach for its communities[201].

Western Australia's *Voluntary Assisted Dying Act,* 2019, (Act) came into force on 01 July 2021[202]. It caters for both E and assisted suicide (AS). It was the second Australian state to permit voluntary assisted dying (VAD) after Victoria, which passed legislation during 2017. Victoria had an 18-month implementation period, which came into effect on 19 June 2019[203]. The reason Western Australia's Act is examined in this Chapter, rather than Victoria's, is because it is broader than the State of Victoria's legislation. For example, Victoria only allows medical practitioners to perform E, whereas Western Australia also permits certain nurses to administer E. This is a novel feature, which is relevant to this thesis, and is accordingly elaborated upon below.

The Act begins with a section that lists eleven principles that must be upheld when performing procedures or fulfilling roles in terms of the Act[204]. Some of these are summarised here to illustrate how social concerns are addressed, such as the need to respect everyone's equality, autonomy, culture, personal values and characteristics, embracing the public and including all health professionals. The need to support the individual at the end of life is mentioned, and their right to choose, ultimately supporting the choices they make. The opportunity for people to experience a high standard of palliative care and other treatments to relieve suffering must be reinforced, and the therapeutic relationship that exists between the 5mentioned as having equal rights to access VAD, equivalent to those living in metropolitan areas, and the need to protect the vulnerable from coercion and abuse is highlighted, among other principles.

Like Canada and the Netherlands, the Western Australian government has created a web page with information comparable to other foreign countries. The public and health professionals can access guidance and insight into the framework established for VAD, which incorporates the process and its regulation. For example, the platform for medical professionals offers the following important insights. Both doctors and nurse practitioners (nurses with advanced medical training) can administer assisted dying procedures, but only if they have been trained and appointed for this role. All medical staff are required to know the contents of the Act and their duties in terms of it. Examples of their duties are that, unless appropriately trained, they may not initiate the topic of VAD in conversation. That would amount to unprofessional conduct under the law. However, they do need to know how to deal with a patient's request for information about dying. A death as a result of VAD may not be recorded as such on the Medical Certificate Cause of Death. The Voluntary Assisted Dying Board needs to be notified by the medical professional who completes the Medical Certificate Cause of Death and who knows or believes that the death was a consequence of VAD. The Act recognises a health

practitioner's conscientious objection to participating in VAD, but health practitioners may not prevent a patient from accessing the service[205].

In terms of the Act, there are eligibility criteria for the roles of an 'Administering Practitioner' (doctors and nurse practitioners, who may administer the lethal substance), and for the role of a 'Coordinating or Consulting Practitioner' (only doctors, who either coordinate the paperwork or do assessments), depending on their level of expertise, from generalist to specialist[206]. This is noteworthy in so far as it contributes to the facilitation and administration of E generally. For instance, besides the requirement of specific approved training and a stipulated number of hours that the health practitioner must have been in clinical practice, they must have a clean track record with the Australian Health Practitioner Regulation Authority (AHPRA). In addition, they have to be considered suitable for the job by the CEO of the Department of Public Service, the entity that assists in the administration of the Act. This must be based on two medical practitioner referees provided by the doctor, or two nurse practitioner referees submitted by the nurse practitioner. Another regulatory safeguard is that only a limited number of registered pharmacists are authorised to supply the VAD substance to be administered. These people form part of a dedicated service called the Western Australia Voluntary Assisted Dying Statewide Service[205].

The eligibility criteria for persons seeking VAD include (a) that the person is 18 years old, and (b) (i) an Australian citizen or permanent resident, (ii) having been in Western Australia for at least 12 months before making a first request for VAD. The person (c) must have been diagnosed with at least one disease, illness, or medical condition, (i) that is advanced, progressive and (ii) will cause death, on a balance of probabilities, within six months, or, if the problem is degenerative, within 12 months; (iii) this condition should be causing suffering that cannot be relieved in a manner the individual considers tolerable. The person (d) is required to have decision-making capacity in relation to VAD, (e) should be acting voluntarily and without coercion, and (f) the request for access to VAD must be enduring[207, 208]. Western Australia specifically excludes people from VAD who are only suffering from a mental disorder or a disability, as does Victoria[208, 209].

Once the person appears to be eligible for VAD, the patient must go through six phases in the VAD process before the final moment of death. This entails other administrative steps to be completed by members of the medical team which are detailed in the Act. At every step the

medical practitioner must complete a form and submit it to the Voluntary Assisted Dying Board that oversees the process.

Phase 1: A 'first request' is made by the patient. This is recorded and, if accepted, a coordinating practitioner takes the matter further.

Phase 2: A 'first assessment' is carried out. If the person is considered to be eligible for VAD, it is recorded, and they are referred for a second assessment.

Phase 3: This next evaluation is called a 'consulting assessment'. It is performed by a specially trained practitioner. The outcome is recorded, and where the person remains eligible for VAD they progress to the next phase.

Phase 4: The patient makes a 'written declaration' which is witnessed and returned to the coordination practitioner who records it.

Phase 5: This phase consists of the patient making a 'final request' to the coordinating practitioner which is duly recorded. A period of at least nine days should elapse between the first request and the concluding stage of the review.

Phase 6 is the last step. A 'final review' is performed by the coordinating practitioner, following which VAD can then be administered.

In total, at least two doctors assess the patient: a coordinating practitioner and a consulting practitioner. Palliative care must be offered and discussed with patients as they proceed through the process of assessment for VAD. In the assessment report form, the consulting doctor must make a note that palliative care and available treatment options, with their likely outcomes, were mentioned[211].

If all is satisfactory, the patient either self-administers a VAD substance in their own time or, alternatively, the administering practitioner carries out the E. However, it is important to note that a practitioner administration is only made if the coordinating practitioner advises the patient that self-administration of the VAD substance is inappropriate for one or more of the following reasons: (i) the patient is unable to self-administer, (ii) the patient has concerns about self-administration, (iii) the method of administration is unsuitable. Where the person is given permission to self-administer the VAD drugs on their own, a contact person is required to be named by the patient, in order to ensure that any remains of the VAD drugs are disposed of afterwards, in accordance with the law[212].

If the administering practitioner ultimately carries out the E, the assisted death must be performed in the presence of a witness who will confirm on a form that a number of criteria were met.

The default procedure of self-administration by the patient without a medical practitioner present (unless the physician accepts a reason to hand the medication over personally), is similar to the law in the state of Victoria, where a concern about the process has been raised. Dutch researcher Onwuteaka-Philipsen, in collaboration with Australian academics Willmott and White, compared a few aspects of the Victoria VAD legislation to the well-established Dutch approach to examine possible weaknesses. One point made was that the default procedure used by people in unsupervised self-administration is potentially hazardous because of the complications that could arise. It may be better managed in line with Dutch guidelines. As discussed in the Netherlands section earlier in the chapter, a Dutch doctor must be present, even with self-administration, to ensure that any complications are resolved, and the outcome of a completed death occurs in the most compassionate and humane way possible[213].

Western Australia has a number of safeguards in place to prevent misuse and abuse of the law. Certain breaches of the Act are punishable, of which examples to illustrate the penalties follow. The offence of an unauthorised person administering VAD results in the penalty of imprisonment for life. This also applies where an individual is induced through dishonesty, coercion or undue influence to self-administer the VAD lethal substance[214]. In the event of a person unduly influencing, coercing or dishonestly inducing a patient to seek access to VAD, the sentence is 7 years of imprisonment, or a summary conviction penalty of 3 years imprisonment and a $36 000 fine[215]. Various other offences are listed with a range of penalties that will require a lot of effort to monitor and enforce. Along opposite lines, for the sake of clarity section 115 provides protection from prosecution for certain persons who do not administer life-saving treatment, such as an ambulance officer who is witness to a person that is assumed to have self-administered VAD drugs and in good faith allows them to die.

Not all Western Australia's Health Services, which are described below, offer VAD. It is dependent upon the availability of suitably trained staff, the capacity of the health service to provide VAD, and whether participation in VAD aligns with the values of that specific health service[208]. The Act requires the CEO of the Department of Public Service to issue a standard explaining how the State intends to facilitate access to VAD (the 'access standard') for persons normally resident in Western Australia and how regional residents will get access to VAD. This

includes how the State will make medical professionals available, and others who perform functions under the Act for them. It also includes how they will obtain the prescribed VAD medications and receive information about accessing VAD. Once prepared, the document must be published on the website[216].

It will be interesting to observe over time how the complex Western Australian VAD infrastructure develops and settles down to work efficiently. Understandably, the Act has attempted to create safeguards and cross-checking of information to avoid mistakes, comparable to the requirements for recording data in the Netherlands. The process that a team of health practitioners must go through, which has not been described here in detail, seems to be extremely laborious for all involved. Forms asking for repetitive information need to be filled in, and strict time frames must be met, some of which are very short. All of this could require dedicated medical personnel to facilitate VAD almost exclusively. However, similar to Canada's Act, the final provision of the Act, section 164, has built in Western Australia's commitment to review the Act's operation and effectiveness as soon as possible after the second anniversary of the provision, and thereafter at no more than five yearly intervals. The report must be published within 12 months of the stipulated timeframes, so feedback can be expected by mid-2024.

South Africa would likely need to double its staff and administrative resources in order to meet the provisions under this Act.

4.1.5.3. Social and cultural environment

In order to better understand the social context into which the VAD law has been introduced, a brief insight into Western Australian society is presented.

Geographically, along the southwestern coast, Perth and its surrounds is the centre for just less than two-thirds of all the inhabitants. Aboriginal communities lived in the western region of Australia long before European settlers arrived in Perth in 1829. Sadly, most of the aboriginal population was destroyed through disease, starvation, and by being killed. They have managed to remain a small presence of less than five percent of the State's citizens, although their numbers - made up of young people - are gradually increasing around the Greater Perth area now. Approximately half of the Aboriginal residents are under 25 years of age, compared to this age-group making up only a third of the rest of Australian society.

Western Australia's moderate wealth is due to a number of factors. Its economy is supported by some unprocessed primary products such as mining. The main mineral exported is iron ore, which makes up around a quarter of the GDP. Sheep farming, horticulture, a small amount of forestry and fishing, and some degree of agriculture, which is limited by the scarcity of fresh water and fertile soil, also contribute. However, the service sector contributes by far the most to the GDP[217].

The largest majority of Western Australian residents come from English ancestry, including sizeable communities from Scottish, Irish and Italian origins, and a mixed group from German and Dutch roots. A significant but small neighbourhood of Chinese people have also made the area in and around Perth their home. The immigration trend is increasing the population, rather than the number of births exceeding deaths. The immigrants are mainly from east Asian countries and South Africa, whereas the immigration of people from Britain and Europe has decreased over time.

The language spoken by the majority in Western Australia is English, and Christianity is the religion that approximately three-fifths of the inhabitants embrace. Buddhists and Muslims make up a minor portion of the community. A substantial minority, that is increasing in number, does not associate themselves with any faith. This trend is comparable to the rest of Australia[218].

Australia has a universal public healthcare insurance plan, Medicare, that is financed through a general government and tax levy. It is administered at a regional level and citizens are automatically enrolled. They receive free public hospital care, and a large amount of coverage for the services of medical practitioners, pharmaceutical products, and selected other services. Approximately half of Australians supplement their Medicare with private insurance to cover private hospital and dental care, amongst other services. The federal government incentivises this by paying a rebate towards the premium. Households that earn higher-incomes and who have not purchased private insurance are penalised with additional tax charges[219].

Bearing in mind South Africa's hope and struggle to introduce universal health care, the history of Medicare in Australia was fraught with tension. It took 10 years for Medicare to be established, with the health Bill having failed to pass three times. Finally, a new Parliament passed the health legislation in 1974, allowing free public health care and subsidised private health care. This, too, was threatened when a change of government severely restricted free

health care to a limited number of retired persons who met a means test. Eventually, in 1984 the present Medicare system was introduced[219].

The Western Australian public health system, 'Western Australia Health', is made up of a Department of Health, six Health Service Providers and Health Support Services. The Health Service Providers are responsible for the communities in their local areas and are managed by Health Service Boards. Five of the Health Service Providers are metropolitan and one is the WA Country Health Service (WACHS), which caters for seven health regions outside of the metropolitan areas. This Country Health Service for the outlying areas functions through a network of health facilities such as regional and integrated district hospitals, nursing posts and community health centres. Service delivery programs offer a full selection of health services for adults and children under the WACHS[220].

Western Australia's health infrastructure offers a combination of services provided by the Australian and State Governments as well as private service providers. Residents may receive free public health services as public patients or choose to be private patients and pay private rates, usually through additional health insurance. Costs would otherwise be high. Those who are eligible for Medicare and who are admitted as public patients do not pay for accommodation, surgery, medication, and other in-hospital services, but they are not in a position to choose when they have their operations, nor who is appointed as their doctor and specialist.

Three kinds of hospitals are available: public hospitals, which are managed and owned by the State; private hospitals, administered by private organisations and companies, and public hospitals that are in partnership with private organisations, which provide free health care. At a public hospital a person may choose whether to be admitted as a public patient or as a private patient. Private patients can choose who to see for their consultations. Outside of hospitals the general practitioner is usually the first person to assess someone in need of attention. If necessary, the patient is then referred to a specialist. Closer to the community needs, Nursing Posts fulfil the role of primary health care management. They also ensure that basic health care and treatment are offered in the outlying areas of Western Australia, and doctors visit these areas on a regular basis[221].

To help with introducing voluntary assisted dying into Australia's health system, a comprehensive website for use by the public, health and legal practitioners, the media and

policymakers, has been created by White, Willmott and Neller of the Queensland University of Technology (QUT). They acknowledge the fact that incorporating VAD into the range of health services available is a legal, ethical, and social policy issue[201]. The website includes information about all of Australia's Assisted Dying services and informs people about related topics, for instance withholding and withdrawal of treatment, nutrition, and hydration. It also guides them on matters such as advance directives and palliative care. This website follows a concept initiated in Canada by Dalhousie University's Health Law Institute[222], and is worth reproducing in South Africa, should South Africa embark on a similar path in the future.

4.1.5.4. Comparison with South Africa

The Western Australian health service is not completely different to the South African model. South Africa's district primary health clinics are managed by nursing sisters similar, in principle, to the Nursing Posts described that manage outlying districts in Western Australia. They rely primarily on skilled nurses, while doctors commute. In addition, the patient's ability to choose either a public or private sector hospital, as long as the patient can afford to pay the difference in service fee, is also comparable to South Africa's.

In Gauteng in South Africa, the most populace province, an attempt was made to establish private wards in a few of the large public hospitals. Called Folateng private wards, the problem that became apparent was that there was a shortage of beds for non-private seriously ill people, while empty beds stood in the private wards. Medical specialists appealed to the government health department to close the private wards and rather allocate the space to public patients most in need of medical care[223].

If South Africa wanted to consider legislation for assisted death in the future, the conservative set of criteria for VAD that Western Australia has introduced, which only permit terminally ill people access to assisted death, is a framework that seems well suited as a starting point for introducing radical assisted death legislation. Québec and Canada also began with only allowing the procedure for terminally ill people. They have broadened the criteria after a period of time had passed and the community asked for the law to be amended.

Another helpful tool that Australia has to offer is the comprehensive website by Queensland University of Technology, aimed at informing all stakeholders about the law and its implementation. Effective clear communication with the public has been well produced on the

internet by each of the countries studied thus far. It would be an important step forward for South Africa to embrace simply with regard to communicating about its available health services and how to access them, especially for people who are seriously ill.

South Africa has a long way to go in order to create a similar functional health infrastructure. Re-designing the entire South African health system to be more efficient and combining private and public health services in a similar way to Western Australia's system, without compromising the overall quality of health care, will require a lot of thought and planning and trust.

4.1.6. Colombia

4.1.6.1. Introduction

Colombia was uniquely the first Latin American country to permit euthanasia, but it had been driven by a judicial process primarily, and not through legislation. This is the reason for looking more closely at the relationship between the country's political and judicial entities. Colombia is an important comparison for South Africa because of being closer to South Africa's background than any other country described in this thesis. Its classification as a developing country, its political structure, and social challenges, especially dealing with the great divide between wealth and poverty, are similar to the problems confronting South Africa.

The Republic of Colombia in the northwest of South America, is strategically positioned next to the Caribbean Sea as its north-western border, and the North Pacific Ocean just below it in the west, while a shared border with Panama divides the two bodies of water. In the south it has Ecuador and Peru as neighbours, and on its east side, Venezuela is north-east, and Brazil south-east. The Andes mountains take up two fifths of the western region, while the hot and humid Amazon Region, with its precious rain forest, is situated to the southeast below the equator, giving Colombia interesting contrasting geographical characteristics. Most of the population is located in the cool higher mountainous land on a plateau. Bogotà, the huge capital city is found here. However, some indigenous groups still live in the equatorial forests and savannas, undisturbed by modern society and culture[224].

The country has a history as a colony of Spain, and people remain proud of their Spanish language, as well as still being associated with a strong Roman Catholic faith. The society is

predominantly of mixed Indian and European descent, (mestizos) with large minority groups from African and European extraction[224].

Political infrastructure

Colombia is a republic, like South Africa, where the president is elected by popular vote. Public power is distributed between the executive, legislative and judicial arms of government. The legislature (Congress), being bicameral, consists of a Senate and House of Representatives. The executive is supported by a cabinet of ministries. Administration of the country is achieved by dividing the land into 32 departments plus the capital district of Bogotà. Each department has an elected governor in place and elected legislature. Departments, in turn are split up into municipalities, each headed by an elected mayor[224].

The judicial system is based on civil law, made up of codes and laws, which differs from South Africa's jurisprudence founded on common-law, and the creation of precedent. Colombia's judiciary comprises four high courts that are divided by their subject matter, and lower administrative and civil courts. Specifically, the Constitutional Court reviews the constitutionality of laws when challenged by a citizen, even if no explicit cause of action exists. Besides other work it has, the Constitutional Court can also choose to review lower court decisions that have constitutional aspects to ensure the protection of a person's rights and give an ultimate finding. (Acción de Tutela)[225, 226].

Camilla Jaramillo Salazar, an associate researcher of the activist law firm DescLAB/Laboratory on Economic, Social and Cultural Rights, has been part of the team that took some of the Colombian 'right-to-die' cases to the Constitutional Court to change the law. Her view was that the decriminalisation of euthanasia was not a result of campaigning or because Colombia was a very liberal country, but rather a consequence of the Constitutional Court just doing its job, using the normative nature of the Constitution and the principle of effectiveness of fundamental rights. She described the Court as their greatest ally for handling difficult ethical topics such as abortion, same sex marriage and drugs[227].

4.1.6.2. History of E Legislation

Colombia brought in the Colombian National Constitution in 1991. It decriminalised E in May 1997, following a Constitutional Court case that upheld a person's right to die with dignity. In

an ironic twist of fate, the case challenged the criminal code as being contrary to the right to life, human dignity and equality because being convicted of euthanasia was punishable with only a light sentence of imprisonment of between 6 months and 3 years. The plaintiff argued that such a lenient sentence did not offer people protection, but amounted to a licence to kill, in contrast to other heavier sanctions for conduct directed against life. His concern was also that this norm strove to eliminate people with serious health problems, like the intention behind eugenics[228].

Relying on a published English translation of the Spanish judgment[229] (the accuracy of some wording may not be correct), the reasoning of the court appeared to be that its jurisprudence had already established that the right to life could not be construed as the mere existence of a person. Implicit in the right was that a person should live in a state of health they personally found to be satisfactory to give life its value. The Court concluded that there was no absolute duty to be alive, and even if a person supposed, according to their personal religious or philosophical beliefs, that a duty did exist, it was not appropriate to enforce this attitude on other people who did not have the same opinion. Accordingly, a person who wished to end their life because of an extreme affliction that made their life no longer worth living, had the absolute right to end it without restraint. Furthermore, forcing a person to be subjected to ongoing extreme suffering against their will would amount to inhuman treatment, which the Constitution outlawed because it would negate both human dignity and one's right to autonomy. Where this occurred, the Court suggested that a person would be being seen merely as an instrument for the preservation of life: an abstract value, rather than an end in themselves.

In the situation where a person was terminally ill and wished to end their life in order to die with dignity, the Court held that their consent should be clearly articulated to a person who was sufficiently competent to take the decision to end their life, based on knowledge of the disease, prognosis and treatment options. For this reason, only a doctor was eligible to perform E because of the ability to provide and interpret the patient's medical information, and to furnish the proper conditions for a dignified death. Under these circumstances the doctor's actions would not be unlawful.

In summary, the Court stated that euthanasia was not a form of 'social cleansing', which would be incompatible with the social and constitutional state of law. It accepted that a person's right to life incorporated a right to dignity and self-determination, and included the decision to voluntarily end life and to die with dignity when the patient was suffering intolerably,

perceiving the value of life to be so worthless that the person preferred an early death. It named three elements necessary for a person to be allowed to be euthanised. These were that the patient voluntarily consented to it, that the procedure was to be performed by a doctor, and that the person's disease was in its terminal phase. Finally, the Constitutional Court asked the Congress of the Republic to prepare regulations to facilitate access to E[229, 230].

Despite the ruling, over the next 17 years no progress was made by the Congress of the Republic to formulate legislation and create an infrastructure for access to E. According to the World Federation of Right to Die Societies' (WFRtDS) website, three Bills were placed before Congress over time, but had been rejected[231]. The Constitutional Court had also not passed another judgment on the right to die until 2014, when a petitioner, Julia, came before a lower court with the complaint that her right to an assisted death was refused despite her meeting all the criteria. Julia had been suffering from colon cancer for six years during which time it had spread to other organs. She eventually opted to stop chemotherapy and accept palliative care, but ultimately sought euthanasia. The internal medicine specialist who assessed her refused E on the basis that it would be homicide. He had also expressed doubts about her level of pain and suffering, her unequivocal consent and whether her condition was incompatible with a dignified existence. In addition, the Health Promotion Agency, *Entidades Promotoras de Salud* (EPS), who supplied public health insurance, refused to provide the service because there were no adequate regulations in place to guide them with the process. When Julia approached the court to enforce her rights, the judge refused her request. The Constitutional Court chose to review the case and, before the second hearing was completed, Julia died[232].

In passing judgment, the Constitutional Court's Ninth Review Chamber began by pointing out that, as a consequence of the plaintiff's psychological and physical suffering caused by the delay she had endured while waiting for a dignified death, she had suffered damages. The Court was satisfied that Julia had met the criteria set out in its earlier judgment of 1997, to which it referred. The judge went on to mention comparative law and the regulations that existed in other countries such as The Netherlands and Belgium, which could guide the framework that Colombia ought to put in place[233].

The Court reiterated details from its past judgment of what the consent should incorporate to meet the criteria: that it was to be free, informed and unequivocal, and instructed that interdisciplinary scientific committees were to be formed in the EPS. Its functions were to accompany the patient and family through the process, as well as to ensure that the family was

given counselling related to psychological, social, and medical aspects during all procedural phases and just after the patient's death. It also needed to check that those involved with the process were impartial, and any irregularity, fault or crime was to be reported to the authorities. The doctor who received the request was required to convene the interdisciplinary committee. It was proposed that a decision ought to be given by the committee within ten days, and the process completed within 15 days, but the patient could withdraw the request at any time. The Court also laid the groundwork for allowing an advance consent to be given should the patient become unconscious, adding that it could be expressed either orally or in writing[234].

On this occasion the Chamber used the case of Julia to give more details regarding what the regulations were to incorporate. The Court instructions included that the patient's autonomy was to be respected and kept confidential. Timely care was to be given, meaning that the patient's request was to be processed within a reasonable time frame that did not prolong the waiting period. The procedure itself needed to be expedited to maintain the person's dignity and to not subject them to an undue burden of suffering. In short, it had to be efficient and quick, without excessive formalities that could impede the right to die with dignity. Finally, medical practitioners who performed the procedures were required to be neutral and were not to allow their own religious, moral, or ethical points of view to interfere with the professional role. However, if they chose not to perform E because of ethical convictions, they needed to put it in writing, stating the reason. The EPS would then be under an obligation to appoint another practitioner for E to be carried out within 24 hrs. The Court asked the Ministry of Health and Social Protection to make the necessary arrangements to set up the operative side of the process, so the inter-disciplinary committees could assess applications for E. It was to include hospitals, clinics, other relevant organisations, and health care providers in order for them to impartially and objectively analyse cases and reach conclusions together on who would be eligible patients for E. Again, the Constitutional Court repeated its appeal to Congress to draw up the legal regulations, also taking this judgment's additional guidelines into account[235,236].

Senator Armando Benedetti eventually placed a fourth Bill before Congress in November 2014[237]. The Ministry of Health complied with the Constitutional Court's order by issuing Resolution No. 1216 of 2015, which set out the protocol for the application of E, and the Superintendence released its Circular 013 in July 2015, with instructions on how to set up the interdisciplinary scientific committees. This was sent to health service providers, establishments administering benefit plans, territorial entities, and users of health services[238]. The first person to die under the new regulations occurred in 2015[239].

Between 2014 and 2020, the Constitutional Court's review chambers ruled on the right to die with dignity several times when people had approached the lower courts to request E services and had been refused. The different contexts and circumstances of these matters were repeated in a more recent Constitutional Court case in 2021 so that the Court's judgments could be applied. Some of these findings are summarised below, using the case report as a reference, to illustrate how the Constitutional Court was the primary overseer of the right to die with dignity, and the driver behind regulations for E coming into force. A discussion of the reason for the 2021 court case will follow in its chronological order[240].

4.1.6.2.1 T-332 of 2017[241]

T-332 of 2017 dealt with an 89-year-old man who, in a deep depression, applied for euthanasia based on his advanced age, poor health, helplessness and loneliness. The Court ultimately refused his request because he was not suffering from a terminal illness. However, it appreciated that the plaintiff needed assistance because of being unable to walk and being utterly dependent on others to care for him, without anyone having come forward to fulfil that role. The problem was a social issue of family abandonment for a person of advanced age.

At a review of an application for guardianship, the Constitutional Court's Seventh Review Chamber, in applying its 'duty of strict verification', investigated the plaintiff's circumstances and confirmed that he had felt abandoned because he had been physically unable to care for himself. Nonetheless, once his children had taken him into their care his request for E was withdrawn and replaced with his right to live in safe conditions. In the Seventh Chamber's judgment it recorded that senior citizens had a special constitutional protection, and although aging was a natural process, certain conditions of illness, poverty and loneliness could result in their physical, emotional, and social vulnerability. It was up to society and families to take on these responsibilities to prevent these conditions from destroying the effective enjoyment of the rights of the elderly. The Court acknowledged that, although the family was one of the most important elements of support for this age group, a source of their self-esteem, confidence, and security, in some situations it could be the main cause of their abandonment. When this arose, the State was required to offer full provision of assistance.

4.1.6.2.2. T-423 of 2017[242]

T-423 of 2017 was a case of a 24-year-old woman, Sofia, who suffered from an aggressive

brain tumour that had metastasized to the rest of her body. She was terminally ill and wished to exercise her right to die with E. Sofia was refused access to E because the physician had said that she could not agree to Sofia's request, and the EPS had informed her, too, that there was no Interdisciplinary Scientific Committee at the hospital in her residential area that could assess the request. Sofia subsequently died without E. When the Sixth Review Chamber heard the case, it held that damages had arisen because of the denial of Sofia's right to die with dignity and that Sofia and her family's suffering had been prolonged by the administrative obstacles that were presented because of neither facilities nor skilled medical staff having been available in her outlying area of residence.

The Court issued orders to bring the health institutions up to a standard of care people expected under the Constitution, to ensure that in future there would not be barriers to access services in outlying areas of the country. These orders included requiring that information leaflets be made available to the public informing them of their rights. The Superintendence of Health was instructed to adopt measures to verify that implementation of the infrastructure and the taking on of suitable personnel by the EPS across the country was progressing. Once more, the Court repeated the calls to Congress to develop comprehensive legal regulations in light of the inconveniences evidenced in this case due to a lack of guidance of those within the health system who were tasked with creating the infrastructure.

4.1.6.2.3. T-544 of 2017[243]

This important case dealt with children, adolescents, and their right to euthanasia, including substituted consent for them. Francisco was born with severe cerebral palsy associated with physical and cognitive disabilities. He communicated through crying and facial expressions. Amongst other disorders, he suffered from difficult-to-control epilepsy and severe gastroesophageal reflux. His parents described him as never happy because of being in pain. At 13 years old, his condition was deteriorating as each day passed and on occasion he had struggled to breathe, requiring oxygen. His parents eventually sought E for him from the EPS to end his suffering and to allow him a dignified death. The EPS denied the service on the basis that there was no procedure to evaluate a substituted consent for a child.

On review, the Fifth Review Chamber found that serious deficiencies were revealed in the provision of health services to Francisco, such as a delay in the delivery of oxygen to his home when he needed it and a lack of access to medical specialists, particularly orthopaedic skills,

when Francisco's body progressively became more distorted and painful. The Chamber saw this neglect as an absence of compassion for the child's situation, and a need for comprehensive care to be given. These facts caused the Chamber to send copies of its report to the National Health Superintendency[244]. The Chamber also criticised the Congress for its slow response in drawing up a complete set of regulations, despite having been asked to draft them a few times already[245].

Regarding children's rights, the Constitutional Court stated that the 'best interests of the child' principle ought to be applied in line with previous case law when it was unclear how the principle should be used, such as in that situation where a request for E was made. It mentioned that children were entitled to special protection under the constitutional right to health of children and adolescents. This additional protection gave them the right to receive preferential attention for access to the benefits of the social security system. The Court referred to its earlier judgments on the nature of the right to die and its close relationship to human dignity, autonomy and the perception of life that goes beyond mere existence, previously discussed above. It said that children had the same rights as adults. Therefore, not allowing children the right to die would amount to subjecting them to cruel, inhumane and degrading treatment, to the detriment of their dignity. The Chamber recognised, however, that some differences would arise in the realisation of the right compared to adults, such as with regard to consent, and the expression of their free will. Consequently, the Court affirmed that experts would need to assist with the technical aspects applicable to children and adolescents, such as (i) describing the condition of the terminally ill person, (ii) the assessment of suffering, (iii) determining the ability to make decisions, (iv) consent according to age and the level of physical, psychological and social maturity. As a general rule, the Court stated that children and adolescents would consent through their representatives, but they still needed to be consulted at an appropriate level for their cognitive, emotional and psychological development. Professionals would be required to also give guidance on how to convey information, and the consent of both parents would be mandatory, unless for other reasons, this parental role was substituted for a legal representative[246].

In summing up, the Fifth Chamber repeated the general steps necessary to be followed for the E process to be applied to a child or adolescent. The E process required: (i) the child, adolescent or legal representative, being parents or others, to express their will freely, stating that the patient was suffering from a terminal illness and experiencing intense pain that led them to want to exercise the right to die a dignified death; (ii) the statement was to be made to the treating

physician; (iii) the physician was then required to convene an interdisciplinary scientific committee; (iv) the patient or representative was to repeat the unequivocal intention to die. Once compliance with all the requirements was established, within ten calendar days the patient would be asked again to confirm their decision; (v) if it was affirmative, the committee was to schedule the procedure for the time chosen by the patient or within 15 days after validation of the decision to die; (vi) throughout the steps of the process, the emotional maturity of the patient was to be borne in mind and, if necessary, alternative mechanisms were to be engaged for substituted consent to be given by both parents or the legal representative. The Court instructed the Ministry of Health and Social Protection to arrange for health providers to form the interdisciplinary committees and to propose a medical protocol for children that could be drafted by a range of experts for use by the medical practitioners going forward. Furthermore, it asked the Ministry to also present a Bill for the regulations, and then repeated the call to the Congress of the Republic to issue comprehensive legislation for the right to die. As a last request, the Chamber asked the Ombudsman to make the nation aware of the content of the judgment and to take any other measures necessary to generate public awareness of their rights, citizen agency and public debate. The Court observed that without a legal framework in place, there was a normative vacuum that prevented the various health entities from making decisions[247].

Resolution 825 of 2018 came into being as a consequence of Francisco's case[248]. In general, it allowed children from 12 to 18 years of age to request the exercise of their right to a dignified death and, exceptionally, children between six years old and 12, depending on their level of cognitive development and their understanding of the irrevocable nature of death.

4.1.6.2.4. T-721 of 2017[250]

T-721 of 2017 dealt with another case of substituted consent surrounding a 23-year-old adult who had been in a permanent vegetative state for eight years. Her mother, acting as her legal representative, had requested E for her, but it had been refused because her condition had not been classified as 'terminal', technically, in that there had been no clear medical assessment of life expectancy, as she had suffered from a degenerative irreversible chronic disease. In addition, the patient had not signed an advance directive requesting E, so, in light of the regulations at that time (Resolution 1216 of 2015), E was not permissible. As an alternative, the mother had requested whether it was possible to allow a 'limitation of therapeutic effort'. (From the context this phrase seems to refer to withdrawing and withholding of treatment).

The Fourth Review Chamber, in its appraisal, explained that the right to a dignified death had several facets to allow someone the power to control the exercise of that right: (i) the euthanasia procedure, (ii) limitation of the therapeutic effort or readjustment of care procedures, and (iii) palliative care. The Court remarked too, that it had witnessed some shortcomings with the Social Security System in Health regarding implementation of Resolution 1216. An example of a shortcoming was the availability of substituted consent only if the adult themselves gave permission in writing in an advance directive. This provision thus discriminated against those who could not express themselves.

The Chamber ruled that in the present case the substituted consent of the patient's legal representative was valid, although the Court supported the stricter vigilance of the medical professionals and staff in observing the requirements when substituted consent was being offered, in general. The Chamber also expressed its view that the entities had failed the patient by not evaluating the patient's medical condition using the range of analyses offered by the Resolution. This involved viewing her situation as having no reasonable prospect of recovery, observing her total dependence, and her lack of contact with the environment or perception of herself, which would have justified the limitation of therapeutic effort. By omitting to limit the therapeutic effort, the Court found that the EPS and other health bodies had unnecessarily prolonged the suffering of the patient and her immediate family. They also had unjustifiably restricted timely palliative care because the patient had not been classified as having a terminal illness. This finding was made because the health service had argued that palliative care only applied to terminally ill patients and not those with chronic, degenerative, and irreversible diseases that had a high impact on the quality of life. Providing palliative care would have included management of pain as well as other symptoms, taking into account psychological, physical, emotional, social and spiritual aspects of the patient and her family[251].

The patient died during the review process after a crisis that was finally managed with palliative care[252]. In light of the Court's findings, it declared that damages had occurred and ordered the health providers to adjust their internal protocols to enable compliance with the regulations on the right to die with dignity. The Ministry of Health was instructed to adapt Resolution 1216 of 2015's rules about the process and conditions for substituted consent, as well as those pertaining to limitation of therapeutic effort and care measures. Once more, the Chamber placed on record its request to Congress to create the legislation for the right to die[253]. The publication of Resolution 2665 of 2018 about advance directives was produced by the Ministry of Health and Social Protection as an outcome of this case. It permits a person from 14 years old onwards,

with minor formalities, to create an advance directive[254].

4.1.6.2.5. T-060 of 2020[255]

T-060 of 2020 also dealt with a person who did not have a classified 'terminal illness'. The matter was about a 94-year-old patient, María Lira, who experienced anxiety disorder, schizophrenia, Alzheimer's disease, hypothyroidism, high blood pressure and severe occlusive arterial disease. Her daughter, as her unofficial agent, had sought permission for her to be allowed E in terms of Resolution 1216 of 2015. As with the previous case, E was refused because no advance directive existed verifying that the patient had appointed her daughter to be her legal representative, and the problems suffered by María Lira were not proven to be classified as terminal disease.

The Ninth Review Chamber expressed its awareness of the fact that the latest updates to the regulations from T-721 of 2017 had not yet been issued, so the most recent findings on substituted consent had not been implemented. Nevertheless, the judge accepted that the conditions had not been met for terminal illness, although Maria Lira was extremely vulnerable due to her comorbidities and advanced age. It also acknowledged that the EPS had been providing María Lira with the services she needed to treat her chronic medical disorders, to manage her pain control and to maintain her quality of life. The Review Chamber repeated that the fundamental right to die with dignity materialised not only by offering E, but also through alleviating suffering, by ensuring that the best and most comprehensive care was given. The purpose of the health service remained to achieve the highest level of well-being and optimal living conditions for the remainder of the person's life. The judge concluded that this approach accorded with the WHO's definition of health, which was not limited to only the absence of disease but also consisted of a state of physical, mental, and social well-being[256].

The Constitutional Court, in its 2021 judgment[257], having presented the relevant case law, then concluded its history of the E cases by summarising what they had contributed to the Colombian law related to the right to die with dignity. Specifically, the right could be exercised in three ways, as had been highlighted in its jurisprudence: (i) through palliative care, regulated by Law 1733 of 2014, intended to control pain and suffering associated with diseases, where no therapeutic measures or effective healing could be achieved any longer; (ii) by the restriction of the therapeutic effort, consisting of limiting or suspending interventions that supported life

when they may cause greater suffering; and (iii) through the benefit of death, by applying forms of euthanasia, where the criteria for the justification of killing were fulfilled.

The Court shared further that it appreciated that the statutory law would continue to develop as had been witnessed in other jurisdictions but proposed that the effectiveness of the right depended on providing services properly, the training of the EPS, other entities and medical staff, and having acceptable conditions for expressing either one's own consent or substituted consent. Moreover, it pointed out that the case scenarios, in their particular contexts, did not replace clear statutory legislation enacted by the Congress of the Republic. However, because of their subjectivity, the case reports helped to add details to the scope of the right. All the Chambers of the Constitutional Court indicated that a lack of legislation has been one of the primary barriers to people accessing the law. The Court also identified the need to educate everyone to help them understand the scope and content of the right to die with dignity[258].

(i) Right to die and right to health.

It appears that an important part of the voluminous C-233 2021 Constitutional Court judgment was to summarise and reiterate, - probably for the convenience and education of readers, - the entire process of the judges' reasoning that went into introducing E law in Columbia. It has many facets, including the discussion of the relationships between the right to die with dignity and the right to life and dignity, but also the right to die with dignity and the right to health, for the Columbian community. The information is presented here because of its relevance to the South African context, too.

The Court began its examination with a reference to Colombia's National Constitution which encapsulated the meaning of the right to health from International Human Rights Law. It encompasses enjoying the highest possible level of physical, emotional, and psychological wellbeing, while prohibiting discrimination in access to health services, and recognising a valid claim to access specific services and benefits that are necessary to achieve wellbeing[259].

Thus, to fulfil the right to health, the Court made it clear that an adequate system of public health needed to exist with a complex institutional, technical, and scientific infrastructure in place, defined by Congress in terms of the law. Public Administration had to address health plans and conditions that would give an effective and efficient service. The Constitutional Court explained that, for the application of the law, it conceptualised the health system in accordance

with International Human Rights Law, using four sub-divisions: (i) availability, which included the provision of sufficient goods, services, professional staff, and health care centres; (ii) accessibility, described as having two aspects: a physical dimension, where services ought to be geographically within reach of the entire population, especially for the vulnerable community, and an economic dimension, that referred to the affordability of the health service and included the directive for non-discrimination; (iii) acceptability, which embraced ethical standards, cultural appropriation of services, and inclusion of differential approaches, such as to cater for gender, age and ethnicity; (iv) quality, in services that reflected appropriate medical and scientific knowledge[260].

The Court compared the relationship between the right to health and the right to die with dignity as a humanitarian bridge over which a person progressed towards fulfilling the right to a dignified death. This bridge, it suggested, was built through the provision of health services, palliative care, and the specific benefits to die, or through the omission of ongoing therapeutic effort. However, it underlined the fact that, for as long as there was no regulation of the legal infrastructure through statute, the bridge would be built on minimal foundations that the Court can establish. The judges explained that they held this opinion because their legal findings had the normative authority of the Constitution, but that they would always be less than the force of statute, as the court judgments were based on limited contexts of information. In comparison, the Constitutional Court viewed the Congress of the Republic as having democratic legitimacy. It could receive comprehensive, full information, taking the necessary time for deep deliberation with assistance from a range of experts across the board. In emphasizing the link between the two, the Court said that this was why, when a person died in the midst of suffering as a result of a failed health service, when entitled by law to a dignified death, it declared that consummated damages had arisen, as demonstrated in certain of the case reports[261].

(ii) Palliative care.

In comparing Colombia's health environment to that of South Africa's, another important aspect was presented by the judges in case C-233/21: the discussion about palliative care. The Court commented that despite introducing palliative care law in 2014 (law 1733 of 2014), Colombia was rated 68th out of 80 countries in the World Ranking of Palliative Care in 2016. At that time, it had 23 of 32 departments with palliative care services, amounting to 72% of departments, but only 6% were in public facilities, while 80% belonged to the private sector and 14% were independent[262]. Following the adoption of the 'Inter-American Convention on

Protection of the Human Rights of Older Persons' in Washington on 15 June 2015, Colombia subsequently expanded its regulation of palliative care during 2020[263]. The Ministry of Health also issued 'Guidelines for comprehensive care in palliative care' in the hope that they would provide the necessary guidance to implement or strengthen the development of palliative care[264]. At the time of the hearing of case C-233/21, Colombia had 514 specialised palliative care services, amounting to 40% coverage nationwide[262]. According to a 2022 research publication[265], Colombia was ranked 42nd out of 81 countries for palliative care, when graded by the researchers, while South Africa was ranked 73rd on the same scale. Unfortunately, there appears to be little evidence in English research papers of exactly how the Colombian public is experiencing the introduction of E into society, when palliative care seems to be available to less than half of the inhabitants. The OECD report on Colombia's health-at-a-glance for 2019 recorded that only 47% of the population were satisfied with the overall quality of health care they received[266].

During July 2018, Colombia answered questions about their elderly people and palliative care for the United Nations Working Group on Ageing[267]. Law 1733 of 2014 defined palliative care as being care for a patient with a terminal, chronic, degenerative, and irreversible disease, where the control of pain and other symptoms would require medical, social, and spiritual support to achieve the best possible quality of life. In addition, psychological and family support were to be offered during illness and grief. The Colombian spokesperson explained that the national legal framework created three types of institutions for elderly long-term care: welfare centres, social protection centres and care institutions for either temporary or permanent care. However, the greatest barrier to access was the high cost of long-term care and the shortage in supply of social and health services. For individuals who required long-term care services, there were substantial out-of-pocket expenses because health services and supporting social services were not yet integrated. Consequently, most of the care for the elderly was provided by the family or community. Sadly, a lack of knowledge about how to care effectively, as well as limited financial and physical resources, remained a problem to improving the ageing person's quality of life. Nonetheless, the older person had a right to comprehensive social security and food subsidies in case of indigence according to Article 46 of the National Constitution. The spokesperson conveyed that a major challenge for receiving palliative care was availability and access itself. Apparently 70% of those who die would have had a chronic disease that would have led to circumstances where palliation could have been beneficial, but there seemed to be only a limited demand for it, besides the shortage of its availability. (The Court recorded only 40% having access to it, as mentioned earlier). Although this comment was made, it was also

said that what information they had indicated that there is an increasing need for palliative care. The ability to offer palliative care services was described as being at an early stage of development, but it was a work in progress and public finances were hoped to be allocated to these vulnerable groups in the future. The fact that palliative care was still not integrated with long-term care was pointed out as a failing. However, social protection services were beginning to introduce it at a basic level.

A last concern mentioned was that very little support for medical care and dying at home existed because of a lack of clarity regarding precisely what care was required to be funded with resources from the health sector. Some types of care would depend upon funding from other sources. The spokesperson suggested that once these questions had answers, they would begin to draft a proposal.

So, there are many plans to improve palliative care and long-term care, besides the law related to it having been enacted since 2014. Yet nothing had reached fruition by 2018, despite euthanasia also having been performed from 2015. The spokesperson revealed in his responses to the United Nations Working Group that no research had been carried out on end-of-life care of the elderly in Colombia to date. This meant that no evidence was available of what the real conditions were like within the ageing community or, for that matter, other vulnerable groups, nor the extent of need, suffering or even the support that is actually being given.

4.1.6.2.6. Sentencia C-233 of 202[268]

In 2021, the request brought to the Plenary Chamber of the Constitutional Court was to revise the Criminal Code, Act 599 of 2000. The complaint was that Article 106 excluded people with grave illnesses or disorders who were not terminally ill from accessing E, despite their very poor quality of life and wish to die. Article 106 prohibited mercy killing as a criminal offence, punishable by imprisonment of between 16 to 54 months except when performed by a doctor, if a patient suffering intolerably from a terminal illness requested E and voluntarily gave consent to its administration.

Article 106 had been analysed in 1997 when the Court first ruled that E was permissible, after a split bench decision of six votes in favour to three against the change in law[269]. The present complaint, specifically, was that the Article ignored the prohibition of cruel, inhuman and degrading treatment, the free development of personality and human dignity, as well as the

opportunity for people who were suffering intensely, without the possibility of relief, to access the right to die with dignity. The Court accepted that the Article was partially unconstitutional for this reason, and adjusted the exception to Article 106 as follows: (i) mercy killing would not be incurred when the conduct is carried out by a doctor, (ii) with the person's free and informed consent, prior to or after the diagnosis of the person's condition, and provided that, (iii) the patient suffers from intense physical or mental suffering, arising from bodily injury or serious and incurable illness. The Chamber reiterated that all the other jurisprudence pertaining to E that had been established over time still applied. The result of the hearing was a split bench again, of four who concurred and 3 who dissented, reinforcing what a contentious subject euthanasia continues to be. Another exhortation was made by the Constitutional Court to the Congress of the Republic to enact law that would facilitate implementation of the right to die with dignity in light of what the Court described as a persistent legal vacuum[268].

There appears to be some tension that has arisen between the Colombian judiciary and the legislature, which creates a thought-provoking situation. Where the legislature's role is to draft the law and the judiciary's role is to interpret and apply the law, and on occasion strike it down as unconstitutional, here the Constitutional Court, in essence, has created new law. Through its interpretation of the right to life, an additional right was established, the right to die with dignity. However, despite numerous appeals by the Constitutional Court to the Congress of the Republic to draft legislation in order to allow for the realisation of this right, the Congress has been slow to respond. The judiciary has stepped on moral ground that the legislature does not appear to accept or is not ready to embrace. As a legal writer observed, the Colombian Congress has one primary duty, to promulgate the laws of the Nation. However, its hesitancy with legislating on the current most controversial topics indicates its reluctance to accept them into law. The consequence of this unresponsiveness is that the Constitutional Court has had to formulate judgments to develop the law in the absence of Congress, notwithstanding the issues having a crucial social, ethical and legal impact on society, which would also be Congress's responsibility to control. The result is that the Constitutional Court's judgments now have a similar latitude and autonomy to the high court decisions of common law countries[225], such as South Africa. Despite the 2021 judgment, no further legal progress with drafting seems to have been made yet.

Finally, in 2022, the first two people not with end-stage disease, but rather chronic degenerative conditions, were permitted to be euthanised. The case of Victor Escobar who had severe chronic obstructive pulmonary disease and other medical problems was fought in court for two years,

while doctors, clinics and lawyers had opposed him. The euthanasia of Martha Sepúlveda, who suffered from amyotrophic lateral sclerosis, also known as Lou Gehrig's Disease, followed soon afterwards. Her death had similarly been delayed, even though her application was submitted four days after the 2021 judgment that allowed E for non-terminal patients. It was initially refused based on the old law, until Camilla Jaramillo Salazar from the activist law firm, DescLAB, gave Martha legal assistance by bringing a tutela action to court, similar to the cases described in earlier paragraphs. This action was successful. DescLAB has reported that since 2015 up to October 15th 2021, 178 people with terminal illness have chosen to die by means of E[239, 271].

4.1.6.3. Latest legislation

On 11 May 2022, the most recent 'right-to-die' judgment was handed down by the Colombian Constitutional Court, C-164 of 2022[271]. The issue was that, although E was decriminalised, assisted suicide remained a crime. Members of DescLAB, who were the plaintiffs again, took the matter to court to introduce physician assisted suicide as an alternative to euthanasia. The Constitutional Court found in their favour.

Finally, Colombia will allow both E and PAS as options to end lives[272].

4.1.6.4. Social and cultural environment

In order to better understand the context of the law and its society, some general information is presented about how Colombians live. Colombia has one of Latin America's largest economies. It is classified as an upper middle-income economy, based on its rich natural resources. Seen as an emerging market economy, the Covid pandemic has had a grave impact on the country. There are concerns that years of progress could now be reversed, particularly for the impoverished communities, leaving greater income inequality (the Gini coefficient was 54.2 in 2020 for Colombia, South Africa was 57.7 in 2018[273]), and labour informality than before the pandemic. According to the Organisation for Economic Co-operation and Development (OECD), in 2018 the government passed a timely and much wanted tax reform, which was nevertheless overruled by the Constitutional Court. The administration passed it at the end of 2019 again, but the drawn-out process expended a large amount of political capital[274]. It appears evident that the judiciary impacts on the legislature in a number of different domains, not always perceived to be in a positive way.

Weak structural policy settings preclude more than half of income earners from formal jobs and social protection, which limits growth of the economy because businesses cannot become more productive. Also, inadequate skills, associated with one's socio-economic background keep many people out of the formal labour market. In 2022 it was reported that productivity growth has now fallen behind peers[274].

Problems in Colombia named in the OECD report for 2022 are rising inflation, public debt and government corruption, despite efforts to reduce it, which worsens inequalities by creating an uneven playing field. This description could have been for South Africa, too. Public trust in institutions is low but there is no whistle-blower legislation in place. Informal employment makes up around 60% of workers. These workers are not covered by social security, so have no protection except health benefits. They also do not contribute to tax revenues. However, formal workers pay contributions to public health insurance, while informal workers get almost the same benefit package for free[275]. Early school dropout and unemployment has risen since Covid, exacerbating the situation. Covid exposed major gaps in social protection, especially among the informal workers. Half the population over 65 years of age is not covered by pension benefits so depend on government support. The OECD report advises that an expansion of social programmes is necessary to focus on vulnerable populations in rural areas. Also, better digital connectivity is needed for the public sector, households, and businesses because penetration rates are still low, despite an attempt to improve it. Furthermore, broadband speed is slow and costly, whether using fixed or mobile telecommunications[274].

Colombia is noted to be among the worst of the Latin American countries in terms of its deep-rooted problem of poverty. Bogotà, comparable to many Latin American cities, is surrounded by slums, because the population outnumbers available stable housing. These shantytowns are typically erected by large numbers of migrant workers drawn to the cities seeking work. The Housing Institute tries to deal with the problem by organising the construction of accommodation for the low-income rural and urban communities[276].

Many health problems exist that the Ministry of Health has attempted to solve by encouraging involvement of individual communities to take on projects through independent effort. Some examples of endeavours are the construction of an infrastructure to supply drinking water; public education on subjects such as basic sanitation, home maintenance, a balanced diet, and personal cleanliness. Educational instruction is also offered about the health hazards that exist associated with the operations of various industries and organisations. In the damp poorly

drained rural areas, particularly the lowlands, malaria and dysentery are a frequent problem, and occasionally cholera epidemics. Despite some improvement in conditions related to health, those living in the more isolated regions still face serious challenges, particularly among the poor where malnutrition leads to further complications[276].

In 2019, Olga Wilches[277], a Professor of Nursing in Colombia, wrote that the national law had established programmes that included arrangements to assure people of their quality of life and dignity, pain control as well as spiritual and psychological support for the patient and family. Nonetheless, fulfilment of these expectations had been minimal or absent for the majority of Colombians. Her experience was that the people who received palliative care used private health professionals and facilities at a considerable financial cost to themselves. Most individuals had expressed their preference to spend their last days at home, which would make their situation more bearable for them. However, Wilches explained that many died in a hospital, suffering and alone. For family members, too, additional difficulties arose while their loved one was admitted with a chronic or terminal condition, such as affording the costs of commuting to the hospital or finding the time to assist their relative outside of their other commitments. Life could be difficult.

Wilches reported that there were many reasons why a large section of the population was not receiving palliative care. Some of these explanations pointed to a lack of public awareness that the right to palliative care existed, barriers erected by the Colombian health system itself, problems with coverage and adverse economic decisions, such as the authorities not wanting to spend money on resources for patients who had no cure. Another setback was that medical practitioners were not taught, or had very little training, in end-of-life management. Part of the compassion of medical practitioners was their understanding of the intricacy of the dynamic between patients with chronic and terminal illnesses, their relatives and the health system[277].

4.1.6.5 Comparison with South Africa

Colombia is a complex environment of the very wealthy and extremely poor, living in relatively close proximity to each other, as well as a mix of third world and first world health services. Although Colombia does not yet have an efficient process for the provision of E, the Ministry of Health still perseveres and has achieved some success with its roll-out. Many other health challenges remain, including offering palliative care as a readily available alternative to E, in order for the availability of E to be an ethical option and not the only one to relieve pain and

suffering. On the other hand, if good palliative care is only a distant dream, it could be argued that not having E available is a form of cruel and inhuman treatment, too, and death is a better option than a long, drawn-out process of intolerable misery, especially where Congress has not shown the will to cooperate and keep up with the needs of the health service.

There are a few similarities to the situation in South Africa that have already been highlighted, such as the political structure and the social challenges in a disparate society, including the impact of the Constitutional Court in ensuring that the right of access to some health services has been realised. It was only as a result of the pressure brought to bear on government by the Treatment Action Campaign bringing a case to court that the general distribution of Nevirapine medication to treated HIV symptoms (human immunodeficiency virus) was finally achieved for many sick, frightened and dying people[278]. Whether South Africa is willing to introduce E legislation despite the country's lack of palliative care on the basis that having the option of assisted death is preferable to having no option at all to reduce intractable suffering, remains to be seen.

Summary of countries that permit euthanasia

Not all the countries or states within countries that have E legislation have been discussed, but the intention for introducing the selected countries was to give examples of the different models that exist. Nonetheless, every region may well add to knowledge regarding what is suitable for the South African context.

Some countries not discussed but which have now accepted termination-of-life law include:
Spain: in June 2021, E and PAS law came into force[279].
New Zealand: in November 2021 the End of Life Choice Act 2019 took effect[280].

All the countries examined in the thesis accept E, and most also PAS, as a legitimate end-of-life decision, alongside palliative care which is mostly legally required to be offered first. Generally, the criteria that are consistent throughout all the countries include that a person must be an adult, who is capable of exercising legal capacity to give full informed consent. The person is to personally request the termination of life, because of an underlying medical condition that is permanent and causes unbearable suffering and cannot be relieved by any means acceptable to the patient. Each country has its own additional or modified criteria in accordance with that society's expectations.

In addition, every country's legislation has made it the responsibility of its healthcare system to facilitate the individual's right to terminate life. Most commonly, doctors have the duty to administer E and carry the accountability for doing it ethically, in line with the accepted standard of care expected of the medical profession. Other professionals who are necessary to enable the process, such as pharmacists and, under certain circumstances, nurses, are also not guilty of an offence by helping the doctor and patient to fulfil the request for an assisted death. Except for Colombia, the countries described are fairly wealthy, with strong governmentally based social commitments, financed to some extent by taxation of the people. They have sophisticated healthcare infrastructures, and the public's relationship with the medical profession is built on a high level of trust. Doctors are relied upon to be disciplined and ethical with self-reporting of their E cases. This reporting subjects them to scrutiny by peers and governmental bodies who oversee the E service and can lead to prosecution if it is found that a decision to carry out E was made for the wrong reasons. All the countries respect and accept the medical practitioner's right to object to perform E on the grounds of conscience, provided for in the law.

The regulation of E and PAS apparently requires an extensive infrastructure to ensure that safeguards are in place and effective, and that trust between the medical sector and public is maintained. For the service to be of a high standard and as safe as possible to prevent misuse or abuse, the administration and paperwork appears to be onerous, both at the level of the health practitioner and with the oversight by the boards, culminating in the important ongoing publication of reports reflecting the impact of E and PAS on society.

B. Assisted Suicide only, permitted

4.1.7. Switzerland

4.1.7.1. Introduction

Switzerland is an important country to examine for the purpose of this thesis because it has an unusual approach to assisted suicide (AS) in that it does not require a doctor to carry out the procedure. In contrast to other countries, AS is described as not medicalised, but rather facilitated through voluntary organisations. Pillonel[281] observed that the political culture of Switzerland towards AS 'reflects the reluctance of medicine to recognise the practice. Its legitimacy is based on a process of social recognition, advanced by a citizen's movement, and debated in the public sphere'.

The Swiss Confederation is a land-locked country in central Europe, surrounded by Germany in the north, Austria and Lichtenstein to the east, Italy in the south and France as the western border. It is small in size, being approximately 220 km from north to south and 350 km at its widest section from west to east. Switzerland has picturesque tall snow-capped mountains, deep lakes and neat agricultural farmlands with a high population density[282].

Functioning as a federal state, it has two legislative houses within the Federal Assembly: a National Council and a Council of States in which each canton is represented. The Federal Council is the executive branch of government, only consisting of seven people. The president of the Federal Council is the head of the state and government. Switzerland's Constitution has been in force since 1848. However, it was substantially revised and updated in 2000. A unique feature of the Constitution is that the people make many of the decisions through referenda and initiatives. Consequently, the people ultimately hold the sovereign power. They can call a vote on any issue by obtaining 100 000 signatures.

The Swiss Confederation (central state) is made up of 23 federal states or cantons, of which three are divided in half as demi cantons, but function as full cantons, so 26 cantons altogether. Each canton has its own Constitution, Legislature, Executive and Judiciary. They have broad authority and exercise power that is not specifically held by the federal government. Matters such as taxation, education, transport, the public security, social services, and health policies are mainly decided upon at the cantonal level[283].

The judicial system is uniform across the country and comprises a Federal Supreme Court based in Lausanne, where judges are elected by the Federal Assembly for six-year terms. Each canton has its own judicial infrastructure of civil and criminal courts, too. The Swiss Civil Code of 1912 has been copied and used as a framework for administration of justice in many other countries[284].

The third level of government is at the local level of communes, or municipalities, incorporating cities, towns, and villages. They usually also have a fair amount of autonomy in running their own affairs. The local laws deal with topics such as streets, buildings, water, energy prices and parking regulations[283.]

Switzerland's population is a mix of French, German and Italian communities. French, German

and Italian are also the official languages, as well as Romansh, which is spoken locally. Switzerland has maintained the world's oldest democracy for around 700 years, despite the diverse ethnic groups, religions, and languages.

4.1.7.2. History of AS Legislation

According to the academic writers Hurst and Mauron, the earliest federal penal code of 1918 was stated by the federal government of the time to be interpreted as follows: 'In modern penal law, suicide is not a crime … Aiding and abetting suicide can themselves be inspired by altruistic motives. This is why the project incriminates them only if the author has been moved by selfish reasons'. Motive was the measurement of whether a crime had been committed or not. As society was taken up with suicides driven by honour and romance, motives related to healthcare did not concern society, and a physician did not have to be involved with the final deed[70]. In fact, the drafters had not considered assisted suicide from a medical perspective at all. The draft Criminal Code, after being submitted to Parliament in 1918, was approved finally in 1937, and included the current Article 115[285].

Article 115 of the Swiss Penal Code prohibits assisting with suicide where the motive is for selfish reasons. Its words are: 'Art. 115: Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty'[6]. Clearly, where the intention is altruistic, the act is accepted. A duty to save life usually cannot override the altruism permitted for suicide. Article 115 also does not stipulate that a doctor must participate in the suicide, and the patient does not need to be terminally ill[70]. The only requirement for condoning the killing relates to an unselfish motive, in contrast to the South African criterion of an intention to kill, where motive is irrelevant.

Once an AS has occurred, the administrative process followed is that it is reported as such, and a police inquiry is initiated, as with all unnatural deaths. If the prosecuting authorities are satisfied that no crime has been committed because of an unselfish motive, the case is closed. However, in the rare situation that doubts are present surrounding the competence of the patient to consent, a prosecution begins[70].

The problem that arose because of this vague law was that people were dying for reasons other than medical ones. In 2008, researchers[286] referred to information from two Swiss right-to-die

organisations, Exit Deutsche Schweiz, founded in Zurich in 1982, the largest right-to-die organisation helping Swiss residents, and only exceptionally non-residents, and Dignitas, founded in Zurich in 1998, a large organisation that offers the service to non-residents. The period examined was twenty years ago, from 2001 to 2004, where a total of 421 cases were reviewed: from Dignitas there were 274, and 147 from Exit. The writers found that a number of people requested AS because of weariness of life (around 25%) rather than for a serious medical illness or a hopeless medical condition. This was despite both organisations having criteria that needed to be satisfied before AS was facilitated. The Exit statutes actually set out the evaluation that applied only to people over 18 years old with legal capacity, to ensure that their decision to die was thoughtfully arrived at and consistent. They had to also be suffering unbearably from a disease with a futile prognosis, or a serious disability. However, Exit Deutsche Schweiz recorded deaths for 'other' reasons such as blindness, paralysis, and 'general weakness' to be 34.1%.

The conclusion reached by the researchers was that the organisations were often confronted with elderly people of around 80 years of age who were not suffering from a terminal disease, but who were given AS in Switzerland because of respect for their self-determination, as opposed to the attitude of the Netherlands, where these types of requests were refused. This difference was explained to be because the Netherlands has a E/PAS system that is completely medicalised, requiring recognised medical reasons for permitting death[286]. Switzerland, on the other hand has created a system, inadvertently, that is primarily non-medical, and not controlled by federal law, driven by the voluntary societies[285].

Switzerland is unique in not specifying the role of doctors in AS. Volunteers, who are not necessarily medical, provide this assistance through non-profit organisations[285]. In comparison, other European E/PAS countries, Canada, Australia and Oregon, USA, see the role of a medical practitioner as an important safeguard against abuse and error, and, in addition, they can ensure that a painless death would ensue. Pharmacists are similarly relied upon for the prescription medication. Hurst and Mauron noted that Swiss law had clearly distinguished between whether AS should be allowed or not on one hand, and the role of medical practitioners to participate in it on the other, avoiding moral desensitisation linked to E and AS. The authors recorded that in 2001 the Swiss Parliament rejected a Bill that would have prohibited doctors from participating in AS[70].

However, a Swiss researcher, Bosshard[287], in response to Hurst and Mauron, drew attention to

the fact that, since the era in which the legislation was enacted, by 2003 AS was discussed almost only in the setting of a serious or incurable illness. Consequently, the consulting medical practitioner would be the person who had the conversation with the patient about their end-of-life hopes and anxieties and who offered alternatives such as palliative care. Doctors would be confronted with the request for AS. Bossard's opinion was that more doctors were becoming amenable to supporting the patient's wish if other options were found to be unacceptable to the patient and almost all doctors would work with a Right-to-die Society. Thus, the doctor would write the prescription, but the volunteer organisation would facilitate the action.

In general, in 2003, doctors did not appear to be willing to be involved with AS. Some expressed this firmly, as illustrated by Bury's comments[288] that the doctor's role was limited to providing all options for treatment, confirming the diagnosis and counselling. His view was that after the consultations, if the patient chose to die, the doctor's function was over, and where the request was not linked to some underlying medical problem, there was no reason for the doctor's involvement at all. He supported volunteers being trained to provide the technical side of assisting in suicide, such as setting up the intravenous line for a lethal injection, similar to the role phlebotomists fulfilled in the hospitals who were not trained in medicine. In addition, at that time Bossard and other writers[288, 289] aired the view that there was a real need for legal and ethical clarity surrounding the role of doctors and their responsibilities related to AS in Switzerland.

In fact, the Swiss Academy of Medical Sciences (SAMS), in its 2004 version of *Medical-ethical guidelines, End-of-life care*, stated that AS was not a part of the physician's activity. The wording was 'On the one hand assisted suicide is not part of a doctor's task, because this contradicts the aims of medicine. On the other hand, consideration of the patient's wishes is fundamental for the doctor-patient relationship. This dilemma requires a personal decision of conscience on the part of the physician. The decision to provide assistance must be respected as such'[290]. These sentences were understood to mean that doctors could assist as citizens under the law, outside of their medical identity and professional body's oversight.

Over time, legal cases were mounting up. In 2006, Mr Haas, suffering from severe bipolar affective disorder, approached the Swiss Federal Supreme Court because doctors were refusing to prescribe 15mg of sodium pentobarbital for him to commit suicide, despite Dignitas being prepared to assist him[291]. His argument was that he was entitled to be able to end his own life without risk or pain and without endangering third parties. However, national legislation

required that this drug could only be dispensed with a doctor's prescription. Furthermore, the doctor had to prescribe it within the boundaries of medical science, so an underlying medical diagnosis was required. Monitoring of doctors' compliance with legislation was the responsibility of the cantonal supervisory authorities for doctors, meaning that if doctors did not comply, they would be open to a sanction.

The complainant also argued that his personal freedom and protection of private life included a right to commit suicide, in line with the rights and freedoms guaranteed by the European Court of Human Rights (ECHR). He contended that for these rights not to be merely illusory, the State had a duty to facilitate access to medication for him to achieve self-determination[292]. The Court replied that the complainant had misunderstood the legal and constitutional point of departure, and the Federal Supreme Court's case law was clear that there was no general freedom of action that a person could invoke for every state act that affected his freedom. Personal freedom did not protect against any physical or psychological discomfort. The scope of protection of personal freedom as well as the limit of the admissibility of interference in this freedom were to be specified in each individual case, in view of the type and intensity of the impairment, as well as with regard to a possible special protection of the person concerned. Accordingly, the right to one's own death was to be distinguished from the complainant's claim to AS on the State or on third parties. The Court said that the person who wanted to die was not entitled as a matter of right to assistance with suicide or euthanasia if he was unable to end his life himself. Importantly, the Judge reiterated that in principle, the State had the obligation to protect the right to life, but it did not force someone to continue to live against their will. There was no converse conclusion to be made that there was a positive duty on the State to ensure that a dangerous substance chosen by the person, or some other instrument, was available for the suicide[293]. The medical prescription requirement for the supply of sodium pentobarbital was based on a clear, sufficiently accessible, and foreseeable legal basis, to protect the health and safety of the population and to prevent the risk of abuse and the associated criminal offences.

The Federal Supreme Court concluded that where AS was permitted by using medical means, which should be decided by the legislature primarily, it was reasonable for the process to be controlled with medical rules, including the requirement of a doctor's prescription for lethal medication. It referred to the SAMS 2004 Guidelines for clarity regarding procedural correctness and repeated the steps that were the standard to follow. The Court accepted that there could be situations where a person suffering intolerably from an incurable mental disorder might be justified in being assisted with suicide, but a psychiatrist had to first confirm this in

an in-depth expert report[294]. (These findings relating to the requirement of a prescription for the use of sodium pentobarbital in an AS were confirmed later by the ECHR in Haas's case[295], followed by the case of Gross[296], during the period of 2009 to 2013.)

On hearing about the Federal Supreme Court's findings that mental illness could justify AS, the Swiss Federation of Medical Doctors was indignant and published its objections in a medical bulletin[297]. They said that it was dangerous to allow AS where it was difficult, or even impossible, to diagnose whether a person's wish to die was a consequence of the psychiatric illness itself.

Then, during 2008, despite the silence of the SAMS guidelines, a 70-year-old medical practitioner was sanctioned for prescribing sodium pentobarbital to elderly patients following only one interview with them. The Department of Health of the Canton of Zurich took the decision not to renew the medical license and the Federal Court supported it[298]. Again, in June 2009 a psychiatrist was prosecuted and convicted of homicide by recklessness for prescribing medication for two mentally ill patients[299].

The vagueness of the law was now causing the government concern. In the same year, 2009, the federal government contemplated introducing legislation to regulate the imprecise state of management of AS and to prevent abuse suspected of the voluntary organisations who continued to push the boundaries of the law. For example, Dignitas was by-passing the professional monitoring processes in place by keeping lethal drugs on its property, which was stopped after a court order enforced the law[300]. The Swiss Federal Council presented two alternative draft Bills to the Swiss parliament. It had wanted to establish minimal rules that would also prevent AS from becoming a profit-making business. In addition, the government intended to promote palliative care and suicide prevention strategies to reduce the number of suicides[301]. However, after much debate and deliberation, in mid-2011 Parliament determined that specific legislation for AS would not improve the confused environment but would rather have additional disadvantages such as legitimising the Right To Die organisations and making the value of life seem relative in the mind of the public, so that suicide would be more readily chosen as a reasonable option. It also mentioned that the doctors' professional bodies did not support turning assisted suicide into a medical practice and would not willingly accept the change in legislation. They did agree that the prescription of fatal medication should be each doctor's personal decision and responsibility, though[302].

Through 2010, legal challenges had continued to be brought to the Federal Supreme Court. Again, a person had asked for her right to AS by means of access to sodium pentobarbital, it being the safest option for a pain-free, risk-free death. The person was Ms Gross who was born in 1931 and had wanted to end her life for many years by the time she sought legal assistance. She explained that she was becoming more and more frail as time passed and was unwilling to continue suffering the decline of her physical and mental faculties. Ms Gross had attempted suicide in 2005 and then became an institutionalised psychiatric patient for 6 months. Her Swiss legal battle had begun in 2008 and ended in 2010, when, by April, the Federal Supreme Court had rejected her appeal on the same basis as Haas's case, so she approached the ECHR[303].

Gross's matter was finally heard in the ECHR in 2013. This Court criticised the lack of clarity surrounding the law related to AS in Switzerland. It observed that there was no legal indication of whether, or when, doctors could prescribe lethal medication for someone in the position of Ms Gross. The Court stated that the guidelines did not amount to law. Nevertheless, they were having a chilling effect on doctors who would otherwise have prescribed lethal medication for cases that may not have been associated with terminal illness but were still legitimate in terms of the anguish and suffering that the patient was experiencing, as in the case of Gross. Gross's personal situation had fallen outside the scope of the Guidelines. The Judges commented that the uncertainty Gross must have experienced regarding the outcome of her request about a very important facet of her life had to have caused her great anxiety. In this instance, the Court held that because of her suffering, Article 8 of the Convention: respect for her private life, had been violated. The ECHR acknowledged that Switzerland could well be confronted with difficulties in reaching political agreement on such controversial issues, as these questions had a profound ethical and moral bearing on society. Still, the Court said, such challenges were part of a democratic process that could not be avoided by those responsible for governing the country[304]. Notably, this judgment was handed down after Switzerland had tried, and failed, to decide on suitable legislation for AS in 2011.

(i) Advance Directives as legal instruments

On 1 January 2013, new legislation was enacted in Switzerland, the Law on the Protection of Adults[305]. It introduced advance directives and living wills as legal instruments to allow for representation in the event of incapacity. They are legally binding, as indicated in Article 372 of the Swiss Civil Code[306]. Switzerland differentiates between the two documents. Advance directives cater for people with legal capacity appointing either a natural person or a legal entity

to take over their personal or financial care in the event of incapacity, or to represent them in legal matters. The advance directive must stipulate the tasks that are delegated and can include precise instructions. It should be written by hand or be certified by a notary public. The other document, a living will, is drawn up by a legally capable person to indicate which medical treatment they consent to in the event of losing their legal capacity. They can appoint a natural person as a proxy to discuss medical decisions and procedures on their behalf, giving specific instructions.

SAMS then updated the 2004 Guidelines to incorporate it[307]. SAMS is a Swiss research funding institution, financially supported by the Swiss federal government, which describes itself as a 'bridge builder between science and society'. It collaborates with private foundations. Amongst other projects that it has, such as the promotion of professional training in clinical research, SAMS clarifies ethical questions related to medical developments and their effects on society[308]. The Guidelines had ethical weight, with consequences for an ethical breach by medical professionals, but were not applicable as law because they were produced by a non-governmental organisation[309].

In fact, in 2014 the nongovernmental Right-to-Die organisation, Exit ADMD (Association pour le Droit deMourir dans la Dignité), added a criterion that went beyond these 2004 SAMS directives. It specifically inserted that it was prepared to intervene at the request of patients who suffered from disabling age-related poly-pathologies, even in the absence of life-threatening illness. In all cases, the patient needed to produce a request in writing or by notarial deed, as well as a complete medical file. In addition, the individual had to be of legal age with full intellectual capacity to understand and be domiciled in Switzerland[310]. According to the Swiss Civil Code's Article 16[306], 'everyone is presumed to be capable of judgment within the meaning of the law, if they do not lack the capacity to act rationally by virtue of being underage, or because of a mental disability, mental disorder, intoxication or similar circumstances'. Exit ADMD, which caters for French-speaking Swiss residents, at that time was chaired by a doctor who examined all the requests and advised whether patients met the criteria or not[310].

Burkhardt *et al*., who analysed Exit ADMD's archived files, found that over time there had been an increase in the number of deaths as a result of poly-pathologies. This was possibly because it had gained more acceptance, although it was still seen as a controversial reason for suicide among the Swiss communities. A higher incidence of AS was found in urban areas compared to the rural ones. The researchers linked this result to a larger population density in

the urban regions, and also because of a greater religious influence in the rural cantons. The vast majority of members chose to die at their own homes. Nursing homes could choose whether to accept AS or not and could lay down their own criteria for acceptance of AS within legal parameters[310].

More recently, during May 2022, SAMS released its latest update of the *Medical-ethical Guidelines on dying and death*[311]. The revised version reflects a detailed expansion on the information related to the role of doctors with AS. These guidelines are important because they limit the range of opportunity for AS by making the criteria and procedure to access it more stringent. The guidelines state that AS for healthy persons is not medically or ethically justifiable, unless they can prove that their suffering is unbearable and that other options have been unsuccessful or have been rejected by the patient as unreasonable.

(ii) SAMS Medical-ethical Guidelines 2022

The new guidelines appear to be thoughtfully considered and well-written. The words of 2004 have now been amended so that AS is not categorically placed outside of doctors' duties but rather is a personal ethical dilemma for each individual to decide upon. It reads: 'At stake, on the one hand, is their autonomy in the exercise of their profession; on the other hand, they are being asked to display empathy and compassion, which are also required by their professional ethics. Respect for professional ethical norms and the values deriving from them is one of the fundamental duties of medical professionals'[312]. The guidelines continue by acknowledging the controversy surrounding whether supporting the person who wants to commit suicide is compatible with the duties that medical practitioners have to the public. Doctors are then given the leeway to decide for themselves and are reminded that they are always allowed to refuse to participate. The authors concede that, because of Switzerland's law recognising AS, and the range of attitudes towards its management expressed by medical practitioners and society, the conflicts between the ethical prerequisites for self-determination and those for the protection of life cannot be resolved. Another potential stumbling block highlighted by SAMS is that if a set of objective criteria were formulated for AS, questions about their limits would be difficult to answer, and people who met the criteria might feel they had an automatic right to be given AS resulting in pressure on medical practitioners to assist them. Furthermore, the new guidelines have added that, to justify why AS 'should be considered a medical matter at all', symptoms or functional impairments must exist that are identifiable as medical conditions[313].

Reading the content of the new guidelines, it appears as if the medical fraternity is becoming more steeped in the process of assessing eligibility for AS than they had previously wanted. This impression is strengthened by the fact that the guidelines begin the particular section of assisted suicide by reinforcing the fact that the 'true role' of physicians in managing end-of-life situations is to relieve the patient's symptoms and offer support[314]. Doctors are told that they do not have a responsibility to offer AS, nor must they feel compelled to implement it. Even though AS is legally acceptable, SAMS and the FMH (Foederatio Medicorum Helveticorum), which is the Swiss Medical Association, have stated in the guidelines that AS is not a medical procedure that society can demand from them. These sentiments resonate with the comments made by the government in 2011 when it decided not to accept either of the proposed Bills for regulating AS to prevent the public from viewing AS as a right in itself.

The medically ethical circumstances in which AS may be justifiable are presented according to four points of analysis applied, after which the doctor must be satisfied that the person is eligible. They are firstly that the patient must have the capacity to make the decision. Where there is a history of a mental disorder, dementia or some other concern, a specialist evaluation of the person's capacity should be performed in accordance with the law[315]. Secondly, the wish to die should be made autonomously and be well-considered. Two in-depth discussions are to be conducted at least two weeks apart to ensure that the decision is well-considered and enduring. Thirdly, severe suffering must be experienced, borne out by an applicable diagnosis or prognosis. The doctor needs to be persuaded that it is understandable why, under the circumstances, the person does not wish to continue living, and the doctor must document this insight. Fourthly, the consideration of alternatives must have been discussed. Other interventions ought to have been tried and found not to be efficacious or have been rejected by the patient. An additional independent third party, who does not have to be a medical practitioner, must ultimately confirm that the first two points have been met. All steps are required to be recorded. If the patient still persists with a request for AS, the doctor may assist and then takes personal responsibility for the participation[316].

The guidelines appear to have successfully 'medicalised' AS in that, if doctors are going to prescribe a lethal drug for the purpose of AS, they must be convinced that there is a rational medical basis for it, otherwise their behaviour could be labelled as unethical, leading to consequences from their oversight body. Doctors, practically, have the ability to veto a decision for assisted suicide, too, so wield power over the individual's self-determination, in this regard.

In a media release on 19 May 2022, the Swiss Medical Association, FMH[317] informed the public that it had adopted the revised guidelines into its code of ethics after The Chamber of Physicians, its authoritative body, voted to accept it. Their reason given was to offer more precise rules for doctors and patients to follow because, in the past, the guidelines were too vague. Although they do not carry the weight of law, the vast majority of doctors are members of the Association and therefore abide by their ethical rules. FMH represents 43 000 members and is the umbrella body for 90 medical organisations. After ten years of doctors expressing their anxiety with this dual role foisted upon them to heal as well as to assist with death, they have been given some clarity on how to approach it.

The acceptance of the guidelines into the medical ethical code, specifically the revised chapter 6.2.1 dealing with Assisted Suicide, had caused an outcry from private right-to-die groups such as the non-profit activist organisation Dignitas, and Exit ADMD. Dignitas released a statement on 25 May 2022[318], voicing its objection to the fact that the SAMS guidelines had received 'statutory status'. It pointed out that both the SAMS and FMH were private organisations who did not have the authority to make law, but once the FMH accepted the guidelines into its statutory rules of conduct they became internal directives that members of the FMH would follow as self-imposed conduct. A court would also use the code of conduct as an indication of the acceptable standard of professional behaviour, when relevant, so the decision to incorporate the SAMS guidelines into the FMH code was significant.

Dignitas claimed that 90% of medical practitioners were members of FMH. Consequently, almost all doctors would abide by these revised guidelines. Issues for them were two important new details: the first was the fact that a doctor was to interview the patient twice, at least two weeks apart, although exceptions could be made to the time-lapse, where justified. This was a problem, not because of the requirement of two interviews, which had been a necessity in the canton of Zürich for a long time, but because of the two-week delay between meetings. Dignitas wrote that many people travelled to Dignitas from abroad and would need to stay in Switzerland for a longer than expected time-period, at great expense, while often extremely unwell. It acknowledged, though, that these circumstances ought to be treated as an exception justifying a shortened time frame[318].

The second concern was that the new guidelines removed the measurement of suffering from the subjective view of the patient to a more objective assessment made by the doctor, associated with a medical diagnosis, which Dignitas saw as both more labour-intensive and paternalistic

of the FMH, undermining an individual's self-determination. Dignitas said that this would lead to the need for increased detail in the doctor's internal documentation and reports while assessing a patient sent from Dignitas for a consultation. In addition, the reports submitted by Dignitas to be reviewed for AS eligibility would need to be in-depth and comprehensive about diagnosis, progression of the illness or disorder, the history of treatments, medication, and other relevant information, making it even more difficult for suffering patients to access AS through Dignitas. Dignitas confirmed that even before the updates, when there were difficult cases where patients presented with mixed physical and psychological distress, physicians were sensible and responsible in their observations of the patients, performing careful assessments before permitting PAS. If it were otherwise, the doctors would have exposed themselves to potential disciplinary sanctions from the Swiss Cantonal Health Authorities who could have withdrawn their licences to practice. Families of patients might also have lodged formal complaints against them if they were dissatisfied with the outcome[318].

The founder of Dignitas, lawyer L.A. Minelli reiterated that their intention as an organisation was to make end-of-life choices safe for everyone involved: for the patients, their families and the doctors. Dignitas held the view that the tightened guidelines made access to what they believed was presently the best means of committing suicide, sodium pentobarbital, more difficult than other options. The organisation concluded its media statement by declaring that it would monitor the reception of the guidelines going forward and discuss them with various parties, including consulting doctors and medical and legal experts[318].

(iii) Recent developments.

In the meantime, completely aside from all the controversy surrounding the more stringent role of the doctor related to AS, a 3D-printed capsule has been designed for death. Its creator, Philip Nitschke, the founder of the Australian activist group Exit International, hopes it will be used in Switzerland to de-medicalise AS in the future[319]. The capsule, called Sarco because it looks like a sarcophagus, allows a person to lie down inside it, then a transparent cover is closed over them as a seal. Once the person is settled, a button inside can be pushed to release nitrogen from the inside. After a short time frame, hypoxia and hypocapnia set in resulting in death[329].

Despite Nitschke having suggested in interviews that organisations in Switzerland were interested in his invention, and that it had passed legal scrutiny, apparently both Exit and Dignitas have denied any interest, saying that their lethal medication is effective. In fact,

Nitschke was found to have misled the journalist who interviewed him for Swiss news regarding his facts about its legal status, too. However, a new association called Pegasos, established in 2019 and based in Basel, may be supporting him, implied in the wording of the website, briefly alluded to below.

4.1.7.2.2. Euthanasia in Switzerland.

The investigation of Switzerland's legal environment would not be complete without a few comments about the place for euthanasia as an option for death. Euthanasia is illegal in Switzerland under Article 114 of the Penal Code, despite ongoing debates about it being decriminalised. It is, however, dealt with as a lesser offence than murder or culpable homicide in terms of sentencing[285].

In 1997, a proposal was placed before the Swiss parliament to decriminalise E. The federal government then commissioned a working group to investigate the prospect and the majority supported the idea. The criteria were comparable to the way other countries had begun this course of action, by limiting it to a competent, terminally ill patient, who was suffering intolerably and had made a persistent request. The twist was that the working group, made up of doctors, ethicists, and lawyers, explicitly included a clause where the performance of E could be done by non-medical personnel on the understanding that they would not be committing a greater offence than that of a medical practitioner. According to Hurst and Mauron, the reasoning was that it would be hazardous to establish an environment where non-legal helpers could be prosecuted while doctors were not. Ultimately, Parliament did not support the proposed amendment to the law and the debates have been ongoing.

Then, in 2009, a young woman of 43 years old who was suffering from an advanced degenerative neurological disease, amyotrophic lateral sclerosis (ALS), approached the Exit association to request AS. Based on her medical file and her full capacity for judgment, Exit was willing to support her wish. The accompanying doctor, Dr Daphne Berner, a former cantonal doctor from the area of Neuchâtel, carried out the interviews with the patient and finally went to see her on a date arranged in order to perform the AS set-up procedure for IV administration of the drug. However, once in the presence of the patient, Dr Berner observed that the patient had deteriorated rapidly and was no longer physically capable of rotating the tap of the IV line to allow the in-flow of the pentobarbital. The doctor decided to proceed with the process by turning the tap open herself, in place of the patient, as the patient had reiterated

her request to end her life with AS. When the medical examiner arrived on the scene, Dr Berner made a full disclosure of what had occurred, and the Public Ministry of Health was notified. An investigation was ordered, including a forensic autopsy in accordance with the law, because direct active euthanasia is prohibited under Article 114 of the Swiss Criminal Code, (murder at the request of the victim)[310].

A trial was held in 2010 at the Boudry Correctional Court to prosecute Dr Berner. At the time of the hearing, there was a great deal of internet support from people who praised her compassion and courage, giving insight into public sentiment. Dr Berner was, in fact, finally acquitted by the court on 6 December 2010. Judge Bastien Sandoz held that Dr Berner was faced with no other alternative but to preserve the patient's free will and human dignity. Not to have acted, he said, could have been considered as cruel treatment. The acquittal was based on the defence of a state of necessity, under Articles 17 and 18 of the Swiss Criminal Code, in circumstances where the patient was paralyzed to the point that she could no longer help herself. For this reason, the act was lawful and excusable[321]. The wording of the Articles is notable, because, like Article 115 permitting assisted suicide for unselfish reasons, this law also caters for the exercise of a 'higher value'. Article 18 incorporates 17 and reads as follows:

'Art. 18: 1. Any person who carries out an act that carries a criminal penalty in order to save himself or another from immediate and not otherwise avertable danger to life or limb, freedom, honour, property or other interests of high value shall receive a reduced penalty if he could reasonably have been expected to abandon the endangered interest. 2. If the person concerned could not have been reasonably expected to abandon the endangered interest, he does not commit an offence'[6].

Dr Jean Martin, who had been a member of the Swiss National Ethics Commission, studying the subject of assisted suicide for two decades, and having published two in-depth reports on the topic, considered the verdict to be correct. He wrote that he supports the idea of allowing 'euthanasia exceptions' where one accepts that euthanasia may be tolerated in certain circumstances. He referred to a review produced in France that shared the sentiments that a 'euthanasia exception' could be provided and controlled through the legal system, where the judge made the final decision, after considering the circumstances of each case. In this way a general law would be avoided. Dr Martin said that he supported this approach because, importantly, it did not obscure the vague character of the practical limit between assisted suicide and euthanasia[321].

The insight he gave was an interesting outlook. He explained that, in his experience, the law could create a framework of principles but could not do justice to the very private dimension of the situation that medical practitioners faced when confronted with the reality of the relationship between the doctor, the patient and the relatives. Dr Martin believed that the medical staff involved were confronted with dilemmas that clearly relate to a state of necessity, and rather than refusing to notice, it was better to look for acceptable solutions. Another provocative aspect of his writing is that Dr Martin expressed the same attitude towards formalised legislation as the government discovered in 2010 when various draft Bills were debated with stakeholders: that detailed legislation would be perceived as legitimising public authority, presumably to control self-determination, which Swiss society protected passionately as a right to be respected, according to opinions in the literature[310, 285, 321, 70]. He stated that it was important to avoid this happening, where obstacles or delays were put in place that were disproportionate to the exercise of the freedom of choice, under the pretext of protecting Swiss residents who were mentally competent to decide for themselves what they wanted for their own lives. His opinion was that the choice to die was part of their intangible freedom of choice as a society. Therefore, the vagueness surrounding the legal and ethical question of death was a necessary 'rampart' to protect these rights. Dr Martin acknowledged that this theory that 'vagueness' was beneficial was surprising and one would struggle to convince those who saw life as clearly split into 'right and wrong' that it was essential.

A final observation Dr Martin shared was that the model of the state constructing oversight commissions to authorise or refuse E or PAS, which would necessarily be public in character, should not be done. In Switzerland people had apparently suggested cantonal commissions to oversee AS decisions in the past, and the same problem alluded to above arose, that suicide apparently would become endorsed by an official body with a 'stamp of approval', potentially changing the social mindset towards AS, it becoming more normal and acceptable within society. Furthermore, Dr Martin pointed out that by the state taking responsibility for decisions through its commissions, it reduced the individual responsibility of the doctor to the patient, which could also affect the rigour with which these decisions had been treated up until now.

4.1.7.3. The Right-to-Die Associations

In order to understand how the system works to achieve AS in Switzerland, the following information is presented for comparison with other countries that are discussed in the thesis. The entities are all nongovernmental institutions, and are not-for-profit, as required by law.

(i) EXIT Deutsche Schweiz and ADMD

Exit Deutsche Schweiz, for German-speaking residents, founded in 1982, has its headquarters in Zurich, while the French-speaking Exit ADMD headquarters are situated in Geneva. Zurich's Exit website[322] advertises that it assists with living wills, offers palliative care through its foundation, gives counselling for problems related to old age or illness, has suicide prevention interventions, and performs 'physician-assisted suicides'. These services are available to members at no additional cost after the annual fee of 45 Swiss Francs (as at 2022) is paid. There are currently 50 trained PAS assistants who would have undertaken special training for a year and been assessed by the University of Basel, as required by the Exit society.

The criteria applied by Exit Deutsche Schweiz are self-imposed through its by-laws and internal guidelines. Exit ADMD will help people with hopeless prognoses, unbearable symptoms, unacceptable disabilities, and persons who are suffering in old age, while taking their psychosocial situation into account. With regard to mental health disorders, people are only assisted after careful assessment by two independent experts and a finding of the Society's Ethics Commission. These cases are rare. Where a disability such as Alzheimer's disease is present, only people who are still capable of exercising their own capacity to consent may be helped, unless a living will has been prepared. These standards are more detailed than the general legal standard which requires legal capacity, an autonomous, persistent and duly considered wish to die, with no coercion, done under their own hand[323].

The Exit Deutsche Schweiz procedure for AS is as follows: when a member of Exit has reached the decision to commit suicide, 1) they must submit a certificate confirming they have the capacity to make judgments, and any medical or hospital reports available for review. 2) Once reviewed and found to be acceptable, an end-of-life attendant will visit the person to discuss the situation and interview them. Alternatives to suicide such as palliative care and hospice are also investigated with the person. 3) If the member persists with the request, confirming the desire to die, preparations for PAS will commence and a doctor must be asked for a prescription. This prescription could be given either by a general practitioner, the attending physician, or a consulting physician affiliated with Exit. 4) Exit head office will obtain the drug for the member and have custodianship over it until it is used. 5) If, and when, the member decides to pursue AS, the date and place of the death is co-ordinated with the attendant. 6) On the date, the attendant brings the lethal substance, which is either in an oral form for ingestion once dissolved in water, or as an intravenous infusion. The setting may be at the member's home or at a venue

provided by Exit. The attendant sets the ambiance as part of the preparation and people who are close to the member may be present. Once the lethal medication is taken by the member, whether swallowed or by turning on the tap of the infusion, there are a few moments to say goodbye before respiratory and cardiac arrest set in and death is accomplished. 9) Legally, the death is classified as an unnatural death, so the Swiss police are notified in order for them to come and inspect the process. A medical officer of health accompanies them to certify the death, and a district attorney may also be present to do a legal inspection of the documents and that other legal provisions were observed. Exit claims that autopsies are extremely rare because it is careful to abide by all the rules[323].

According to Exit Deutsche Schweiz's published information as at 31/12/2021, around 3 500 requests for AS are received per annum, but only 1 328 cases are approved post review and ultimately 973 ASs performed[322]. Clearly, by referring to 'physician' assisted suicide, Exit does not differentiate between the doctors' medical role linked to healing and their assistance with suicide. In truth, AS could not occur without the doctor's prescription at this stage, when sodium pentobarbital is the favoured drug of choice.

(ii) Dignitas.

Dignitas was founded in 1998[324], with the philosophy 'To live with dignity - To die with dignity'. It has consistently held that it offers a service of support and guidance for anyone struggling 'in' life, whether wanting to commit suicide because life's problems have become too great, or for those at the end of life, because the burden of illness or suffering has become intolerable. People are directed to the support they need, most often telephonically. Dignitas also educates and instructs on how to prepare advance directives or living wills under Swiss law and will retain the documents in safe custody for the day they may be required.

Besides the wide range of daily advisory work that it does, Dignitas is also an activist group, committed to assisting the fight for people's human rights worldwide, so that individuals can determine their own time and manner of their death. Consequently, it is well-versed in the law and participates in legal actions that arise[324]. On its website, it proclaims that it has the goal of becoming unnecessary, which will happen once every country allows access to legal and safe help for people to realise their end-of-life wishes, and this becomes embedded in healthcare systems. Within Switzerland, too, Dignitas would like the service they offer to be part of the public healthcare infrastructure, comparable to the Netherlands, Belgium, and Canada. This

sentiment indicates that despite the protestations by Swiss doctors that it is not part of medical practice, society views it differently, associating the process of AS with healthcare services. The concept is medicalised because of the legal requirement that a doctor must write the prescription for lethal medication, and the ethical requirement that a prescription can only be written once the doctor is personally satisfied that a medical assessment justifies the prescription. In fact, Dignitas uses the terminology of 'physician-supported assisted suicide', as does Exit.

Dignitas is renowned for having opened its doors to foreigners who wanted to die on their own terms, and consequently, it has a substantial number of supporters and members throughout the world. As of 2021 it recorded 11 024 members[325]. Only members can benefit from the provision of AS. Dignitas states that it will procure the barbiturates required to facilitate a quick and painless end to life, but it still needs a doctor's prescription in terms of the law. Swiss residents are often able to obtain their prescriptions from their family GPs now, otherwise Dignitas will refer them to a doctor who is prepared to help the association, as is the case with non-residents. The procedure Dignitas uses complies with the general medical guidelines already explained above. In addition, Dignitas stipulates that there are always at least two people present at an accompanied death so that they can testify to the course of events[326].

Pre-requisites for AS include that a person needs to be a member of Dignitas, an adult of sound judgment, and possess a minimum of physical mobility to administer the drug. Also, in order to receive the cooperation of a Swiss doctor which is essential, a person must be suffering from either a disease that will result in death, or an unendurable incapacitating disability, or unbearable and uncontrollable pain. The documentation that Dignitas asks for is a biographical sketch or CV in which the member's circumstances are described, including whether their next of kin support their wish for AS and to what extent, and if any of them would accompany the patient to Switzerland so that the staff have a clear picture of their personal background. Up-to-date medical reports, with two or three older records, are also to be submitted. The most recent report should not be more than four months old. This information should include great detail about the case history, diagnosis, prognosis and, preferably, treatments that were tried, as well as other suggested measures discussed. Once the Swiss doctor is provisionally satisfied that the person has a situation that fulfils the criteria for justifying AS, the member is given permission to travel to Switzerland. However, the doctor only finally consents to prescribe the lethal dose of barbiturates once the patient has had a personal consultation with the doctor[326].

In terms of current cost, Dignitas asks for a once-off joining fee of 200 Swiss francs (CHF), (approximately €193). Thereafter, annual membership is at each member's discretion, but at least CHF 80 is required to be paid, and if members are unable to make this payment Dignitas is open to re-negotiate the fees[327].

There has been controversy in the media surrounding some of Dignitas's practices in the past, such as it filming deaths using gas and plastic bags during 2008 in order to have evidence that the decision of the person to die was voluntary and the death was by suicide. The information was exposed in a British newspaper at the time, claiming that the footage was received by the Crown prosecutor of Zürich[328]. According to the article, the reason for the alternative method of suicide was to avoid the prescription and medical supervision which was more complicated and costly. No alternative methods in use have been alluded to in 2022 on the Dignitas website. Another incident over which Dignitas was criticised was for allowing double suicides for couples wanting to die together. In 2009, a lot of publicity was given to the case of the British music conductor, Sir Edward Downes, who, at 85 years of age, with his wife, Joan, aged 74, flew to Dignitas for a double suicide. Joan had terminal cancer and her husband, who was almost completely blind and deaf, depended on her as his primary caregiver. The family reported that they had enjoyed their lives and died happy, after having spent 58 good years together[329]. Despite these controversial stories from years gone by, Dignitas submitted to case reviews done by researchers in 2009 who confirmed that all their documents were consistent with the government records of reported deaths[286]. Dignitas has continued to sustain an active presence in activism with ongoing support.

A noteworthy comment on the website is that in its experience, Dignitas finds relatively few people who have joined as members take advantage of the service for AS offered. It is of the opinion that people appear to feel sufficiently protected once their instructions have been captured in an advance directive or living will, stating that no life-prolonging measures must be used if a life-threatening situation arises, so that a natural death ensues. Members have renewed confidence also knowing that they are able to choose when they have had enough of coping with a hopeless situation. Dignitas suggests that the sense of security in this knowledge is of the utmost importance to 'mature human beings'[326].

(iii) Pegasos-Association

This new voluntary assisted dying (VAD) association was established as recently as August 2019[330]. It is situated in Basel and markets itself on being both a Swiss and an English language

service, as well as having a 'minimal-bureaucracy approach' to death. It costs €100 as a joining fee followed by annual payments, and €10 000 for the procedure with all the administration pre- and post-service. It is open to foreigners[331].

The website explained that the procedure to end life must be performed by the individual. Generally, the intravenous method using Nembutal seemed to be favoured by the association, but if preferred, the person had the choice of drinking the medication with an anti-emetic drug, to prevent vomiting. The website went on to say that 'other approaches are also available', which could be discussed once the VAD application was approved[332]. These comments just might have been alluding to the Sarco pod which was rumoured to be introduced in Switzerland in 2022, mentioned earlier[320].

For the IV method, the person needed to be able to turn the tap situated on the IV line that was attached to the cannula in the arm, in order to begin the infusion. If the person was unable to rotate it because of weakness or disability, the website described an alternative device that could be used which had been specifically developed by Pegasos. A single bump was necessary to start the infusion. This could be achieved through movement of the arm, body, or feet. Even a slight turn of the head, or by using the tongue, a flow could be achieved. Another notable feature was that pets were welcome as part of the family support[332].

In conclusion, each nongovernmental Swiss association has specific features that appeal to different needs. For the health sector, this arrangement of having assisted suicide outside of the public health infrastructure may be a less controversial and less complex model than what other European countries have implemented.

4.1.7.4. Public health sector

Despite the existence of the nongovernmental organisations, between 2013 and 2014 two Swiss cantons, Vaud and Neuchâtel, adopted legislation to clarify the rights and duties surrounding AS for citizens within their areas. Hurst and Mauron[333] explained what happened in Vaud. Vaud voted in legislation during 2013 to allow residents access to AS in state-run and state-subsidised healthcare institutions[334]. The Vaud Public Health Law, translated from French, prohibited healthcare institutions that had public-interest status from preventing AS being performed in a healthcare facility where a patient or resident had requested it. However, certain conditions had to be fulfilled[335]. A written request needed to be submitted to the management of the

establishment or care facility. The request was then checked by the doctor in charge in consultation with the healthcare team, or treating doctor and the representative or relatives, depending on the circumstances, to ensure that three criteria were met: the person requesting AS had the capacity for judgment, the decision was enduring, and the person was suffering from a serious and incurable illness or sequelae, such as from an accident. If there was any concern that the person was being coerced or that a mental disorder was present, a psychiatrist was required to make an assessment. The provisions of the Act also required that all alternatives to AS, especially palliative care, had been considered and that the person felt no other option was suitable. Vaud's website indicated that it was up to the responsible physician to decide in writing whether to allow the AS or not. Reasons were to be given justifying the outcome, with comments on whether the conditions were met, whether the person was able to go home, if admitted in hospital, and whether the patient could sue the Cantonal Mediation Office or the Vaud Complaints Review Commission if there was a disagreement. This information was to be conveyed to the person within four weeks[334]. Hurst and Mauron mention too, that once permission was given, although it was not clearly stated, the understanding was that the person seeking AS would contact a right-to-die association to take the process further. Also, employees of the institutions were not allowed to be involved in the AS in their professional capacities. The authorisation given by the institution would therefore have only been to allow AS to proceed on the premises, without an undertaking to provide it. Although the legislation was viewed as somewhat limiting, Hurst and Mauron explained that this legislation was significant because it was the first time in Switzerland that a law had made it a duty to refrain from preventing AS under certain conditions[333].

4.1.7.5. Social and cultural environment.

Portrayed as wealthy and orderly, Switzerland is described as having enduring stability and political neutrality. This has made it the perfect choice for the headquarters of a wide range of both governmental and non-governmental organisations, some of which are associated with the United Nations, which Switzerland joined in 2002. It is also a major financial centre. The economy is based largely on international trade, banking, and light and heavy industries. However, tourism and agriculture are also important contributors to the country's income[282].
Compulsory social security insurance was initiated at the federal level in 1948 for annuities and pension allowances to be paid out to senior citizens, widows, orphans, and people with disabilities. It was inadequate to cover the cost of living, so mandatory occupational pensions were introduced later, financed by employers and workers. More recently, a voluntary private

pension scheme was also started, motivating people by offering tax incentives. In addition, employers and employees contribute financially towards unemployment insurance which is a federal law. The destitute receive additional financial support from the general revenue of the Swiss Confederation as well as cantons[336].

Universal health insurance is also a federal law, although the health infrastructure is organised within the cantons, extremely decentralised, resulting in varying contributions toward health between the cantons. The range of coverage offered under the mandatory health insurance includes most visits to medical practitioners, hospital care, pharmaceutical products, home care, devices, medical services associated with long-term care, and physiotherapy. Private health insurance can be purchased to supplement services that are not paid for by the mandatory insurance. This gives a wider choice of medical practitioners and the opportunity to use better hospitals[337].

Overall, a quarter of total expenditure goes toward social welfare payments, which is significant. Unsurprisingly, the Swiss care and services are considered to be among the best in the world. Switzerland was ranked as first out of 31 countries in 2021, the second year in a row[338].

4.1.7.6. Comparison with South Africa

As with almost all the previous countries examined, and in contrast to South Africa, Switzerland is well-established, stable, and wealthy, with a strong social infrastructure. The health system is considered to be good, and everyone benefits from universal health care.

Switzerland is unique in its approach to assisted suicide, keeping it outside of the health infrastructure. Although doctors are necessary to assess patients so that prescriptions for the lethal medication can be given, they are excluded from any further professional involvement if they choose, and nongovernmental organisations take over to manage the final process.

The model is attractive because of isolating the practice of AS in a manner that does not confuse the role of medicine, nor the health system, with killing those who do not wish to receive medical care any longer. It also prevents moral desensitisation of staff by them not being part of an ongoing process.

If South Africa chose to embrace AS law in the future, these are the same reasons why South Africa could benefit from keeping the practice of AS out of the over-burdened public health system, allowing not-for-profit nongovernmental organisations to manage it.

4.1.8. Oregon, USA

4.1.8.1. Introduction

Oregon is presented here as a comparison to Switzerland and an example of the assisted suicide law that is applied in some states in America because it was the first one to embrace it. Currently, 11 states have permitted MAID (medical aid in dying) along similar lines to Oregon, with minor variations. No state allows euthanasia. Alphabetically, those with MAID legislation in place as of January 2023 are California, Colorado, District of Columbia, Hawaii, Maine, New Jersey, Oregon, Vermont and Washington. Montana has legalised the choice to terminate life through a Supreme Court ruling, but has no statute enacted yet, and nor has New Mexico, which has also ruled through the court that terminally ill patients may receive lethal medication[339].

Oregon is one of the 50 constituent states of the United States of America. It was admitted as the 33rd state in 1859. The borders of Oregon are the Pacific Ocean to the west, Washington state in the north, Idaho to the east and Nevada and California in the south. Consequently, Oregon has a fascinating and diverse landscape of mountains, desert systems, rain forests and rivers[340].

Oregon's Constitution was adopted as early as 1857. Its government, similar to the model of America's federal structure, is composed of three branches of authority, an Executive branch, the Legislature and the Judiciary[341,340]. The Executive branch is made up of five representatives, one of whom is the Governor, Oregon's head of state. The Executive is responsible for administration of the laws through departments, boards and commissions that formulate regulations comprising the Oregon Administrative rules.

The Legislature consists of a State Senate and House of Representatives to draft and update the law related to topics such as health, education, and general welfare, as well as deciding upon aspects of the economy and the environment.

Oregon's third branch of government, the Judiciary, interprets and enforces the law. It has its

own Supreme Court with seven justices. This court has oversight over all the other courts. A separate Court of Appeals exists, composed of 10 judges. It hears criminal and civil appeals, except for death-penalty (capital) cases and tax matters, heard by a specialised Tax Court. It also reviews administrative matters related to state agency. Another important role is to ensure that the actions of the executive and legislative branches comply with the state Constitution. At a lower level, the circuit courts are the courts of general jurisdiction.

Oregon has 36 counties that have considerably more local discretionary authority than those in other states. Many counties are governed by a judge and two commissioners, while approximately a quarter of the counties have chosen home-rule charters, allowing them to establish their own form of government, still in line with the state and federal constitutions. Consequently, they may not criminalise conduct that state law allows, nor allow conduct that state law forbids[342].

4.1.8.2. History of E legislation

As an initiative of the people of Oregon lobbying for assisted death law, The Oregon Death with Dignity Act (DWDA) was passed in a general election on 08 November 1994 by a margin of 51% to 49%[342]. Being permissive law, the DWDA was immediately followed by an injunction until it was lifted, resulting ultimately in its enactment on 27 October 1997[343].

Further interest surrounding assisted death was ignited during 1996 and 1997, when, in the matters of *Vacco v Quill* (New York) *and Washington v Glucksberg* (Washington), a few physicians and their terminally ill patients challenged their states' bans on assisted suicide[344]. Their contention was that the help of a doctor to facilitate a terminally ill person's choice of the time and manner of their deaths was part of their constitutionally protected liberty interest. The Court rejected these arguments and said that while each person had a right to refuse life-sustaining treatments, they did not have a Constitutional right to be assisted by a doctor to end their lives. The Court drew a distinction between 'letting die', which was already legally permissible, and 'making a person die', declaring that the distinction was 'important, logical, rational and well-established', in line with the fundamental principles of causation[345]. It held that the interest in deciding the 'time and manner of one's death' did not encompass a protected right to assisted suicide[346].

The two landmark Supreme Court decisions confirmed that the US Constitution did not protect

a right of a person to have the help of a physician to end that person's life. However, the states were encouraged to decide for themselves whether to permit the law or not, and under what circumstances. These cases were seen to be the catalysts that drew attention to the plight of the dying patient and their end-of-life care. The Court further acknowledged that dying patients had a federal constitutional right to adequate medication to relieve pain, even if it hastened death.

Then, in 2006, a legal challenge was brought to Federal Court by the State of Oregon to overturn an interpretive rule issued by the US Attorney General to overturn the DWDA, in the case of *Gonzalez v Oregon* (originally Ashcroft v Oregon)[347]. The interpretive rule determined that the use of controlled substances to end a life was not a legitimate medical practice. Therefore, dispensing and prescribing drugs with that purpose in mind was unlawful under the Controlled Substances Act. This Act had been promulgated in 1970 to regulate the manufacture, distribution, dispensing, and possession of controlled substances. The result was that a divided panel of the U.S. Court of Appeals (6:3) held the interpretive rule to be invalid because the Attorney-General did not have the authority to make such as a rule. It also held that, by trying to forestall state law related to medical practice, the rule impermissibly altered the 'usual constitutional balance between the States and the Federal Government'[348]. Consequently, the legal validity of states allowing PAS as part of medical practice was confirmed.

4.1.8.2.1. Death With Dignity Act, Oregon Revised Statutes[349]

In terms of the Act, eligibility for assisted death is much more conservative than Switzerland's conditions. It only allows (1) adults over 18 years of age, (2) who are mentally competent to make decisions, (3) suffering from a terminal illness and who have approximately less than six months to live, to choose to end their lives by obtaining a doctor's prescription for lethal drugs that must be ingested themselves. The personal ingestion of medication is the final protection in place to ensure that the act is entirely voluntary. Besides making oral requests, the person is required to make a written request to the attending doctor, signed in the presence of two witnesses, one of whom must neither benefit from the death of the person nor be a relative[350].

The Oregon government website[343] points out that the DWDA does not indicate whether all other treatment options must have been exhausted before the person is eligible for a prescription, nor does it mention any health insurance payment requirements for the treatment of disease. This aligns with the E law of other countries discussed previously that simply require

the conversation about alternative care and treatments to have been initiated between doctor and patient.

The Oregon DWDA also stipulates that health care providers are under no legal duty to participate in MAID and they can prohibit other health care providers from performing MAID on their premises[351]. Health care providers are defined in the Act as persons authorised by law to administer health care, including health care facilities[352].
Differences between the American states compared to most other E and PAS countries are the life expectation limit of only six-months left to live, and that the patient need not express that they have unbearable or intolerable suffering that cannot be alleviated[58].

4.1.8.2.2. DWDA Safeguards[353]

To prevent errors and malpractice, the DWDA has enacted certain precautionary measures. Two physicians are to be involved in the assessment process. Both an attending physician who is managing the patient, and a consulting physician who has confirmed the diagnosis and prognosis, need to verify the correctness of the details of the patient's residency, diagnosis, prognosis, mental competence, and voluntariness of the request in writing. There are forms to be completed by the doctors in terms of the DWDA. The attending doctor must have given the patient full information to ensure that an informed decision had been reached. This discussion should have covered the diagnosis, prognosis, potential risks of taking the medication prescribed, the probable result of ingesting the lethal substance and any reasonable alternatives to MAID that were available such as comfort care, hospice care and pain control. The doctor is also required to suggest that the patient inform their next of kin of the decision, and to stress the importance of having a second person with them at the time that they ingest their prescribed medication, which should not be taken in a public place. If one of the physicians is of the opinion that the patient's judgment is impaired because of a psychological or psychiatric disorder such as depression, the patient needs to be referred for counselling.

In total, the doctor receives two oral requests and one written request. There are also two waiting periods, one between the oral requests (15 days between an initial oral request and a written request to allow for a period of reflection) and the second between the receipt of the request and fulfilment of the prescription of 48 hours[353, 354]. At the second oral request stage, the DWDA makes it necessary for the attending doctor to remind the patient that they can withdraw the request at any time. Just before the prescription is ultimately written, the attending doctor must

check that the patient has made an informed decision. Once satisfied, the doctor is to either dispense all the medication, including the required ancillary medication directly, if authorised to dispense, otherwise, with the patient's written consent, they must contact the pharmacist to inform them of the prescription and its use. The DWDA stipulates that the doctor should deliver the prescription personally, or by mail, and then the pharmacist may either dispense the medication to the patient, the attending physician or an expressly identified agent[353].

In line with the rules promulgated under the Act, the doctors are expected to report all prescriptions issued to the Oregon Health Authority (OHA), Center for Health Statistics. As previously alluded to, doctors are not obliged to prescribe prescriptions. They must be willing to participate voluntarily, so can refuse to be involved.

The next level of monitoring that has been instituted is with the submission of all completed, signed, and dated forms listed in terms of DWDA to the Center for Health Statistics within 7 calendar days of writing the prescription. The forms are i) the patient's 'Written Request for Medication to End My Life in a Humane and Dignified Manner' form, confirming full awareness and understanding of the decision to have MAID, handed to the attending doctor. (The patient is instructed to keep a copy at home, too); ii) the 'Attending Physician's Compliance Form', which has a checklist ensuring each provision of the DWDA has been completed; iii) the 'Consulting Physician's Compliance Form', also with a checklist of facts to be completed; and iv) if necessary, a 'Psychiatric/psychological Consultant's Compliance Form'. Aside from these forms, the dispensing health care provider has a responsibility to submit a copy of a form that is filled in with all the details related to the prescription that has been dispensed, a 'Pharmacy Dispensing Record'. Submission must be within 10 calendar days of dispensing the medication[355].

The final provision under the section of Safeguards in the DWDA reinforces the fact that death by lethal injection, mercy killing, or active euthanasia is outlawed, and that actions performed in terms of the DWDA do not constitute suicide, assisted suicide, mercy killing or homicide[353].

Once the patient has either taken the medication or died from natural causes, and the attending physician has either been notified or was present at the death, the doctor is required to send in a final document about the details of the death. The 'Attending Physician Follow-Up Form' asks a series of questions for research purposes, including the reason why the patient chose MAID, and whether they ultimately utilised MAID, after all. This is to gauge the situation at

the time of death and to try to understand a little more about the psycho-social aspect of the decision[356].

The law does not require a doctor to be present at the death, but if the patient chooses this, it is acceptable, as long as the doctor does not administer the lethal medication personally. The attending doctor for the patient is also allowed to complete the death certificate. The OHA, Center for Health Statistics, advises doctors to insert the underlying disease as the cause of death, not MAID, and indicate that the manner of death was 'natural'. The reasoning behind this is for confidentiality to be preserved, while the Center receives full information through submission of the obligatory forms for statistical purposes[343]. Notably, the DWDA specifically provides that the decision to take lethal medication must not affect life, health or accident insurance or annuity policies, nor should the making of a request for medication affect the sale, procurement or issuance of a life, health or accident insurance contract or annuity policy, including the rate charged for these contracts[353].

4.1.8.2.3. DWDA Oversight[343]

Significantly, the law does not provide a specific system of oversight or regulation of medical practitioners who are involved with PAS, in contrast to the countries that offer E. The DWDA only requires that an annual statistical report be published by the OHA to share information about the patients and physicians who are involved with MAID[353]. Thus, the OHA is responsible for collecting data about participation in MAID and compiling the report. However, because it has not been assigned to check the process, it does not verify that patients meet the criteria or confirm any other facts related to eligibility, time frames and other details. The Oregon government website[343] explains further that the OHA also does not interpret the statute except for the section that pertains to it on reporting requirements. No other oversight regulation of the doctors exists beyond what is normally expected for medical care within the health system. Consequently, doctors carry all the responsibility themselves for ensuring that criteria are met and that no errors are made. Nonetheless, if the OHA does become aware of non-compliance within the information received from a doctor, this would be reported to the Oregon Medical Board which can investigate further and implement disciplinary action, if appropriate[343].

The OHA cross-checks the death certificates against the forms submitted. A follow-up call is then made to the attending doctor to confirm whether the death was a result of ingesting lethal

medication or natural. All patients and physicians are guaranteed confidentiality because the state does not release this information. Physicians who participate are referred to by codes in the report, whereas no reference is made to the patients' identities. The OHA also does not recommend doctors to people seeking assistance with suicide to protect their identities[343]. It is interesting to note that on the government website it says that after approximately a year all source documentation is destroyed.

4.1.8.2.4. Recent updates to the law

Oregon amended the law on 24 July 2019 to create an exception to the 15-day waiting period between oral requests[357], in order to allow certain terminally ill people quicker access to assistance with dying, where the physician foresees that the patient is likely to die before the time has passed. Those with less than 15 days left to live may by-pass the waiting period. Likewise, if the attending doctor believes the patient has less than 48 hours to live, the last time frame can be ignored. In both circumstances where the statutory time-period is not completed, the doctor is expected to submit a medically confirmed certificate of the proximity of death, along with a medical record[343].

In March 2022, Oregon ended the residency requirement for MAID following a successful court challenge by a national advocacy group called Compassion & Choices that sued Oregon on the grounds that the law was discriminatory and unfair to dying patients[358, 357]. The action was based on Dr Nicholas Gideonse's complaint that, as a family practice physician and palliative care specialist, he could not assist his patients who resided in the neighbouring State of Washington when they sought a prescription for assisted dying, so had to refer them elsewhere in Washington, interrupting their continuum of care. Washington also has MAID law in place, but within Clark County where his patients resided, there were many healthcare facilities that, for religious reasons, did not permit MAID. Dr Gideonse and the State of Oregon defendants entered into a settlement agreement where the Oregon Health Authority, the Oregon Medical Board, and the Multnomah County District Attorney all agreed not to enforce the requirement for residency. Oregon Health Authority also undertook to initiate a legislative request for the deletion of the residency condition in the DWDA.

4.1.8.2.5. Advance Directives

A separate aspect to consider for a person preparing for an assisted death is end-of-life care if

they are unconscious. The Oregon government addressed this problem by means of a special government form called a POLST form. 'POLST' refers to 'Physician Orders for Life-Sustaining Treatment' and every patient is encouraged to complete one. It can be registered with the Oregon POLST registry. The form, which is similar to an advance directive, reflects the wishes of the person for medical treatment if a situation arises that requires emergency medical services. It is here where the instructions to not resuscitate are recorded in the event that the person is found unresponsive, or the lethal medication has not worked as expected. Doctors apparently keep these forms at their consulting rooms, and they also need to sign and date the form for it to be valid[343].

It is worth mentioning that the state promotes the POLST form because of some printed words that might cause concern for a person when preparing their written request in Oregon. In the patient's Written Request form for medication, discussed above, there is a sentence phrased as follows: 'I further understand that although most deaths occur within three hours, my death may take longer, and my physician has counselled me about this possibility'[359].

In contrast to other countries discussed where alternatives to oral ingestion are offered, Oregon only allows this mode of intake for the lethal medication to end life, despite well-documented evidence from the Netherlands about the problems with the method. Even Switzerland offers the alternative of an intravenous cannula with a tap that can be turned, particularly where a person is already terminally ill. In 2019, researchers published data trends from Oregon and Washington related to MAID[360]. They looked at all Oregon's published reports in the period from 1998 to 2017 and Washington's reports from 2009 to 2017. Overall, the time-lapse between drug intake to coma took from 1 to 660 minutes (11 hours) and from drug ingestion to death from 1 to 6240 minutes (4,3 days). However, in Oregon, the median time from ingestion to coma was 5 minutes and to death 25 minutes. Complications were experienced in 5,4% of Oregon patients (34 out of 626), while eight patients regained consciousness after the lethal ingestion. Importantly, the researchers declared that it was unknown whether complications had occurred in 50% of Oregon patients who had received drugs because of an amendment in 2010 to the follow-up questionnaire that only allowed comments about the time and circumstances of the death if the doctor had been present at the death. However, of the total numbers of cases for Oregon and Washington combined, 4% experienced complications, primarily being difficulty with swallowing, or regurgitating the dissolved drug solution. Most patients who requested MAID prescriptions were suffering from cancer or other terminal illnesses that were difficult to palliate. The general reasons people gave for having chosen MAID were loss of

autonomy, inadequate pain control, an impaired quality of life, and a small number mentioned financial constraints. Those who sought assistance in dying tended to be White, non-Hispanic, insured people with some college education.

In conclusion, the researchers proposed that there was substantial room for improved integration of palliative care, social support services and case management in end-of-life decision-making so that people who were confronted with terminal illness had more options. Yet, in Oregon they reported that enrolment in hospices had been as high as 87,8%, possibly partially explained by the number of insured patients in the data set[360]. Rotella, J., the chief medical officer of the American Academy of Hospice and Palliative Medicine (AAHPM), commented in 2019[361] that the opportunity to receive palliative care in out-patient settings was limited mainly because of a lack of funding. He added that reimbursement by the federal government's Medicare scheme was insufficient at that time, and no one ought to be faced with accepting assisted dying just because they could not access palliative care.

A notable comment made by the researchers was that during the 2019 Oregon legislative session, the suggestions put forward as amendments for the MAID legislation included (i) redefining the term 'ingestion' to incorporate any method of introducing medication into one's body, as well as the term 'self-administer', (ii) removing the requirement that a person should have only six-months left to live, and (iii) creating an exception to the waiting periods so they were shortened where patients had limited life expectancies. It appears that only the exception to the waiting periods was accepted for amendment[360].

Compared to countries that allow E or PAS, the USA has extremely restrictive laws. Hannig, A.[362], a professor of Medical Anthropology who studies medicine from a cultural perspective, wrote that although the laws were meant to reduce suffering, sometimes they increased it. She had explored how access to MAID was altering the way people in America died and found that an assisted death was not an easier option than a natural one because there were numerous hurdles to overcome at a point in life when the person's health was deteriorating quickly. The requirement of the expectation that there was less than six months left to live was apparently the same as for an admission to a Hospice facility. A criticism Hanning expressed about the MAiD time frame was that the criterion excluded people who were suffering from a protracted degenerative disease with an unknown prognosis, for example Amyotrophic Lateral Sclerosis. Only once their breathing was becoming severely impaired, which would already be causing distress, fear, anxiety, and discomfort, would they be most likely to be eligible. Another

problem with the six-month time frame was that some died waiting for the time-periods to elapse, while others became too frail to be able to ingest the bitter toxic substance such as the ALS patients who also lost their ability to swallow, besides the ability to breathe. Hannig described the resulting distress over their difficulty to swallow as producing anguish about the timing of their death: if lethal medication was taken too early, they lost out on a life still worth living, and if they waited too long, they could miss the chance for what they perceive to be a more peaceful death. Some chose to die earlier for this reason.

4.1.8.3. Social and cultural environment

Oregon is described as having a reputation for being culturally progressive because of embracing liberal laws that accepted assisted dying for terminally ill patients in 1997, first out of all the states, followed by the decriminalisation of medical marijuana in 1998[340].

However, Hannig identified that a cultural stigma and moral uncertainty still existed among Americans, despite seven in ten Americans purportedly supporting MAID. This was evidenced by the numerous religious healthcare facilities that refused to allow MAID on their premises[362]. Other researchers support this conclusion and agree that many doctors have moral objections to AS. Blanke, C., a professor of medicine at the Knight Cancer Institute in Portland, Oregon who does participate in MAID, confirmed that patients complained that after their physicians had refused to assist them, they also did not refer the patients to someone else, because they purportedly did not know of other doctors who were prepared to write prescriptions for AS[363]. Once the patients had made contact with Blanke, often they were already too frail to proceed with AS. Blanke considered that this amounted to patient abandonment in the face of legislation that permitted MAID. Although no doctor was to be coerced into participating against their will, Blanke believed they ought to refer a patient who requested AS to someone else. Another doctor pointed out that the legislation did not provide for additional medical training of physicians which he believed to be a barrier to acceptance of AS and one of the shortcomings of the law. However, in 2018, a *Medscape* ethics report indicated that the opinions of doctors were slowly shifting towards more acceptance, as 58% of doctors who responded were in support of MAID for terminally ill patients[364].

Hannig's research indicated that in the rural areas of Oregon, along the coastal corridor in the west, patients regularly struggled to find two medical practitioners who would assess their health and confirm their request for medication, or a pharmacist who was prepared to dispense

the medication, especially where Catholic health systems ran the town's health infrastructure and there was only one hospital. Many hospices did not support MAID either, causing patients to feel deserted. People who lived in nursing homes and assisted living facilities, likewise, found that MAID was prohibited on their premises, obliging them to make alternative arrangements such as utilising a motel nearby for their death. Hannig observed that ironically, while attempting to reclaim control over the end of their lives, terminally ill people experienced control withheld in the process. She saw MAID as having reframed the way people now viewed medicine: not as a means to extend life, but as a means to shorten the process of dying. At the point where the prospect of death was more appealing than the prospect of life, the choice of when and how death could occur offered them comfort[362].

Like Switzerland, there are Right-to-Die Societies in Oregon that are willing and available to support people who are finally ready to ingest their lethal medication, such as 'Compassion & Choices', the oldest non-profit organisation in this line of work. The organisation advertises that they work with healthcare providers to integrate MAiD into end-of-life care in several ways[365].

Oregon's Health Infrastructure is briefly described to compare it to the universal health care systems of some other countries discussed, such as The Netherlands, Canada, Australia, and Switzerland, although each country has an individualised framework to suit their societies.

The United States does not have universal health insurance coverage, but a mix of public and private insurers and healthcare providers, including 'for-profit' and 'not-for-profit' entities. The national Medicare insurance is provided by funds from the federal government, available for everyone over 65 years of age, supporting programs that assist those with disabilities, veterans, and people in the low-income group. It also offers Medicaid. The Children's Health Insurance Program States covers features of local coverage, while private insurance is the dominant form of payment for health services, supplied mostly by employers. Around 8.5% of the population remain uninsured[366].

Oregon offers the Oregon Health Plan, (OHP) which is free health coverage (Medicaid) for those who meet specific eligibility criteria such as income. This health plan covers medical, dental, and mental health care, including assistance with addictions. The OHP has local health plans called coordinated care organisations (CCOs) in which most OHP members are enrolled.

A CCO is a network consisting of a variety of health care providers such as doctors, nurses, pharmacies, counsellors, and dentists, who work together within the local communities to assist people who receive health care coverage under the OHP. The focus of CCOs is the support of health and prevention, and the management of chronic illnesses, such as diabetes, to avoid unnecessary emergency visits to hospitals[367]. If people have other insurance, or some specific medical reason, they may not be put in a CCO. Those who are not in a CCO have Oregon Health Authority pay for care in a fee-for-service arrangement. Under these circumstances, the person must find providers who accept this arrangement and can bill Oregon Health Authority for services rendered[367].

With regard to MAID, the DWDA does not specify who must pay for this procedure. Individual insurers are entitled to decide what they will cover, as with all procedures. The DWDA does make it clear, though, that MAID is not classified as suicide, so insurance benefits should not be affected by choosing it as an option[343].

4.1.8.4. Comparison with South Africa

Oregon's reliance on private medical insurance to pay for services is similar to South Africa's private sector environment, while Medicare is more comparable to the public sector's support of those who cannot afford private insurance. This difference between public and private insurance implies that there is a difference in the range of services offered, such as access to palliative care, which is restricted to the terminal phase of life, when people with chronic degenerative disorders would benefit from the care as well.

Oregon's restrictive approach to PAS has the benefit of keeping the assessment by doctors of eligible patients less complicated than in the more permissive countries where existential suffering and pain without terminal illness sometimes need to be measured. The greatest barriers to accessing AS appear to be only having six months left to live, which is difficult to predict, and finding a physician willing to help if the person lives in a more conservative area of Oregon.

Another factor that may be limiting is the cost of going through the process, but it was not clear in the literature how much it would be and whether all insurance companies would cover the expense. Palliative care also appears to incur a cost that some people may not be able to afford if they have no or limited health insurance. Like AS, Hospice is available to offer support

through the last six months of life for a terminally ill person, but, in general, the impression is that doctors require more training to feel comfortable dealing with end-of-life issues and AS.

Summary of countries that permit assisted suicide

Switzerland and Oregon were examined as examples of societies who embrace AS. Switzerland is as permissive in its informal law, as Oregon is restrictive in its legislation.

The attraction of a country only allowing AS, as opposed to E, is that the individual takes full responsibility for their autonomous decision, without another person, typically a medical professional, having to carry the moral burden of actively taking a life at the request of another. The personal act also reinforces the conviction that the individual has reached a firm decision to end their life and is not ambivalent about it, which offers some comfort. Where there is a choice between either E or AS, research shows that people prefer E, while doctors prefer AS[58]. Psychologically and morally, this is an important diversion of opinion between the doctor and patient, and something to ponder.

Researchers compared the frequency of assisted deaths in two countries who offered both E and AS, Netherlands and Belgium, with two countries that offered only AS, Switzerland and the USA's Oregon, during the period 2007 to 2017[368]. Their conclusion was that AS continued to rise substantially in the E countries, with AS making up 3.5% of the deaths in the Netherlands during 2016. In contrast, trends in Oregon were increasing much more slowly, at that time less than 10% of the Netherlands. In Switzerland, however, where there was no legal monitoring, the rate of increase in AS was comparable to that of the E countries, actually approaching a rate closer to Belgium's. It is to be noted, though, that Belgium appeared to under-report unnatural deaths on death certificates[369]. The researchers pointed out that in 2012, there were a higher number of AS cases in the E countries, compared with Oregon and Switzerland. They suggested that this could have been because the doctors provided the drugs themselves although the patients swallowed the medication. However, more recent data indicated that Switzerland's lack of legal regulation could explain why their numbers of AS are increasing rapidly towards Belgium's baseline. Another factor was that people without terminal illness were being authorised to have an AS, while Oregon's AS law remained limited to those with an expectation of less than six months to live. Those living in Oregon obtained the lethal drugs from pharmacies themselves, to ingest in their own time. The writers recorded that around 36% of Oregon patients who received the drug did not in fact use it but died from their disease.

Regarding the methods to terminate life, the option in Switzerland for performing AS by means of an intravenous line and tap appears to be more humane than Oregon's only method available, the oral ingestion of lethal medication. Additionally, the alternative gadgetry associated with intravenous lines alluded to by the Swiss nongovernmental organisation, Pegosos, that still allows a person with limited movement to administer the toxic drugs, may be worth further investigation by countries who want to help a wider group of people and reduce discrimination of those with physical limitations.

Even though the person carries out their own death, Swiss doctors are confronted with having to assess a wider range of reasons for a person choosing to commit suicide compared with Oregon. Concerns by Swiss doctors have been raised that it is very difficult to objectively measure the subjective experience of pain and existential suffering in order to justify writing the prescription requested by the patient. For example, a controversial dilemma is how to deal with a person who is 'tired of life'.

Research carried out in Switzerland investigated existential suffering. Gaignard and Hurst[370] explained that people who were 'tired of life' often experienced the meaning and value of life as unclear, with no consistency on how to treat it. Symptoms included the consequences of physical deterioration, loneliness, fear of the future, being a financial burden and the loss of pleasurable undertakings. A recent definition put forward by doctors to understand being 'tired of life' suggested an 'incapacitating state of despair resulting from an inner realisation that life is futile and without meaning'[371]. Gaignard and Hurst illustrated its complexity when they drew attention to the crucial connection that, besides other problems, the loss of self-identity was found to always be associated with physical decline, and people viewed the image of themselves as defining their entire identity. For instance, the research described that all participants had mentioned that one of the inducements of a loss of identity was a deteriorating physical appearance. This was accentuated in the contrast of the image they had of themselves before the onset of illness, compared to the person they perceived they had become after illness had set in. Afflictions re-defined them. The researchers established further that society's perception of the elderly and progressing physical frailty, which was influenced by social contexts, could exacerbate suffering, because it affected the way in which older people saw themselves.

Additional contemplation is necessary to imagine what alternatives could be offered as an intervention for this group of people. It is valuable information to bear in mind for palliative care to be successful, too. Chapter 7 will discuss palliative care in South Africa.

4.2. COUNTRIES COMPARED WITH SOUTH AFRICA

This chapter has examined most of the countries that permit E and/or PAS in detail in order to establish how they have integrated E and/or PAS law into their social infrastructure and health sector. I have also looked superficially at the kind of society that makes up each region in an attempt to understand better why the law was perceived to be necessary and embraced.
No country is the same as South Africa, but similarities and differences gleaned through comparisons have been mentioned at the end of each country's section and may prompt further research for decision-makers seeking guidance when they are confronted with whether to introduce assisted death legislation as an end-of-life option or not. A summary is offered below.

4.2.1. Differences identified

The European countries, Canada, Australia and the USA have been stable and wealthy for a long time, most having an established, mature social security infrastructure that the people actively contribute towards through taxation, as well as support conceptually. Generally, the countries have also become more secular, so are not limited by the idea of life being sacred and therefore not to be ended prematurely when suffering, or the fear of suffering, becomes intolerable.

In contrast, South Africa, although rich in natural resources, has many economic challenges as a developing country with a relatively new democracy since Apartheid was brought to an end. There is political pressure because people feel a deep sense of frustration with the slow transition to a better life beyond poverty. Unemployment is high, so many people are still totally dependent on government financial support to subsist but are not contributing to the national fiscus by paying taxes. Consequently, social grants are minimal compared to the cost of living and people are struggling to survive, compounding the problem of poverty. Despite life's hardships, South Africa still has large groups of people who are spiritually aware and who respect life on a spiritual level, thus would not readily support hastening death, although in general, secularisation is undergoing a global shift.

A third difference is that, often the request for E was first initiated by the people as a popular demand. In regions such as The Netherlands and Oregon, legislation was ultimately promulgated because of a majority vote, motivated by their high regard for autonomy and privacy. South Africa, in contrast, has not had a large activist movement demanding the right

to die, even though the question was researched in 1997, when assisted death started to become topical overseas. Requests have only arisen through recent case law, as illustrated in chapter 3, and the activist group, Dignity SA, is made up of a concentrated minority of people with a particular profile, so there is not a clear representation of how much real interest there is in having E/PAS law. Furthermore, the wish to kill someone before their natural death seems anathema in the culture of many of South Africa's local communities who have been raised with a more communitarian philosophy which extends to valuing their elderly and caring for the frail and sick, as a family duty.

In addition, the attitude of the local doctors, represented by the South African Medical Association, is more conservative than the Benelux countries, following the WMA in its rejection of E and PAS. Many medical practitioners have expressed the view that administering a lethal medication would be contrary to their role as healers and comforters. On the other hand, most of the Dutch and Belgian medical practitioners appear to be willing to facilitate E and bear the responsibility for its administration readily, based on their respect for people's freedom of choice. Belgium, in fact, acknowledged that doctors would hasten death of seriously ill patients, sometimes without their consent, to remove the burden on families and caregivers. Instead of this information causing alarm in the public domain, however, it appeared to be understood and accepted by some as reasonable. Thus, the E law in Belgium introduced E legislation as an attempt to regulate the killings instead of it happening in secret.

An important feature of the E/PAS countries is that they reflect a great amount of trust in their respective health services, which is required for the ex-post-facto monitoring of E framework that they have implemented, Colombia being the only exception. In contrast, South Africa's National Health Department has been riddled with scandal and corruption in the recent past which has undermined public trust.

Lastly, it is significant that every country where E and/or PAS has been introduced has promoted palliative care, and often incorporated it into the end-of life law that has been promulgated to ensure that people have an opportunity to benefit from it before they finally decide that death is their best option. Palliative care in South Africa, on the other hand, has been a very limited service despite the many people who have needed it, especially for pain control. However, very recently palliative care has now received attention from the government to be developed to increase its availability for everyone, explained in more detail in chapter 7.

Colombia is an exception to the norm in almost every respect because it is a far more unequal society than the other countries that have allowed E/PAS. It may be that allowing E was a more appealing way to uphold people's dignity precisely because palliative care was inaccessible to most of the population, and no better alternative existed other than death. Compared to South Africa at present, Colombia claims to have more available palliative care services. It is disconcerting to imagine that South Africa, too, could bring E into law because no better option existed to escape the fear of intolerable suffering.

4.2.2. Similarities identified

Considering similarities, Canada and Australia have more in common with South Africa than the Benelux countries seem to have. Their past colonial histories are similar, including the ultimate suppression of indigenous people who have now to recover and regain their dignity, equality, and autonomy by re-establishing lost culture and traditions. A difference between those countries and South Africa, though, is that South Africa's majority is made up of indigenous people, so the re-establishment of an African culture that appreciates community, dignity and respect for self-determination should not be an impossible task. Consequently, both Canada and Australia's approaches and challenges to rolling-out a health service that will provide E/PAS should offer valuable insights if South Africa follows suit.

Colombia, like South Africa, has a high GINI coefficient because of deep-seated poverty and unemployment, contrasted by pockets of extreme wealth which exist side by side, reinforcing the country's gross inequality. Informal workers participate in the workforce while not contributing to the government's tax base and are also not adequately protected by the state with regards to social needs. Many problems exist with the infrastructure, including corruption. Another similarity is that Colombia has a comparatively influential judiciary, whose Constitutional system has made a difference by reaffirming human rights and giving a voice to people who have been in great need of support because of the government's hesitancy or lack of will to improve the quality of care people have received in the past. It remains to be seen how the South African Constitutional Court will reason when it analyses the right to life, dignity, and privacy, among other rights, in the context of a request for assisted death.

4.2.3. Ethical theories identified

The primary ethical philosophy of the regions that have introduced E/PAS legislation is one of respect for dignity, autonomy, and privacy. It is a human rights focus that resonates a

deontological foundation. The medical profession continues to uphold the bioethical principles of respect for autonomy, beneficence, and justice, but can argue for the application of beneficence and nonmaleficence from both perspectives of being either a proponent or opponent of assisted death. Canada draws attention to the important bioethical principle of justice in its vocalisation of the need to ensure that everyone receives the same opportunity for E/PAS regardless of where they reside, amongst other barriers to access that must be overcome. In South Africa, there is now a mix of the traditional philosophies of communitarianism and *Ubuntu*, but also the assertion of respect for human rights, particularly individual dignity, autonomy, and equality, expressed through applying humanism. A focus on scarce resources and justice may also be gaining traction and may become a more developed theme as time passes.

The human rights-based arguments in terms of a Constitution, but also from a moral universal perspective, have been successfully applied to real situations in many of the countries discussed, especially in the Columbian courts, which have upheld respect for autonomy, privacy, the right not to be treated cruelly, and to have access to health care.

4.3. CONCLUSION

Having completed the comparison between South Africa and other countries that have incorporated law permitting assisted death, both from a social and legal perspective, the next chapter examines the draft End-of-Life legislation that was proposed in 1998 for South Africa, following a large research project carried out by the South African Law Reform Commission. This exercise brings me a step closer to proposing the legal suggestions for an ethico-legally based end-of-life framework to assist doctors with end-of-life decision-making.

Table 3: Comparison of Law by country

	Adults	Minors	Terminal illness only	Suffering	Euthanasia	Assisted Suicide	Doctor (Dr)/ Nurse/Other perform	Advance directive	If permanently unconscious	If conscious but no capacity
		(Y/N)	(Y/N)		(Y/N)	(Y/N)		(Y/N)	(Y/N)	(Y/N)
Netherlands	18	> 12 + parent >16 -17 with parent knowledge	N but underlying medical cause	Unbearable, no prospect of improvement No better alternative	Y intravenous	Y oral	Dr	Y 16 up.	Y +AD but (coma) = no suffering, so no E. (2018 Code)	Y + Advance Directive
Belgium	18	Y if capacity to discern; terminal.	N medically hopeless condition, by illness or accident	Constant, physical or mental unbearable, can't be alleviated	Y	N	Dr	Y 18, emancipated minor Valid indefinitely.	Y	N
Luxembourg	adult	N	N hopeless med condition; accidental or pathological condition	Constant, unbearable phys. or psych suffering. No prospect of improv.	Y	Y	Dr	Y	Y	N
Canada	18	N	N grievous irremediable medical condition: serious incurable disease, illness or disability. Advanced state of irreversible decline in capability	Enduring physical or psychological suffering, intolerable to them; not relieved in way person finds acceptable.	Y	Y oral	Dr /nurse practitioner	Advance consent if death reasonably foreseeable and already approved for MAID	Y + written declaration. but lost capacity to consent.	Y+ written declaration. but lost capacity to consent.
Western Australia	18	N	Y < 6 mo term illness or < 12 mo for neuro degenerative.	Cannot be relieved in way person finds tolerable.	Y	Y oral	Dr /nurse practitioner	Y Only withdrawal of treatment	Y	Y?
Colombia	Y	Y	N serious incurable illness	Physical, psychological pain	Y	Y	Dr	Y	Y death must be imminent	Y death must be imminent
Switzerland	Y	N	N diagnosis of functional impairment	Diagnosis source of severe, intolerable suffering, dr agrees	N	Y oral/line	Others	Y, not AS, but withdrawal of treatment	'Incapacity'	'Incapacity'

Oregon	18	N	Y < 6 mo	Not stipulated as requirement.	N	Y oral	Others	Y withdrawal of treatment	Y	Y
United Kingdom draft	18	N	Y < 6 mo	Not required. Progressive condition, cannot be reversed	N	Y oral/line	Dr	Y legally binding For treatment	Y	Y?
South Africa old draft per thesis, Ch 5	**18**	**N**	**Y but not only terminal illness, injury, physical or mental condition**	**intractable, unbearable condition, extreme suffering.**	**Y**	**Y**	**Dr**	**Y**	**Y**	

Expansion of law:

- Babies, minors: Canada, Netherlands, Belgium, Colombia
- Mental illness: Canada, Netherlands, Belgium
- Tired of Life: Switzerland

Table 4: Safeguards built into E /PAS law by country

SAFEGUARDS	Eligibility not restricted to end of life	Request for E / PAS: oral or written	Time frames to procedure	Minimum no. of consultations pre-approval	Psych consult	Drs/Nurse/Other required to be present at PAS	Committee Review	Training	Resident (r); Death cert. discloses E/PAS	Special unit exists
	Physical (Y/N) or mental illness (Y/N)			Attending dr, consulting dr		Diagnose & present at death			(Y/N)	(Y/N)
Netherlands	Y Y	Oral, need not be repeated; Child >12 parental assist	None stipulated	2 (+1 for mental)	If necessary	Dr diagnoses & is present at PAS	After	Training offered	N but not practical for non-r. Y	Y
Belgium	Y Y injury or pathological condition or for mentally ill only;	Written, repeat. Child: + agreement of legal representative	If not terminal, 1 month post written request to lapse	Adults: 2 + 1 if death not soon. Child 2+1 for mental capacity.	Adult: If necessary. Child: always	Dr. No PAS law but still done and recorded	After	Training offered	N but not practical for non-r N 'natural'	Y
Luxembourg	Y N	Written, repeated	Reasonable time frame	2	If necessary	Dr diagnoses & is present	After		Y	
Canada	Y Y but mental illness pending 2023	Written – foresee death & not foresee	0 – foreseeable Not foreseen = 90 days from assessment 1	2 if foresee death, need not agree. 3 if not foreseen and specialist necessary	Not specified	Dr/nurse practitioner diagnoses & is present	After	Training suggested	Y ?	
Western Australia	N N	2 oral 1 written declaration	9 days from 1st request	2	If necessary	Dr /nurse practitioner diagnoses. Other contact person for PAS	After	Training required	Y; N	
Colombia	Y N not mental illness	Written application	unknown	unknown	unknown	Dr? unknown	Before		Y ?	N
Switzerland	Y Y but controversial	2 oral discussions	2 weeks apart, Swiss guidelines	1+1 to verify capacity &	If necessary. Lack of capacity	Doctor diagnoses NGO: others at PAS	None	Training offered	N Y	Y

				autom; does not have to be doctor						
Oregon, USA	NN	2 orals, 1 written req. (Form)	Not < 15 days between orals. No < 48hrs after written for script	2 (not independent required) If depressed +1	If necessary	Dr diagnoses; Others at PAS	After, sample but not formal review to check	Training improved	Y, & for other US residents; N	Y
UK draft	NN	Written declaration (Form)	Not < 14 days from declaration; Or 6 days if near	2	Not specified	Dr diagnoses Dr/nurse at PAS	High court before		Y; 'assisted death'	N
South Africa old draft per thesis, Ch 5	**Y N?**	**2 oral, 1 certification of request**	**oral 7 days apart + not >72hrs before death (4 days)**	**2**	**Not specified**	**Dr diagnoses & is present**	**Before or after, undecided**		**Not specified**	

Expansion of law:

- Babies, minors: Ca, Nl, Be, Col
- Mental illness: Ca, Nl, Be
- Tired of Life: Switzerland

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CHAPTER 5: THE SALRC END-OF-LIFE BILL

5.1. INTRODUCTION

In the previous chapter I compared the law and social environments of foreign countries that had incorporated E and/or PAS legislation into their legal framework. The object was to understand how the law was integrated into each country's infrastructure, as well as to compare the countries to South Africa's environment. Bossard, *et al.* in their 2008 research of the doctor's role in assisted dying in selected European countries[1] found that doctors' attitudes and practices in end-of-life decision making depended primarily on the country in which they lived. Their law and their medical ethical positions developed in highly country-specific ways.

In Chapter 5, I examine South Africa's law and medical ethical position through critical analysis and comparison of South Africa's draft End-of-Life Bill to the foreign law presented in chapter four. Bearing in mind the different contexts from which the foreign law originates, this provides guidance to develop the legal aspect of the ethico-legal framework for end-of-life decision-making in South Africa. An alternative legal framework for South Africa is then offered, with reasons motivating the changes. Drawing on the ethical and legal analysis of Chapters 2 and 3, I highlight the ethical and regulatory gaps in South African law related to end-of-life decision-making and advance a framework to address these issues.

Beauchamp and Childress assert that a change in the law is a powerful symbol of change - social change, public convictions, morality, spiritual shift - and a basis upon which further change will occur[2]. This is certainly true of euthanasia legislation.

5.2. HISTORY OF THE PROPOSED *END OF LIFE DECISIONS ACT* OF 1998

The South African Law Reform Commission's proposed *End of Life Decisions Act* of 1998 was developed as a result of a Discussion Paper and final report, Project 86, that began over 30 years ago.

In October of 1991, the South African Voluntary Euthanasia Society (SAVES) at the time, wrote to the South African Law Reform Commission (SALRC), suggesting that it consider legislation for a 'living will' document. The objects of the SALRC in terms of its Act[3] are to pursue research related to all branches of the law with a view to making recommendations to

improve, develop, modernise or reform it[4].

The following year the Commission approved the proposal as a research topic, but expanded it for the sake of completeness to include euthanasia and the preservation of life. By 1994, Working Paper 53 was published with a draft bill for discussion[5]. The object of the Paper was to present the concepts related to end-of-life issues to the South African public for an open debate. It initially focussed on the ways people could put an end to their lives indirectly. In the same year, on the 27th of April 1994, a democratic government came into being with a new Constitution, and apartheid was ended[6]. During the period that followed, June 1994 to October 1996, input was received from various sources, including two workshops, submissions, and participation from the general public. A great deal of response was elicited, so much so that the Commission explained that it would proceed to prepare its final report using a 'sober and practical' approach, and avoid moralising and theorising[7].

5.2.1. SALRC Discussion Paper 71, Project 86

Once the research phase was complete, Discussion Paper 71 was produced in 1997 for further public comment on *Euthanasia and the Artificial Preservation of Life*[8]. In light of the great interest that the topic generated amongst the public, and the fact that more conversation was needed around the concept of euthanasia and the artificial preservation of life, the second discussion paper incorporated the ways in which people could directly put an end to their lives. The Commission suggested *inter alia* the following points for public consideration: (i) the circumstances in which it would be lawful for a doctor to withdraw life-sustaining treatment of a person in a persistent vegetative state (PVS); (ii) the right of a person to refuse life-sustaining treatment even though this refusal may hasten death, including if this refusal is in a written directive; (iii) the right of a doctor to alleviate pain and distress according to responsible medical practice, by increasing a medicine dosage even if the secondary effect may shorten the patient's life; and (iv) whether a doctor should comply with a competent patient's well-informed request for the administration or provision of a lethal agent to end life.

A draft bill was also framed as an annexure, purely to focus attention on the range of difficulties associated with the topic, for further debate and dialogue.

5.2.2. Final SALRC report, Project 86

A final report, Project 86, was produced the next year in 1998[9]. The Commission explained the need for research on the subject of end of life decisions in terms of advancements in medicine, and the fact that people were living longer, although for some the quality of life remained poor. It pointed out that society now lived in an environment where medical skill routinely interrupted the natural process of life by saving, transforming or prolonging life. Consequently, people could not embrace medical interference with life and then pretend that the process of dying could not be interrupted on the pretext that death, unlike life, should happen naturally and 'be left to nature'[10]. It was therefore necessary, it said, to explore alternative choices besides a natural death.

The global emphasis on autonomy was also mentioned as an important social development to be recognised, such as where a person would prefer to refuse medical treatment, even if the refusal caused their death. The National Health Act (NHA)[11], which took effect in 2005, ultimately provided for the situation where a person could refuse treatment. The entire NHA is structured, as far as possible, to respect a person's right to self-determination. Section 8, for example, reinforces the entitlement of a patient to participate in all decisions that affect their personal health and treatment, regardless of whether someone has a limited capacity to understand. Bearing in mind that the SALRC report was completed in 1998, a more recent reference to autonomy from the Constitutional Court is apposite. During 2016, a matter came to court about the limitations of surrogacy as an alternative for infertile individuals, namely *AB and Another v Minister of Social Development)*[12]. Remembering the lessons South Africa had learnt, Justice Khampepe, in her discussion of autonomy, mentioned the 'recent academic trends' of seeing autonomy as relational in character. Referring to a number of writers from the early 2000s, she said that 'to be autonomous is to be socially and politically connected, rather than an agent of unfettered individual choice'. Khampepe, J. asserted that this attitude resonated with the Court's continuing support of *ubuntu*, as explained in *Makwanyane*[13].

This opinion becomes relevant when one considers that the practice of assisted death is not a purely autonomous act: others are involved to give it effect. Furthermore, it was observed that in a number of instances the Court had associated the opportunity to make autonomous choices and life-changing decisions with dignity, in that 'autonomy and control over one's personal circumstances are a fundamental aspect of human dignity'[14,15].

Three chapters of the Report were dedicated to focussed discussions: 'Chapter 3, The artificial preservation of life where the patient is clinically dead', 'Chapter 4, Cases where the patient is competent to make decisions', and 'Chapter 5, The incompetent patient with no prospect of recovery'. These sections covered all the difficult, controversial, and ethical aspects of end of life decision-making that confronted both patients and medical practitioners. The SALRC highlighted that terminally ill patients were being managed on an informal basis without clear law in place. As a result, a level of uncertainty remained in the mind of the public and with medical practitioners, about what approaches were lawful in different situations. Furthermore, doctors were concerned about exposing themselves to litigation and professional censure if they made decisions that were not supported by those closest to the patient.

Five recommendations were suggested by the Commission for the drafting of possible legislation: i) a doctor may implement the cessation of medical treatment of a patient who is being kept alive artificially while there is no spontaneous circulatory or respiratory movement, or who has no brainstem impulse; ii) accept the refusal of medical treatment by a mentally competent person, even if this decision would result in their death; iii) a doctor or nurse may alleviate the suffering of a patient by administration of sufficient prescribed medication to relieve pain, even if it shortens their life; iv) where a patient is no longer mentally competent, a doctor can give effect to an advance directive or enduring power of attorney to stop treatment, provided the instructions were given when the patient was mentally competent; v) a doctor may stop the treatment of a terminally ill patient who is unable to communicate their decisions, provided that the decision accords with the family's wishes or is in response to a court order[16]. In considering a way forward to deal with requests from people who sought assistance with dying, the SALRC proposed a number of options crystallised from the input received during the research process. Option one was to leave the law as it is, because the arguments in favour of euthanasia were not convincing enough to weaken South Africa's prohibition on intentional killing. The protection of life would be considered the cornerstone of the law and social relationships. Although the Commission accepted that individual cases existed where euthanasia could be justified, that was not enough to institute a general policy embracing euthanasia[17].

Option two allowed the medical practitioner to make the decision whether the terminally ill person met the criteria for E, regulated by legislation. Following the assessment, the doctor either prescribed the lethal medication or administered it to the patient. The patient would need to be mentally competent and suffering unbearably. Strict safeguards would be in place to

prevent abuse[18].

The last suggestion, option three, was for a multi-disciplinary panel or committee to make the decision in line with legislation that regulated it. It would analyse requests according to set criteria. The new draft bill, the *End of Life Decisions Act of 1998* was annexed again for further deliberation[19].

During 1999, on the 22nd of February, according to Rosenthal on the website 'Euthanasia Exposed', the Justice Portfolio Committee was briefed regarding various projects that the SALRC had undertaken, including Project 86[20]. The National Assembly then referred the Project 86 report to the Portfolio Committee on Justice and Constitutional Development, and the Select Committee on Security and Constitutional Affairs on 1 March 2000[21]. Following this, the National Council of Provinces reported the same referral on 2 March 2000[22]. Rosenthal puts forward that apparently, on considering Project 86's report, the government must have settled for Option 1, which was the *status quo*. However, Rosenthal displays an email on his website indicating that in 2004, Member of Parliament C. Dudley, representing the African Christian Democratic Party (ACDP), published a Notice of Motion that she intended to initiate a debate on the End of Life Bill and its implications[23]. He writes that the subject continued to be brought up numerous times in Parliament, but always received stiff opposition, and was obviously generally not supported, because nothing materialised[24].

In the most recent annual report of the SALRC, 2019/2020, its Annexure C, which lists all the projects that the Commission has undertaken, has a note next to Project 86 stating that the report is still under consideration by the Department of Health since 1999[25].

Contrary to popular belief, this project was not instigated or obviously supported by Nelson Mandela as a personal interest, despite him having been President at that time. The SALRC carries out research on many topics to facilitate change, and Project 86 was simply one topic amongst many. As recently as 2018, the question of why Project 86's draft Bill on End of Life Decisions did not reach fruition was put to the Parliamentary Monitoring Group by Ms D. Carter[26]. She raised the topic of the SALRC's project by stating that it was undertaken 'at the behest of the former President, Mr Nelson R Mandela…' and asked whether it would be revised and re-introduced in time to come. The response she was given was that the former Minister of Justice, Minister Omar, who received the report in terms of s7(1) of the South African Law Reform Commission Act, 1973, referred it to the Minister of Health at the time, Dr NCD Zuma,

in June of 1999. He had recommended to Dr Zuma that the sections of the Bill which focussed on the stopping of treatment, palliative care and advance directives were extremely important to both patients and the medical profession, so the enactment should not be needlessly delayed. However, because public participation was important on the question of whether active euthanasia should be incorporated into the law, and if so, on what basis, Minister Omar suggested that an *ad hoc* select committee of Parliament be formed to think about the issue in section 5 of the Bill, which was euthanasia, under the heading 'Cessation of Life'. With regard to Ms. Carter's second question, whether the Bill would be revised and re-introduced in 2018, the reply was that it would not, as it was now in the hands of the Minister of Health.

The publication of Project 86 indicates what an enormous amount of effort and work went into researching and considering all the aspects of end-of-life decision making, and the possible inclusion of the choice of assisted suicide and euthanasia. In-depth analyses of arguments were presented, with references, for and against this new law from many different angles. Finally, a framework for the proposed Draft Bill was offered by the SALRC, which incorporated the various legal possibilities canvassed within the report.

5.3. DRAFT END OF LIFE DECISIONS ACT OF 1998

A critique of the Draft *End of Life Decisions Act of 1998*[27] (SA Bill) is now presented, having regard to the previous chapter on comparative foreign law, including further suggestions to update it.

All the common end-of-life scenarios are catered for by the Commission. The SA Bill is broader than some of the foreign Acts in this respect, and very insightful as a foundation for South African drafters.

Whether or not the draft law ever materialises, the document is useful in focussing attention on what medical practitioners face as the most common and controversial end-of-life decisions. Thus, it contributes towards the requirements of the ethico-legal framework that is proposed in this thesis.

Annexure 1 presents the original draft End of Life Act of 1998 for ease of following the analysis presented.

5.3.1. Section 1. Definitions

The SA Bill has 11 terms that are defined[28]. I suggest a number of words to be added to the list of definitions in order to make it more comprehensive, and some recommendations to update terms in light of new law and the foreign Acts reviewed in Chapter 4.

(i) 'Assisted suicide', 'Euthanasia', Assisted death'.

As a starting point, definitions for 'assisted suicide' and 'euthanasia' are absent in the SA Bill. They would be helpful inclusions because there is a great deal of inconsistency between the terminology in the literature, as well as in the courts. Recognised terms in this legislation, if it were enacted, would add clarity. Canada uses 'Medical Assistance in Dying' (MAiD) to refer to both euthanasia and physician assisted suicide[29], while Western Australia refers to 'Voluntary Assisted Dying' (VAD) to cover these processes, specifically pointing out that it is not 'suicide' in this context[30]. The SALRC in Project 86 spoke of 'cessation of life', to mean the active intervention of a medical practitioner to end life. However, the South African Constitutional Court settled for 'physician administered euthanasia' (PAE) to describe 'voluntary euthanasia,' where a medical practitioner administers lethal drugs to a person, and 'physician assisted suicide' (PAS) for a patient who obtains a prescription for lethal drugs in order to terminate their own life[31]. PAE and PAS are very similar acronyms and therefore could be confusing. 'Euthanasia' (E) and 'physician assisted suicide' (PAS) are proposed as the alternative terms.

The logic in support of this reasoning is based on the work of the Ethics Task Force from the European Association of Palliative Care (EAPC), that took on the project of attempting to create consistency across the definitions used in Europe[32]. As mentioned in chapter 1, they explain that 'euthanasia', within its accepted meaning, is active behaviour not passive, so it is unwarranted to talk of 'active' or 'passive' euthanasia. It is also never 'involuntary' (against the person's will) or 'nonvoluntary' (where the person is unable to consent), because that would be unlawful killing, or murder. Thus, it is unnecessary to speak of 'voluntary euthanasia'. This understanding of euthanasia accords with the Dutch concept and the trend of its perception in Europe.

The term 'euthanasia' excludes withholding or withdrawing futile treatment, or nutrition and hydration, as well as the practice of terminal sedation. These actions could possibly be referred

to as ‘cessation of life-sustaining medical treatment’, a phrase from the SA Bill, section 8(1), which already defines ‘life-sustaining medical treatment’ to include the maintenance of artificial feeding. Alternatively, the words ‘Ending of life’ have been used in the Swiss Medical Guidelines, 2022, meaning: ‘Death deliberately brought about in the most painless and least distressing possible manner’[33], but this definition is overly broad in the setting of the SA Bill.

The following EAPC definitions for euthanasia and physician-assisted suicide are put forward as templates for suggested supplements to the list:

*‘**Euthanasia**’ means a medical practitioner intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request.*

*‘**Physician-assisted suicide**’ means a medical practitioner intentionally helping a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request.*

Lastly, ‘assisted death’ could be applied to refer to both E and PAS, because the word ‘dying’ is less accurate in the context of someone who is not in their terminal phase of an illness[34]. Accordingly, 'assisted death' will be included for ease of reference to refer to both E and PAS or either of them, depending on the context.

***‘Assisted death’** means euthanasia and/or physician assisted suicide.*

Other additions to the list are:

(ii) ‘Attending doctor’

The British Assisted Dying Bill[35] (British Bill) has definitions for each of the doctors that manage and assess the patient. These are incorporated into the South African list below. Labels for the doctors make it clear in the sentence who is being referred to, so adds brevity:

*‘**Attending doctor** means a suitably qualified registered medical practitioner from whom the person has requested assistance to end their life.*

(iii) ‘Independent doctor’

This definition is also extracted from the British Assisted Dying Bill[36]:

*‘**Independent doctor** means another suitably qualified registered medical practitioner who is not a relative, partner or colleague in the same practice or clinical team, of the attending doctor.*

(iv) ‘Psychologist’ and ‘Pharmacist’

Psychologist and ‘pharmacist’ are also defined to reflect their professional registrations.

‘Psychologist’ means person registered as such in terms of the Health Professions Act 56 of 1974.

‘Pharmacist’ means person registered as such in terms of the Pharmacy Act 53 of 1974.

(v) ‘Mentally competent’

This definition should be included in the SA Bill to bring consistency because of the different descriptions used, such as ‘mentally competent,’ employed as part of the section 3 heading, but ‘of sound mind’ used in s3(1)(a). It is modified from the definition of ‘capable’ in Oregon’s Death with Dignity Act[37]:

*‘**Mentally competent**’ means that in the opinion of a court or in the opinion of the person’s attending doctor or independent doctor, psychiatrist, psychologist, a person has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with that person’s manner of communicating if those persons are available.*

(vi) ‘Competent agent’

The drafters of the SA Bill chose to explain the meaning of ‘competent witness’ in the Definitions list but did not include ‘competent agent’ mentioned in s6(2). For the sake of completeness, a definition for ‘competent agent’ is suggested:

*'**Competent agent'** means a person of the age of 18 years or over, who is capable of making decisions on behalf of a person contemplated in section 6(2), and who has accepted that position as stated in a written mandate in terms of s7(1)(a)(i) of the National Health Act 61 of 2003.*

(vii) 'Drugs'

A definition of drugs is included for the sake of clarity.

*'**Drug(s)**' means medicine(s) and medication as defined in section 1 of the Medicines and Related Substances Act No,101 of 1965.*

The range of words that currently appear in the 'Definitions' section of the SA Bill are now examined.

(viii) 'Competent witness'

The first term listed is 'competent witness', which is used in s6(3) of the SA Bill with regard to advance directives and powers of attorney that must be witnessed for authenticity. The definition states that a 'Competent witness' means a person of the age of 18 years or over who at the time he witnesses the directive or power of attorney is not incompetent to give evidence in a court of law and for whom the death of the maker of the directive or power of attorney holds no benefit.'

This definition is adequate for its purpose, although it is unclear why competency is specified negatively. A clear statement that the witness '… is competent to give evidence ...' would be concise. Furthermore, as a power of attorney is no longer valid from the moment the principal is mentally incapable of making decisions, such as with unconsciousness, it has been replaced with the National Health Act's section 7 provision where a written mandate permits surrogate decision-making. It is proposed that the following alterations are made:

*'**Competent witness**' means a person of the age of 18 years or over who at the time he witnesses the directive or **written mandate in terms of s7(1)(a)(i) of the National Health Act 61 of 2003 (written mandate)** is competent to give evidence in a court of law and for whom the death of the maker of the directive or **written mandate** holds no benefit'.*

(ix) ‘Court’

The definition of ‘court’ is updated to align with the broader definition stated in the Constitution at section 166(c).

*‘**Court**’ means the High Court of South Africa in accordance with s166(c) of the Constitution of South Africa.*

(x) ‘Family member’

The SA Bill states that when ‘family member’ is used ‘in relation to any person, (it) means that person’s spouse, parent, child, brother or sister.’ The context in which ‘family member’ is applied in the Bill is under Option 3, section 5(1)(e), which refers to who may be appointed as members to an ethics committee that has the task of deciding whether a person who has requested E or PAS is eligible or not. A family member must be appointed as one of the members of the panel. Reference is also made to ‘interested family members’ in sections 7(3), 8(2) and 9(2) with regard to sharing information. Notably, ‘spouse’ is defined separately to include ‘a person with whom one lives as if they were married or with whom one habitually cohabits’, but the word actually only appears in the definition of ‘family member’. The separate entry could be avoided if, for instance, after ‘spouse’, the words 'de facto partner’ were included, as seen in Western Australia’s definition of ‘family member’: ‘the person’s spouse, de facto partner, parent, sibling, child or grandchild’[38]. Furthermore, the inclusion of ‘grandchild’ in its list of relatives is prudent, bearing in mind that elderly people often have adult grandchildren who are active family members. Additionally, instead of ‘brother or sister’, it has ‘sibling’, which has the benefit of brevity and is gender neutral. For South Africa, clarification of ‘de facto partner’ would be added to read ‘de facto partner in a permanent co-habiting relationship’.

South Africa’s definition may not be sufficient for the unique environment of South African society, where the common family structure traditionally remains an extended family that embraces cousins, aunts, uncles and adopted children, spanning more than one household[39]. On a cultural level, senior aunts and uncles are particularly important when serious decisions need to be made[40]. Consequently, the position on the ethics committee may be filled more suitably by a relative not presently listed under ‘family member’ in the SA Bill. However, it is also worth noting what the drafters of the National Health Act (NHA) had decided upon when it was

published in 2003, because they would have probably been aware of the important relationships. In the definition of 'user'[41], relatives are named for the situation where a user is incapable of taking decisions. They include: 'the person's spouse or partner or, in the absence of such spouse or partner, the person's parent, grandparent, adult child or brother or sister, …'. For the purpose of substituted consent, section 7(1)(b) of the NHA adds the words 'in the specific order as listed' to avoid conflict, which is helpful.

For a broader definition to be considered, in the British *Assisted Dying* Bill[42] (which only includes England and Wales, not Scotland or Northern Ireland), the word 'relative' is preferred. The British definition for 'relative' has a wider scope than those discussed, but this is because it is only used in a context to exclude people, so intends to be both wide and specific. In England, no relative is allowed to sign a declaration requesting a person's death to avoid self-interest:

'Relative' – 'a) the spouse or civil partner of that person; b) any lineal ancestor, lineal descendent, sibling, aunt, uncle or cousin of that person or the person's spouse or civil partner; or c) the spouse or civil partner of any relative mentioned in paragraph b), and for the purposes of deducing any such relationship, a spouse or civil partner includes a former spouse or civil partner, a partner to whom the person is not married, and a partner of same sex.'

This British definition of the word 'relative' may be more suitable for the South African context because it's meaning is more inclusive, but it is too wide for end-of-life decisions. However, the designated people in the list can be reduced in order for it to be applicable to the local environment. For example, the legal consequences of a civil union in South Africa are accepted to be the same as a marriage[43]. It would therefore be unnecessary to specify 'civil partner' separately. Also, with the right to equality, it should be needless to stipulate 'partner of the same sex'. Lastly, the context of 'family member' in the SA Bill would be unlikely to include a 'former spouse', so could be excluded.

The new definition proposed for South Africa is presented below. As the definition of 'spouse' is now incorporated and abbreviated, the separate entry can be deleted:

*'**Relative**' means a) a spouse, de facto partner **in a permanent co-habiting relationship**; b) parent, grandparent, adult child, adult grandchild, sibling, **aunt, uncle, cousin.***

(xi) ‘Intractable and unbearable illness’

The phrase ‘intractable and unbearable illness’ is next in the list to be reviewed. It is compared to the definition of ‘terminal illness’, because the concepts are meant to be exclusive according to the denotation of ‘intractable and unbearable illness’. They are explained as separate terms in the SA Bill, but are actually very similar in meaning in the SA Bill, and insufficiently differentiated. They are also used together in only one place of the SA Bill, as one of the nine eligibility criteria to end one’s life, in section 5(1): ‘a) the patient is suffering from a terminal or intractable unbearable illness’. Elsewhere in the draft Act, ‘terminal illness’ is referred to frequently and on its own, such as when discussing directives in s6(1) and unconsciousness at s8(1).

‘Intractable and unbearable illness’ has the meaning in the SA Bill of ‘an illness, injury or other physical or mental condition, but excluding a terminal illness, that-

a) offers no reasonable prospect of being cured; and

b) causes severe physical or mental suffering of a nature and degree not reasonable to be endured.’

A number of foreign Acts, for instance from the Netherlands[44], Belgium[45], Luxembourg[46] and Canada[47] discussed below, combine into one definition the person’s medical requirement with the criterion of suffering, like the SA Bill has done. However, for the sake of clarity, the medical problem and the suffering requirement will be commented on separately.

These countries are relevant as comparisons because they all provide both E and PAS. They do not stipulate, as a safeguard against error and abuse, that a person seeking assisted death must have a terminal time frame left to live, such as a prognosis of 6 months. South Africa’s draft Bill is structured in the same way.

Bearing this in mind, as it stands in the SA Bill, the phrase ‘intractable and unbearable illness’, with its meaning of ‘an illness, injury or other physical or mental condition that offers no reasonable prospect of being cured’, is too vague and wide, if the intention behind the law is for it to be applied in exceptional circumstances. Problems such as HIV, paraplegia, anorexia nervosa and a gangrenous limb could arguably all be included under the term. However, it

should not be easy to meet the criteria for E or PAS, because this would undermine the primary duty of the State to respect and protect life.

Phrases of other Acts, such as from Belgium and Luxembourg that have similar terms, talk of 'a medically futile condition', defined as 'a serious, incurable disorder caused by illness or accident' (translated)[48,49]. Alternatively, the Canadian Act which is more specific, refers to a 'grievous and irremediable medical condition', meaning 'a serious, incurable illness, disease or disability, and the person is in an advanced state of irreversible decline in capability'[50]. This definition is attractive because the requirement of a person being 'in an advanced state of irreversible decline in capability' is a safeguard to justify assisted death when it is most rational.

In order to narrow and sharpen the meaning of the South African expression, the following changes are proposed: instead of using the word 'intractable' in the phrase, which suggests 'difficult to control or manage'[51] the word 'irremediable' is better suited, because it is more succinct in its meaning of 'permanence' and 'irreversibility'[52], which must be a requirement for E or PAS. Also, in place of 'unbearable', it being a subjective measurement of suffering, 'grievous' is suggested, meaning 'very severe, serious'[53] or 'characterised by severe pain, suffering'[54]. Then, the label 'illness' should be replaced with 'condition', because 'illness' is most commonly defined as a disease or sickness 'of the body or mind'[55] that does not encompass 'injury', but 'condition' has wider scope. Accordingly, the more explicit Canadian phrase and definition are recommended for the foundation of the South African phrase, with a small variation added, to use 'injury' instead of 'disability'. In addition, the incorporation of both the words 'irremediable' and 'incurable' remove the need for subsection a) 'offers no reasonable prospect of being cured'. The first part of the new proposed term and definition, without the reference to suffering at this stage, would read as follows:

*A '**grievous and irremediable medical condition'** means a serious, incurable disorder, disease or injury, and a) the person is in an advanced state of irreversible decline in capability.*

(xii) The reference to 'suffering' is now examined:

The criterion of suffering is crucial in jurisdictions that do not have a 'terminal illness' requirement for access to assisted death. Examples are the Benelux countries that allow E or PAS for both somatic (physical) and non-somatic suffering, such as psychiatric, mental, or existential distress. This is because it is the primary justification for allowing assisted death.

However, typically the suffering should stem from a medical condition[56,57,58]. Thus, the dimension of a person's suffering becomes a vital measurement to permit assisted death[34].

Turning to the standard of suffering described in the definition in the SA Bill, it reads: the intractable and unbearable illness '… b) causes severe physical or mental suffering of a nature and degree not reasonable to be endured'. The wording of b) is open-ended, not indicating who would make that assessment of a subjective experience that only the patient can truly measure. Consequently, it is unclear whether a doctor's assessment of the patient's suffering could contradict the patient's description of their experience, resulting in the patient not meeting the standard necessary to fulfil this criterion and thereby not being eligible for assisted death. This scenario was illustrated in Colombia's case report of a woman who suffered from colon cancer. Her doctor, when assessing her for E, expressed reservations that her suffering was to the degree she described, discussed in Chapter 4[59].

The reason for South Africa's open-ended statement may be so that others are able to make decisions about a person's suffering if they are no longer capable of communicating it themselves. This is implied from the reference to 'terminal illness' in section 8(1) of the Bill, which regulates the conduct of a medical practitioner involved with an unconscious patient in the absence of a directive. The definition of terminal illness in the Bill includes 'extreme suffering'.

In contrast, the Western Australian requirement of suffering indicates that the terminal condition should cause 'suffering to the person that cannot be relieved in a manner that the person considers tolerable'[60]. Canada's Act also stipulates that the range of grievous conditions listed, or the state of decline, should cause a person 'enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable'. Both countries undoubtedly accept that the extent of suffering experienced is personal, and the person's explanation is almost sufficient by itself to meet the criterion.

This is helpful because the literature has highlighted the problems doctors experience with trying to assess suffering. In the Netherlands and Switzerland[61,62], for the patient to meet the 'suffering' criterion standard, doctors are guided to try to reach the point where the patient has 'convinced' them that their suffering is unbearable, so that they believe the severity of the person's suffering more than just empathetically.

Oregon and England, on the other hand, do not ask for the person or the medical practitioner to comment on the patient's suffering because it is irrelevant. Their criteria of a terminal illness and a prognosis of less than six months left to live is sufficient to qualify for assisted death[63,64]. Curiously, Western Australia makes it a prerequisite to have both a time frame, being an end-of-life limitation of six months with terminal illness, or 12 months limitation if the person has a neurodegenerative disease, and suffering, as described above[65]. The wording of the phrase accepts that it is enough to meet the suffering standard if the individual finds their own suffering intolerable, so it allows the person to express the extent of their suffering without a medical practitioner second-guessing them. Thus, it is unclear why suffering should be stipulated as necessary at all in Western Australia, other than possibly to ensure that the patient and doctor have had a conversation about available palliative interventions.

South Africa, comparatively, also offers assisted death without the necessity of a terminal illness, hence it has no life-limitation clause. It is therefore important for the patient to explain to what extent they are suffering in order to justify why they would prefer to die rather than remain alive. Likewise, it would be vital for the doctor to try to judge accurately how much suffering someone is experiencing in their particular circumstances to rule out treatable depression. In order to cater for South Africa's more wide-ranging Bill compared to the foreign Acts that only focus on E/PAS, the sub-section on suffering should remain open-ended until the terminology has been tested for practicality. If it proves to be too vague, an amendment can be made at a later stage.

A liberal interpretation of the definition of a 'grievous and irremediable condition' without a time frame built in for the predicted natural death, may pose challenges in the future. Based on Canada's experience of its first 6 years, recorded in a recent article published in 2022, an increased number of people sought E, where 10 064 people chose MAiD in 2021 alone[66]. SA's draft Bill has the potential to be just as permissive. The South African definition ought to be interpreted more narrowly than broadly. This is advisable to avoid doctors viewing a person who is requesting assisted death as 'understandably' depressed in the context of their poor health, therefore seeing the solution to the problem as assisted suicide rather than offering the person counselling about alternative interventions[67].

The reference to suffering as 'of a nature and degree not reasonable to be endured' or 'intolerable', evokes individual interpretations of suffering by doctors based on their personal values[68]. Doctors overseas likewise state that their policies, guidelines, and legislation lack

clarity of what 'hopeless or unbearable suffering' means, necessitating a personal interpretation[69]. Dholakia[70] observes more specifically that the difficulty with interpreting the meaning of 'intolerable suffering' for the justification of assisted death is understanding and assessing it in terms of its normative role. A reason for this is that it is unclear whether the emotional aspect of suffering is what is overwhelming for the patient, or rather what underlies the suffering that makes the suffering 'not reasonable to be endured'.

The only adjustment recommended for sentence b) of the original definition is to repeat the list of conditions that could cause suffering, as illustrated in the final definition presented below. In line with Canada's example, an advanced state of irreversible decline in capability is included as one of the aspects that could cause suffering separately to the underlying condition itself. Canada's Act specifies that their definition, which is almost identical to what has been produced for South Africa, does not include mental illness as an illness, disease or disability[71]. Western Australia also has an exclusionary provision for a person who only suffers from a mental illness or only a disability[72].

Accepting mental illness alone for assisted death is very contentious because the extent of suffering is apparently difficult to assess[73]. This has been evident in The Netherlands with legal repercussions for Dutch doctors if their decisions regarding a person's eligibility are found by the Dutch Review Committee not to have met the established 'Due Care' standard. With the consequences of a wrong decision impacting only after the fact, anxiety must keep doctors vigilant when confronted with a difficult dilemma such as mental illness or existential suffering. In the Dutch case of Brongersma in 2002, which dealt with existential suffering, the court, applying criminal law, found the doctor guilty of not exercising due care[74]. The reason was because existential suffering was defined by an expert in court as unbearable suffering of life without any clinical cause, and without any hope of improvement[75]. Accordingly, the person had no underlying medical condition to justify E being administered. De Vries[74] holds the view that the Dutch judiciary has now reached the limits of its definition of 'hopeless and unbearable' suffering. He concludes that these too should be the limits within which to allow E.

The final amended definition is proposed as follows:

*A '**grievous and irremediable medical condition'**, means a serious, incurable disorder, disease or injury, and*

a) the person is in an advanced state of irreversible decline in capability; and

b) that disorder, disease, injury or advanced state of irreversible decline in capability causes that person severe physical or mental suffering of a nature and degree not reasonable to be endured.

(xiii) 'Terminal illness'

'Terminal illness' was defined independently in the SA Bill to denote 'an illness, injury or other physical or mental condition that-

a) in reasonable medical judgment, will inevitably cause the untimely death of the patient concerned and which is causing the patient extreme suffering; or

b) causes a persistent and irreversible vegetative condition with the result that no meaningful existence is possible for the patient.

It is evident that there is a fair amount of overlap with the SA Bill's definition of 'intractable and unbearable illness', although 'terminal illness' is used far more frequently, and on its own, in the following circumstances: in s4(1) where medication is insufficient to relieve symptoms and should be increased; in s5(2) when assisted death is requested and an independent doctor must confirm the terminal illness, (although intractable illness is not mentioned); in s6(1) for promoting the preparation of advance directives; in ss7(1)(a) and 8(1) where there is no directive but the person is unable to communicate or make decisions about their care; and s9(1) for an application to court for withdrawal of treatment.

'Terminal illness' differs from 'intractable and unbearable illness' in two respects: that the person's condition results in an 'untimely death', which implies that death is reasonably foreseeable, although a time frame is not stipulated, and secondly, that the term includes someone who is in a permanent vegetative state, with no meaningful existence.

The first objection is to the phrase 'untimely death'. The word 'untimely' seems to be inappropriate because it means 'happening at an 'unsuitable time', or more often, 'unexpectedly early'[76]. It is a superfluous description of death and could be deleted or replaced with words that are less cryptic, such as 'death within six months'. However, the phrase does create the

expectation that the person is in a dying phase of life. To accommodate this fact, the words 'the person is in an advanced state of irreversible decline in capability' were inserted. Although they are similarly vague in terms of a time frame, it is hoped that these words would incorporate the concept of terminal illness and its associated suffering.

Secondly, subsection b) 'a permanent vegetative state', does not fit well with the description of a terminal illness, despite the definition including an 'injury' or a 'condition'. The word 'illness' is associated primarily with a disease[77], yet a traumatic brain injury could also lead to a permanent vegetative state. Furthermore, as indicated in the court case of *Clarke v Hurst*[78], a person can exist in that condition for many years. It is submitted that a 'persistent and irreversible vegetative condition' should either be described and defined as such, separately, or would, in fact, be adequately covered by the new definition proposed. Hence, it is suggested that the definition of terminal illness be deleted, and the new definition relied upon to replace it and cover both original definitions.

(xiv) 'Lawyer'

The label of 'lawyer' has been replaced by more recent law with the designation of 'legal practitioner.' Both attorneys and advocates are now regulated under a single Act called the Legal Practice Act, 28 of 2014. This Act has repealed the Attorney's Act, 1979 and the Admission of Advocates Act, 1964[79]. Thus, the definition to replace the entry of 'lawyer' would be:

'Legal practitioner' *means an advocate or an attorney as defined in section 1 of the Legal Practice Act 28 of 2014*[80].

(xv) 'Life-sustaining medical treatment'

The definition of 'life-sustaining medical treatment' is accepted without comment.

*'**Life-sustaining medical treatment'** includes the maintenance of artificial feeding.*

(xvi) 'Medical practitioner'

The registration for a medical practitioner is now in terms of the Health Professions Act 56 of

1974, a shortened title for the same Act, which was substituted in 1997[81].

'Medical practitioner' *means a medical practitioner registered as such in terms of the Health Professions Act 56 of 1974.*

(xvii) 'Nurse'

In the SA Bill, 'nurse' refers to a person registered in terms of the now repealed Nursing Act. The updated Act is the Nursing Act 33 of 2005, s31. Authorisation as a prescriber of medicines is in terms of s56(1) of the current Nursing Act where the Council may register a person who meets the specified criteria under this section.

'Nurse' *means a nurse registered as such in terms of the Nursing Act 33 of 2005, s31(1) and if qualified to prescribe medication, authorised as a prescriber in terms of sections 56(1) and 56(6).*

(xviii) 'Palliative care'

The definition of 'palliative care' in the SA Bill is limited in its scope compared to the definition offered in the Western Australian Act[82]. That Act includes the words 'preventing, identifying, assessing, relieving or treating the person's pain, discomfort or suffering in order to improve their comfort and quality of life'. In the context of the SA Bill, the definition of the standard of palliative care is retained as it is in the original draft, replacing 'terminally ill patient' with the new proposed definition of 'a person with a grievous and irremediable medical condition'. The undertaking to treat psychosocial suffering as a separate aspect of care is, however, a major commitment. It undertakes to remediate psychological suffering as a result of social issues such as family problems, abuse, depression and anxiety[83].

*'**Palliative care'** means treatment and care of a person with a grievous and irremediable medical condition with the object of relieving physical, emotional and psychosocial suffering and of maintaining personal hygiene.*

This ends the discussion about the list of words in the 'Definitions' portion of the SA Bill.

5.3.2. Sections 2 to 4, Conduct of medical practitioner, refusal of treatment

These sections recommend legislation to assist medical practitioners by providing clarity on contentious end-of-life decisions in respect of both the patient and the doctor.

Section 2. Conduct of a medical practitioner in the event of clinical death

Section 2 offers legal criteria for doctors to apply when making an assessment to confirm death. The National Health Act, in 2003, defined 'death' as 'brain death'[84]. In addition, the latest guidelines from the Critical Care Society of Southern Africa, published during 2021, offer new details that comply with international standards[85]. Brain death and circulatory death remain the accepted terms for defining death in a hospital environment[85]. 'Brain death' (used in preference to the term 'brain-stem death') means death determined on neurological grounds. 'Circulatory death' (used in preference to 'cardiac or cardiorespiratory death') means death determined on circulatory grounds. Accordingly, section 2 of the draft Act is up-to-date and accepted without correction.

2(1) For the purposes of this Act, a person is considered to be dead when two medical practitioners agree and confirm in writing that a person is clinically dead according to the following criteria for determining death, namely –

a) the irreversible absence of spontaneous respiratory and circulatory functions; or
b) the persistent clinical absence of brain-stem function.

(2) Should a person be considered to be dead according to the provisions of subsection (1), the medical practitioner responsible for the treatment of such person may withdraw or order the withdrawal of all forms of treatment.

Section 3. Mentally competent patient may refuse treatment

Section 3 lays out the right of a person to refuse medical treatment. It has already been mentioned above that the National Health Act, (NHA) of 2003[11] has incorporated this right.

Since the 1998 SALRC Report, the right to refuse medical treatment as set out in the NHA has become legally acceptable. In section 6 the NHA ensures that consent is received from a fully informed patient by stipulating what information must be shared with the patient. It includes at

s6(1)(d), that '1. Every health care provider must inform a user of - (d) the user's right to refuse health services and explain the implications, risks, obligations of such refusal'. However, following a refusal of recommended treatment, the user has a duty to sign a discharge certificate or release of liability for the hospital, so the institution is protected from litigation[86]. A 'user' is defined in the NHA as the person receiving treatment in a health establishment or using a health service[84]. The user is someone over 18 years old, otherwise, if the patient is younger, 'user' includes the parent, guardian or another person authorised by law to act on the patient's behalf. In addition, where the patient is incapable of making decisions, the term 'user' incorporates the spouse, partner, or, in the absence of these people, the parent, grandparent, adult child, a brother or sister, or another person authorised by law to act in that person's stead. Consequently, it allows an alternative person to refuse treatment as the patient's proxy if the patient is incapable of taking decisions. This is reinforced in section 7, too, which caters for alternative consent[87].

Should the legislature decide to promulgate this SA Bill to regulate end-of-life management, and this section is retained, either in addition to, or in preference to the NHA's provisions, the wording could be slightly adjusted according to the following suggestions. The child's age is reduced to 12 years and older, to align with The Children's Act, 2005, which accepts that a child can give consent from this age, even for surgical interventions, with the assistance of a parent or guardian[88]. Also, the words 'of sound mind' are replaced with 'mentally competent' to align with the definition section's wording, as clarified above.

3(1) Every person –

(a) above the age of 18 years and ***who is mentally competent****, or*

(b) above the age of ***12 years, who is mentally competent*** *and assisted by his or her parents or guardian,*

is competent to refuse any life-sustaining medical treatment or the continuation of such treatment with regard to any specific illness from which he or she may be suffering.

(2) Should it be clear to the medical practitioner under whose treatment or care the person who is refusing treatment as contemplated in subsection (1) is, that such a person's refusal is based on the free and considered exercise of his or her own will, he or she shall give effect to such a

person's refusal even though it may cause the death or the hastening of death of such a person. (3) Care should be taken when taking a decision as to the competency of a person, that an individual who is not able to express him or herself adequately, should not be classified as incompetent unless expert attempts have been made to communicate with that person whose responses may be by means other than verbal.

(4) Where a medical practitioner as contemplated in subsection (2) does not share or understand the first language of the patient, an interpreter fluent in the language used by the patient must be present in order to facilitate discussion when decisions regarding the treatment of the patient are made.

Section 4. Conduct of medical practitioner in relieving distress

The administration of sufficient medication as necessary to reduce distress and to give comfort during the terminal phase of life is now accepted as the appropriate standard of medical care to be made available to patients[89]. However, there is no law in place to support the ethical guidelines at this stage and it would be helpful for medical practitioners, lawyers and the public to have certainty about these matters as is proposed in the SA Bill.

In section 4(1) it is interesting to note that nurses were included when the original draft was written, with no mention that a doctor must prescribe the higher or more frequent dose of medication required to reduce the suffering, although nurses were not given the authority to administer euthanasia elsewhere in the draft Act. The recognition of a nurse practitioner in this capacity, who has the appropriate training to prescribe and administer medication, is a practical step towards ensuring access to palliative care, in time to come. This is mentioned again when section 5(4) is discussed.

For the sake of consistency and clarity, the words 'or a nurse' are deleted from this section. An amendment can re-introduce them at a later stage if nurses are given this authority. Also, 'terminal illness' is replaced with the phrase 'grievous and irremediable medical condition'.

4(1) Should it be clear to a medical practitioner responsible for the treatment of a patient who has been diagnosed by a medical practitioner as suffering from ***a grievous and irremediable medical condition*** *that the dosage of medication that the patient is currently receiving is not adequately alleviating the patient's pain or distress, he or she shall –*

(a) with the object to provide relief of severe pain or distress; and

(b) with no intention to kill

increase the dosage of medication (whether analgesics or sedatives) to be given to the patient until relief is obtained, even if the secondary effect of this action may be to shorten the life of the patient.

(2) A medical practitioner who treats a patient as contemplated in subsection (1) shall record in writing his or her findings regarding the condition of the patient and his or her conduct in treating the patient, which record will be documented and filed in and become part of the medical record of the patient concerned.

5.3.3. Section 5, E and PAS

Section 5 of the Act offers legislation for E and PAS in the SALRC's Options 2 and 3, while Option 1 provides the reasons why the SALRC thought it should be excluded.

Option 1: Confirmation of the current position

The Commission formed the view that it would be impossible to put adequate safeguards in place to ensure the voluntariness of E and to prevent incidences of involuntary euthanasia. The dilemma of E could also not be viewed as the interests of one person separated from the interests of society as a whole. In addition, the SALRC emphasised that by declining to incorporate E into the law, society was duty-bound to care properly for the elderly, the disabled and the dying, despite the limitations that existed on healthcare resources. Palliative care also was required to be of a high standard and be more widely available, with additional training in this specialty offered to medical practitioners as a priority[90].

It should be stated that even if E and PAS were legalised, adequate, good care should be available and accessible to all who need it, particularly for the vulnerable groups identified. As mentioned in the previous chapter, Belgium considered it to be unethical to offer E without high quality palliative care in place at the same time[91]. Also, in Canada, the First Peoples have said that if they cannot access health services and palliative care, but E is made available, there is factually no choice for them in respect of how they cope with suffering except death, and that

is not a choice[92].

Option 2:

Section 5. Cessation of Life (Assisted Death)

Section 5 provides for both euthanasia and physician-assisted suicide. The heading 'Cessation of life' is ambiguous because it does not indicate that the section only covers assisted death and excludes other ways of ending life such as withholding and withdrawing of treatment. Similar to the name of England's draft law, the 'Assisted Dying Bill'[93], it is proposed that the heading should state frankly that it regulates 'assisted death' or 'euthanasia and physician-assisted suicide' and not resort to euphemisms. The reason the word assisted 'death' is chosen as opposed to assisted 'dying' in this context is because, based on the SA Bill's wording, it will not be mandatory for people to only have a few months left to live when they request assistance to die compared with the requirements of England's Bill. Furthermore, the term covers both the process of E and PAS in its meaning[34].

Devettere suggests that euphemisms are used, not to clarify the reality of an action, but to manipulate people's emotions by masking the truth behind the words of what is actually happening. In the case of euthanasia, he remarks that the reason it is done is to gain support for the process by making the fact that physicians are assisting with death or actively killing the person sound more acceptable. Another criticism voiced is that by being misled, people avoid honest robust debate about the important ethical dilemma that medical practitioners are confronted with of whether it is ever acceptable and noble to assist patients when there are other options available. Devettere comments that the decision to legalise E and PAS ought to be able to withstand differences of opinion despite using direct language[94].

The following modifications are offered for this section. Replacements of certain words or additions are indicated by those in bold. In this context 'medical practitioner' means 'attending doctor'; 'some or other' is replaced with 'a' and 'terminal illness' is updated to a 'grievous and irremediable medical condition'.

*5(1) Should a medical practitioner (**attending doctor**) be requested by a person to make an end to the person's suffering, or to enable the person to make an end to his or her suffering by way of administering or providing **a** lethal agent, the **attending doctor** shall give effect to the*

request if he or she is satisfied that –

(a) the person is suffering from a ***grievous and irremediable medical condition;***

(b) the person is over the age of 18 years and mentally competent;

In 5(1)(c), 'adequately' is replaced with 'fully' in accordance with the NHA's criteria for full knowledge[95]; 'illness' becomes 'medical condition' to broaden the scope; and 'his or her' is replaced with 'the'.

(c) the person has been ***fully*** *informed in regard to the* ***medical condition*** *from which he or she is suffering, the prognosis of* ***the*** *condition and of any treatment or care that may be available,* ***including the benefits, risks, costs and consequences, and the right to refuse health services with its implications****;*

In 5(1)(d) the word 'voluntary' is preferable to 'free' because the meaning of 'voluntary' is unambiguous, used on its own, compared with 'free' which could mean without physical coercion. The addition of 'well' to 'considered' is for emphasis, but not vital.

(d) the request of the person is based on a ***voluntary*** *and* ***well****-considered decision;*

In 5(1)(e) the timing between the person's requests and assisted death is one of the legal safeguards employed to ensure certainty that the person really wishes and intends to die. Bearing this in mind, the SA Bill's proposed time frame of seven days between the requests, and no more than 72 hours before the doctor can perform assisted death is quite brief compared with foreign jurisdictions, particularly with non-terminal conditions. South Africa's initial time frame of seven days between requests will be discussed first followed by comments on the second time frame of 72 hours in which to perform assisted death.

The Netherlands and Luxembourg do not stipulate a time frame, except that in Luxembourg it must be a 'reasonable period of time' between interviews to establish the evolution of the patient's condition. In contrast, Belgium[96] requires a month to pass between the patient's written request and euthanasia for a non-terminal illness, and Canada[97] has legislated a 'clear' 90-day period from the patient's first assessment until death, if death is not foreseeable. In the past, Canada had stipulated a 10-day reflection period after the written request where death was

foreseeable, but subsequently found overwhelming support to remove the reflection period because health care providers had shared that, in their experience, patients had already considered their decision over a long time before requesting MAiD[98]. Switzerland's guidelines[99] for all patients, whether the patient is terminally ill or not, suggest two weeks between two detailed discussions, unless death is imminent, where an exception to shorten the time frame can be made.

With regard to the countries that impose the criterion of a limited lifespan in order for someone to be eligible for assisted death, on the whole, the time frames appear to be more limited, such as in Western Australia[100]. There, patients must have either less than 6 months to live with a terminal illness, or, if the disease is neurodegenerative, 12 months. so the law stipulates that nine days must elapse from the first request to the final request, unless either death or loss of decision-making capacity is imminent, in which case a shorter time frame would be justified. Oregon requires not less than 15 days between oral requests[101], and the British draft law proposes a waiting period of not less than 14 days from the patient's written declaration[102], unless unconsciousness or death is close, where time frames may be reduced in both countries. England then reduces the waiting period to six days if the person will not survive for a month beyond the signing of the declaration.

The various time frames appear to be arbitrary but average around 14 days overall for people with a limited lifespan left to live. It is suggested that the 14-day time frame should be applied in South Africa, where a range of grievous and irremediable conditions may qualify for assisted death if the person has reached 'an advanced state of irreversible decline in capability', according to the definition of a grievous and irremediable condition. An exception can also be made to shorten the time-period for someone who may not retain decision-making capacity during this assessment phase, similar to the British draft law.

With regard to the second time frame of 'no more than 72 hours before the medical practitioner gives effect to the request', it is unclear why a maximum time-limit of four days is enforced for performance. It is possible that the drafters wanted to ensure that a person did not wait for too long before the process was performed, but this specification should be unnecessary unless problems with compliance are envisaged. It may be that the time frame could result in needless pressure on medical staff to comply with the Act if there were consequences for non-compliance. The foreign countries that add a time-period between assessment, contemplation and the ultimate performance of assisted death specify a minimum time lapse, not a maximum.

Oregon mentions ‘no less than 48 hours’ between the patient’s written request and writing the prescription’ unless the patient may die, in which case it can be written at any time following the written request[103]. It is suggested that a maximum time frame should not be prescribed, but rather a minimum. Thus ‘not more than’ should be changed to ‘not less than’ and 72 hours could be reduced to 48 hours. The reduced hours are because the first time frame has been doubled to 14 days. Alternatively, this restriction could be removed, as it now serves a different purpose from being a time-limit which affects the doctor. The new time-lapse gives a patient a further opportunity to reconsider their decision, but, according to Canada’s experience[104] it is probably unnecessary because the person tends to be certain by the end of the whole assessment process.

Other alterations in the provision are the inclusion of ‘enduring’ to replace ‘self-contradiction’ and the addition of the word ‘attending’ before medical practitioner. Where it adds clarity, the word 'requester' is used to distinguish between the people referred to within a paragraph, but it is not used throughout the document.

*(e) the request has been **enduring and** repeated by the person **(requester)** on two separate occasions at least **14** days apart, the last of which is **no less than 48 hours** before the **attending doctor** gives effect to the request.*

In 5(1)(f), the British Assisted Dying Bill’s comprehensive Declaration section[105] has been combined to some extent as a possible modification of the present South African provisions, highlighted in bold type. The insertion reiterates that the criteria for voluntariness, full information, and a settled decision, have all been met leading up to the request. The word ‘signed’ has been moved to provision g), and the word ‘attending doctor’ replaces ‘medical practitioner’.

*(f) the **requester**, or person acting on the **requester’s** behalf in accordance with subsection (6), has completed **a** certificate of **request which states that he or she has a voluntary, clear, settled and informed wish to end his or her life and** asks the **attending doctor** to assist the **requester** to end the **requester’s** life;*

In 5(1)(g) the sentence is ambiguous because it could mean either that the doctor has signed as a witness, or, watched the patient sign the certificate. Although the doctor may not sign as a witness because there would be a conflict of interests, the certificate ought to be signed by the

attending doctor to confirm that the criteria for eligibility are fulfilled. The independent doctor should also sign this certificate so that the certificate confirms, in one document, that the patient and doctors have complied with all the legislative steps. This would be a safeguard comparable to the British Bill's requirements for their patient Declaration[105]. These safeguards are now incorporated into g) in bold type.

(g) ***the certificate of request has been signed by the requester or*** *person acting on the* ***requester****'s behalf in accordance with subsection* ***(3)****,* ***in the presence of the attending doctor and a witness (who must not be a relative or directly involved in the person's care or treatment) who signed the certificate in the patient's presence;***

(i) and that certificate has been countersigned by the attending doctor and

(ii) the independent doctor, who is not a relative, partner or colleague in the same practice or clinical team, of the attending doctor;

neither of whom may also be the witness required under (g).

In (h) and (i) there are no alterations other than exchanging the word 'patient' for 'person' to be consistent with the fact that E and PAS would not only being available for terminally ill patients.

(h) an interpreter fluent in the language used by the ***person*** *is present in order to facilitate communication when decisions regarding the treatment of the* ***person*** *are made where the medical practitioner as contemplated in this section does not share or understand the first language of the* ***person****;*

(i) ending the life of the ***person*** *or assisting the* ***person*** *to end his or her life is the only way for the* ***person*** *to be released from his or her suffering.*

In subsection 5(2), the proposed amendments follow on from subsection g)'s changes. They are also based on the British Bill's wording of a similar provision[106] which is very specific. A complete change is introduced in that the revised provision now refers back to the point before countersigning the patient's request, as opposed to the original provision's wording that referred to a time before giving effect to the request. The amendment is more accurate in light of the

newly introduced countersigning by both doctors in (g). Subsection 1(d) was added in the list of important facts to be confirmed because voluntariness is a vital aspect of the process.

*(2) **Before countersigning a person's certificate, the attending doctor** to whom the request to make an end to a **person's** suffering is addressed as contemplated in subsection (1), **and** an independent medical practitioner (**independent doctor**) **with whom he or she has** conferred **and** who is knowledgeable with regard to the **grievous and irremediable condition** from which the **person** is suffering, **having separately** checked the **person**'s medical history and examined the **person and each independently of the other, must have** confirmed the facts as contemplated in subsection (1)(a),(b),**(d)** and (i).*

In subsection 5(3) only the designations of the doctors are added.

*(3) **The attending doctor** who gives effect to a request as contemplated in subsection (1), shall record in writing his or her findings regarding the facts as contemplated in that subsection and the name and address of the **independent doctor** with whom he or she has conferred as contemplated in subsection (2) and the **independent doctor** shall record in writing his or her findings regarding the facts as contemplated in subsection (2).*

Subsection 5(4) is presumably referring to both the administration of euthanasia and the prescription of a lethal agent for assisted suicide, although it is uncertain whether the doctor must be present at the death of an assisted suicide or not. In the British Bill, which only allows assisted suicide, a health professional is required to remain with the person until their death[107], but it is sufficient compliance if they are in in another room, as long as they are within close proximity to manage any complications that might arise with the process. Likewise, in The Netherlands the medical practitioner must also be present for PAS or remain in the vicinity[108]. In Canada the health professional remains present at an assisted suicide if a written arrangement was entered into with the patient[109], and both a nurse practitioner and a doctor may perform it. Similarly, Western Australia permits a suitably trained nurse practitioner to administer the lethal substance besides medical practitioners, but they are not required to be present at an assisted death once the prescription is issued[110].

Considering the rural areas of South Africa, if E and PAS are brought into law, it may improve access by allowing suitably trained nursing staff to participate in the administrative process. According to the final SALRC Report 86[111], suggestions flowing from the SALRC Discussion

paper 71 mentioned this idea, together with allowing other possible categories of people who could assist with aspects of E and PAS. The concept was not embraced in the final draft Act, possibly because of a concern about safeguards, although the reason for limiting the task to doctors only is not explicitly expressed.

The amendment to subsection 5(4) caters for assisted death as well as euthanasia by the insertion of the following words, indicated in bold type, so it conforms with a new subsection that is inserted as 5(5): '… or, for assisted death using self-medication, a duly appointed assisting health professional as contemplated in (6)(B)(b), who must remain with the person until the person has died or, alternatively has revoked the request to die. For the purpose of this subsection it is sufficient if the assisting health professional is in close proximity to, but not in the same room as, the person who self-administers the lethal medication'.

*(4) The termination of a **person's** life on his or her request in order to release him or her from suffering may not be effected by any person other than a medical practitioner **or, for assisted death using self-medication, a duly appointed assisting health professional as contemplated in (6)(B)(b), who must remain with the person until the person has died or, alternatively has revoked the request to die. For the purpose of this subsection it is sufficient if the assisting health professional is in close proximity to, but not in the same room as, the person who self-administers the lethal medication**.*

A new subsection 5(5) has been introduced to include the regulation of assisted suicide in South Africa with more particularity. This extra section is based exclusively on the British Assisted Dying Bill[112]. It presents a few important details of the process from which South Africa could benefit. The original subsection 5(5) is moved further down in the document to facilitate a logical progression. It may be better structurally, ultimately, to create an additional section rather than another subsection so that the numbering is not too cumbersome, but for the purposes of analysis the original framework is maintained.

(5) Assisted death using self-medication

(A) The attending doctor of a person who has made a valid request may prescribe medicines for that person to enable that person to end their own life.

(B) Any medicines prescribed under subsection (A) may only be delivered to the person for

whom they are prescribed –

(a) by the attending doctor; or

*(b) by an **assisting health professional** who is –*

(i) another medical practitioner; or

(ii) a nurse;

who has been authorised to do so by the attending doctor;

(c) after the attending doctor or assisting health professional has confirmed that the person has not revoked and does not wish to revoke their request;

*(C) In respect of a medicine which has been prescribed for a person under subsection (A), an **attending doctor or** assisting health professional may –*

(a) prepare that medicine for self-administration by that person;

(b) prepare a medical device which will enable that person to self-administer the medicine; and

(c) assist that person to ingest or otherwise self-administer the medicine; but the decision to self-administer the medicine and the final act of doing so must be taken by the person for whom the medicine has been prescribed.

As stated in the British draft[113], regulations would need to stipulate a) the range of medications which need to be prescribed for both E and PAS; b) the form and manner in which the prescriptions are to be issued; and c) the manner and conditions under which such medicines are to be dispensed, stored, transported, used and destroyed. In Oregon's Act[114], Western Australia's Act[115], and that of Canada[116], the pharmacist must be made aware that the prescription is for assisted death. Once the pharmacist is notified, it would be important to address when the prescribed medicines can be delivered and how to handle these medicines should the person change their mind about self-administration. Accordingly, Section 5, subsection (D) could continue on from the example above as follows:

(D) The attending doctor or an assisting health professional-

(a) must only deliver any medicines prescribed under this section to the person for whom they have been prescribed immediately before their intended use; and

(b) in the event that the person decides not to self-administer the medicine, must immediately remove it from that person and, as soon as reasonably practicable, return it to the

pharmacy from which it was dispensed.

The Western Australian legislation is extremely detailed, comprehensive and rigorous with respect to managing and recording every step that is taken towards both forms of assisted death[117]. There are many safeguards in place, and it will be interesting to see how efficiently the Act works in time to come. For South Africa, if euthanasia becomes lawful, it would be worth considering having a witness present when the lethal drug is administered, as Western Australia has done[118], who can verify that the person's decision had not changed and that there was no coercion.

The Divisions of the Western Australia Act on prescribing, supplying, and disposing of the VAD substance span 12 provisions with many subsections[119]. Legislation to regulate who would be authorised suppliers and disposers of the medication also exists in the stipulations. For the South African Act, information that micro-manages the process would possibly be better suited in regulations.

The original subsection 5(6) continues below. It is proposed that subsection (6) be moved up into the position of subsection 5(3) to create a more logical progression, so that both forms of signing of the certificate are dealt with at the same time. This repositioning will be implemented in the final presentation of the draft at the end of this chapter. Its terminology has been updated to remain consistent with the rest of the draft: 'patient' is replaced with 'person', (who is also referred to as the 'requestor', when necessary), and 'the medical practitioner' is specified according to their new definitions. The second reference to 'the person' has been deleted, and the last reference to 'request' is replaced with 'invitation' to create a slightly less clumsy sentence.

'(3)' ~~*(6)*~~ *If a* ***person (requester) ,*** *who has orally requested his or her* ***attending doctor*** *to assist to end the* ***requester****'s life, is physically unable to sign the certificate of request, any person who has attained the age of 18 years, other than the* ***attending doctor*** *referred to in subsection (2) above may, at the* ***requester's invitation*** *and in the presence of the* ***requester*** *and both the* ***attending and independent doctors****, sign the certificate on behalf of the* ***requester.***
In subsection 5(7), 'patient' has been replaced by 'person' and 'medical practitioner' by 'attending doctor,' printed in bold. As safeguards, some foreign Acts have legislated built-in opportunities for the doctor to check whether the person would like to rescind their request in order to ensure that the person's decision is enduring. For example, Oregon[120], at the person's

second oral request, requires that they be reminded that they can change their mind at any time. Canada's Act has an explicit condition that, immediately before MAiD is administered, the person is given a final opportunity to retract their request and then must expressly consent to receive the lethal substance[121]. The British Bill requires confirmation that the person's decision is not revoked just before the medicines are delivered to that person's home[122]. Western Australia[123], in comparison, first has the three formal requests by the person seeking VAD. Then, in addition, there are no less than seven other provisions that either reinforce in some written form a reminder that the person can rescind their request, such as in the doctor's and pharmacist's instructions to the person on what to do for self-administration, or reinforce the requirement of confirmation that the person's decision is voluntary, such as through the administering health professional and a witness to the euthanasia who must record it.

In contrast, South Africa just makes a general statement that a person is always allowed to retract their decision. This provision is somewhat ineffectual if no nurse or medical practitioner actually reinforces the point to the person seeking assisted death. A good time to confirm the decision would be just before the prescribed substance is either delivered or administered to the person. With this in mind, subsection 5(5)(B)(c) has now been added to the new section above, taken from the British Bill's example.

(7)(a) Notwithstanding anything in this Act, a ***person*** *may rescind a request for assistance under this Act at any time and in any manner without regard to his or her mental state.*

(b) Where a ***person*** *rescinds a request, the* ***person's attending doctor*** *shall, as soon as practicable, destroy the certificate of request and note that fact on the* ***person's*** *medical record.*

The word replacements for the original words in subsection 5(8) are printed in bold below. 'Patient' is replaced by 'person'.

(8) The following shall be documented and filed in and become part of the medical record of the ***person*** *who has been assisted under this Act:*

In (a), a reminder is added for the date of the request because it has a bearing on the new required time lapse under subsection 5(1)(e).

(a) a note of the oral request of the ***person*** *for such assistance,* ***including the date when it***

***was made**;*

(b) the certificate of request;

In (c), the doctor's opinion has been expanded to confirm that each of the eligibility criteria has been met and to explain the reasons why the person is eligible for assisted death.

*(c) a record of the opinion of the **person's attending doctor explaining** that the **person has met each of the eligibility criteria as contemplated in subsection 1 and the reasons for this opinion, including** that the **person's** decision to end his or her life was made freely, voluntarily and after due consideration;*

In (d), 'medical practitioner' is changed to 'independent doctor'.

*(d) the report of the **independent doctor** referred to in subsection (2) above;*

The note in (e) does not need to reiterate that the criteria have been met for the request to be valid but rather is a wider confirmation that all the requirements in the Act have been met. Either in regulations or in additional subsections, guidance would be helpful for the steps to be taken to carry out the request, and for the substance used and its administration. As discussed in Chapter 4, The Netherlands has very comprehensive guidelines on substance use and methods of administration[124].

*(e) a note by the **person's attending doctor** indicating that all requirements under this Act have been met and indicating the steps taken to carry out the request, including a notation of the substance prescribed.*

The original subsection 5(5) is now moved to 5(9) below, after which other important new general provisions could be added. The adjustments in the provision are that 'patient' is replaced by 'person' and 'to be released from suffering' is replaced with the words: 'for assisted death'.

***(9)** A medical practitioner who gives effect to a **person's** request **for assisted death** as contemplated in this section shall not suffer any civil, criminal or disciplinary liability with regard to such an act provided that all due procedural measures have been complied with.*

Another suggested inclusion would be a provision stating clearly what entry should be inserted in the death certificate as the reason for death. Again, the foreign law offers a range of responses. As discussed in Chapter 4, the Oregon Health Authority, Center for Health Statistics, instructs doctors to insert the underlying disease as the cause of death rather than MAiD, and the 'manner' of death is labelled 'natural'[125]. Belgium's Act also affirms that a person who dies from E in accordance with the law dies a 'natural death'[126]. Likewise, Western Australia stipulates that the doctor must not include any reference to VAD in the cause of death certificate[127].

If the death certificate is misleading it could create problems for the state to keep accurate statistics of assisted deaths because they cannot cross-check medical records against death certificates. The British Bill has legislated that any regulations made under their Birth and Deaths Registration Act 1953 must provide for the cause of death to be recorded as 'assisted death'[128]. It seems reasonable for South African doctors to continue to fill out the notice of death[129] honestly, in accordance with the present law[130], in the same way that death from HIV (the human immunodeficiency virus) was required to be stipulated but handled in a confidential manner to avoid stigma. Statutory Acts that cater for the investigation into 'unnatural deaths' would need to be amended to accommodate 'assisted death' on a death certificate[131, 132]. The death certificate would be an important record of the trends of deaths if assisted death law was promulgated in the future.

Another matter on which legal clarification would be important, which could be inserted under 'general provisions', is how insurers treat this unnatural death in contracts. A clause stating that no insurance company may penalise or incentivise a decision to choose assisted death would be fair. This has been incorporated into the Oregon statute which, as an example, is reproduced below[133]. It is incorporated into the amended draft Act with a small amendment, numbered subsection 5(10). The word 'patient' has been swapped for 'person' in bold and the words 'receiving the administration of, or…' have been inserted to include E.

(10) 'The sale, procurement, or issuance of any life, health or accident insurance or annuity policy or the rate charged for any policy shall not be conditioned upon or affected by the making or rescinding of a request, by a person, for the medication to end his or her life in a humane and dignified manner. Neither shall a qualified ***person's*** *act of* ***receiving the administration of, or*** *ingesting medication to end his or her life in a humane and dignified manner have an*

effect upon a life, health, or accident insurance or annuity policy.'

In a similar vein, Oregon ensures that it is illegal for any provision in a contract, will or other agreement to influence a person's decision to either request or rescind a request for assisted death[134]. Such a provision may be helpful as a safeguard in the SA Bill, although it should be unnecessary because contracts with such provisions would arguably be against the good morals of society (*contra bonos mores*).

If this option is followed, a review process would also ultimately need to be provided for in the Act.

Option 3:

Section 5. Decision-making by panel or committee.

Colombia was originally the only example in this thesis of a legal system that required an interdisciplinary committee to decide on cases before they were allowed to access E or PAS. The summary of the case law judgment that initiated the interdisciplinary committees described the panel as being able to have a discussion about the patient's case under 'objective and impartial circumstances'[135]. During 2021, Spain's new E law, LO 3/2021[136] commenced. It also requires the government to establish an *ad hoc* committee called a Guarantee and Assessment Committee for each Autonomous Community to implement and monitor E procedures to ensure that they are lawful.

England, too, in its British Assisted Dying Bill, has proposed that the High Court (Family Division) carry out a pre-PAS assessment and confirmation of a person's application for assisted dying. This is in preference to a Review Committee critiquing the doctors' decisions and medical documents *ex post facto*[137]. The SALRC in its report recorded that such a panel would be more appealing for people who did not trust E legislation because of the potential for its abuse[138].

In subsection 5(1), E is specifically mentioned and not PAS with regard to the need for approval from an Ethics Committee. It is unclear why PAS cases are not mentioned. Logically, all requests should be included for approval, regardless of the person's chosen method to end their life. A reference to the panel issuing a certificate for E or PAS once the case has been

considered, has also been inserted in the amended subsection, so that the family has a document that can be shown to the entity that will facilitate the assisted death.

Subsection 5(1) is amended with the replacement of the first reference to 'euthanasia' with 'assisted death', the inclusion of the additional words 'or physician-assisted suicide' and 'in the form of a certificate issued', to link the provision more effectively with subsection 5(4)(a)(iii) below. The word 'patient' is replaced by 'person' in bold type throughout the subsection and the reference to 'five' persons is changed to 'four'.

*(1) **Assisted death** may be performed by a medical practitioner only, and then only where the request for the euthanasia or **physician assisted suicide** of the **person** has been approved **in the form of a certificate issued** by an ethics committee, constituted for that purpose and consisting of **four** persons as follows:*

In 5(1)(a) 'attending doctor' is in place of 'practitioner attending', to ensure uniformity of terms used.

*(a) two medical practitioners other than the **person's attending doctor**;*

(b) one lawyer;

In 5(1)(c), if the relative of the person mentioned in (e) is not included in the panel, for the reasons given below at (e), it is unnecessary to have a panel member present who shares the home language of the person. Presumably the purpose of this clause is to facilitate understanding between the relative and the panel.

~~*(c) one member sharing the home language of the **person**;*~~

(d) one member from the multi-disciplinary team;

In 5(1)(e), the inclusion of a family member on the panel is a contentious and problematic addition. No reason is provided for their inclusion, except that the SALRC report[139] gives the impression that members of the public bring their own medical documents to the committee and present their case. This informality would not be realistic, having seen how much effort the foreign assessments demand in order to establish a person's eligibility for assisted death. If the

patient cannot attend in person, the relative could influence the panel by either undermining the request of the patient or emphasising the patient's wish inappropriately. Their presence would interfere with the objectivity of the panel and could cause more confusion than clarity, making a final decision impossible. Information from the relatives would be better placed in, and ought to be part of, the doctors' reports, if it contributed to providing insight into the patient's context in some way that was relevant. In the amended draft, subsections (c) and (e) are excluded.

~~*(e) one family member..*~~

In subsection 5(2), because a certificate is issued in terms of this subsection according to subsection 5(4)(a)(iii), the words 'and issue a certificate' are added for clarity and consistency.

(2) In considering, and in order to approve a request ***and issue a certificate,*** *as contemplated in subsection (1), the Committee has to certify in writing that:*

In 5(2)(a), 'person' is used instead of 'patient', 'euthanasia' is replaced with 'assisted death' and 'free' is replaced with 'voluntary'.

(a) in its opinion the request for ***assisted death*** *by the* ***person*** *is a* ***voluntary****, considered and sustained request;*

In 5(2)(b), 'patient' is exchanged for 'person', and the phrase 'terminal or intractable and unbearable illness' is replaced with the updated term 'grievous and irremediable medical condition'.

(b) the ***person*** *is suffering from a* ***grievous and irremediable medical condition;***

In 5(2)(c), 'euthanasia' is replaced with 'assisted death' in order to include both E and PAS.

(c) ***assisted death*** *is the only way for the person to be released from his or her suffering.*

In subsection 5(3), the time frame ensures that the case is heard within three weeks but does not stipulate by when a decision must be given to the person who is waiting for an outcome. It is suggested that a decision should be reached by the end of the meeting. Thus, an insertion of the words 'and a decision reached on the same day whether or not to allow assisted death' is

made, and the term ‘euthanasia’ is replaced with ‘assisted death’.

*(3) A request for **assisted death** must be heard within three weeks of it being received by the Committee, **and a decision reached on the same day whether or not to allow assisted death.***

Subsection 5(4) onwards indicates that the Committee carries the responsibility for all the subsequent paperwork that must be recorded, in contrast to it being the task of the attending doctor under Option 2. This shifts the responsibility of the entire process onto the government, from deciding who is permitted to access E/PAS, through to reporting back to the state, and then afterwards capturing the information for statistical purposes, which would be important.

In 5(4)(a), the requirement that the report be sent to the Director-General of Health by registered post seems to be a sensible way of ensuring that hard reliable evidence exists as a record of potential deaths. Information should also be captured in a secure data base that protects confidentiality. The prescribed manner and prescribed period in which to report the deaths are not indicated but would be inserted in regulations that ultimately specify the micro-management of the Act. The only change to the wording in (a) is replacing ‘euthanasia’ with ‘assisted death’.

*(4)(a) The Committee which, under subsection (2), grants authority for the **assisted death** must, in the prescribed manner and within the prescribed period after **assisted death** has been performed, report confidentially to the Director-General of Health, by registered post, the granting of such authority and set forth –*

In 5(4)(a)(i), ‘patient’ is replaced by ‘person’.

*(i) the personal particulars of the **person** concerned;*

In subsection 5(4)(a)(ii), to add uniformity to the provision, the word ‘euthanasia’ has been replaced with ‘assisted death’.

*(ii) the place and date where the **assisted death** was performed and the reasons therefore;*
In 5(4)(a)(iii), the plural ‘certificates’ has been changed to the singular ‘certificate’, because it makes sense that one certificate would be issued per person’s request.

*(iii) the names and qualifications of the members of the committee who issued the **certificate** in*

terms of the above sections; and

According to 5(4)(a)(iv), it would seem that any medical practitioner can perform E without necessarily having participated in the Committee's assessment of the person preparing for E. This may be a realistic and practical approach to E and PAS with the advantage that, for the medical practitioner, attention is focussed just on the action and not on the person - a possible criticism of the process[140]. The psychological consequences of such decisions on Medical practitioners are as yet unknown and are discussed more fully further on. The alternative, that is requiring the original attending doctor to perform E, may create a barrier to access if many doctors are unwilling to participate in the final act.

(iv) the name of the medical practitioner who performed the euthanasia.

In 5(4)(b) the Director-General only receives the report once E or PAS is completed, so the purpose of this provision appears simply to be for quality control and possibly for research purposes.

(b) The Director-General may call upon the members of the Committee required to make a report in terms of subsection (4) or a medical practitioner referred to in subsection (1) to furnish additional information as he may require.

Subsection 5(5) does not specify who must document and file the list of information below, but it could either be the Committee or the attending doctor. Although the attending doctor would have had the original medical record, this record, or a copy, would probably be required to be sent to the Committee for their assessment. In addition, only the Committee would have the final report, which would have been sent on to the Director-General. A system would have to be established where a file incorporating the confidential medical record, the certificate and the final report is put together in order to be sent back to the attending doctor for safekeeping. There is no indication of what must happen to the final medical record other than storage.

The word 'patient' is replaced by 'person'.

*(5) The following shall be documented and filed and becomes part of the medical record of the **person** who has been assisted under this Act:*

*(a) full particulars regarding the request made by the **person;***

(b) a copy of the certificate issued in terms of subsection (2);

(c) a copy of the report made in terms of subsection (4).

Ultimately, Section 5 of the SA Bill would need to be addressed further to include the following matters: i) for Option 1 - designing a model for the structure of a review process, already mentioned earlier in the chapter; ii) preparing regulations that state who is responsible for record-keeping of the types of deaths that occurred, and the legal requirement of publishing these statistics to maintain transparency surrounding the process. This is important to give insight into the social impact the law would have, as well as the practical impact on other resources such as the health system, mortuaries and forensic pathologists, if they are responsible for issuing death certificates; iii) a time frame for re-assessment of the Act once it is in force, to identify weaknesses and cater for amendments - a suggestion is possibly after five years, as provided for by Canada[141]; and iv) a section indicating what sanctions could be expected for non-compliance with the Act.

Lastly, some Acts, such as Oregon[125], provide pro-forma documents to assist with different sets of information gathering, explained in Chapter 4. Although helpful, certain styles of forms have been criticised, such as if they have tick-boxes that may stop a person applying their mind to the information being filled in[142]. On the other hand, forms help people to meet the minimum requirements that satisfy the administrative process as safeguards. This ends the analysis of Section 5 on E and PAS.

5.3.4. Sections 6 and 7, Advance Directives and Powers of Attorney

Sections 6 and 7 propose legislation to give Advance Directives and Powers of Attorney legal force.

Section 6. Directives as to the treatment of a person with a grievous and irremediable medical condition

Section 6 of the SA Bill proposes legislation for the effective use of advance directives in terminally ill persons. However, advance directives would be useful for anyone permanently no longer capable of communicating their wishes, so it is suggested that the heading be changed

from ‘terminal ill person’ to ‘person with a grievous and irremediable medical condition’.

There has been a persistent wish that the government legislate on these matters to give more details about how exactly decisions to withdraw treatment can be reached without medical practitioners being concerned that they could still face prosecution for an action performed in good faith[143, 144]. In 2012, the South African Medical Association (SAMA) drew up guidelines for the drafting of advance directives and living wills[145]. It does not differentiate between two types of documents but uses the terms ‘advance directive’ and ‘living will’ interchangeably. It refers to a document that states the person’s wish to refuse medical treatment in certain situations in the future, unlike Switzerland, where the two documents fulfil different needs and are legally enforceable[146].

In February 2019, following SAMA’s example, a private Bill was brought to Parliament by Ms. D. Carter to incorporate advance directives and enduring powers of attorney into the NHA through an amendment[147]. Although it was a good idea in order to provide legal certainty, unfortunately, when the 5th Parliament was dissolved in May 2019, the Bill lapsed automatically in terms of Rule 333(2) of the National Assembly and nothing more was done[148]. Parliament does have the power to revive matters, but no further progress has been made with the Bill and it remains amongst many other Bills in the National Assembly[149].

McQuoid-Mason[150] offers a wider definition than SAMA of an advance directive, it being an instruction by a person concerning their wishes for both future medical treatment or its cessation, should they become incompetent to express themselves in time to come. In addition, the person can name someone of their choice to give consent on their behalf, or refuse it, depending on the circumstances. The advance directive therefore combines the idea of a ‘living will’ with an ‘enduring power of attorney’. This broader definition is supported by the SALRC[151] and Grove[152] who has published on the topic. The document carries no legal weight but amounts to a request and an indication of the person’s choices regarding their own medical treatment. Additionally, enduring powers of attorney are not legal in South African law because at common law they become invalid once the principal who gave the power to another loses the capacity to make decisions themselves[153, 150].

The NHA[154] envisages the need for alternative consent to be provided for a person who either lacks legal capacity or who is incapable of granting consent. In accordance with section 7(1)(a)(i), if a user has become unable to provide informed consent but has mandated someone

in writing to grant consent on their behalf, the mandate will be legally acceptable. It appears as if this section could now resolve the problem of the common law. However, McQuoid-Mason[150] does raise the problem that the law is vague as to whether only a temporary state of incompetence is envisaged or whether this could apply to permanent situations. It is arguable that the proxy remains a valid appointment where the incompetence is permanent. Unambiguous legislation in the future would provide certainty. The NHA is clear though, that an appointed proxy takes precedence over family members and partners, unless a court order intervenes. This is helpful guidance[155].

The Patients' Rights Charter[156, 157] supports the preparation of living wills or advance directives to guide those who would take over the decision-making process in the event of people losing their capacity to express themselves. This document was produced by the Department of Health in 2007, to enhance people's knowledge about their right of access to health care services through teaching them what their rights and duties are. Amongst other information, it explains their right to refuse treatment, the right to receive palliative care and to decide what should happen to them when facing death.

In the SALRC Report 86, it was suggested that a patient could be asked on admission to a hospital what their wishes were should they no longer be able to decide for themselves about continuing treatment. They could also be asked to appoint a person as a proxy decision-maker at that time, if they preferred to do so. This at least would be a current record of their wishes in the context of their health at the time of the admission[158].

Turning back to the SA Bill, in subsection 6(1), 'of sound mind' is replaced by the defined term 'mentally competent', and 'competent' is replaced with the words 'capable of issuing' to provide a better flow. In line with the new heading, 'terminal illness' is replaced by 'grievous and irremediable medical condition'.

6(1) Every person above the age of 18 years who is ***mentally competent*** *shall be* ***capable of issuing*** *a written directive declaring that if he or she should ever suffer from a* ***grievous and irremediable medical condition*** *and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, medical treatment should not be instituted, or any medical treatment which he or she may receive should be discontinued, and that only palliative care should be administered.*

Subsection (2) creates the enduring power of attorney as an extension of the NHA's provision for a proxy[154] discussed above. Accordingly, the references to 'power of attorney' are replaced with the NHA's written mandate in terms of s7. The following changes are made: 'power of attorney' is replaced with 'a written mandate in terms of s7(1)(a)(i) of the National Health Act 61 of 2003 (written mandate)'. and the phrase 'becomes terminally ill' is replaced with the words 'develops a grievous and irremediable medical condition'.

(2) A person as contemplated in subsection (1) shall be competent to entrust any decision-making regarding the treatment as contemplated in that subsection or the cessation of such treatment to a competent agent by way of ***a written mandate in terms of s7(1)(a)(i) of the National Health Act 61 of 2003 (written mandate)****, and such* ***a written mandate*** *shall take effect and remain in force if the principal develops a grievous and irremediable medical condition and as a result is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof.*

(3) A directive contemplated in subsection (1) and a ***written mandate*** *contemplated in subsection (2) and any amendment thereof, shall be signed by the person giving the directive or* ***written mandate*** *in the presence of two competent witnesses who shall sign the document in the presence of the said person and in each other's presence.*

Subsection (4) relates to a person who has given no instructions regarding their wishes for future care. Therefore, it is suggested that the provision could be better positioned under section 8 which specifically focusses on situations where there are no advance directives.

The NHA now recognises court-appointed curatorship and guardianship roles for the purpose of substituted consent where people are incapable of managing their own affairs[159]. This position is prioritised in the NHA over the decisions of family members[155].

If the 'cessation' of 'medical treatment' includes withdrawal of nutrition and water, then this is a far-reaching provision, applying the legal principles established in *Clarke v Hurst*[160] discussed in chapter 2. It dispenses with the need to obtain a court order, with the words 'in the absence of any court order'. Such decisions have been recognised in international medical guidelines to be ethical, acceptable compassionate steps taken by medical practitioners towards the alleviation of persistent suffering[161]. However, the subsequent guidelines produced by the Health Professions Council of South Africa (HPCSA)[162] do not have the protection of law. They

do provide evidence in court of the standard of good practice required of a medical practitioner, as stated in *Pandie v Isaacs*[163]. This provision confirming the law is to be welcomed.

A point to bear in mind is that many families find the thought of their loved one dying from withdrawal of nutrition and hydration abhorrent, despite them believing that the patient would not choose to continue life in a vegetative state either. According to research, in circumstances where a patient is in a permanent vegetative state or similar condition, such concerns have prevented them from seeking assistance to end the life of their relative, and wait rather for a natural death which could take many more years[164]. If the South African law is changed to permit E/PAS, the family or the doctors would be entitled to ask a court for an order to allow E in preference to the patient experiencing a slow death over a period of two to three weeks from withholding nutrition and hydration. A possible alternative to euthanasia would be terminal sedation, although, factually, the patient may not be showing much distress that would justify deeper sedation.

Subsection (4) is amended with the words 'becomes terminally ill' replaced with 'develops a grievous and irremediable medical condition', and the word 'their' is added before 'medical treatment' to be gender neutral. The provision will be repositioned and numbered as 'section 8(1)', but for convenience it is repeated below so that the explanation can be followed.

(4) When a person who is under guardianship, or in respect of whom a curator of the person has been appointed, ***develops a grievous and irremediable medical condition*** *and no instructions as contemplated in subsection (1) or (2) regarding* ***their*** *medical treatment or the cessation thereof have been issued, the decision-making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator.*

Section 7. Conduct in compliance with directives or written mandates by or on behalf of persons with grievous and irremediable medical conditions

This section heading is adjusted to incorporate the new terms proposed by replacing the words 'terminally ill persons' with 'persons with grievous and irremediable medical conditions.'

Subsection 7(1)'s introduction is accepted without change.

7(1) No medical practitioner shall give effect to a directive regarding the refusal or cessation of medical treatment or the administering of palliative care which may contribute to the hastening of a patient's death, unless –

In (a), 'terminal illness' is replaced by 'grievous and irremediable medical condition', but it does not follow that because of this condition the person is unable to communicate. In order to correct the sentence, the words 'and is therefore unable' are deleted and replaced with 'resulting in the inability'.

(a) the medical practitioner is satisfied that the patient concerned is suffering from a ***grievous and irremediable medical condition resulting in the inability*** *to make or communicate considered decisions concerning his or her medical treatment or the cessation thereof; and*

In (b) the word 'his' before 'expert' is deleted to create better flow when reading, and 'his or her' is replaced with 'their'.

(b) the condition of the patient concerned, as contemplated in paragraph (a), has been confirmed by at least one other medical practitioner who is not directly involved in the treatment of the patient concerned, but who is competent to express a professional opinion on the patient's condition because of expert knowledge of the patient's illness ***and their*** *examination of the patient concerned.*

In subsection (2), although the provision is qualified by the words 'in so far as this is reasonably possible', the requirement that the doctor verify the authenticity of the advance directive, and the competency of the patient when the directive was issued, is not practical[165]. This is particularly so if the doctor did not have a long-standing relationship with the person, nor originally received the advance directive for placement into the medical file. Where a family member presents the doctor with the advance directive, the family member should be responsible for proof of its validity to avoid creating an administrative burden. Upon receipt of any proof, if the doctor is still not convinced that the directive is authentic, it cannot be honoured unless the withdrawal of treatment is accomplished on another basis such as futility, or a court order.

South Africa has not had law for directives until this proposed draft Bill, so initiating a national

database for advance directives could be helpful in the future[165] if this draft Act comes to fruition. Luxembourg, for example has such a data base at its National Commission for Control and Assessment[166].

The two confirmations in the provision required of the doctor are to establish that the document is authentic, meaning 'of undisputed origin', 'real or true'[167], and that the issuer was mentally competent at the time of signing. However, for the document to be authentic, two competent witnesses, who have no benefit from the person's death, would have signed in one another's presence, and their witness was to the fact that the issuer affixed their signature to the document, but not that the person was necessarily mentally competent. For clarity, the word 'authentic' could be replaced with 'valid' which means 'legally binding due to having been executed in compliance with the law'[168], and that would include that the person was mentally competent at the time of the signature. The following adjustment to the provision is proposed: 'authenticity' is deleted and replaced with 'validity'.

(2) Before a medical practitioner gives effect to a directive as contemplated in subsection (1) he shall satisfy himself, in so far as this is reasonably possible, of the ***validity*** *of the directive and of the competency of the person issuing the directive.*

In subsection (3) the words 'family members' are exchanged for 'relatives'.

(3) Before giving effect to a directive as contemplated in subsection (1), a medical practitioner shall inform the interested ***relatives*** *of the patient of his or her findings, that of the other medical practitioner contemplated in paragraph (b) of subsection (1), and of the existence and content of the directive of the patient concerned.*

In subsection (4), similar to subsection (2) above, the word 'authenticity' is replaced with 'validity' and 'or its legality' is deleted. Also, the words 'as regard to' are replaced with 'of'.

(4) If a medical practitioner is uncertain as to the ***validity of*** *the directive, he shall treat the patient concerned in accordance with the provisions set out in section 8 below.*

(5) (a) A medical practitioner who gives effect to a directive as contemplated in subsection (1) shall record in writing his or her findings regarding the condition of the patient and the manner in which he or she implemented the directive.

(b) A medical practitioner as contemplated in paragraph (b) of subsection (1) shall record in writing his or her findings regarding the condition of the patient concerned.

(6) A directive concerning the refusal or cessation of medical treatment as contemplated in subsection (1) and (2) shall not be invalid and the withholding or cessation of medical treatment in accordance with such a directive, shall, in so far as it is performed in accordance with this Act, not be unlawful even though the performance of the directive might hasten the moment of death of the patient concerned.

5.3.5. Sections 8 and 9, Incompetent patients

Sections 8 and 9 provide legal instruction for the situation where an advance directive does not exist, and the patient is incompetent to make health care decisions.

Section 8. Conduct of a medical practitioner in the absence of a directive

From 2005, when the NHA commenced, provision was made for substituted consent to be obtainable from the immediate family in the order of the user's spouse or partner, otherwise the parent, grandparent, an adult child or a brother or sister[155]. As mentioned earlier, a family member fulfils this role only if a proxy has not been appointed in writing by the user, and there is no one authorised to grant consent in terms of another law or court order[169].
This provision has been moved from subsection 6(4) to become subsection 8(1). It simply confirms the status of curators and guardians in the NHA and therefore could be excluded from the Act.

(1) When a person who is under guardianship, or in respect of whom a curator of the person has been appointed, ***develops a grievous and irremediable medical condition*** *and no instructions as contemplated in subsection 7(1) or 7(2) regarding* ***their*** *medical treatment or the cessation thereof have been issued, the decision-making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator.*

Original subsection 8(1), now subsection (2), apparently specifically focusses on institutionalised patients receiving care, not those receiving care at home. For this reason the purpose of the provision seems to be to free up scarce hospital resources where treatment has

become futile, in order that the patient may be managed at home. This impression is based on the fact that the medical practitioner initiates the conversation with the family and not the family with the medical practitioner. The HPCSA Guidelines on ethical practice support this stance because the HPCSA explains that, even when it is not in the best interests of the patient to remove them from ongoing medical interventions that are supporting them, for a scarce resource such as the intensive care unit's bed or renal dialysis, it is ethical to withdraw treatment in accordance with national criteria[170].

Subsection (2) has the following amendments: changing 'is in a state of terminal illness' to 'has a grievous and irremediable medical condition'. A 'state of terminal illness' is not separately defined from 'terminal illness' so is vague in its meaning but implies 'an advanced state of irreversible decline in capability' which is part of the meaning of the new term used. The gender-neutral word 'their' replaces 'his or her' and 'or power of attorney' is replaced with 'written mandate'.

(2) If a medical practitioner responsible for the treatment of a patient in a hospital, clinic or similar institution where a patient is being cared for, is of the opinion that the patient ***has a grievous and irremediable medical condition*** *as contemplated in this Act and is unable to make or communicate decisions concerning his or her medical treatment or its cessation, and* ***their*** *opinion is confirmed in writing by at least one other medical practitioner who has not treated the person concerned as a patient, but who has examined* ***the patient*** *and who is competent to submit a professional opinion regarding the patient's condition on account of* ***their*** *expertise regarding the illness of the patient concerned, the first-mentioned medical practitioner may, in the absence of any directive or* ***written mandate*** *contemplated in section 6(1) and (2) or a court order as contemplated in section 9, grant written authorisation for the cessation of all further life-sustaining medical treatment and the administration of palliative care only.*

The original subsection 8(2) is now subsection (3). The number references within each provision below have accordingly been adjusted. The words 'family members' have been swapped for 'relatives'. Relatives remain the final decision-makers regarding cessation of treatment. The medical practitioner may not legally enforce their decision in the new subsection 8(2) unless they believe that it is in the best interests of the patient[171], similar to the requirements of section 7(1) and 7(2) where an advance directive or written mandate exists. If there is no consensus between the family and the medical practitioners and there is a need to free up scarce medical resources, then a court order would be the appropriate route to follow.

*(3) A medical practitioner as contemplated in subsection (**2**) shall not act as contemplated in subsection (**2**) if such conduct would be contrary to the wishes of the interested **relatives** of the patient, unless authorised by a court order.*

Original 8(3), now subsection (4).

*(4) A medical practitioner as contemplated in subsection (**2**) shall record in writing his or her findings regarding the patient's condition and any steps taken by **them** in respect thereof.*
Original 8(4), now subsection (5).

*(5) The cessation of medical treatment as contemplated in subsection (**2**) shall not be unlawful merely because it contributes to causing the patient's death.*

Section 9. Powers of court

The point has been made that the Act gives the court very wide discretionary authority in the situation where a patient has given no advance directive or written mandate and is incapable of communicating or making decisions any longer[172]. Furthermore, hospitals that want to make scarce resources available to patients could use this Act as a mechanism to achieve that end[173] as indicated in subsection 8(2). Such court orders would be consistent with judicial competence exercised in the past. Firstly, in *Clarke v Hurst's* case[174] the High Court did not rely on the living will that the patient had signed in order to reach a decision to end his life. Secondly, in the *Soobramoney* case[175], the Constitutional Court found in favour of the State rationing its limited resources so that those patients who would benefit from the resources in the long term could be given an opportunity to do so, while futile cases would be denied access.

In subsection (1) the changes to the provision are that 'terminally ill' is replaced with the words 'person with a grievous and irremediable medical condition'. The second phrase of 'a state of terminal illness' is replaced with 'in an advanced state of irreversible decline in capability', which is part of the definition of a 'grievous and irremediable medical condition'. Therefore, the meaning has not been expanded but remains consistent throughout the document.

*9(1) In the absence of a directive by or on behalf of a person **with a grievous and irremediable medical condition** as contemplated in section 6, a court may, if satisfied that a patient is in **an advanced state of irreversible decline in capability causing severe suffering***

and unable to make or communicate decisions concerning his or her medical treatment or its cessation, on application by any interested person, order the cessation of medical treatment.

In subsection (2) the term 'family members' is exchanged for 'relatives'. Subsections (3) and (4) remain unchanged.

(2) A court shall not make an order as contemplated in subsection (1) without the interested ***relatives*** *having been given an opportunity to be heard by the court.*

(3) A court shall not make an order as contemplated in subsection (1) unless it is convinced of the facts as contemplated in that subsection on the evidence of at least two medical practitioners who have expert knowledge of the patient's condition and who have treated the patient personally or have informed themselves of the patient's medical history and have personally examined the patient.

(4) A medical practitioner who gives effect to an order of court as contemplated in this section shall not thereby incur any civil, criminal or other liability whatsoever.

5.3.6. Section 10, Conscientious Objection

Section 10 is the final section that provides a conscience clause for medical practitioners who choose to not manage end-of-life dilemmas.

Section 10. Interpretation

This provision is positioned so that it applies to the whole draft Act, but it is submitted that a medical practitioner cannot refuse to be involved in all of the SA Bill's end-of-life provisions that ultimately result in death. This is so more than 20 years after the draft was proposed, because attitudes have changed towards death, and there have been new legal and ethical developments. For example, compliance with the SA Bill's section 7 about advance directives should be uncontroversial because the NHA has legislation that allows a user or their proxy to refuse medical treatment[176]. Advance directives are simply another form of refusal of unwanted treatment in the future. In essence, the doctor's duty to treat is being terminated by the patient[172]. Additionally, the NHA does not provide medical practitioners with a conscientious objection clause. It is absent under the list of 'rights of health care personnel' where it would otherwise

have been suitably positioned if the right existed with regard to the NHA's provisions[177].

Likewise, in section 8 of the draft Act, the conduct of a medical practitioner in the absence of a directive should also have limitations with regards to a medical practitioner's right to conscientiously object. According to the HPCSA Guidelines, futile treatment that is continued indefinitely is unethical practice[178]. Therefore, to conscientiously object to the termination of treatment and its replacement with palliative care instead, would not be upholding an acceptable ethical standard of practice.

It is proposed that the conscientious objection clause be positioned at the end of section 5 so that it applies to E and PAS specifically. This positioning of the clause would be comparable to foreign countries that have the legislation[179] (discussed in Chapter 4), as well as the British Assisted Dying Bill[180]. Furthermore, the conscientious objection clause should apply to everyone directly involved in the performance of assisted death, which would include nurses and pharmacists.

In section 10, the suggested adjustments to the provision are: that 'this Act' be replaced with 'section 5', and 'a nurse or a pharmacist' be added after 'medical practitioner' to cater for the new assisted dying provisions. Furthermore, the words 'or any ethical code to which he or she feels himself or herself bound' is very broad and a simpler statement is offered from the British Bill to replace it: 'participate in anything to which that person has a conscientious objection'. The clause is repositioned at section 5(11) under Option 1 and at section 5(6) under Option 2.

10. The provisions of ***section 5*** *shall not be interpreted so as to oblige a medical practitioner,* ***a nurse or a pharmacist*** *to* ***participate in anything to which that person has a conscientious objection.***

5.3.7. Final recommendations for the draft End of Life Decisions Act of 1998

This exercise highlights the fact that, ultimately, a separate statute should be promulgated for E and PAS, and a separate statute enacted for End of Life Choices related to palliative care.

The main reasons are the following:1) fundamental terminology differs between the two groups of people: not everyone who seeks E and PAS is a patient, or terminally ill. However, those who seek palliative care in South Africa are often already seriously ill and frail by the time they

are given support in the health service. 2) E and PAS are not medical treatments for exclusively medical conditions, so are never offered as treatment by medical practitioners. The choice for E or PAS is a social response to a range of suffering stemming from various sources, which is canvassed in Chapter 4. 3) E and PAS should not be confused with medical care by being placed in the same document as palliative care. This misleads the public into believing that E and PAS are medical options for care, which factually they are not. 4) The incorporation of E and PAS legislation into the same document as other important End-of-Life legislation for which the medical profession has a need, may delay any statute from being finalised in the near future. Finally, 5) a combined document will be extremely cumbersome and dense given the need to differentiate clearly between the two.

A serious focus on the improvement of palliative care would be necessary before an Act permitting E and PAS would be acceptable ethically. Thus, an urgent reason for promulgating End of Life legislation without E/PAS would be to strengthen the guidelines that currently exist but do not have the weight of law, discussed further in chapter 6. The SALRC supported such an initiative[181], including improved psychological, spiritual and social care for the patient and those closest to the suffering person. Lastly, general public education would be a vital component of ensuring proper use and access to new health services that are made available, such as broadened palliative care amenities.

After considering a large amount of material related to E and PAS, the SALRC concluded that, legally speaking, there is no distinction between euthanasia and physician-assisted suicide, although arguably there is an important evidentiary difference[182]. This is correct according to the legal description of forms of intent recognised in South African law, referenced in Chapter 3.

Both euthanasia and assisted suicide would lead to a conviction of murder without an amendment to the criminal law. However, one just needs to consider the following scenarios to appreciate the practical differences in the way that people may be killed: a soldier in active combat, a High Court judge sentencing a convicted murderer to death, and gun sellers in gun shops who could be compared to a medical practitioner handing a prescription for lethal medication to someone who may choose never to use it. However, only the soldier is likely to actually experience killing another human being because of an instruction to kill. Yet this is what E and PAS legislation ultimately asks of a doctor.

Table 5 presents the revised and updated End of Life Decisions Act.

5.4. CONCLUSION

This chapter has dissected the first South African End of Life Decisions Bill with a view to updating it in light of foreign and local law that was promulgated after its publication. However, I am of the opinion that the section within the Act on E/PAS as an end-of-life option is problematic. If South Africa is contemplating including it, then the E/PAS law needs to be a separate statute to keep it outside of the health infrastructure.

With this separation in mind, I will offer an alternative framework for assisted death in the next chapter, based on some foreign examples, and justified why a number of different choices were made. The changes I effected were because I perceived the SA Bill encompassing E and PAS to be too permissive for South African society, comparable to the examples of The Netherlands, Belgium and Canada. Those countries do not require terminal illness or a limited remaining lifespan as criteria for lethal medication to be administered to cause death[183].

In the alternative model I put forward a different set of eligibility criteria instead, to narrow down the category of people who would qualify for assisted death: I did not consider permissiveness as an appropriate entry point for introducing E/PAS legislation into the community.

TABLE 5 : Revised and updated draft End of Life Decisions Act

Section 1. Definitions

'Assisted death' *means euthanasia and/or physician assisted suicide.*

'Attending doctor' *means a suitably qualified registered medical practitioner from whom the person has requested assistance to end their life.*

'Competent agent' *means a person of the age of 18 years or over, who is capable of making decisions on behalf of a person contemplated in section 6(2), and who has accepted that position as stated in a written power of attorney, or mandate in terms of section 7(1)(a)(i) of the National Health Act 61 of 2003.*

'Competent witness' *means a person of the age of 18 years or over who at the time he witnesses the directive or written mandate in terms of section 7(1)(a)(i) of the National Health Act 61 of 2003 (written mandate)* ***is competent*** *to give evidence in a court of law and for whom the death of the maker of the directive or written mandate holds no benefit.*

'Court' *means the High Court of South Africa in accordance with s166(c) of the Constitution.*

*'**Drug(s)**' means medicine(s) and medication as defined in section 1 of the Medicines and Related Substances Act 101 of 1965.*

'Euthanasia' *means the intentional killing of a person by a medical practitioner by means of the administration of drugs, at that person's voluntary and competent request.*

'Grievous and irremediable medical condition'*, means a serious, incurable disorder, disease or injury, and*

(a) the person is in an advanced state of irreversible decline in capability; and

(b) that disorder, disease, injury or advanced state of irreversible decline in capability causes that person severe physical or mental suffering of a nature and degree not reasonable to be endured.

'Independent doctor' *means another suitably qualified registered medical practitioner who is not a relative, partner or colleague in the same practice or clinical team, of the attending doctor.*

'Legal practitioner' *means an advocate or an attorney as defined in section 1 of the Legal Practice Act 28 of 2014.*

'Medical practitioner' *means a medical practitioner registered as such in terms of the Health Professions Act 56 of 1974.*

'Mentally competent' *means that in the opinion of a court or in the opinion of the person's attending doctor or independent doctor, psychiatrist, psychologist, a person has the ability to make and communicate health care decisions to health care providers, including communication*

through persons familiar with that person's manner of communicating if those persons are available.

***'Nurse'** means a nurse registered as such in terms of the Nursing Act 33 of 2005, section 31(1) and. if qualified to prescribe medication, authorised as a prescriber in terms of sections 56(1) and 56(6),*

***'Palliative care'** means treatment and care of a person with a grievous and irremediable medical condition with the object of relieving physical, emotional and psychosocial suffering and of maintaining personal hygiene.*

'Pharmacist' means person registered as such in terms of the Pharmacy Act 53 of 1974.

***'Physician-assisted suicide'** means the intentional assistance provided by a medical practitioner to a person to enable them to commit suicide by means of the provision of drugs for self-administration, at that person's voluntary and competent request.*

'Psychologist' means person registered as such in terms of the Health Professions Act 56 of 1974.

***'Relative'** means a) a spouse, de facto partner in a permanent co-habiting relationship; b) parent, grandparent, adult child, adult grandchild, sibling, aunt, uncle, cousin;*

Section 2. Conduct of a medical practitioner in the event of clinical death

(1) For the purposes of this Act, a person is considered to be dead when two medical practitioners agree and confirm in writing that a person is clinically dead according to the following criteria for determining death, namely –

(a) the irreversible absence of spontaneous respiratory and circulatory functions; or

(b) the persistent clinical absence of brain-stem function.

(2) Should a person be considered to be dead according to the provisions of subsection (1), the medical practitioner responsible for the treatment of such person may withdraw or order the

withdrawal of all forms of treatment.

Section 3. Mentally competent patient may refuse treatment

(1) Every person –

*(a) above the age of 18 years and **who is mentally competent**, or*

*(b) above the age of **12 years, who is mentally competent** and assisted by his or her parents or guardian,*

is competent to refuse any life-sustaining medical treatment or the continuation of such treatment with regard to any specific illness from which he or she may be suffering.

(2) Should it be clear to the medical practitioner under whose treatment or care the person who is refusing treatment as contemplated in subsection (1) is, that such a person's refusal is based on the free and considered exercise of his or her own will, he or she shall give effect to such a person's refusal even though it may cause the death or the hastening of death of such a person.

(3) Care should be taken when taking a decision as to the competency of a person, that an individual who is not able to express him or herself adequately, should not be classified as incompetent unless expert attempts have been made to communicate with that person whose responses may be by means other than verbal.

(4) Where a medical practitioner as contemplated in subsection (2) does not share or understand the first language of the patient, an interpreter fluent in the language used by the patient must be present in order to facilitate discussion when decisions regarding the treatment of the patient are made.

Section 4. Conduct of medical practitioner in relieving distress

*(1) Should it be clear to a medical practitioner responsible for the treatment of a patient who has been diagnosed by a medical practitioner as suffering from **a grievous and irremediable medical condition** that the dosage of medication that the patient is currently receiving is not*

adequately alleviating the patient's pain or distress, he or she shall –

(a) with the object to provide relief of severe pain or distress; and

(b) with no intention to kill

increase the dosage of medication (whether analgesics or sedatives) to be given to the patient until relief is obtained, even if the secondary effect of this action may be to shorten the life of the patient.

(2) A medical practitioner who treats a patient as contemplated in subsection (1) shall record in writing his or her findings regarding the condition of the patient and his or her conduct in treating the patient, which record will be documented and filed in and become part of the medical record of the patient concerned.

Section 5. Assisted Death (OPTION 2)

*(1) Should a medical practitioner (**attending doctor**) be requested by a person to make an end to the person's suffering, or to enable the person to make an end to his or her suffering by way of administering or providing **a** lethal agent, the **attending doctor** shall give effect to the request if he or she is satisfied that –*

*(a) the person is suffering from a **grievous and irremediable medical condition;***

(b) the person is over the age of 18 years and mentally competent;

*(c) the person has been **fully** informed in regard to the **medical condition** from which he or she is suffering, the prognosis of **the** condition and of any treatment or care that may be available, **including the benefits, risks, costs and consequences, and the right to refuse health services with its implications**;*

*(d) the request of the person is based on a **voluntary** and **well-**considered decision;*

*(e) the request has been **enduring and** repeated by the person **(requester)** on two separate occasions at least **14** days apart, the last of which is **no less than 48 hours** before the*

attending doctor *gives effect to the request.*

(f) the ***requester****, or person acting on the* ***requester's*** *behalf in accordance with subsection (3), has completed* ***a*** *certificate of* ***request which states that he or she has a voluntary, clear, settled and informed wish to end his or her life and asks*** *the* ***attending doctor*** *to assist the* ***requester*** *to end the* ***requester's*** *life;*

(g) ***the certificate of request has been signed by the requester or*** *person acting on the* ***requester****'s behalf in accordance with subsection (6),* ***in the presence of the attending doctor and a witness (who must not be a relative or directly involved in the person's care or treatment) who signed the certificate in the patient's presence;***

(i) and that certificate has been countersigned by the attending doctor and

(ii) the independent doctor, who is not a relative, partner or colleague in the same practice or clinical team, of the attending doctor;

neither of whom may also be the witness required under (g).

(h) an interpreter fluent in the language used by the ***person*** *is present in order to facilitate communication when decisions regarding the treatment of the* ***person*** *are made where the medical practitioner as contemplated in this section does not share or understand*

the first language of the ***person****;*

(i) ending the life of the ***person*** *or assisting the* ***person*** *to end his or her life is the only way for the* ***person*** *to be released from his or her suffering.*

(2) ***Before countersigning a person's certificate, the attending doctor*** *to whom the request to make an end to a* ***person's*** *suffering is addressed as contemplated in subsection (1),* ***and*** *an independent medical practitioner (****independent doctor****) with whom he or she has conferred* ***and*** *who is knowledgeable with regard to the* ***grievous and irremediable condition*** *from which the* ***person*** *is suffering,* ***having separately*** *checked the* ***person****'s medical history and examined the* ***person and each independently of the other, must have*** *confirmed the facts as contemplated in subsection (1)(a),(b),****(d)*** *and (i).*

(3) *If a **person (requester) ,** who has orally requested his or her **attending doctor** to assist to end the **requester**'s life, is physically unable to sign the certificate of request, any person who has attained the age of 18 years, other than the **attending doctor** referred to in subsection (2) above may, at the **requester's invitation** and in the presence of the **requester** and both the **attending and independent doctors**, sign the certificate on behalf of the **requester.***

(4) ***The attending doctor** who gives effect to a request as contemplated in subsection (1), shall record in writing his or her findings regarding the facts as contemplated in that subsection and the name and address of the **independent doctor** with whom he or she has conferred as contemplated in subsection (2) and the **independent doctor** shall record in writing his or her findings regarding the facts as contemplated in subsection (2).*

(5) *The termination of a **person's** life on his or her request in order to release him or her from suffering may not be effected by any person other than a medical practitioner **or, for assisted death, using self-medication, a duly appointed assisting health professional as contemplated in (6)(B)(b), who must remain with the person until the person has died or, alternatively has revoked the request to die**. **For the purpose of this subsection it is sufficient if the assisting health professional is in close proximity to, but not in the same room as, the person who self-administers the lethal medication**.*

(6) *Assisted death using self-medication*

(A) *The attending doctor of a person who has made a valid request may prescribe medicines for that person to enable that person to end their own life.*

(B) *Any medicines prescribed under subsection (A) may only be delivered to the person for whom they are prescribed –*

(a) by the attending doctor; or

*(b) by an **assisting health professional** who is –*

(i) another medical practitioner; or

(ii) a nurse;

who has been authorised to do so by the attending doctor;

(c) after the attending doctor or assisting health professional has confirmed that the person has not revoked and does not wish to revoke their request;

(C) In respect of a medicine which has been prescribed for a person under subsection (A), an ***attending doctor or*** *assisting health professional may –*

(a) prepare that medicine for self-administration by that person;

(b) prepare a medical device which will enable that person to self-administer the medicine; and

(c) assist that person to ingest or otherwise self-administer the medicine; but the decision to self-administer the medicine and the final act of doing so must be taken by the person for whom the medicine has been prescribed.

(D) The attending doctor or an assisting health professional-

(a) must only deliver any medicines prescribed under this section to the person for whom they have been prescribed immediately before their intended use; and

(b) in the event that the person decides not to self-administer the medicine, must immediately remove it from that person and, as soon as reasonable practicable, return it to the pharmacy from which it was dispensed.

(7) (a) Notwithstanding anything in this Act, a ***person*** *may rescind a request for assistance under this Act at any time and in any manner without regard to his or her mental state.*

(b) Where a ***person*** *rescinds a request, the* ***person's attending doctor*** *shall, as soon as practicable, destroy the certificate of request and note that fact on the* ***person's*** *medical record.*

*(8) The following shall be documented and filed in and become part of the medical record of the **person** who has been assisted under this Act:*

*(a) a note of the oral request of the **person** for such assistance, **including the date when it was made**;*

(b) the certificate of request;

*(c) a record of the opinion of the **person's attending doctor explaining** that the **person has met each of the eligibility criteria as contemplated in subsection 1 and the reasons for this opinion, including** that the **person's** decision to end his or her life was made freely, voluntarily and after due consideration;*

*(d) the report of the **independent doctor** referred to in subsection (2) above;*

*(e) a note by the **person's attending doctor** indicating that all requirements under this Act have been met and indicating the steps taken to carry out the request, including a notation of the substance prescribed.*

*(9) A medical practitioner who gives effect to a **person's** request **for assisted death** as contemplated in this section shall not suffer any civil, criminal or disciplinary liability with*

regard to such an act provided that all due procedural measures have been complied with.

*(10) The sale, procurement, or issuance of any life, health or accident insurance or annuity policy or the rate charged for any policy shall not be conditioned upon or affected by the making or rescinding of a request, by a person, for the medication to end his or her life in a humane and dignified manner. Neither shall a qualified **person's** act of **receiving the administration of, or** ingesting medication to end his or her life in a humane and dignified manner have an effect upon a life, health, or accident insurance or annuity policy.'*

*(11) The provisions of **section 5** shall not be interpreted so as to oblige a medical practitioner, **a nurse or a pharmacist** to **participate in anything to which that person has a conscientious objection.***

Section 5. Decision-making by panel or committee (OPTION 3)

(1) ***Assisted death*** *may be performed by a medical practitioner only, and then only where the request for the euthanasia or* ***physician assisted suicide*** *of the* ***person*** *has been approved* ***in the form of a certificate issued*** *by an ethics committee, constituted for that purpose and consisting of* ***four*** *persons as follows:*

(a) two medical practitioners other than the ***person's attending doctor****;*

(b) one lawyer; and

(c) one member from the multi-disciplinary team.

(2) In considering and in order to approve a request ***and issue a certificate,*** *as contemplated in subsection (1), the Committee has to certify in writing that:*

(a) in its opinion the request for ***assisted death*** *by the* ***person*** *is a voluntary, considered and sustained request;*

(b) the ***person*** *is suffering from a* ***grievous and irremediable medical condition;***

(c) ***assisted death*** *is the only way for the person to be released from his or her suffering.*

(3) A request for ***assisted death*** *must be heard within three weeks of it being received by the Committee,* ***and a decision reached on the same day whether to allow assisted death or not.***

(4) (a) The Committee which, under subsection (2), grants authority for the ***assisted death*** *must, in the prescribed manner and within the prescribed period after* ***assisted death*** *has been performed, report confidentially to the Director-General of Health, by registered post, the granting of such authority and set forth –*

(i) the personal particulars of the ***person*** *concerned;*

(ii) the place and date where the ***assisted death*** *was performed and the reasons*

therefore;

*(iii) the names and qualifications of the members of the committee who issued the **certificate** in terms of the above sections; and*

*(iv) the name of the medical practitioner who performed the **assisted death**.*

*(b) The Director-General may call upon the members of the Committee **regarding the** report in terms of subsection (4) or **the attending doctor** referred to in subsection (1) **or the medical practitioner referred to in subsection 5(4)(a)(iv)** to furnish additional information as he may require.*

*(5) The following shall be documented and filed and becomes part of the medical record of the **person** who has been assisted under this Act:*

*(a) full particulars regarding the request made by the **person;***

(b) a copy of the certificate issued in terms of subsection (2);

(c) a copy of the report made in terms of subsection (4).

*(6) The provisions of **section 5** shall not be interpreted so as to oblige a medical practitioner **or a nurse** to **participate in anything to which that person has a conscientious objection.***

Section 6. Directives as to the treatment of a person with a grievous and irremediable medical condition

*(1) Every person above the age of 18 years who is **mentally competent** shall be **capable of issuing** a written directive declaring that if he or she should ever suffer from a **grievous and irremediable medical condition** and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, medical treatment should not be instituted or any medical treatment which he or she may receive should be discontinued and that only palliative care should be administered.*

(2) A person as contemplated in subsection (1) shall be competent to entrust any decision-making regarding the treatment as contemplated in that subsection or the cessation of such treatment to a competent agent by way of a written power of attorney, and such power of

attorney shall take effect and remain in force if the principal ***develops a grievous and irremediable medical condition*** *and as a result is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof.*

(3) A directive contemplated in subsection (1) and a power of attorney contemplated in subsection (2) and any amendment thereof, shall be signed by the person giving the directive or power of attorney in the presence of two competent witnesses who shall sign the document in the presence of the said person and in each other's presence.

(4) When a person who is under guardianship, or in respect of whom a curator of the person has been appointed, ***develops a grievous and irremediable medical condition*** *and no instructions as contemplated in subsection (1) or (2) regarding* ***their*** *medical treatment or the cessation thereof have been issued, the decision-making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator.*

Section 7. Conduct in compliance with directives or written mandates by or on behalf of persons with grievous and irremediable medical conditions

(1) No medical practitioner shall give effect to a directive regarding the refusal or cessation of medical treatment or the administering of palliative care which may contribute to the hastening of a patient's death, unless –

(a) the medical practitioner is satisfied that the patient concerned is suffering from a ***grievous and irremediable medical condition resulting in the inability*** *to make or communicate considered decisions concerning his or her medical treatment or the cessation thereof; and*

(b) the condition of the patient concerned, as contemplated in paragraph (a), has been confirmed by at least one other medical practitioner who is not directly involved in the treatment of the patient concerned, but who is competent to express a professional opinion on the patient's condition because of expert knowledge of the patient's illness and ***their*** *examination of the patient concerned.*

*(2) Before a medical practitioner gives effect to a directive as contemplated in subsection (1) he shall satisfy himself, in so far as this is reasonably possible, of the **validity** of the directive.*

*(3) Before giving effect to a directive as contemplated in subsection (1), a medical practitioner shall inform the interested **relatives** of the patient of his or her findings, that of the other medical practitioner contemplated in paragraph (b) of subsection (1), and of the existence and content of the directive of the patient concerned.*

*(4) If a medical practitioner is uncertain as to the **validity of** the directive, he shall treat the patient concerned in accordance with the provisions set out in section 8 below.*

(5) (a) A medical practitioner who gives effect to a directive as contemplated in subsection (1) shall record in writing his or her findings regarding the condition of the patient and the manner in which he or she implemented the directive.

(b) A medical practitioner as contemplated in paragraph (b) of subsection (1) shall record in writing his or her findings regarding the condition of the patient concerned.

(6) A directive concerning the refusal or cessation of medical treatment as contemplated in subsection (1) and (2) shall not be invalid and the withholding or cessation of medical treatment in accordance with such a directive, shall, in so far as it is performed in accordance with this Act, not be unlawful even though the performance of the directive might hasten the moment of death of the patient concerned.

Section 8. Conduct of a medical practitioner in the absence of a directive

*(1) When a person who is under guardianship, or in respect of whom a curator of the person has been appointed, **develops a grievous and irremediable medical condition** and no instructions as contemplated in subsection 7(1) or 7(2) regarding **their** medical treatment or the cessation thereof have been issued, the decision-making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator.*

(2) If a medical practitioner responsible for the treatment of a patient in a hospital, clinic or similar institution where a patient is being cared for, is of the opinion that the patient ***has a grievous and irremediable medical condition*** *as contemplated in this Act and is unable to make or communicate decisions concerning his or her medical treatment or its cessation, and* ***their*** *opinion is confirmed in writing by at least one other medical practitioner who has not treated the person concerned as a patient, but who has examined* ***the patient*** *and who is competent to submit a professional opinion regarding the patient's condition on account of* ***their*** *expertise regarding the illness of the patient concerned, the first-mentioned medical practitioner may, in the absence of any directive or* ***written mandate*** *contemplated in section 6(1) and (2) or a court order as contemplated in section 9, grant written authorisation for the cessation of all further life-sustaining medical treatment and the administration of palliative care only.*

*(3) A medical practitioner as contemplated in subsection (**2**) shall not act as contemplated in subsection (**2**) if such conduct would be contrary to the wishes of the interested* ***relatives*** *of the patient, unless authorised by a court order.*

*(4) A medical practitioner as contemplated in subsection (**2**) shall record in writing his or her findings regarding the patient's condition and any steps taken by them in respect thereof.*

*(5) The cessation of medical treatment as contemplated in subsection (**2**) shall not be unlawful merely because it contributes to causing the patient's death.*

Section 9. Powers of court

(1) In the absence of a directive by or on behalf of a person ***with a grievous and irremediable medical condition*** *as contemplated in section 6, a court may, if satisfied that a patient is in* ***an advanced state of irreversible decline in capability causing severe suffering*** *and unable to make or communicate decisions concerning his or her medical treatment or its cessation, on application by any interested person, order the cessation of medical treatment.*

(2) A court shall not make an order as contemplated in subsection (1) without the interested ***relatives*** *having been given an opportunity to be heard by the court.*

(3) A court shall not make an order as contemplated in subsection (1) unless it is convinced of the facts as contemplated in that subsection on the evidence of at least two medical practitioners who have expert knowledge of the patient's condition and who have treated the patient personally or have informed themselves of the patient's medical history and have personally examined the patient.

(4) A medical practitioner who gives effect to an order of court as contemplated in this section shall not thereby incur any civil, criminal or other liability whatsoever.

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CHAPTER 6: THE SOCIAL SUICIDE MODEL: AN ALTERNATIVE

6.1. INTRODUCTION

In Chapter 5, I scrutinised the first South African End of Life Decisions Bill with a view to updating it in light of foreign and local law that was promulgated after its publication. However, in my opinion the legislation related to E is too permissive for South African society, should South Africa pursue such an undertaking. As an alternative, in this chapter I propose a different assisted death model and discuss the consequences.

6.2. ALTERNATIVE ASSISTED DEATH FRAMEWORK

Besides the two options (2 and 3) put forward for assisted death in Section 5 of the SA Bill and having reflected on the insight gained about different E/PAS frameworks from foreign jurisdictions, I present an alternative assisted death framework which may be better suited for the South African context, should South Africa embark on such a law. Essentially, the proposition is to keep assisted death out of the health infrastructure, as Switzerland has done, with some other variations proposed. Justifications are given for the recommended choices.

Firstly, the scope of eligibility to undertake E and PAS is considered.

6.2.1. Criteria for eligibility

The Canadian ethicist, Udo Shuklenk, speaking of Canada's transition to E/PAS law after six years of observation, emphasises that the most important question to ask regarding the application of this law on society is what the scope of the legislation is meant to be[1]. This resonates deeply within one's conscience when people seek assisted death for reasons other than intolerable suffering because of a biological condition causing intractable pain, for example. In rural Canada, where a lack of the social determinants of health plays such a big role in lowering the quality of life, there is a concern that people would rather choose a premature death than remain alive. People suffer 'intolerably' for reasons that could otherwise be solved if there was the will to invest time and money to improve their social environments. Some of the Canadian nurses' guidelines actually require them to ensure that a patient is not seeking MAiD because of a lack of other supports. However, the guidelines do not offer instructions on how nurses should assess this or resolve such problems[2].

Other than having no law in place at all, as the SALRC's Option 1 nominates (5.2.2 above), Oregon's legislated MAiD criteria would, in my opinion, be advisable for South Africa. If a person is an adult, they are eligible for MAiD if they fulfil the following conditions: they have the ability to make and communicate health care decisions; it has been determined by two physicians, one independent of the other, that they are suffering from a terminal disease; they have voluntarily expressed the wish to die, by making a written request for medication for the purpose of ending their life in a humane manner[3]. 'Terminal illness' is defined as 'an incurable and irreversible disease that has been medically confirmed, and will, within reasonable medical judgement, produce death within six months'[4]. Furthermore, Oregon stipulates that no one qualifies for MAiD only by virtue of age or disability[5].

This conservative law attempts to serve the purpose of offering a 'peaceful death' instead of a traumatic death, although some literature suggests that the death can be more traumatic than a natural one[6]. The focus for doctors, then, would be to try to judge the remaining lifespan until death, instead of trying to second-guess the extent of a person's suffering. For the most part, people are reported to suffer emotionally more than physically[7].

The SALRC presents both E and PAS as possibilities regarding access to hastened death. However, my view is that this aspect of the SALRC's Report is not supported.

6.2.2. Assisted suicide

The alternative model I recommend allows only for assisted suicide, and not euthanasia. A reason for this proposition is that by allowing assisted death, a person's right to self-determination is maintained, and the certainty of their decision to die is confirmed in the act of carrying it out. Essentially, it is a social decision, not a medical one, that the person makes[8].

Research has shown that, at an emotional level, people would rather be euthanised by a doctor than to have to kill themselves. Medical practitioners, on the other hand, would prefer individuals to kill themselves, partly because of the certainty that the decision is then entirely the person's own[9]. Furthermore, imposing the task of killing on someone else, as euthanasia requires, has the potential to cause psychological harm to the agent. The perpetrator must continue to live with the knowledge alone, bearing an unnecessary burden once the lethal administration is completed. This is investigated further below.

The pros and cons of the SALRC's Options 2 and 3 are now compared.

6.2.3. Doctor v panel

Option 2 offers a framework where the doctor is the primary decision-maker regarding whether or not the person requesting assisted death meets the eligibility criteria. A number of advantages of the model where doctors remain responsible for decision-making include that: (i) the patient's autonomy to express themselves is respected, as well as the doctor's independence to assess the patient and reach a decision (e.g. Canada); (ii) the process can be fairly quick when only two medical practitioners are involved in the matter (e.g. Switzerland); (iii) the attending doctor may know the person seeking assisted death, so would be in a better position to empathise, understand and accurately gauge the state of the person's suffering first hand (e.g. Netherlands); (iv) the experience takes the form of a personal relationship between the doctor and the patient until the concluding act is undertaken (e.g. Oregon).

Disadvantages are that with a doctor making the final onerous decision instead of a panel (i) a much greater 'paper trail' is necessary to prove that all the legal requirements were met in case there is a query (e.g. Australia); (ii) the increased work load and its process creates an emotional burden which could produce burn-out (e.g. Netherlands); (iii) a skilled review committee would have to be established to oversee and police both the health system and the medical professionals involved with assisted death across the medical platform, in accordance with the legislation that is in place (e.g. Netherlands); (iv) offering E/PAS is an extra administrative burden on a health infrastructure that is already under strain; (e.g. Canada) (v) the new role of the doctor to actively assist with the termination of life may affect the perception of the profession and the doctor-patient relationship, because end-of-life decision-making is aided by trust, but being prepared to kill someone contradicts the belief that the doctor cares about the patient[6].

Option 3, the alternative choice of having a decision-making panel, has the following pros. In the final SALRC Project 86 Report, people highlighted a number of relevant facts in this regard[10], such as (i) that it would bring in a multidisciplinary approach, and that (ii) there could not then be a perception that patients or relatives had been influenced by a doctor. In addition, (iii) the impression that the process could be open to abuse would be markedly reduced, as a panel would have verified the rationality of a request in an objective manner. (iv) The panel, being responsible for making the concluding decision, would protect the integrity of trust, so

important in the doctor-patient relationship. Although a medical assessment may still need to be performed by the medical practitioner, a frank discussion from both the person seeking assistance to die and the doctor could ensue with a sense of calm, because the final clearance for eligibility would be out of the doctor's hands. Another advantage of a panel is that (v) once the doctors' medical assessment of their patient is complete and the file submitted to a panel, their involvement in assisting with death may be over should they choose not to proceed beyond that point. In some respects, this protects the identity of the medical profession as an essentially healing line of work, and the reputation of the medical practitioners involved.

Disadvantages of a panel are (i) that it is labour-intensive, involving more decision-makers with different expertise (e.g., Colombia) (ii) It is an administrative burden on the health system which is already under-staffed if hospitals are required to form the panels themselves (e.g. Colombia)[11]. (ii) It would take longer for the individual to have their case assessed and to receive an answer. The doctor first has to assess, and then undertake the clerical challenges associated with organising the meeting to suit all participants, as reflected in the SA Bill's insertion of a time-constraint at subsection (3). (iii) A panel organised by the government could be perceived negatively as legitimising public authority over assisted death[12] and (iv) endorsing assisted death with a 'stamp of approval' that will markedly shift the social mindset[13]. This was a concern expressed regarding proposed Swiss legislation described in Chapter 4. However, a change in social sentiment would happen regardless of the eventual framework chosen; (v) a legal framework incorporating a committee could remove the responsibility from individual doctors to apply their minds fully when assessing the person who seeks assisted death, another concern with reference to the Swiss doctors[13]. Sneiderman and McQuoid-Mason have succinctly summed up this option as an onerous, paternalistic approach, where bureaucratic hindrances are placed in the person's path[14].

Medical practitioners are viewed by society as respected people with integrity[15]. Consequently, in most countries they are trusted and fulfil the supplementary role of gatekeepers of the law and a safeguard against abuse, only having their decisions checked after the E/PAS event is completed[16]. An advantage of the multidisciplinary ethics committee is that it has oversight over the process and the standard of medical practitioners' reports submitted to it.

6.2.4. Multi-disciplinary Panel

For South Africa, a multi-disciplinary panel in the form of an ethics or assessment committee

is advocated. This view is motivated by the fact that the panel framework is particularly suited to a situation where people lack trust in the public health system and its staff[17].

Without a panel, a doctor could be vulnerable to criticism after performing an assisted death that not all relatives may have supported. However, with a panel, relatives can receive reassurance once authorisation is given and before the act is carried out, that there is nothing sinister in the decision-making process: an independent group of people with no personal interest in the outcome would have considered the merits of the case objectively.

Close relationships tend not to develop between patients and doctors in the public health service due to the high numbers of patients that pass through the health system. At the same time, doctors and nurses rotate between different departments while in training, which prevents medical practitioners from getting to know their patients well. Consequently, a beneficial rapport, which would assist the doctor to better evaluate the patient's suffering and mindset, is less likely to develop between the doctor and patient. Although this is a disadvantage of the public health service, it could also mean that it might be easier to write out prescriptions for lethal doses of medication given a less personalised context and more objective assessments.

Stahle, a Swedish researcher, promotes the idea that the act of moral disengagement in order to perform E and PAS, makes it easier to dehumanise the person[18]. (This concept is examined later in the chapter.) He explains that moral disengagement increases in proportion to the distance from the action. That is why opinion polls are an unreliable measurement of support for E and PAS, a deduction that British academics made when measuring public interest in assisted dying[19]. Bearing Stahle's opinion in mind, the panel would function at a level more removed from the patient than in the doctor-patient relationship. The panel would rely only on the paperwork to reach its conclusion and would never actually meet the patient. Thus, reaching conclusions could be morally relatively straight forward.

The panel eliminates the individual responsibility of the medical practitioner and associated stress of making a mistake. This may be preferable to the anxiety related to reaching assisted death decisions that are only judged after the procedures have been performed and death has ensued. A review board always holds the threat that a previously wrong decision could lead to a prosecution.

A certificate authorising the request, as well as a report explaining the decision should be issued

by the Committee. The committee's report needs to be inserted into the patient's file along with a copy of the certificate of request, and then the file should be sent back to the attending doctor's office. An original certificate ought to have been handed to the person who requested assisted death so that they can prove at the time of their PAS date that they have permission to receive the toxic drugs.

Data capturing would be an important aspect of the job, to be sent on to a central bureau so that the statistics surrounding assisted death are known and publicised. In this way the government and public can establish at a national level how well the model is working. The committee would eventually be able to give feedback and provide doctors with guidelines regarding what information is required for the process to run efficiently, and what types of cases, if any, are rejected for failing to meet criteria. Unfortunately, at this stage, the Health Professions Council of South Africa may not be in a position to offer medical practitioners' direction or reliable oversight to give the public peace of mind, as it has been dogged with its own inefficiencies, conflicts of interest and poor management[20].

Once the panel has issued a certificate, the responsibility to write out the prescription (or administer a lethal injection for E, as proposed in the SA Bill) falls back onto the medical practitioner.

6.2.5. Responsibility for E or PAS procedure

I argue that medical practitioners should not be seen as the exclusive agents for administering E or PAS. Many medical practitioners have expressed the view through their representative bodies, for example South Africa's Hospice Association[21], and the Swiss Medical Association[22], or through their behaviour described in the literature, such as in Oregon[6], Canada[7], and England[23], that they would prefer not to participate in this aspect of end of life care. Notably, in Canada, oncologists, neurologists and cardiologists make up only 2% of MAiD providers, despite the patients who are seeking hastened death having cardiac, respiratory or neurological conditions, and cancer[7].

Having said that, the concepts of E and PAS have been medicalised[24, 22]. Notably, this has occurred through legislation, which reflects the view of the populace, and the courts around the world which assume that the position of 'agent' to someone who wants a hastened death is a task best suited for the medical professional[25, 26]. Writers justify the association as a logical

choice because only a medical practitioner can competently decide whether a person is seriously ill or whether the disorder could result in intolerable suffering. Moreover, they are the only ones who can prescribe medication, the method of choice at this stage, for a quick and painless death. Although this is all correct, the flaw in the reasoning is that death is seen as a medical treatment that can be dispensed.

When assisted death is requested, from the recipient's perspective it is rational for a doctor to prescribe (and be present, for PAS) or inject the medication into an intravenous line because they have knowledge about how much to administer and how to manage any complications. However, from the perspective of many medical practitioners, the request misuses and misapplies their knowledge by prescribing or inflicting a *fatal* dose of medication. Worse still, the complication is that the person remains *alive*, and is not killed. This paradox, for the medical profession, is absurd.

Pharmaceutical companies have stopped supplying lethal drugs used in executions because they decided that it caused harm to their company's reputation, according to the activist legal group against human rights abuses, Reprieve, UK[27, 28]. Yet this reputational damage has not been addressed as a concern on behalf of the medical profession or the health sector when accommodating E or PAS, despite the contradiction. Both the medications and the medical practitioners are simply utilised as a means to an end, instruments of death.

Because of the Swiss Medical Association's resistance to participation in assisted death, Switzerland allows more extensive involvement from non-medical people, as do the American states that allow AS, compared to countries that also legalise E[29].

Medical Associations and other representative bodies object that it would be unethical for doctors to participate in assisted death because they are trained to heal and prevent illness[30]. Doctors report that they lack the specialised skill to communicate effectively[30]. They lack training to assess suffering[26]. For many, they do not wish to participate in E or PAS for a range of personal reasons[31, 25]. And yet, medical practitioners have been universally and officially designated as the ones responsible for actively facilitating hastened death. The responsibilities are contradictory. The moral dilemma is profound. Bossard *et al*. describe the tension between the medical profession and society in this regard as a power struggle[32].

To make the legislation less onerous, all countries have inserted a conscientious objection

clause that allows those doctors who oppose the law to refuse to participate. However, the problem is that access to assisted death is only made available through doctors being prepared to be involved. Where there are insufficient numbers of keen participants, witnessed in Canada over the years post MAiD legislation, demand for assistance will outstrip supply[7].

Unsurprisingly, some academics are now challenging the right of the medical professional to conscientiously object, because their refusal to involve themselves hampers the public's access to the 'medical service' of E/PAS[33, 34].

6.2.6. Conscientious objection

Some writers consider that personal ethics and public policy should be kept separate from one another because it is an irresolvable matter of disagreement amongst society. As such, it is better overlooked by public policy[35]. The proposition is that the way in which a person chooses to die at the end of their life is a private matter between the doctor and the patient, therefore the public should simply allow those doctors who are willing to assist the patient to do so, confidentially. Those doctors who choose not to be involved with E and PAS should be left alone based on their right to freedom of conscience.

However, Devettere foresees a grave drawback with this approach. He says that hastening a person's death is rarely only a private concern, and alters the common good[36]. I believe this to be true. Eventually, consensual killing would need to be legally regulated to manage dissent, otherwise there would be an atmosphere of lawlessness. This trend was recorded in The Netherlands and Belgium, as mentioned in Chapter 4.

Recently, the right of a doctor to freedom of conscience has been criticised as a failure in their duty to a patient if it is exercised by the doctor against the patient's wishes[33]. Doré, a Belfast palliative care consultant, noting the impact of the societal moral shift in countries where assisted death is permitted, comments that medical practitioners who refuse to practice PAS are perceived to have questionable ethics. The argument is that they place their moral interests before the welfare of their patients[37].

Stahl and Emanuel[34] highlight the problems of allowing medical practitioners to exercise their conscientious objection based on their religious beliefs or moral convictions. The entitlement to refuse actually does cover a wide range of ethically contentious issues. In the USA, health

care legislation that allows conscientious objection for abortion is mentioned, in vitro fertilisation, dispensing contraception, aid in end of life care, and most recently, the treatment of lesbian, gay, bisexual, and transgender patients. The writers contend that medical practitioners choose their profession and therefore have an obligation to provide, perform and refer patients for the interventions that are available, to meet the standard of care offered by the health system. This is in line with the main responsibility of doctors, to put the interests and well-being of their patients first, as stated in the various medical Codes of Ethics[34]. Consequently, they conclude that the conscientious objection clause negates a central tenet of the profession, that the patient comes first.

Stahl and Emanuel do accept, however, that there is a place for conscientious objection in situations where the medical community is still deciding whether participation in an intervention is appropriate or not, such as with PAS. The medical practitioner, they say, must then ensure that a timely referral is made so the person seeking MAiD can still be assisted appropriately.

British medical practitioners have responded defensively to literature criticising the conscientious objection clause[38]. In comments directed at a hard-hitting early article of reproach by Professor Savulescu in 2006[39] who is a trained medical doctor, now academic, they suggested that patients would not benefit from medical practitioners who no longer applied their ethical thought to their practice of medicine. Simply implementing protocols or the law[40] is inadequate because the law is not invariably just[41]. It was claimed that this would allow the State and institutions too much power, to the detriment of the whole health service. A psychiatrist, A. West, also responded by saying that 'personal integrity underpins the doctor-patient relationship. The values of the individual doctor are our safeguard against the institutional abuse of medicine'[42].

Then again, according to research in Quebec, most medical practitioners who choose not to participate in MAiD do not avoid it based on moral or religious grounds, but rather because of reasons such as the emotional burden, perceptions of incompetence, the high workload and fear of psychological consequences, including stigmatization and medico-legal repercussions[43]. This explanation does not necessarily delegitimise the use of the conscientious objection clause because it still supports the fact that the sphere of work is emotionally problematic. Like other specialised fields, it should be dealt with by those who have an interest in it or, at least, do not mind.

The conscientious objection clause needs to remain in place for E/PAS to make certain that killing by doctors is not enforced as a norm, and because it is not a recognised medical treatment or decision. Bearing in mind that it is not a recognised health care, the role of doctors in promoting PAS during consultations must be addressed.

6.2.7. Offering assisted death as an end-of-life option

If PAS legislation were to be a reality, it is important to consider whether assisted death should be offered by medical practitioners as a 'treatment choice' during medical discussions about end-of-life choices. That would be to comply with the requirements of the National Health Act for the consent process, even if the patient did not initiate the conversation. The Act provides that a person must be given 'full knowledge' of the range of generally available options, including benefits, risks and costs of treatment[44]. A concern is that death will always be cheaper than an admission to hospitals for palliative care, or chronic medication[45], especially with complex pathology. It could also be seen as a solution to reducing the burden on family and care-givers faced with a protracted dying phase. In addition, the patient may associate death with fear of pain, and anxiety about losing independence and dignity[37].

My opinion is that this option should not be mentioned unless the patient introduces the topic themselves because it is not a treatment. It is, rather, a refusal of treatment. Although the patient's right to refuse treatment must be mentioned by the doctor, I argue that there would and should not be a legal obligation on the doctor to go further and mention ways that a patient could kill themselves. The writer, Lo[46], adds that not every question a patient has about assisted death is with the intention to adopt it. He suggests that, besides gathering information, they could be working through their own concerns or expressing distress, or trying to ascertain what the doctor's opinion is of their particular situation. He believes that doctors should not raise the topic first in case patients think it is being recommended.

Doré, puts forward that by introducing the additional option of PAS into law, the patient invariably feels pressure to consider it as a reality, weighing up the prospect of relieving the family of a burden or, as he says, worse, forcing a burden on a family to have to care for them. Furthermore, Doré believes that even the action of disregarding the choice is itself a constant challenge because of the sense that by staying alive the person is producing a problem for others to confront, so it would be better to get assisted death over and done with. He reports that some of the reasons people have given for choosing an early death in the Oregon 2021 report are that

54% felt a burden, a number that has doubled in 10 years, and 8% said they had financial distress, so 62% died because of social reasons. Doré suggests that society has an entrenched responsibility to watch over people when they are at their most vulnerable, protecting them from being open to suggestion or coercion[37].

Once the patient has raised the topic, if it appears that the patient would like to pursue the chance of a hastened death, but the medical practitioner does not want to assist, this should be conveyed early on in the assessment process and ideally the patient should be referred to another practitioner who is prepared to fulfil that role[47].

6.2.8. Mental wellbeing

The psychological and social burden of assisting to accelerate death appears to be underestimated by those who propose and promulgate the E law. This possibly occurs because it is recognised that to make decisions that affect others is far easier than making decisions that would impact on the decision-maker personally[45, 48].

The medical professional is tasked with carrying out E/PAS by the government and lawyers who legislate and then enforce compliance with the law, but who will never have to experience killing someone themselves[25]. Comparatively, where a Federal Court judge passes the death sentence but does not perform the execution personally, the judge is not subjected to the full impact of the decision that was made[49]. One just has to contemplate allocating the role of killing people to a different sector of society with similar attributes to appreciate how irrational conferring such an onerous burden on others is. Sectors of society that are held in high regard by the public, not unfamiliar with suffering and death, and can be trusted to carry out the procedure in accordance with the law, would include religious leaders such as priests, rabbis and Imams, judges, senior lawyers, possibly soldiers. Yet the thought of any of them being instructed to perform E would cause most of them alarm.

There are situations, such as in the context of terminal illness and the prospect of imminent death, that the medical role of ‘care’ can be thought to encompass assisted death. However, the literature highlights that when a request for assisted death is first made to the medical practitioner, confusion and distress are often triggered in them, both personally and professionally.

Doctors attempt to accommodate the legal requirements while holding their own professional ethics in mind and catering to society's expectations of them as compassionate caregivers[30]. Frolic describes the procedure of E/PAS as 'emotionally challenging, highly regulated, legally risky and morally/politically contentious'[50].

The process has been portrayed as also causing strain on the doctor-patient relationship[30, 51]. For example, the situation may arise where the patient initiates the topic to actually establish the doctor's point of view of whether or not their circumstances are hopeless. The doctor could be perceived as recommending assisted death if voicing support for it, and conversely, rejecting the patient if not in favour of participating in the assisted death, but being willing to refer the person to a colleague[46]. Where a person asks for death, but their end of life is not readily foreseeable, the request can be even more psychologically taxing for a physician because the physical context of the patient does not align with hastening death from a clinical perspective[25]. Furthermore, the amount of time required to manage assisted death cases, from assessment through to performing the procedure, is substantial[26], and the practise is typically an 'add-on' to normal clinical responsibilities, not a specialty on its own[50].

Although Dutch and Belgian physicians tend to be the most willing medical group to support E and PAS compared to other countries[29], in 2011 research maintained that 86% of the Dutch doctors felt an emotional burden and dread when faced with performing E[31]. Interviews with the doctors identified that the actual decision to go ahead with the death is neither easy to reach nor uncomplicated[31]. This may be associated with the responsibility of, and enduring exposure to helping patients to reach the decision and then being the provider of its outcome, even when death offers a release for the person who is ending their life.

When medical staff frequently have to either make end-of-life decisions for their patients or facilitate the decision-making process with relatives, such as in an ICU environment, intense emotions can present that eventually cause moral distress[52]. Furthermore, in the countries that permit E/PAS as an extension of available end-of-life choices, medical practitioners may become morally disengaged in order to support it[53].

Both moral distress and moral disengagement are appraised next in the context of a medical practitioner's mental well-being.

i) Moral distress

The presence of moral distress was first labelled as such in nursing literature during the 1980s[54], and has only recently been researched amongst medical practitioners. Moral distress is defined by the British Medical Association (BMA) as 'the psychological unease generated where professionals identify an ethically correct action to take but are constrained in their ability to take that action'[55]. It goes on to explain that even without knowing what the morally correct action should be, the medical practitioner can experience moral distress from the perception that a moral transgression has occurred.

The BMA clarifies the concept further, as a sense of disquiet arising from circumstances where institutionally prescribed conduct does not align with moral principles. Some causes of this condition are thought by the BMA to be from the medical practitioner feeling powerless or lacking agency, alternatively, as a result of structural limitations, such as inadequate resources, staff, training and time. Significantly, the doctor who is experiencing moral distress does not have to have been the person who acted or failed to act, because moral distress can arise from witnessing the moral transgressions of others[55]. In other words, the person experiences their integrity as having been breached[52].

Additionally, the BMA warns that continued moral distress can ultimately cause moral injury which leads to compromised function and enduring psychological damage. Moral injury is described as a feeling of overwhelming wrongdoing and shame, sometimes generating a feeling of having been deceived, anger and extreme moral disorientation. This condition may be a component of serious mental health problems[56].

'Burnout' is distinguished from the above terms because it is not invariably associated with an ethical element, but is portrayed as overtiredness, professional pessimism or reduced professional capability because of persistent workplace stress[56]. South African medical practitioners have been suffering from burn-out for a long time, although this phenomenon is associated with doctors throughout the world[57]. It is important to mention that the presence of burn-out in a medical practitioner reflects emotional and physical exhaustion over an extended period, depersonalisation at an interpersonal level, associated with bearing feelings of negativity towards the job and detachment from it, and a sense of low personal accomplishment, linked to 'feelings of incompetence and a lack of achievement at work'. Researchers found that exhaustion and depersonalisation were a result of work overload, while the attitude of having

achieved very little personally stems from the scarcity of resources[57].

Even without burnout stemming from a moral dimension, the South African medical practitioner's frame of mind presently is not conducive to them administering E/PAS. They are at risk themselves of being victims of serious depression.

Interestingly, the research sourced on moral distress has been mainly from countries where E and PAS are not permitted, namely Italy and the United Kingdom, so, much of the moral distress described is associated with end-of-life care decisions that exclude hastened death[52]. Feelings of inadequacy arise in the medical practitioner because of being unable to relieve pain effectively[54] or for not achieving a 'good death' for the patient[52]. A stressful factor that has been mentioned by Italian nurses[54], the British intensivists[52] and Dutch physicians[51], is managing the expectations of relatives. South Africa would be in a similar position, considering the importance of the extended family.

The problems are that, where the patients are unconscious, the medical staff have no clear insight into what their preferences would be regarding end-of-life care[52]. Relatives may either demand continued medical interventions in the face of futility or conversely, they request withdrawal of any further medication when the medical practitioners believe there is still a chance for improvement. However, in England, the primary responsibility to decide is on the doctor because, unlike South Africa, relatives have no legal right to be their surrogate decision-makers[54]. Medical practitioners experience tension between doing what is legally correct and what is morally correct, despite guidance from end-of-life frameworks[52]. The continuing communication and consultations needed with the family, a vital part of reaching ultimate consensus, can take time and are emotionally draining. British researchers have stated that approximately 13% to 20% of patients in intensive care die mostly from decisions not to escalate interventions and/or the removal of life-support apparatus[52].

Bearing this research in mind, the proposed British legislation to allow assisted death for the terminally ill where patients only have six months left to live may well relieve some of the moral distress experienced in England. On the other hand, it could, by its very nature, add to the complexity of the problem of moral distress.

Literature suggests that the professional identity of the doctor as someone who alleviates suffering, provides good care, improves the quality of the patient's life and who is a support for

patients and relatives, is challenged by a patient's request for assisted death. The doctor's core values and beliefs, which are part of their professional identity, create ethical tension on how to respond professionally to the needs and wishes of the patient, without causing the patient additional harm.

Equally, some doctors believe that not carrying out assisted death causes a greater harm[30].

ii) Moral disengagement

Stahle[53] suggests that mechanisms of moral disengagement are employed by medical practitioners to cope with the conflicting roles of healer and agent to a hastened death. He puts forward that it may be harmful to their mental wellbeing over time because the process of selective moral disengagement can change one's personality. This opinion is explained, with reference to Osofsky *et al*'s research[58], by way of three methods of selective moral disengagement which target either the behaviour of the agent, or the role of the agent, or finally, the recipient.

The first method uses moral justification to excuse the *behaviour of the agent* performing the act. This is achieved by (i) expressing the well-intentioned ends to justify the means. Also, frequently seen is the (ii) use of euphemistic language to sanitise the conduct so that it sounds compassionate. The variety of choice of words that countries have coined to refer to assisted death demonstrates the point[59]. 'Medical Assistance in Dying' MAiD from Canada[60], and the fact that death certificates must be misleadingly labelled as 'natural death', evident in the law of Belgium[61], for example, are designed to avoid stigma.

Another moral justification mechanism Stahle identifies is (iii) making exonerative comparisons that dress-up the 'injurious behaviour' in a more positive light to make the act more psychologically acceptable. An example of an exonerative comparison is where it is emphasised that the alternative to E/PAS is an end filled with pain and suffering. This mindset was highlighted in the Netherlands, with the government's attempt to amend the Euthanasia law to promote the benefits of assisted suicide for the elderly who felt that their lives were completed and who had a death wish, but who would not meet the criteria of 'hopeless and unbearable suffering'[62]. (iv) Rationalising, that prescribing lethal medication for self-administration is a 'good' because it reduces a person's anxiety, also falls into this category. Stahle says that giving E/PAS a high moral and social purpose not only removes self-censure

but, additionally, promotes self-approval[63].

Applied to E/PAS, the moral justification is to alleviate pain of someone with an incurable condition, at the end of their life. The premise is that the situation is hopeless and the act is merciful, and that they will die soon anyway. Stahle's criticism of justification is that the law allows the doctor to reinforce this impression as a foregone conclusion by being prepared to support the patient's wish, in essence agreeing with them, if they had any doubts before the consultation[64]. Yet, he says, along with other doctors, the time frame until death is seldom accurate[65] and the assumption is wrongly made that the last phase of life is always meaningless, because there have been testimonies that broken relationships have been mended and people have changed their attitude towards death[66].

The second method identified by the researchers obscures or reduces the agent's *role* in the injurious act, labelled 'displacement of responsibility'[63]. The agent views their actions as a consequence of being told what to do rather than being personally responsible for the act. By not identifying as the causal agent, the actor is released from self-condemning feedback. In this manner responsibility is diffused. When personal agency is obscured in this way, the application of moral agency is also lessened.

Diminishing or ignoring the harmful result of the action achieves weakened moral control associated with the outcome of the act, and if no injurious result is perceived, there is then little reason for moral self-regulation to be activated. An illustration given is that with E/PAS law, the person is seen as responsible for their own voluntarily made decision, free from coercion.

However, Stahle and other commentators point out that the person may often subtly be influenced in a certain direction by their relatives and their doctor's response to questions once the law is in place[67]. The fact that the law exists at all applies pressure that would otherwise not have been present as a choice. E/PAS is given both a political and social stamp of approval, which is what Switzerland has tried to avoid by ultimately rejecting any enabling legislation[68].

Allowing only assisted suicide and not euthanasia transfers the responsibility onto the person to carry out the act of self-administration. This lowers the threshold for legalisation and makes it more palatable for medical practitioners to accept. Additionally, not requiring the doctor to be present at the death, as in Oregon, makes the process even more tolerable.

The third method Stahle says is used by people to disengage from the fact that they are committing an unpleasant act, is aimed at the *recipient* of the action, 'dehumanising' them[69].

The recipient is divested of human qualities and may be blamed for what is happening to them, even for bringing suffering upon themselves. For instance, the suggestion that a person's quality of life is so low that they have no dignity left, makes death appear to be a better alternative because their life is not worth living. Loss of dignity is often associated with being dependent on others for all their needs. Patients feel as if they are a burden on their families[70].

Emphasising the patient's limitations and reduced possibilities for an independent life are described by Stahle to be dehumanising because these people are perceived to have a lower protection value. He calls attention to the fact that a normally socialised person is protected by their conscience from purposefully killing someone else, which is viewed as the most serious crime in moral perception[71]. The South African legislature and judiciary support this stance through the South African Constitution by protecting the right to life[72].

A medical practitioner who has developed moral desensitisation[73] as a result of the demands to assist with death would be a hazard to society. Such a doctor would also represent a failure of the system as a result of society, it having changed the medical practitioner meant to care about life into someone who no longer cares whether another lives or dies.

Connecting E and PAS to the medical profession clearly gives the administration of death a positive medicalised hue which makes E/PAS more acceptable psychologically. Being associated with medical care reinforces the act of E/PAS as one of compassion and beneficence[74]. However, the psychological features associated with being an agent to assist another to kill themselves, particularly if the context appears to be wrong for a medical practitioner, have been shown to be problematic. It is not correct for society to assume that killing is an extension of medical practice, because it is not. These are good reasons to exclude the performance of assisted death from the medical domain.

An insight into introducing E legislation to the health sector resonates in the following story: doctors in Belgium described that in 2005, subsequent to their E legislation having come into force in 2002, at least once a week elderly hospitalised patients in their 70s and 80s would become anxious when a nurse came to give them a tablet or injection. They would ask whether it was to end their lives and would want reassurance that the medication was not intended to

euthanise them[75].

Bossard *et al.*[76] found that in the face of resistance from doctors to participate in E/PAS when it was first introduced, their attitude was that if society wanted to have the choice of assisted death as an end-of-life option, the communities were also to assume responsibility for it as widely as possible. It was proposed that any 'lay-people' with enough life-experience could join professionals such as the clergy, pharmacists, nurses, social workers, and others to take on decision-making jointly, especially in difficult cases. The researchers formed the view that dealing with questions such as spiritual issues, coercion, and symptom control, for example, were handled more effectively by appropriately trained advisors. This was in line with the Swiss Academy of Medical Sciences' position at the time, considering that the job of the medical practitioner was to discuss the medical condition and its consequences with the patient, establish whether the patient was at the end of life, and if so, suggest alternatives to medical interventions, such as palliative care.

As an alternative to using the health infrastructure, I suggest that not-for-profit nongovernmental organisations (NGOs) be established to facilitate the process of PAS throughout the country so that medical staff are not associated with causing unnatural deaths by killing people. The process should remain as removed from the health sector as possible.

6.2.9. Nongovernmental organisations (NGO)

A framework that utilises a not-for-profit organisation to oversee assisted death in South Africa would align with current law which prohibits turning the demand and supply of human materials such as tissues, including organs, blood, blood products, gametes[77] or babies through surrogate motherhood[78] into a business for profit.

The health system should not be coupled with actively causing death while trying to offer primary health care, hope and healing. As mentioned previously, the South African community already has the opinion that the public health infrastructure is untrustworthy with regard to ensuring care that is always in the best interests of patients and their families[79].

An outsourced system would help to build trust in the public health sector's services, avoiding any confusion surrounding where assisted death occurs. It would also ameliorate concern that there would be pressure towards choosing a premature death[6], or worse, that an involuntary

death could occur without relatives being made aware, as expressed in Belgium's example of patient anxiety. Finlay *et al.* also suggested creating a separate process for E/PAS outside of the health care sector, for the proposed British assisted dying framework, based on similar reasons[80].

My motivations in support of NGOs are these:

6.2.9.1. No coercion of health care staff to participate

Despite a conscientious objection clause in the draft SA Bill, practically, it could be difficult for public service medical practitioners to refuse to be involved in PAS if an instruction is given by a senior staff member to a junior that they must assist because of a shortage of staff[52]. The same problem would apply to nurses, pharmacists and psychologists refusing to participate.

Trainees have been shown to suffer greater moral distress than more experienced senior staff[52] and are susceptible to coercion because of the hierarchical system of the health infrastructure. For example, South African junior doctors have frequently worked hours far in excess of the stipulated limit in their contracts despite attempts to improve their working conditions[81].

On the other hand, if the right to conscientious objection is respected, in the absence of a separate organisation offering the service of hastened death, conscientious objectors could pose an obstacle for people to have access if the demand for death is higher than the number of medical practitioners prepared to assist them. Canada, for instance, is unusual in having hospitals willing to facilitate MAiD as part of their service provision, but the country has found that waiting lists have developed because too few doctors wish to join in, which has led to implementing a triage system in certain areas[50].

6.2.9.2. Avoids increased workload

Another reason for the health sector not to be drawn into the assisted death framework is that organising the roll-out at a practical and administrative level is onerous because of the nature of the work.

For example, an increased workload could be caused by a number of factors:

(i) The new law would draw additional people into the health system who would not normally ask for a doctor's appointment but who now seek two assessments in order to access assisted death. While the health service is constantly managing acute or chronic illnesses that require staffs' medical attention, this new cohort of people would be asking for a consultation purely to fulfil the social purpose of terminating their lives, a completely different category compared to which medical professionals normally apply their minds.

(ii) A medical file would need to be compiled. Two assessments by medical practitioners must be booked and performed. The file needs then to be transferred to an ethics panel. The ethics panel may also draw staff from the public sector or be an independent body which is remunerated for their services.

(iii) On the return day booked for the death, some form of admission would be required. A medical practitioner would need to confirm that the certificate of request is in order, and to establish the choice of ingestion of the lethal substance.

(iv) Preparation of the medication for ingestion, or alternatively, the insertion of a canula with a tap into the arm, if that is the preferred method of administration, would also need to be overseen by medical professionals.

(v) Complications such as vomiting or not dying for hours, may extend the time further. This is a reason for a doctor to be available - to ensure death ensues.

(vi) A staff member would finally need to complete any subsequent paperwork to record the death, similar to other deaths in a hospital, and prepare the body for transfer before it can be removed. On the death-day, the whole process, from start to finish, may take hours.

Outpatients being admitted to manage the process in order to die could arguably be an unnecessary diversion of scarce staff and health resources.

6.2.9.3. Rooms remain available for medical treatment

It would be preferable for people who are ready to ingest their lethal medication to have their own room where loved ones can be with them at the end of their life. However, private space in a state hospital is not always available. Other seriously ill patients may also need their own

rooms for important reasons, such as to reduce the spread of an infectious disease, or for a burns patient to be isolated away from infection for their own protection.

In independent premises, a personal space could be created, consisting of an attractive bedroom for the person at the end-of-life, with a lounge or waiting area for their family to have privacy during their time of sadness. The ambiance can be set according to the person's wishes along similar lines to the service offered by Swiss NGOs, described in Chapter 4.

6.2.9.4. A specialised team can be formed

The NGO can organise a dedicated multidisciplinary team of appropriately trained spiritual counsellors, traditional healers, psychologists, community care-givers and death doulas (lay caregivers) who would offer social, emotional and practical support to the person who is about to die and to those who are present at the death[82].

Sensitivity during the preparation for death, at the time of the death, and afterwards, with continuing grief counselling, is an aspect of care that medical practitioners are not automatically trained to provide. Specialists in these fields are available and well equipped to fulfil some of the roles of support[83].

Furthermore, clinicians dealing with MAiD express disquiet when they are confronted with a patient who asks for assisted death, but who has not met any or all of the criteria to ensure that their affairs are in order, such as resolving relationship issues, and making peace with the life they have lived[30]. These concerns are possibly better suited to being followed up by NGO staff.

NGOs could train their own technicians so that those assistants have a range of appropriate skills to support the person and those close to them on the day of their death. This would be similar to the Swiss NGO, Exit, that sends its staff for training through the University of Basel[84], which is described in Chapter 4.

Medical practitioners and nurses willing to work for or with such NGOs should be allowed to do so without censure from their professional bodies for unethical conduct. Those in turn who are unwilling to participate remain outside of the framework free from criticism or coercion.

Medical professionals working with the NGOs would be in a position to handle walk-in

assessments comparable to Dignitas's service in Switzerland[85], as the files would still have to be submitted to a panel for the certificate to be issued in compliance with the law, removing any concerns about dishonesty.

Another advantage of this framework is that there is a possibility that nongovernmental entities could become more mobile, meaning that they could assist people in their homes, if this were feasible and preferable to the requesting person and their family.

6.2.9.5. Record of management in one place

After the panel phase, all the final processing surrounding the assisted death, including the ultimate submission of the data to an oversight entity, could be managed by the NGO. Records of certificates of request, the type of administration of the lethal agent, any complications and other information, would then remain accessible from one source, not scattered throughout the country at different hospitals within their complex organisation. Data would be more easily cross-checked, and research could be done. That would be an important government responsibility, for it to remain constantly aware of the repercussions on society as a result of the new law.

6.2.9.6. Other services can eventually be offered

Swiss NGO models described in Chapter 4 support this proposed structure for South Africa. In addition to that, The Netherlands has a nongovernmental organisation. Founded in 2012, the *Expertisecentrum Euthanasie*[86], originally a Right-to-die organisation known as an End of Life clinic, changed its name in 2019 after expanding to offer a range of services as a professional health care organisation. It offers support to physicians who assist patients whose own doctors cannot help them to die for personal, psychological, or professional reasons. It provides training and refresher courses to doctors and has a regional network of approximately 140 medical practitioners.

South Africa's NGOs could eventually offer a broader range of services such as giving guidance to people wanting to draw up Advance Directives, or advice on access to palliative care before they opt for a hastened death. Dignitas has a help line for suicidal individuals to put them in contact with the right people for counselling. The hope is that by offering the intervention it will reduce the number of suicides. However, recent research has indicated that the number of

non-assisted suicides have not decreased[87]. In fact, there are opinions that non-assisted suicides have increased since countries have legalised assisted suicide. It is possible that the concept becomes 'normalised' in people's minds as an acceptable option to avoid suffering of any kind, including financial and economic stress[37].

6.2.10. The alternative model, in summary

The alternative model only permits assisted suicide carried out by the person themselves. They either ingest a lethal substance or have a canula with a tap they can rotate to allow the flow of a fatal medication by intravenous administration, inserted into their body. This is based on the model in the UK Bill[88].

For patients who request PAS and who are already using the public health service for the management of their medical conditions, the medical practitioners who would normally monitor the patient could enable the smooth progression of the assessment process up to the point where the panel makes a decision.

A. Assessment

Once the person has made an oral request for assisted death, a doctor would need to examine the person initially to see whether they are eligible in terms of the stipulated criteria. The doctor writes a medical report for the file, recording when the oral request was made. If the attending doctor is provisionally satisfied that the person is eligible, the person can make a formal 'Written Request' for assisted death at any stage. It is witnessed by one independent witness, signed by them in the presence of the doctor, the attending doctor countersigns, and this, too, is inserted into the file.

The person is then referred to an independent medical practitioner who writes an independent report. The person must be seen within a period of 14 days. The doctor will examine the patient impartially in order to check if they meet the criteria, which includes confirming the person's wish to die. If there is any concern about the person's mental competence to make the request for AS, or there is a suspicion of coercion for some reason, a psychiatrist should be asked to form an opinion after consulting with the person independently, too.

The person's file in which the doctors' reports have been placed, as well as the signed and

witnessed Written Request, must then be submitted to an appointed Ethics Committee for its consideration.

B. Panel

The Ethics Committee is required to meet, reach a decision and convey the outcome to the person and their attending doctor within three weeks of receiving the file. Where necessary, the panel can ask further questions from whomever they require information. When satisfied, a report is written, and an 'authorisation certificate' issued for assisted death. Both the attending doctor and the requesting person are informed of the outcome. The file, with the Committee's report and the certificate inserted inside, is then sent back to the attending doctor's office so that the certificate can be given to the requesting person. An original certificate should be handed over and a copy kept in the file.

When the person is ready to die, they can either notify the attending doctor so that a prescription can be prepared or take the certificate to the NGO for one of their doctors to issue the prescription instead. It is possible that the patient's medical file, or the panel's report may be required to cross-check that all is in order.

C. Nongovernmental organisation (NGO)

Where the person is using the private health sector, if the attending doctor chooses not to assist with the death, the person should approach an NGO established for this purpose. Likewise, a patient using the public sector, or their relatives should be able to ask an NGO to help them to die on a date to be mutually agreed upon. The hospitalised person would then need to be transferred to the NGO's venue for the purpose of AS.

In more rural communities where extended family or neighbours assist with care for the terminally ill person, an NGO unit that could travel to the person's home may be preferable, considering that some people may prefer to die in their home, a familiar environment.

The attending doctor facilitates the process by sending the file with the prescription to the NGO, while the requestor would hand over the original authorisation certificate as proof of permission granted and for verification purposes. Otherwise, the prescription could be prepared by an NGO doctor, relying on the Committee's certificate as proof of authorisation and the medical file, as

necessary.

Ultimately, the NGO could keep the patients' files securely and submit the final paperwork related to the death to an oversight body so that it can confirm that there was compliance with the regulations throughout the process.

D. Dispensing medication

Either an independent medical practitioner from the NGO, or the attending doctor, or an agreed assistant of the doctor in terms of the Act, receives the medication from the pharmacist just before it is administered. They are personally responsible for ensuring its correct administration. They are also responsible for the appropriate disposal of the remains afterwards, or all of it, if the person changes their mind and the medication is not used. Regulations would be necessary to ensure procedural safeguards and guidelines are implemented for the handling of the lethal medication. These would be required from the point where the pharmacist fulfils the prescription, to the personal handing over of lethal medication to a responsible person from the NGO representing the person seeking assistance to die, up to the final stage of the pharmacist receiving the remains of the contents of the medication afterwards, for disposal.

Wrapping up, the greatest value of this framework is that the country's national health system is essentially kept separate from actively participating in hastened death. Once the two doctors' opinions of the patient have been reported in accordance with the law and the reports are submitted to an Ethics Committee for a final decision, the doctors need not participate any further if they choose. This protects their traditional role as healer.

6.3. REVISITING OPTION 1

The 1998 report of the SALRC, although written 25 years ago, continues to resonate today in terms of the challenges it listed in South Africa, and the pros and cons of implementing E/PAS legislation[89]. Society still does not respect human life because, as mentioned in Chapter 3, grave human rights violations have continued to occur in South Africa. The health infrastructure has serious financial constraints causing a lack of resources in numerous areas throughout the country, including staffing and medication. Corruption has been uncovered with self-serving politicians holding high office in the health infrastructure, such as the ex-Minister of Health, Zweli Mkize[90], and Dr. David Motau, the Registrar of the Health Professions Council of South

Africa (HPCSA)[20]. There are many problems at a provincial level, too. The irregularities span financial departments and irregular spending[91], human resource departments and staffing[92], supply chain management[93], biohazardous waste disposal[94], and intentional damage to infrastructures[95], to name some of the challenges. The consequences to patients and staff are severe[96]. These issues suggest a lack of genuine interest in people's welfare when they are at their most vulnerable. Accordingly, to introduce assisted death into a failing system with the complex management that is required for its safety, is hazardous.

Regarding the development of the South African common law, the Supreme Court of Appeal, in the case of the Late Stransham-Ford, reinforced the fact that this body of law affects everyone and not just individuals[97]. Accordingly, if the criminal law were to be narrowed to exclude E and PAS, it would be necessary to contemplate how the enabling legislation would impact on the whole medical profession.

In this regard, Wallis, JA put forward some probing legal questions to ponder, such as whether patients' rights justify a change in the criminal law that would directly affect doctors; also, whether the right to healthcare would incorporate an entitlement to the administration and possible delivery of fatal doses of medication, or explicitly exclude it. The Court wondered what the implications would be for palliative care if a patient argued that their dignity was infringed by not being able to choose when and how to die[98]. Wallis, JA also emphasised that foreign jurisprudence always acknowledged the State's legitimate interest in imposing limitations on the practice of E and PAS, including other forms of assisting and supporting suicide. South Africa's case law has borne this out[99]. The difficulty would be to decide what constraints were reasonable and justifiable if a decision were taken to embrace such law.

David Albert Jones[100], a British professor of Bioethics, wrote an article in 2022 highlighting the flaw in the proposition expressed by some Swiss Right-to-die societies that, by allowing E/PAS, lives would be saved because, knowing the option to die existed, if a person could not cope any more, they might not commit suicide. Furthermore, this was an important point on which the Canadian case of *Carter v Canada*[101] was reasoned, that lives were put at risk without E/PAS legislation, which therefore limited the right to life. Paragraph 57 states: 'The trial judge found that the prohibition on physician-assisted dying had the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable. On that basis, she found that the right to life was engaged'. The Judge goes on to say that because the evidence of premature death was not

challenged in the Appeal Court, it was established that the prohibition does deprive some people of life. However, data has proved otherwise.

It is not the prohibition of PAS that caused premature death, but its introduction. Non-assisted suicides have not decreased as expected. America has had a significant total increase in suicides. So having the law is no deterrent but could rather be a reinforcement of a new norm of acceptance.

Jones, through his research, shows that the same trend is evident in European countries. Of note is that the number of suicides among women has risen, including non-assisted suicides, indicating that women are more at risk of avoidable premature deaths. The number of Swiss women who have died has doubled since 1998. These higher suicide rates lead to the conclusion that there are concerning questions about the strategy of suicide prevention.

Interestingly, the latest OECD indicator for the rate of suicide in different countries as at 2023 placed South Africa with the lowest figure overall of 0.6% per 100 000 people[102].

Beauchamp and Childress assert that there are times when conduct that is appropriate for an individual situation may be justifiably prohibited by public rules and laws[103]. In contrast to the legal questions Wallis posed, they ask two moral questions to illustrate their reasoning: 1) whether a doctor is ever morally justified in complying with an individual's request for a premature death, and 2) whether there is sufficient moral foundation on which to defend legalising PAS.

The authors argue that there are cases where a doctor would be able to rationalise assisting an individual patient on a moral basis. However, external factors beyond the private doctor-patient relationship need to be taken into account: medical education, the working environment of the public hospitals and nursing homes, a shortage of effective medication for pain control, access to health services generally, and the social circumstances of many people. These issues could provide enough valid moral reasons, as a matter of public law, not to let medical practitioners become involved in such practices, because some policies would be morally unacceptable[104].

Importantly, Beauchamp and Childress point out that the conclusion that an action is morally unacceptable does not automatically indicate that the State should prohibit it or refuse to back it financially, such as with sterilisation. The converse also applies: where an act is considered

to be morally good, it does not mean that the law should allow it. Essentially, one's opinions about the morality of actions do not include a matching opinion about law and policy. Aside from the question of what is considered to be moral for society, the government will need to weigh up the costs of implementing an assisted death framework, as well as the demand for competing projects such as primary and palliative medical care[105].

Wallis, JA mentions that there is a need to protect the poor, the weak and the vulnerable from decisions that could be detrimental to their well-being[106]. However, the question that must be asked is what they are being protected from? There is no alternative option available to relieve pain and suffering because the health system is overburdened and failing, and the social determinants of health have not been met. A more 'compassionate' outlet may arguably be the opportunity to die early rather than to continue suffering chronically.

Professor Willem Landman put a theoretical question to the SALRC for their report. He based it on the *Soobramoney* case[107] in which rationing of dialysis machinery was held to be acceptable in the face of scarce supplies, even though it led directly to Mr Soobramoney's death. He asked whether, hypothetically, it would not be inconsistent and cruel of the Court to withhold a medical intervention necessary for life in order to preserve a scarce resource, and then also to refuse an assisted death that would shorten the period of suffering: because that person could not access the scarce resource, that left death as the only escape[108].

The Court has acknowledged that palliative care is not widely available. It is provided mainly through voluntary organisations, and, to a limited extent, the private sector[109]. People with reduced financial means would then suffer more, because resources were too scarce, combined with a legal prohibition against assisted death[110].

Culturally, South Africa has its own unique population that is completely different to the countries in the world that have promulgated E/PAS law. The large variety of South African cultures, including eleven official languages, and a range of belief systems within communities, view assisted death in different ways. For many, the concept of E is apparently anathema. According to Makiwane and Kaunda[111], this is because of the communitarian philosophy of *Ubuntu*. *Ubuntu* demands respect for life, happiness and the success of others, including the well-being of the extended family and finally, but most importantly, the prosperity of the people as a group. In the rural areas of the country especially, this has traditionally encompassed care of the elderly, needy and sick.

Mangena and Chitando[112] comment that many contemporary Africans, not just the older community, would find the concept of euthanasia foreign and would consider the very thought of euthanasia unacceptable because their cultures prioritise life in all human conditions. In contrast to the Western idea of euthanasia that distinguishes between active and passive interventions to end life, where withdrawing treatment is viewed as ethical in certain circumstances, the African cultures do not recognise a distinction between the two actions. The writers mention the remarks of the Zimbabwean sociologist, Mararike[113], who said of the Mandela family's decision to remove artificial life support from Nelson Mandela who was in a persistent vegetative state, that it would be seen as tantamount to witchcraft (*kuroya*). He saw the decision as a failure to appreciate the African values of life.

Another observation Mararike shared is that Africans place a high importance on life because they fear the threatening avenging spirits (*ngozi*) of the people they have killed, which they believe could come back to haunt them. However, his terms of reference are from the Shona people, so there are likely to be differences in belief between different cultural groups. Mangena and Chitando also disagree with Mararike that there is no acceptance of euthanasia by the Shona. According to their research it is rather case specific, allowing for exceptional situations of suffering[114].

In the Late Stransham-Ford case, Ms Mayeza, the palliative care social worker who presented evidence on African values, confirmed what has been stated above by Makiwane and Kaunda for South Africans, that the African communities see life as a gift to be protected, so E and PAS would pose a real threat because of the difficult socioeconomic circumstances of much of South African society[115].

Professor Ncayiyana, a gynaecologist and past editor in 2012 of the South African Journal of Medicine, wrote at the time that, although he found the arguments for legalised euthanasia compelling where the quality of life is so low that it is merely biological, South Africa was not yet a safe or appropriate place to introduce such radical legislation. His opinion was that it could only be justified in a context where the best medical care was already being offered with a strong culture for human life. In the circumstances, he said, euthanasia could not be viewed on a 'wish list' to improve the human condition of South Africans[116].

It is significant that the majority of countries still refuse to recognise E and PAS as a necessary addition to end of life care. This supports the attitude that E and PAS remain unacceptable in

principle, and controversial, regardless of the pressure being brought to bear by activist groups.

6.4. CONCLUSION

According to a Dutch retired physician, Rob Jonquiere, it is better to begin with the most obvious cases of suffering before the range of eligibility criteria is expanded, so that people get used to it, and assisted death becomes a normal part of life[117]. Based on this advice, if South Africa intended to introduce legislation for assisted death, it would be prudent to see how well both society and the medical profession responded to it. The introduction of basic legislation would identify problems surrounding implementation and overseeing the process before the net is cast too wide.

E/PAS is a contentious ethical dilemma and accepting E/PAS law into the South African moral fabric must shift public morality towards moral desensitisation, as it has done with the tolerance of abortion. Beauchamp and Childress[118] talk of moral rules being threads in the fabric. When rules prohibiting killing are removed, they compare it to pulling out threads, and the fabric is weakened. Attitudes and beliefs are then modified and could ultimately affect respect for life. Should the assisted death legislation be introduced in South Africa, ongoing research will have to investigate what the consequence of the paradigm shift are for society in time to come.

Speaking from experience in palliative medicine, Doré[37], makes the point that the complications that arise from PAS replace the complex natural deaths people are trying to avoid, which are rare. Most people die in comfort, naturally. He argues that fear of a loss of dignity, rather than suffering from pain, does not justify the number of lives being ended prematurely. Doré expresses the concern that a new suicide epidemic has developed. I developed the same sense throughout the literature, perceiving the growth of what has become a ‘death culture’. Doré imagines that this century could be looked back upon eventually with the same alarm as we do the practice of eugenics of the past.

The next chapter will examine the alternative to assisted death, palliative care in South Africa.

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CHAPTER 7: PALLIATIVE CARE IN SOUTH AFRICA

7.1. INTRODUCTION

Chapter 5 critically examined the proposed End of Life Decisions Act. This included its euthanasia and physician assisted suicide section, which was suggested in the South African Law Reform Commission's Report 86. Some alternatives were offered in Chapter 6, should the government ultimately decide to introduce assisted death legislation.

The draft Act and its analysis have relevance for medical practitioners because they require knowledge of the legal framework. Within that framework they would be able to guide people working through end-of-life decisions. They will also have insight into their own boundaries within which they can make decisions about patients and act on those decisions.

This chapter analyses palliative care in South Africa, which is invariably offered as a legitimate alternative to assisted death in the foreign jurisdictions that allow E/PAS. I probe the role and status of palliative care that is presently available to South Africans, to assess whether this holds true for South Africans as well.

International instruments such as the International Covenant on Economic Social and Cultural Rights[1], and the Convention on the Rights of the Child[2] have identified access to palliative care and pain relief as a fundamental right under the human right to health. Unfortunately, relatively few people in the world receive it. The World Health Organisation (WHO) asserts that pain and struggling to breathe, which cause extreme distress, are the two symptoms most often experienced by patients who would benefit from palliative care. Apparently, up to 80% of people who are suffering from cancer or AIDS, and 67% of those who have cardiovascular disease or chronic obstructive pulmonary disease, could be trying to cope with moderate to severe pain in the terminal phase of their lives[3]. The WHO says that opioids are essential to alleviate this type of pain. One can infer that not having the ability to obtain opioids on an ongoing basis to control pain could result in life seeming no longer to be worth living. If palliative care is not readily accessible, this thought is sobering when contemplating the introduction of E and PAS law into society.

The WHO website offers information on what palliative care entails and how programme managers can integrate it into national health systems[4]. Importantly, palliative care can be

introduced early on in a disease process which differentiates it from Hospice care which typically focusses on the last six months of life. Timeous palliative interventions reduce the need for hospitalisation and therefore the use of hospital services, which is a great advantage to the patient and the health infrastructure[5].

Most palliative care in South Africa is offered by non-governmental organisations[6]. The WHO definition and principles of palliative care[7] have been incorporated into the national Hospice infrastructure[8]. Recent HPCSA ethical guidelines on palliative care, which were provided to medical practitioners in 2019[9], also draw on the WHO principles. So palliative care ought to be of a good standard locally. The definition promotes a holistic view of palliative care as 'an approach that improves the quality of life of patients and their families facing the problem associated with life- threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual'.

7.2. BRIEF HISTORY OF SOUTH AFRICAN PALLIATIVE CARE

7.2.1. Hospice Palliative Care Association

The Hospice Palliative Care Association (HPCA) was founded in South Africa in 1987. This was 20 years after Dame Cicely Saunders established her first hospice, St Christopher's, in England, in 1967[10].

The HPCA is a registered non-profit organisation, functioning as a national charity. Consequently, most funding is received from local communities through fundraising, hospice lotteries, investments and bequests, as well as hospice charity shops. A limited amount of government funding is provided, but the sum varies between provinces[11].

The Association delivers a variety of services to its approximately 89 member hospices and partner organisations, such as advocacy and policy support, education, training, research, quality management, accreditation and mentorship. It also follows up its work with monitoring, evaluating and reporting.

Comprehensive help with palliative care is given by the HPCA to roughly 100 000 people and their families each year[12]. Significantly, around 84% of patients benefit from being nursed

mostly within their communities: either in their own homes, or through hospice day care, or at outpatient facilities[11].

Hospice in South Africa treats a wide range of life-threatening diseases, for instance cancers, motor neurone disease, cardio-vascular diseases, multiple sclerosis, Parkinson's disease and dementia[11]. It promotes support for chronic conditions, from diagnosis of the disease process onwards, where possible, to help with pain control and other symptoms[13].

The initial Hospice booklet that recommended a set of clinical standards for palliative care was already available in South Africa a year after the HPCA began in 1998[14]. Physical, psychosocial, and spiritual care was provided by an inter-disciplinary team with a range of skills. The team was made up of professional nurses and social workers, trained care-givers and social auxiliary workers who visited patients and families and, importantly, educated them to help them cope[15].

In order to fulfil the need to reach as many patients as they could in the face of a chronic shortage of nurses and doctors, attention was focussed on training community caregivers. The South Coast Hospice in KwaZulu-Natal designed a successful Integrated Community-Based Home Care Model which was embraced by HPCA nationally. This model also impressed the National Department of Health who then commissioned HPCA to calculate the cost of the model, establish a training curriculum for care-givers and roll it out in urban, peri-urban and rural communities[15].

In Cape Town, using donor funding, the first Palliative Medicine Unit on the African continent was launched during 2001. It was supported by the Dean and Faculty of Health Sciences of the University of Cape Town (UCT). Drenth *et al.* describe it as world renowned, attracting students from all over Africa to enrol in post-graduate studies. Either a one year Diploma can be undertaken through long-distance learning, or a research-based Master of Philosophy degree in Palliative Medicine. UCT palliative medicine graduates have subsequently used their knowledge at other medical schools nationally to establish under-graduate palliative care training elsewhere in the country[16].

Also in 2001 a mentorship programme was started, based on the Integrated Community-Based Home Care Model, to assist member organisations of HPCA and community providers of care to improve patient palliative care results[15]. However, evidence showed that good governance

was needed to ensure effective clinical care. Subsequent collaboration with the Council for Health Services Accreditation of Southern Africa (COHSASA) led to the development of palliative care standards that could be measured for quality control of member hospice providers. In addition, they met the international requirements for standards accreditation in community settings. This meant that an expert authority had defined the acceptable minimum level of excellence required, with a measurable outcome that was practically attainable for both the palliative care infrastructure established, and the operation of the care process. The accreditation practice began in 2005 with the implementation of these standards, when it was starkly apparent that the need for palliative care far surpassed the existing resources[17].

The next measure introduced in 2009 was a system of rating that awarded stars. It was initiated in order to develop capability and to acknowledge the achievements of Hospice member organisations that offered high-quality palliative care services[17].

From 2012 onwards palliative care training of Traditional Health Practitioners commenced and a training manual was produced that has been translated into various local languages to facilitate distribution[18]. Additionally, in the same year, a very practical and comprehensive legal reference guide, called *Legal Aspects of Palliative Care*[19], was reviewed for hospice staff and legal practitioners to complement palliative care services. Numerous writers and editors contributed to its 13 chapters. The booklet's chapters discuss a multitude of legal challenges related to children, adults and those helping them, and give useful advice with contact details or resources for further information. As Drenth *et al*, have expressed, this booklet has added a valuable dimension to the holistic approach of HPCA in South Africa[20].

The HPCA, in the Legal booklet, identified barriers to palliative care in South Africa that needed to be addressed[21]. At a social level, the sort of problems that arise as barriers include, for instance, patients that deny the severity of their illness rather than confronting it, consequently avoiding seeking help. Unrealistic expectations of treatment for their illness occurs, too, and at times the patient and family disagree on the available options to manage the disease. Advanced care planning is often lacking, and language differences are an added social barrier. Minority groups suffer because of their social status, such as refugees, homeless people, and prisoners, although Hospice has successfully contributed to the improvement of palliative care in Correctional Services[22].

Access barriers to health care facilities, such as transport and transport costs for seriously ill

people, are fundamental problems; there is no government subsidy available for palliative care nor for the reimbursement of physicians; inefficient procurement at clinics and hospitals in remote areas cause stock shortages; and some of the much-needed palliative care drugs are not held at community clinic centres despite them being on an essential drug list[21]. These difficulties are yet to be resolved.

Another project which the HPCA completed in 2012 was updating their comprehensive clinical guidelines in palliative care. Liz Gwyther, the Chief Executive Officer of HPCA at the time, summarised the reasons for the guidelines: to assist practitioners with assessment of the patient, advise on pharmacological and non-pharmacological management of symptoms, recommend how to explain the objectives of treatment to a patient and family members, and to remind the care-giver to involve the interdisciplinary team or alternatively, refer to a more experienced clinician when necessary. The guidelines include the need for care to be administered along the lines of Beauchamp and Childress's four biomedical ethical principles[23], with a fifth important principle added of non-abandonment[24].

It is reassuring to read in the court case of Stransham-Ford that during 2015, when the plaintiff, Advocate Stransham-Ford, was in his final days of life, a palliative care practitioner, Dr. Bruce, recorded that Hospice care administered by the St Luke's Hospice community nurses gave him comfort and relief from his symptoms. He was in the familiarity and security of a family home, and surrounded by people who loved him. He died naturally and in peace. The Court report captured the doctor's description of his patient's experience as follows: 'The impact of palliative care surpassed his expectations and defied his own predictions of a frightening, impersonal and undignified death'[25]. Sadly, this is apparently an experience restricted to the minority of society: the resources for palliative care are still extremely limited compared to the demand. This is discussed further below.

7.2.2. Resolution 67.19

Notably, in 2014, a year before Stransham-Ford's court case highlighted interest in introducing E law into South Africa, the World Health Assembly drew up Resolution 67.19, '*Strengthening of palliative care as a component of comprehensive care throughout the life course*'. This emphasised that access to palliative care should be integrated into all levels of health care as a moral imperative[26]. South Africa as a member state supported the WHO Assembly Resolution on Palliative Care, leading to the National Department of Health publishing a National Policy

Framework in 2017[6].

7.2.3. National Policy Framework and Strategy on Palliative Care 2017-2022

The *National Policy Framework and Strategy on Palliative Care* 2017-2022[27] (Palliative Care Policy Framework) was brought in by the government to address the needs of patients requiring palliative care. Although a few health facilities offered palliative care as a service, it was inconsistently provided across the health system. Independent organisations have tried to fill the gap, but sustainability is a challenge when finances depend almost completely on donations.

Consequently, in order to deliver accessible palliative care to the whole population, the Palliative Care Policy Framework directs attention to tackling structural challenges. These include inequitable access to palliative care, and the social and economic costs associated with a family member giving up work to nurse a patient. The demands of the population's burden of disease are considered, as well as health system challenges. This incorporate service delivery, the health workforce, and access to medical products and technologies for example. Finally, governance and financing are also addressed because, to date, the government's financial support for palliative care has been minimal.

The Palliative Care Policy Framework covers all that is needed for good palliative care to become available for everyone. It is aimed at assisting the many stakeholders to understand the need for palliative care and to be a guide for providing that care. Target groups include policy makers, health programme designers, health department professionals and workers, and NGOs. The framework provides the structure for strengthening what already exists for palliative care service delivery in the health system, and for implementing further resources.

In preparing the Palliative Care Policy Framework, its National Steering Committee estimated that 50% of the population could benefit from palliative care interventions because of the existing high burden of disease. The various phases of the illness trajectory are explained, and the inputs described that would be necessary at each stage to meet the needs of patients. Referral pathways have also been identified.

It is acknowledged that much more training should be made available at an undergraduate and postgraduate level, as well as in-training for care-givers already working in palliative care. Recognition of a specialised field in palliative care is seen to be appropriate. To facilitate

education, training and research, Centres of Excellence at academic hospitals are proposed. At the time the Palliative Care Policy Framework was drawn up, only Gauteng had a Centre of Excellence offering services, education, training, and research in palliative care.

Importantly, the costs of establishing a comprehensive service and its ongoing expenses for service delivery have been estimated[28]. The National Department of Health has put into place targeted outcomes in each province for execution of the palliative care plan.

With regard to the health workforce, which I mentioned was overburdened in the public sector in Chapter 6, the Palliative Care Policy Framework gives the following statistics: there is a severe shortage of medical doctors, with only 0.77 per 1000 patients[29]. However, the Competition Commission's Health Market Enquiry Report provided insight into the public sector, based on 2017 data, that only 0.3 medical practitioners were available per 1000 uninsured people[30]. For this reason, one of the Palliative Care Policy Framework recommendations is to shift palliative care tasks over to nurses by empowering them through legislation to be able to prescribe schedule 6 opioids for effective pain management[29]. However, there is also a scarcity of suitably trained nurses to meet the demand, with only 5 per 1000 people.

A serious deficit that hinders access to palliative care in South Africa is not having identifiable health workers to provide home palliative care, according to the Palliative Care Policy Framework. This problem is exacerbated by minimal available formal training courses and resources, including the absence of discrete roles and responsibilities within the teams of health care workers. The home and community-based health care workers who are in touch with the community's needs, do give support to the patient and family. However, they are not trained in palliative care, and so cannot manage pain and symptoms related to the disease process. As such, their role in supplying palliative care, as well as their level of accountability, is unclear.

The need for more comprehensive training was affirmed in the Palliative Care Policy Framework, together with better reimbursement and help with preventing or managing psychosocial suffering. It is also recognised that a multi-disciplinary team incorporating allied health workers and social workers is better suited to offer holistic care. This has not been part of the public sector's structured service in the past[29].

The Palliative Care Policy Framework accepts that social determinants such as a lack of readily

available clean water, sanitation, education and employment, influence a person's health[31]. Consequently, the poorest of those within communities, and the outcasts - both adults and children - suffer the most because they are totally dependent on the public health sector, which in turn lacks resources to cater for their health needs. In addition, their living spaces have so few resources for comfort and dignity that even receiving home palliative care would not be sufficient. Clearly social problems such as these must be improved for better health to be achieved generally. In order to break the perpetuating cycle of inaccessible services, which cause more inequity, hardship and poverty, the appropriate public sector services have to become available so that poverty does not prevent access.

Many people would prefer to die at home, according to the Swiss Ethical Guidelines on Management of Dying and Death[32]. The guidelines explain, however, that the trend over the past century has been for society to move people who were suffering while dying out of their homes and into institutions: professionals, rather than relatives, take over the role of caring.

As palliative care developed, there has been an attempt to reverse institutionalisation and allow people to have their wish of being in the comfort and familiarity of their own environments. The Swiss guidelines point out that the great desire to be at home can pose difficulties too. This is especially so given that relatives must fulfil the caring role, instead of having medical staff constantly on hand to assist[32].

Unreasonable expectations create additional stress, such as when 'better palliative care' is associated with home nursing. Although the seriously ill person's wish is a central focus, the Swiss guidelines acknowledge the reality of relatives being pushed to their limits unless there is effective and adequate external palliative care support, such as through a home service. It is a misconception, the authors say, to give precedence to the sick person over the well-being of the household, if the demands made are excessive[32].

The Swiss guidelines do not give insight into what an excessive burden would be, but logically, where pain and other symptoms are not well-controlled and no one can sleep because of the anxiety to help, there should be a place for institutionalisation where full-time professional care can take over. A balance must exist. Furthermore, the Swiss guidelines highlight that an increasing number of people do not have relatives who can offer much needed care in the terminal phase of their life[32]. This awareness is particularly important in the rural community where poverty impacts on the social infrastructure and community workers are not equipped to

provide sophisticated medical interventions.

Finally, five goals and the processes required to achieve the objectives discussed in the Palliative Care Policy Framework, are laid out. Schedules for implementation are offered, so that the project is presented as potentially realisable[33]. Unfortunately, the Covid years hampered the speed of the rollout's chronological milestones, but it is hoped that this ambitious *National Policy Framework and Strategy on Palliative Care* (2017-2022) can ultimately reach fruition.

7.2.4. International Association for Hospice and Palliative Care

Interestingly, at the same time that the South African National Policy for Palliative Care was published, the International Association for Hospice and Palliative Care released its position statement on E and PAS during 2017, too[34]. Following consultation and the research of a working group, the document states that no country should allow E and PAS legislation without ensuring universal access to palliative services. This should include suitable medication for pain control and other symptoms such as dyspnoea. In addition, the palliative care units should not be responsible for oversight of E and PAS and medical staff, in line with their personal convictions, should be allowed to refuse to participate.

7.2.5. HPCSA palliative care guidelines

In the course of 2019, the Health Professions Council of South Africa (HPCSA) released its newest guidelines about palliative care[35]. This publication was in line with the Palliative Care Policy Framework's first goal, which is 'to strengthen palliative care services across all levels of the health system'[36]. One of the objectives of the goal was to publish a national set of guidelines and standards for palliative care. According to the Palliative Care Policy Framework timeline[37], the National Guidelines were to be available by the end of 2019, and this was achieved.

The HPCSA Palliative Care Booklet provides medical practitioners with an ethical framework in which to manage patients in need of comfort care who are in the final phase of their lives. It clarifies the accepted approach of doctors to end-of-life management without having the option of E and PAS - a non-medical intervention.

In the HPCSA Palliative Care Booklet, the national shortage of available palliative services is

alluded to again, reinforcing the widespread problem it presents for society[38]. McQuoid Mason and Naidoo explain that the guidelines are a combination of numerous foreign palliative care guidelines, reflecting the authors' efforts to apply an international standard of excellence[39]. They are written with reference to Beauchamp and Childress's four biomedical ethical principles: autonomy, beneficence, non-maleficence and justice[23], following the recommendation of the Kenyan guidelines to bear these principles in mind[39]. Similarly, a reminder to apply the bioethical principles can be found in the 2012 Hospice Palliative Care Association clinical guidelines, referred to in **7.2.1** above, showing consistency of approach.

Of note for this thesis is that, in the HPCSA Palliative Care Booklet, under the heading of 'Non-maleficence and palliative care', there is a reference to E and PAS[40]. It is acknowledged in the text that E and PAS are frequently perceived to be inconsistent with the principle of non-maleficence, because the principle requires one not to cause harm to patients. The text goes on to clarify that the South African criminal courts often do not distinguish between euthanasia and assisted suicide when deciding blameworthiness, which remains classified as murder. Furthermore, the courts perceive E and PAS to be completely discordant with the core tenets of the medical practitioner's role as a healer. Therefore, should a medical practitioner engage in either action, according to the HPCSA, they would be guilty of unlawful and unethical conduct[41].

Where a doctor is confronted with a patient who requests assisted death in the face of suffering and severe anguish, the guidelines in the HPCSA Palliative Care Booklet advise that the medical practitioner should discuss the patient's concerns and fears to establish the reason for the request. With awareness of the issues, other methods of management should be canvassed with them[42]. In the event that medical treatment eases a patient's distress but also shortens their lifespan, the doctor is expected to weigh up whether the medical benefits justify the quicker death before embarking on the course of treatment. Nevertheless, the HPCSA guidelines add that when palliative care does accelerate death, this is not considered to be criminal or unethical conduct, as long as the patient or their legal representative has given informed consent to the therapy[43].

The meanings of both E and PAS are given. 'Euthanasia' is broadly explained as being the 'employment of any medical intervention primarily aimed at ending a patient's life', and 'doctor-assisted suicide' is expressed as 'when the health practitioner provides the means necessary to enable the patient to end their own life'[44]. Being in the context of the guidelines in

the HPCSA Palliative Care Booklet, it is assumed that the author still has a doctor in mind. However, it does apply to other health professionals participating in E/PAS who fall under the umbrella of the HPCSA[45], excluding nurses.

Withholding and withdrawing treatment are also briefly discussed in the HPCSA Palliative Care Booklet because of the importance of the patient continuing to receive palliative care even if active interventions stop[46]. However, this information is provided over and above a separate HPCSA Booklet on the topic of withholding and withdrawal of treatment[47], to which the authors direct readers for further information. The guidelines in the HPCSA Palliative Care Booklet reassure medical practitioners that medical treatment may be withheld or withdrawn in circumstances where a patient either declines ongoing treatment, or additional treatment would be futile, or if further interventions are not in the patient's best interests anymore, because the therapy would simply prolong the dying phase. Under these conditions the doctor's actions would be neither illegal nor unethical. Such decisions can only be reached after consulting with the patient and family and may not be taken without careful consideration. The palliative care practitioner is required to include in the deliberations any preparations that can be made for basic care to be continued once treatment is withdrawn or withheld, as well as offering the patient alternative treatments[48].

The last section, paragraph 10 in the HPCSA Palliative Care Booklet addresses the bioethical principle of justice and its place in making palliative care available for everyone, as hoped for in the WHO's principles of universal health coverage. It reiterates that the WHO expects every South African, regardless of their income, age, or disease type, ultimately to have access to 'a nationally determined set of basic health services, including palliative care', which aligns with the right to access health care, food, water and social security[49] in the South African Constitution[50]. Additionally, the Palliative Care Booklet records that the WHO requires a country to ensure that its 'financial and social protection systems' specifically support the right of marginalised and poor communities to palliative care[51].

The National Policy Framework and Strategy on Palliative Care also mentions justice. It affirms that palliative care should be accessible at every level of the South African health care infrastructure for all patients, from birth until their death. Moreover, the guidelines in the HPCSA Palliative Care Booklet repeat the National Policy Framework's stipulations that health professionals should give special attention to the following vulnerable groups (i) persons with disabilities, (ii) children (including neonates and adolescents), (iii) older persons, including

those living in residential care settings and frail care facilities, (iv) asylum seekers and refugees, (v) inmates of correctional services, and (vi) persons in long-term care facilities such as TB and psychiatric hospitals or residential care facilities[52]. The 2019 HPCSA Palliative Care Booklet therefore supports a removal of the barriers to access of palliative care that the Hospice Palliative Care Association had identified years back in its 2012 Hospice Palliative Care Association clinical guidelines, mentioned earlier.

An important final paragraph to note in the guidelines in the HPCSA Palliative Care Booklet is that medical practitioners are reminded to use South Africa's limited resources in the health sector responsibly, fairly, and effectively. This is a safeguard for all patients to be able to obtain the palliative care they need[53].

As discussed in chapter 3, the *Soobramoney* court case[54] dealt with the question of who benefits from a hospital's scarce resources. Chaskalson, P. mentions an English decision where the English Courts held that it would be objectionable for a court to decide on how scarce medical resources should be used, particularly where there was a chance that the court order for one individual's wellbeing might redirect the resources from other patients who could benefit more from them[55]. I have argued in chapter 5 that a court judgment in support of introducing E/PAS into the South African legal system, which impacts on the health sector, may well result in scarce resources being diverted from the opportunity to provide excellent palliative care. This would disadvantage seriously ill patients, both young and old, who still want to live out their last months or years, but in greater comfort and without fear of a traumatic death.

7.3. INTERNATIONAL INSTRUMENTS

7.3.1. WMA Declaration of Venice

During 2022, in the Declaration of Venice on End of Life Medical Care[56] (WMA Declaration), the World Medical Association updated its recommendations for end-of-life management, which includes pain and symptom control. The WMA Declaration is highlighted in this thesis as a guide towards developing an ethico-legal framework to assist South African doctors with end-of-life decision-making.

The WMA Declaration begins by acknowledging the differences between communities' cultures, religions, attitudes, and beliefs when confronting dying and death. Likewise, the

resources for palliative care vary widely between countries and are unevenly distributed, even within countries. Therefore, the handling of terminal medical care will be influenced to a large extent by all these factors locally, and universal guidelines can, at best, be general suggestions. A summary of each recommendation is made, but the complete document is available as Annexure 3.

1. Palliative care is part of good medical care that avoids distressing symptoms at the end of life and ensures the patient's dignity is maintained.

2. To optimise the treatment of pain, the WMA has drawn up recommendations in a Resolution on Access to Adequate Pain Treatment[57] which records that access to pain treatment is a human right. Governments must therefore provide sufficient resources and pain treatment regulations for medical practitioners to be able to assess and treat pain effectively.

3. A patient with intractable symptoms in the terminal phase of life may be offered deep sedation to unconsciousness as an intervention of last resort, after obtaining consent either from the patient or their surrogate decision maker.

4. A multidisciplinary team is preferable for palliative care, with the doctor as the leader who takes responsibility for a range of matters, such diagnosis and medical treatment plans. Good records of all decisions and the reasons for taking them are both necessary and important - the depth and length of sedation, for example, and the intention to continue, withhold or withdraw future treatment.

5. Collaborative care and bereavement support for the family after the patient's death is recommended.

6. The education of medical practitioners in end-of-life care is important and its establishment as a specialised field.

7. Doctors should be taught about advance directives which encourage patients to document their wishes about treatment, goals, and values, and to appoint a surrogate decision-maker in the event that it may be necessary.

8. Governments and research institutions are encouraged to invest additional resources in developing treatments to advance terminal care.

9. A balance must be kept between the intended benefits of treatments and potential harm to the patient, preferably following national palliative treatment guidelines.

10. Doctors should convey that they are happy to discuss the course of the disease and what to expect with the dying process at any time, confidentially, including guidance with regard to treatments and alternative therapies to improve comfort. Should the patient want to talk about hastened death or committing suicide, the doctor has a duty to discuss it to understand the motivations and reasoning behind the patient's thoughts.

11. A patient's psychosocial and spiritual needs should be spoken about with the doctor so that an optimal quality of life can be achieved, along with effective symptom control. These conversations should be initiated as early as possible and need to be revisited regularly to ensure a death with dignity and comfort.

12. Psychosocial and spiritual resources need to be made available to the patient and their families to assist them with processing anxiety, fear and grief.

13. Patients should be encouraged to appoint a surrogate decision-maker who can help with decisions not included in their advance directives, and to clarify their wishes in respect of medical interventions and palliative measures that could hasten death.

14. Before consent is given by the patient for end-of-life care, the doctor must make certain that the patient has been adequately treated for pain and other discomfort so that suffering does not interfere with decision-making.

15. Once the patient has died, the physician may do what is required to keep organs for transplantation viable, provided they act in line with the ethical guidelines established in the WMA Declaration of Sydney on the Determination of Death and the Recovery of Organs[58]. The transplantation must also be performed according to principles set out in the WMA statement on Organ and Tissue Donation[59, 60].

7.3.2. The EAPC approach to palliative sedation

As mentioned in the Declaration of Venice, deep sedation to unconsciousness can be achieved where symptoms are intractable[61]. The European Association of Palliative Care (EAPC) defines palliative sedation as 'the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers'[62]. Therefore, its purpose is to relieve distressing symptoms through continuous deep sedation, not to shorten or extinguish life.

The EAPC lists seven situations where sedation is indicated as a palliative intervention: (i) transient sedation for noxious procedures; (ii) sedation as part of burn care; (iii) sedation used for end-of-life weaning from ventilator support; (vi) sedation in the management of refractory symptoms at the end of life; (v) emergency sedation, such as for a catastrophic event, like bleeding; (vi) respite sedation; and (vii) sedation for psychological or existential suffering[62].

In 2003, the EAPC Task Force expressed the differences between palliative sedation and euthanasia based on intention, procedure, and outcome: palliative sedation is based on the intention to relieve intolerable suffering, the procedure is to use a sedative drug for symptom control, and the successful outcome is relief from distress. With E, the intention is to kill, the procedure is to administer a lethal drug, and the outcome is immediate death[63]. Thus, the administration and management of palliative sedation is carried out preferably by a medical specialist in palliative care, as part of a medical team[64]. The need for specialist medical care may prove to be a barrier to access for the terminal patient in certain areas of South Africa.

Comparatively, Switzerland reports that palliative sedation has been used in 17.5% of all those admitted for palliative care in the country. Switzerland has the highest use compared to other countries. Having said this, Swiss researchers Camartin, *et al*. state that they have witnessed an increase in use in neighbouring countries too, including the Netherlands. They attribute this to the public's growing awareness of palliative care, including palliative sedation treatment as an end-of-life choice. The fact that people in the process of dying receive more intensive treatment now is a further factor. Interestingly, within their country's four dominant cultures (German, French, Italian, Romansh), the French and German-speaking residents opt for PAS at a similar rate (1.2% and 1.6%), while the Italian community chooses only palliative sedation, not PAS[65].

The Swiss researchers note that in Switzerland's experience, palliative sedation is one of the most challenging areas of palliative care for the medical team, because it affects every facet of the person at a somatic, psychological, social, spiritual, and cultural level[66]. Accordingly, the authors recommend that they follow a good set of guidelines to facilitate decision-making, and thoroughly document and continuously evaluate the treatment plan[64]. This is expanded upon below.

The Swiss researchers recommend the EAPC's 2009 guidelines for palliative sedation[62] and apply Beauchamp and Childress's bioethical principles to illustrate that the guidelines are ethical. For example, patient autonomy is respected when the decision to begin palliative sedation is made in accordance with the patient's expressed wishes, alternatively, on the surrogate decision-maker's advice. The principle of non-malevolence is upheld because research has not shown that palliative sedation shortens life. The principle of beneficence is recognised by the emphasis on decreasing the most problematic symptoms. These symptoms are delirium in the terminal phase, which is avoided, respiratory distress, also reduced, and pain alleviated. The principle of justice is ultimately supported by ensuring that all patients who would benefit from palliative sedation are offered it, so it is not only available at specialised centres but eventually provided for people at home through an outpatient service[67].

The EAPC guidelines and Camartin, *et al*. stress the importance of methodical recording in the patient's record. Information that is advised to be included is an explanation of what the medical reasons are for recommending palliative sedation, adding what the decision-making process involved, the aims of sedation, the planned depth of sedation and its anticipated duration.

The practical aspects surrounding implementing palliative sedation comprise first discussing it as part of future planning with the patient. Then, when suffering becomes unbearable, it is administered after the patient indicates that wish or, alternatively, after a discussion with the surrogate caregiver, as well as the treatment team, rather than the doctor deciding alone. The writers emphasise that it should be conveyed to the next of kin that their role is not to decide whether to commence treatment, but rather to indicate what the patient would have wanted. They should be reassured that the responsibility for the decision is taken by the medical team and not by them.

The drug of choice around the world tends to be continuously administered midazolam, although there are others. Propofol may be added if the response is insufficient. Use of opioids

has been questioned because sedation is a secondary effect, not its primary purpose. However, the level of sedation chosen depends on the symptoms being treated. The duration of sedation also varies widely between patients and can be from a few minutes to several days[68]. Interestingly, the Swiss researchers mention that in contrast to the concern that life may be shortened by palliative sedation, occasionally, life appears to be prolonged through palliative sedation, thought to be because of a reduction in the patient's stress[69].

Palliative sedation is administered mainly for managing the somatic symptoms of delirium, breathlessness, and pain, often associated with the last phase of the dying process. These are also the symptoms people consider to be the most threatening, which causes them anxiety. In recent years Switzerland has recorded the use of palliative sedation for non-somatic complaints, too, such as fear, anxiety, and existential stress, which may explain the higher use of this treatment regimen. Generally, its administration for the handling of refractory symptoms has wider acceptance than for psycho-existential reasons[66].

Palliative sedation has been shown to be very safe if guidelines are followed, and even once it has commenced, treatment of symptoms should continue in order to avoid these becoming augmented. Regarding hydration and nutrition, Camartin, *et al*. are of the opinion that hydration and artificial therapy should be withdrawn because these are superfluous for palliative sedation. However, the reasoning would need to be clearly explained to the family. On the other hand, the EAPC has commented that individual patients, physicians and family members may wish to continue with hydration for humane reasons as a non-burdensome intervention that may even reduce suffering. The decision whether to withdraw hydration and nutrition is independent of the decision to commence palliative sedation and should be discussed separately[62].

The rights of unconscious patients and those who are unable to communicate are recognised by the WMA in their Declaration on patients' rights, which is also relevant to medical practitioners as part of a framework for end-of-life decision-making.

7.3.3. WMA Declaration on the Rights of the Patient

The WMA Declaration on the Rights of the Patient was released in 1981 in Lisbon, It draws attention to the patients' rights which the medical profession endorses and promotes[60]. It has since been amended and editorially revised, and in 2015, was reaffirmed. The pertinent sections for end-of-life situations are extracted below for the sake of completeness.

Primarily, principle four emphasises that a) informed consent must be sought from a legally entitled representative where the patient is either unable to express themselves or is unconscious; b) in the situation that a legally entitled representative is not available, and there is an urgent need for a medical intervention, the consent of the patient can be presumed, unless it is clearly beyond doubt, based on the patient's past firm expression or conviction that consent is refused for the intervention; c) physicians should always attempt to save the life of a patient who is unconscious because of a suicide attempt. (This obviously refers to non-physician assisted suicide).

Principle five focuses on the rights of a minor or legally incompetent patient a) to participate in all decision-making about them, to the fullest extent of their capacity, even if a legally entitled person is representing them. b) Where the legally incompetent person can make reasoned decisions, these decisions must be respected, including their right to withhold sharing information with their legally entitled representative. c) If either the legally entitled representative, or the person mandated by the patient to act, refuses treatment when the medical practitioner is of the opinion that treatment would be in the patient's best interests, the doctor must challenge this decision in the appropriate legal or other institution. In an emergency the doctor must act in the patient's best interests.

Principle six makes provision for diagnostic or treatment procedures to be carried out against the patient's will only in exceptional circumstances if the law specifically allows it and it conforms to medical ethics.

Under principle ten's right to dignity, comparable to South Africa's Constitutional human rights, a) when giving the patient medical care and in a teaching environment, the dignity and privacy of the patient must be respected always, along with their culture and values. b) The patient has a right to relief from suffering that corresponds with the current state of knowledge. c) Terminal patients are entitled to humane end-of-life care and should be given all obtainable assistance to make the dying process as dignified and comfortable as possible.

The final principle states that patients have a right to religious assistance, to receive help from a minister of their chosen religion or, alternatively, to refuse spiritual and moral comfort. This principle implies that spiritual assistance should be offered as part of holistic care and is an important facet of caring.

7.4. MEASURING THE QUALITY OF PALLIATIVE CARE

Following up on the 2014 Resolution for Palliative Care[26], the WHO dedicated its World Hospice and Palliative Care Day in 2021 to 'equity in access to palliative care'. It generated a set of actionable indicators that countries could use locally to assess the development of their palliative care. It replaced past reliance on the commonly used measurement of the consumption of opioid analgesics, which was only one indicator among other considerations that could have been taken into account. The new resource is for policymakers, palliative care programme managers and healthcare workers[70].

Along similar lines, research was undertaken by Finkelstein, *et al.* in 2021 to rank countries' quality of end-of-life care based on each country's expert information which was passed on to the researchers. The intention was to hold stakeholders in each country, including the public, accountable for improving palliative care performance going forward. A new model of 13 indicators was used which focussed on outcomes, not inputs, to measure the quality of care at the end-of-life. South Africa was positioned 73rd out of 81 countries in terms of the palliative care offered to people who are in the process of dying, (Grade F, the lowest of five levels). This indicates that South Africa has failed dismally thus far in making palliative care readily available to those in need of it[71]. Colombia, where euthanasia has been practiced since 2014, has a similarly unequal distribution of wealth to that of South Africa, as alluded to in Chapter 4, but has a comparatively higher rating of the quality of palliative care. In the same research paper, Colombia was positioned 42nd (Grade C)[71].

The WHO has stated that to achieve the best possible palliative care, countries need a supportive policy setting, communities that are empowered, access to essential appropriate medicines for palliative care, effective education and training systems for palliative care workers and professionals, palliative care research, and a focus on the quality of palliative care services[72]. These suggestions focus on improving the supply side of care.

Some literature highlights the view that, compared to those who did not receive care, palliative care consultation teams reduced patient stays in hospital, thereby also decreasing their medical costs[73].

With South Africa's excellent National Policy Framework and Strategy now available, it is a firm hope that palliative care can be markedly improved, and made fully accessible for

everyone, before any E/PAS legislation is enacted.

7.5. DOCTORS' ATTITUDES TO E/PAS V PALLIATIVE CARE

In October 2019, the WMA reiterated its perspective on euthanasia and physician assisted suicide at the 70th WMA General Assembly, held in Tbilisi, Georgia. It remains firmly opposed to E and PAS interventions, upholding the highest respect for human life[74]. South Africa is a member of the WMA[75].

The WMA's standpoint is significant in light of the many countries that have recently and rapidly changed their laws to embrace E/PAS legislation, such as the USA (10 states as of February 2023)[76], Australia (2019 – 2023)[77], New Zealand (2021)[78], Tasmania (2021)[79] and Spain (2021)[80], despite their medical associations being members[81].

The year before the WMA's announcement opposing E and PAS, Sulmasy, D. *et al.*[82] published a paper in 2018 pointing out that, although medical organisations had been asked to adopt a 'neutral' attitude instead of one 'opposed' to E/PAS legislation, it was neither appropriate nor ethically neutral to do so. Members' opinions were divided on the issue, regardless of whether E/PAS was made law. The authors regarded changing position as a fundamental mind shift away from a prohibition that was central to the meaning of medical professionalism. Furthermore, Sulmasy *et al.* argued that an official stand point taken by a medical organisation on a topic became a public statement to society about the practice of the profession. It therefore had social and political ramifications. They believed it to be even more significant with PAS because the burden of putting the process into effect fell upon medical practitioners. Neutrality, they said, gave the message that doctors were no longer opposed to the law because it was, in essence, morally acceptable. The authors contended that an aspect of a profession was that it defined its ethics independently of the government, economic pressures, and the fluctuations of popular opinion[83].

At the time of Sulmasy *et al.*'s article in 2018, the British Medical Association (BMA) was listed as opposed to PAS. However, their statement was made in 2012, six years before Sulmasy's piece was written[84]. In 2021, the BMAs stance changed when they released a new position statement following an Annual Representative Meeting on 14 September. Apparently 49% of the representatives (149) were in favour of changing the BMA's outlook on PAS to 'neutral', 48% voted against it (145), and eight abstained[85].

The attitude of the medical profession can adjust over time along with trends in society and the associated pressures of a change in law, but England does not yet have a statute in place permitting PAS. Their draft Assisted Dying Bill[86] has been in the pipeline for around 17 years now.

The Royal College of Psychiatrists considered the implications of the British draft Assisted Dying Bill, both on mental health care services and the role of psychiatrists in the United Kingdom (UK)[87]. They followed this with a publication in 2022 in which authors Bhui and Malhi presented another side to the debate: they sympathetically described the traumatic experience of a person diagnosed with a terminal illness having to wait for the inescapable endpoint of death. They explained that, besides bearing this knowledge, the patient suffered fear because of anxiety over the expectation of pain, discomfort and disability. Patients imagined, too, the potential loss of cognitive ability which could make it difficult to effectively convey their experience of distress. The authors added that, in practice, where there was no advance directive for the medical team, patients subjected to the withdrawal of life-saving interventions have fluctuations in their consciousness and experience periods of dehydration and starvation. Even when palliative care provides kind and caring support for the patient and their family, the doctors observe the strain it places on everyone who is involved. Within this context of appreciating an emotionally fraught dying phase, the authors accept that medical practitioners, society and legislators have an interest in introducing E/PAS law to avoid a harrowing terminal phase of life, when a means to offer a pain-free end, without protracted suffering, exists[87].

In contrast to the UK, the College of Psychiatrists of Ireland produced their position paper in 2021, firmly opposed to an assisted death law. They stated that allowing doctors to aid suicides was a 'fundamental and irreversible shift in medicine's philosophy and practice'[88]. While they acknowledged the psychological anguish experienced by people facing the end of their lives, their opinion was that an assisted death law ran against both the efforts of general society and psychiatrists, particularly, to prevent suicides. The Irish College affirmed that it supported the global palliative care experts who were of the view that E/PAS was unnecessary to achieve a dignified death, and that, in fact, the act of suicide reduced one's personal dignity. They voiced their concern that permitting the law would increase the number of suicides that would occur in terms of the Act because the criteria are invariably widened over time as a cultural shift is established. Specifically, they saw the law as creating a risk that many more people would die despite having treatable psychological distress or mental illness.

Regarding the USA, an American legal writer, Warwick[89], revealed in 2022 that the medical profession remained intensely divided about its support of PAS legislation. That was despite it being conservative law, only allowing self-administration of lethal drugs for terminally ill people with less than six months left to live. Apparently, American physicians were of the opinion that the existing legislative framework was failing to protect both the interests of the medical profession and those of the patients seeking MAiD, because there were no reliable monitoring mechanisms in place for either the process or the procedure.

Amongst American medical practitioners, proof of the truth that these issues are complex is that both opponents and proponents of E/PAS use central principles of the medical profession to plead their case: either to 'do no harm' or to 'respect autonomy and reduce suffering'. This is according to Moran, M., reporting in Psychiatric News and quoting from a 2018 report of the American Medical Association's Council on Ethical and Judicial Affairs (AMA CEJA). The CEJA's two main functions are to maintain its Code of Medical Ethics and to promote adherence to the Code's professional ethical standards[90]. Although the report was not accepted by the House of Delegates, it mirrored the opinion of its members in the following words: 'For some physicians, the sacredness of ministering to a terminally ill or dying patient and the duty not to abandon the patient preclude the possibility of supporting patients in hastening their death. For others, not to provide a prescription for lethal medication in response to a patient's sincere request violates that same commitment and duty'[91].

Moran observes that the topic of E/PAS is unique in the tension it generates surrounding fundamental questions of what it means to be a doctor. However, the common ground that is identified among the doctors is their acknowledgment of the need for much better access to palliative care and markedly improved communication between doctors and patients about end-of-life care[91].

According to a scoping review that looked at past research from Canada, the USA and certain European countries, as many as 74% to 88% of people who received hospice or palliative care were also shown to have chosen assisted death. There was no comment on the quality of the hospice or palliative care provided, though, nor on the reasons for them opting for assisted death[92]. Rotella, J., a chief medical officer of the American Academy of Hospice and Palliative Medicine (AAHPM), contradicted these statistics, saying that approximately half of dying patients never experienced hospice care, and then those that did only received it in the last weeks or days of life. He gave the reason for this as the reluctance of physicians, patients, and

their families to confront the topic of prognosis, so that the goals of medical management could be appropriately adjusted. Rotella advocated discussing what quality of life meant to patients in their terminal phase of life: people spoke of their loss of identity, loss of control, fear of their future, being a burden to others, and fear of refractory symptoms, both physical and non-physical. He saw the discussion as an opportunity to promote palliative care because, in his experience, for almost everyone, expert palliative care and hospice did improve the quality of their lives to a level that was acceptable to them[91].

The legalisation of assisted death has been met with a spectrum of reserve to outright rejection and hostility from physicians and palliative care associations[92]. Medical practitioners have written about their concerns that palliative care will be replaced with a preferred choice to die, causing greater neglect and under-funding of palliative care services[93]. However, there is acknowledgment and understanding of how the patient's suffering could lead to such a decision when palliative care is not readily available, or available but inadequate to alleviate relentless distress.

Even in the countries that have attempted to combine E/PAS with palliative care as just another end-of-life option, it has not been as smooth a transition as hoped. In 2015, the European Institute of Bioethics examined Belgium's 'integrated palliative care' model, which embraces both palliative care and euthanasia[94] (explained in Chapter 4). The report described two contrasting points of view that have arisen: one asserts that the introduction of E has honestly facilitated the development of continuous palliative care, while the other point of view is emphatic that making E into a 'routine' end-of-life option is dismantling and slowly distorting the concept of palliative care, which is supposed to concentrate on support up until a natural death occurs. The report observes that both Belgians in support of E and those opposed to E are unable to reach consensus on how to measure the impact of the model on medical practice, managing the sick and on the values of their society[95]. Two points worth noting on the Belgium report, however, are that, at the time it was written, the broad definition of 'integrated palliative care' had not been accepted beyond the Benelux countries; and the trend of attempting to blend both concepts in health care had sometimes caused confusion for people.

What is more, patients, caregivers, and institutions encountered new ethical issues such as how to maintain respect for a medical practitioner's right to conscientiously object to participating in E, whether different practices within the same institution were acceptable, and importantly, as the E law became more accepted and routine in society, whether the model did not ultimately

pressurise medical practitioners, their patients, and the public to choose an 'efficient end of life', a concern already canvassed in chapter 5. The Bioethics Report mentions that patients experienced moral distress from being made to feel, at the end of their lives, that they were a burden to their loved ones and to society[96].

The author, D'Yvoire, records that some doctors feel that they experience pressure from patients, families, and colleagues to perform E and they get the impression that they will be viewed badly if they do not cooperate. They perceive a danger in becoming labelled according to their end-of-life philosophy and describe their discomfort approaching external colleagues for help. Apparently, conscientious objection also has a negative impact on the nurses' experience of their own daily work[97].

A Belgian palliative care physician, Dr Catherine Dopchie, held the view that the culture of E was detrimental to the improvement of palliative care. She elaborated that by E being presented as a dignified and courageous solution, efforts to improve palliative care were undermined. As an example, she mentioned that Belgian funding had not been allocated for the spreading of palliative care skills[98]. The report recorded disquiet among some palliative care specialists because doctors were being convinced that the 'act of administering death' also had a place in the 'logic of palliative care'. They were being told this when they attended short courses offered in end-of-life skills at LEIF, (LewensEinde Informatie-Forum) and Forum EOL (End of Life), previously Right-to-die activism groups. Palliative physicians objected to euthanasia being presented in this way as complementary to palliative care and good medical practice[99].

If patients felt the need to embrace a more efficient end of life through using E/PAS even while palliative care was available to them, Davies, who was a proponent and activist of assisted death before he own death, saw the choice of people ending their lives prematurely to spare caregivers hardship and save money, as a gesture of great unselfishness. She argued that choosing E/PAS was an act of altruism that should not be denied a person[100].

On the other hand, when any seriously ill person who is reliant on others for care, and often not out of choice, could think death was a gesture of self-sacrifice, dying for the sake of others, as suggested by Davies, but also claimed to do it in the name of maintaining their own autonomy and dignity, it is arguably more of a reflection of a self-interested, non-caring society and government. The community has, in effect, failed to reinforce that person's sense of individual value and dignity which they lost the moment they needed help and became dependent on others

for assistance.

Logically, a normal response to illness and dependency could be depression which would be compounded if loneliness and a shortage of family support were also present. The Belfast palliative care physician, Doré, referred to in chapter 6, believed that society's role is to create an environment that replaces the family function through nursing homes, social care centres, community palliative care centres and hospices[101].

The most recent opinion on this topic was given in 2023 by Doré. In his article[102], Doré claimed that the Association of Palliative Medicine, the largest representative body of palliative care specialists in the UK and Ireland, was against any change to the law to incorporate assisted death. He made the point that overall, his palliative care colleagues, who had been involved with dying the most, and understood suffering well, all held a similar view and practised their belief in compassion every day. His opinion on the main reason for their united stand against assisted death was that, through palliative care, the doctors realised how vulnerable their patients became, physically, psychologically, spiritually and socially. He suggested that those patients who were approaching the end of their life were possibly the most vulnerable people of all groups, and therefore should be given the greatest protection of all.

In South Africa, during 2021 the South African Medical Association (SAMA) sent out a survey to its members to measure their views on E/PAS in order for SAMA to consider its own position[103]. The objectives of the survey were to assess the knowledge of medical practitioners on E/PAS; to determine their attitudes and perceptions regarding the practice; to establish how willing medical practitioners would be to perform E and PAS, and to assess the opinion of medical practitioners towards its legalisation. Results had not been published at the date of this thesis, but the HPCSA Palliative Care Guidelines (6.2.5 above) stated the position of South Africa's medical professional bodies at that time, which was that as crimes, a medical practitioner who engaged in E or PAS would be guilty of unlawful and unethical conduct.

Devettere reflected on society's request for E/PAS law in his book. He understood that people had the wish to remain independent in death[104]. However, he put forward that an aspiration for control over the end of life was not a reason for it to be given, and in fact was incompatible with the human condition: everyone becomes vulnerable and in need of others at some point in life. He further argued that the desire for control did not automatically morally justify a fundamental change in law, even though autonomy was an important principle to respect.

Devettere defended his point of view using the context of destroying life. When this was the purpose behind a proposal, he suggested that the reasons had to be convincing to uphold such an undertaking: hastened death was a grave and personal act that ought to be a last resort as a solution. He did not say that PAS could never be justified, only that the need for control was an insufficient justification. The decisive moral issue associated with extinguishing human life, according to the author, was whether the desire was reasonable, specifically whether it added to an overall common good for humanity, or at the least was the 'less worse' option[105].

The point Deveterre made was even more relevant when considering that E/PAS law exists to instruct someone else, a medical practitioner, to assist with the requestor's death, which affects the medical practitioner's life too. Ironically, the person's autonomy can only be exercised through dependence on another person to facilitate it, as pointed out in commentary in Chapter 4.

Devettere's concluding thoughts on the topic of E/PAS are worth pondering[105]. He reiterated that deliberately causing another person's death remained an extremely serious action. The first response should be to avoid it, which was consistent with our past human history. However, that was not said in support of an absolute moral prohibition. He acknowledged that there were complex circumstances around euthanasia and particular situations that could make the action of a premature death morally acceptable. Devettere added that an individual good was not invariably a social good. Certain behaviour may not be morally justified, because ethics incorporated both the individual and social consequences of one's conduct. The example given was that people killing each other had always been of great public concern, both legally and socially. Similarly, a medical practitioner killing a patient was not a private medical matter either but impacted on the integration of the wider community.

He highlighted the irony of the improvement of palliative care overseas being matched by the growing trend of permitting medical practitioners to kill their patients through E/PAS legislation. It was even suggested that this was a result of different views in modern ethics, where the principles of autonomy and beneficence, as well as respect for human rights to privacy and freedom of choice, were promoted. These were all concepts applied in support of the right to choose a scheduled death[106].

The final observation made by Devettere was that when applying an ethics of prudential reasoning focussing on living well, one would struggle to find reasons for E/PAS when

palliative care and pain management were effective in reducing suffering in the terminal phase of life. Then again, where it was found not to be effective enough, and the only choices left were between active killing or a harrowing natural death, both being the worst ends of life, prudence guided the doctor to choose the 'less bad' of the two: deep sedation, which, was morally less bad than killing[106].

7.6. PALLIATIVE CARE MODELS FOR MANAGING DEATH

As part of the ethico-legal framework for end-of-life discussions some favoured palliative care models for managing the terminal phase of life are introduced.

The question of what constitutes a good death is central to managing end of life care. Emanuel and Emanuel[107] use the Institute of Medicine's definition to sum it up as follows: '[A] decent or good death is one that is: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.'

In the late 1950s, when social reformer Dame Cicely Saunders introduced hospices, she was reacting to the impersonal and undignified deaths she observed in hospitals: medical personnel lacked skills in palliating their patient's symptoms and gave no thought to attending to the multiple facets of the individual's needs. They ignored care of the social, psychological, and spiritual wellbeing of their patients. Hospitals were criticised for using too much technology, ignoring the wishes of patients and their families, and having insufficient knowledge about patients and their right to autonomous decision-making. The patients felt de-humanised. While hospital settings were associated with 'bad' deaths, her hospices brought in the 'death with dignity' movement of the era[108].

A multitude of research sheds some light on the expectations of patients, families and medical practitioners regarding what they believe to be a 'good' death. American academics Meier, *et al*. have shown in reviewing past articles that some families of dying patients held different views to what the patients themselves perceived as a good death. Likewise, medical practitioners were less accurate in their assumptions about the patient's requirements. Meier, *et al*. postulated that such discrepancies suggested a great need for further discourse between stakeholders about death, so that patient experiences could be improved[108].

Some examples of differing opinions were that family members thought twice as frequently compared to patients (35%) that 'quality of life' as a component of a good death was important. The authors surmise that the explanation for this could be that 'quality' was defined differently between the two groups. Likewise, dignity was thought to be more important to patients than it turned out to be, and therefore rated more highly by family members (70%) than by the patients themselves (55%). Again, this may have been attributable to their different interpretations of dignity: many patients shared that they did not like being treated disrespectfully or without understanding (87%), and that feeling a burden to others deeply reduced their sense of self-worth (87%).

A significant insight was that two-thirds of patients (65%) communicated a wish to have spiritual or other religious practices satisfied as part of their experiencing a good death, whereas fewer family members (50%) realised that this was important. Patients highly valued having end-of-life options that allowed them to retain their autonomy and control[108]. Patients saw their end of life not just as a physical death but also as having psychosocial and spiritual elements to it. Their emotional well-being was a vital part of achieving a satisfactory death, which doctors, and family members affirmed. All three groups were aligned in their opinions that good relationships, freedom from pain, and religiosity/spirituality contributed to a successful death[108].

Medical teams were predictably consistent in their belief that appropriate pain management and the patient's overall comfort were requirements for a good experience of death. This is in keeping with the thinking behind hospice and palliative care. Health teams strove to reduce suffering by improving the quality of life for both their patients and their loved ones. The researchers reiterate that, based on their review of earlier works, more attention must clearly be given to catering for the patient and family's psychological, social and spiritual needs[109]. These are factors that hospice highlights in its end-of-life approach.

Hospice and palliative care teams have already come a long way in identifying the priorities of patients at a practical level. Unfortunately, as has been said before, there are not yet enough palliative teams and resources in South Africa from which everyone can benefit.

Meier *et al*. acknowledge that the USA and Europe are aware that more targeted research is necessary to establish how to measure psychological concerns at the end of life. They suggest that this should preferably be carried out by mental medical practitioners so that effective

screening methods and suitable interventions for dying patients can be developed. They make the valid point that studies into what constitutes a positive death experience should be guided by the dying patients themselves. These results could then improve medical management and help the family to adapt to the needs of the patient more effectively.

Emanuel and Emanuel add that if research could be done to identify and define characteristics of dying patients at high risk of suffering and not coping well, it would allow doctors and health care services to apply resources to those with the greatest need for targeted intervention[107]. In an age of awareness that resources are scarce and medical care costs are high, this would offer valuable information for South Africa. Other useful research would be to establish the predictors of care-giving needs, to assess which patients would have highly demanding care requirements and what the most effective interventions would be for them[107].

7.6.1. Biopsychosocial and clinical model of care

This model, which has much support from empirical research[108], is the traditional model of palliative care associated with a ‘good’ death'. It focusses on the physical, psychological, social, and spiritual domains, taking into account the patient’s and family’s preferences with the intention of improving the dying experience. There are other models besides the original biomedical model of care that exist, but the biopsychosocial one is the most well-recognised[110].

Research shows that, along with treating the patient’s physical symptoms, patients value their ‘functional status’, which entails remaining self-sufficient. This is an important factor for the doctor to manage because it correlates highly with the person’s ongoing independence and quality of life[108].

Steinhauser and Tulsky have written about the range of research surrounding a good death. They have attempted to explain what a good death entails. They describe three factors of significance to dying patients: preparation for death at the end of life, the nature of health care, and life completion. Each is covered briefly below.

Past studies have identified that having the opportunity to prepare for death is meaningful to dying patients. People want to know what to expect in order to put their personal affairs in order, as well as to arrange their finances and business responsibilities. They did not want to be a problem for their relatives and wished to prepare their families for what lay ahead, some even

arranging their own funerals. Families also needed to know what to expect and how to handle the person's death in situations where patients went home from hospital terminally ill. The medical practitioner had to assess how much knowledge the family had in order for them to cope with the dying patient at home, and establish what more they needed, educating them on what to do, including who to call in an emergency or for further advice. Lastly, some research highlighted the need for care provider preparation, where caregivers confronted fear of their own mortality and dealt with their own emotions associated with caring for someone who would die imminently[108].

The 'nature of health care', draws attention to the appropriateness of the level of medical interventions, the patient and family's communication with the health care team, knowing where and how to get answers to questions, and their overall relationship with health care providers to maintain the patient's sense of dignity through being heard and understood[108].

The last domain is of 'life completion', associated with a completed life. This includes the patient's review of their life, achieving closure, coming to peace with the way their life was lived, resolving conflicts, spending time with loved ones and friends, contributing to others, and saying goodbye. Completion may involve personal reflection and spiritual practice or be a communal experience. The patient's contribution to others, besides just being the recipient of care, is described by the writers as part of their need to feel whole as they reach the end of their life[108].

7.6.2. Life cycle medical model

The biomedical model represents the way medicine is commonly practised and is problem-based. It starts with an assessment, generates a problem list, and follows with treatment. From the start of symptoms, the clinical interviews and diagnostic tests chosen are governed and directed by the patient's problems. It is an effective method to focus attention and achieve efficiency and is therefore best suited for acute medicine. As the terminally ill patient's functionality declines and their physical symptoms worsen, the limitations of the biomedical model become clear[111]. Importantly, the model focuses on medical issues only and does not view the patient holistically. Its efficacy is reduced when the patient's problems are more than just their physical ailments and affect other dimensions of their life. The patient is then referred to others for palliative care.

Byock, a palliative care specialist, promotes a life-cycle model that accepts death as the natural end to life. Relying on other researchers' work, Byock adds to the biomedical model the opportunity for growth. The life-cycle model does not replace the biomedical problem-based structure, but rather complements it. It provides a framework in which terminal patients and their families are proactively helped to reach life completion and life closure. This it does through developmental tasks used to assist the patient to work through their issues, to resolve conflicts, exercise forgiveness and acceptance, and to grieve in a healthy manner[111, 108].

Steinhauser and Tulsky see the model's strength as offering the patient an opportunity to experience the growth still to occur at the end of life, which is possible on an emotional and spiritual level, rather than the patient having to accept only the physical decline predicted by the medical model[108].

7.6.3. Goal-based model

Instead of reinforcing the paradigm of a 'good death', Steinhauser and Tulsky support another model for helping patients and families to define and reach goals they set for themselves as illness progresses towards death. The following points describe the model: i) goals differ between patients within the medical context, depending on individual needs; ii), goals change over time as the disease progresses, necessitating ongoing communication and negotiation; iii) by employing goals formulated with the patient, patients become participants in their own treatment - they are regarded as best suited to give input, knowing their own life, strengths and weaknesses; iv) the method acknowledges that a future position in time still exists for the patient, and that contributions towards those goals are ongoing; v) for the medical practitioner, the model is action-based, always offering something new. As such, the model moves away from the perspective that there is nothing more to suggest, a criticism which the authors have of palliative care; vi) the medical practitioner is also reminded to reassure the patient that medical help will be at hand throughout their illness and treatment. Importantly, the medical practitioner is required to listen intently to the patient, to appreciate the patient's background and the setting in which they became ill. The quality of the patient's life is dependent on them receiving attention in a holistic manner[108].

A disadvantage of this method is that it hints at ongoing achievements and productivity, which, if imposed upon the patient, could be counterproductive. Steinhauser and Tulsky warn that the patient's awareness of 'being' in their illness should not be substituted for an awareness of

'doing'.

A few other interesting examples of factors which researchers found improved end-of-life quality are mentioned below.

Culture was highlighted as significant because patients wanted their medical practitioners to be aware of their cultural differences. This was especially so regarding their spiritual beliefs and the influence those had on their end-of-life decision-making. Having knowledge of cultural beliefs is relevant for the medical management of all patients[108]. In South Africa that is particularly important given that traditions strongly influence family behaviour.

For patients, timeframes are important. The period immediately post-diagnosis of a terminal illness, when the patient is hoping for a positive experience, such as 'living with cancer', is differentiated from the period that follows, in which the patient seeks a good experience of dying, leading finally to a comfortable and peaceful death. Thus, the physician should be aware of how to engage with the patient and family in each phase. They should seek the patient's preferences just after the terminal diagnosis is given. That would be the time that choices of alternative treatments are discussed, the combination of palliative and curative interventions introduced, and patients receive assistance to remain a part of their work and social environments. Through the progression of the disease, preparation for the end of life begins by reducing curative treatment and introducing palliative comfort care, planning for hospice support, and drawing attention to finding closure with unresolved concerns in life. Once death is imminent, the physician adjusts the patient's preparation to focus on working more intensively with the family to address everyone's expectations about the patient's care, deciding on where terminal care would be given, and offering education about the last stages of life and death[108].

The location of death affects the patient, the family and the palliative care team, so it is a central question to be considered. According to Steinhauser and Tulsky, studies show that patients prefer 'support services' rather than traditional hospice care. People appreciate having practical assistance at home, meal delivery, transportation, family care, peer support, case management and emergency contacts. Regarding the long-term care setting, more recent research has uncovered that factors such as adequate staffing, the ability of staff to remain 'present' for the residents, the size of the facility and its environment all have an influence on the quality of their end-of-life experience. Studies also emphasise the significance of family-like bonds being

formed between staff, residents and their families, as well as improved communication[108].

In conclusion, the death models related to care acknowledge the vital need for attention to emotional, psychological and spiritual well-being. It is accepted that patients have their own social and personal contexts in which they experience the dying process. Every facet needs to be attended to by the medical team for the patient to feel complete. Consideration of the person's spiritual side is said to be central to their quality of end-of-life experience and offers an opportunity for their personal growth. The writers suggest that this realm may be broached through traditional religion, through nature, or as an encompassing sense of meaning and purpose in life. According to some studies, this need strengthens in significance the nearer the person is to death[108].

7.7. CONCLUSION

In this chapter I presented an overview of palliative care in South Africa with some references to the international entities and instruments that have influenced global standards of palliative care. I also shared three palliative care models that focus on improving the quality of the end of life to the point of ultimate death. Evidently, the availability of palliative care offered in the South African public sector is minimal presently, and the private sector NGOs are over-burdened, so access remains a challenge. However, there is an ongoing hope that the National Policy Framework and Strategy on Palliative Care[112] will be implemented successfully to make a substantial difference to the delivery of palliative care service in the future. The significance of this information is that if E/PAS were legalised in South Africa, doctors would not be able to offer anything better as an alternative to people who, because they were struggling to cope socially, asked for assisted death as an escape from their suffering.

The attitude of the medical profession towards E/PAS was mentioned again in chapter 6 in the context of the influence the law has on palliative care and the profession: the concern is that, without accessible or good palliative care, E/PAS would become an entrenched end-of life solution. South Africa would be vulnerable to such a paradigm shift, should similar legislation be promulgated. Even where palliative care is of a high standard, palliative care specialists have been shown to be concerned that the option of E/PAS undermines the function and value of palliative care. The general lack of support for E law by medical professional bodies is clearly illustrated.

Next, a summary of each of the chapters of this thesis is presented, drawing together points that formulate a framework for doctors in South Africa when discussing end-of-life decisions. A discussion on the proposed framework ensues, and a conclusion follows. Limitations of this research and areas for future research are included.

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CHAPTER 8: DISCUSSION AND CONCLUSION

8.1. INTRODUCTION

Chapter 7 examined the status of palliative care in South Africa and compared it to the standard of end-of-life medical management offered in selected other countries, particularly those where E/PAS legislation has been introduced. The combination of palliative care and assisted death was shown to cause tension within the medical fraternity. This was of particular concern to palliative care physicians who felt that the provision in the health care system of an additional option for hastened death threatened and undermined good palliative care.

I briefly considered what factors patients perceived to be important for them to experience a good natural death and gave examples of palliative care models for dying patients. I concluded Chapter 7 by expressing the hope that the whole South African population would receive greater access to palliative care as a result of the National Policy Framework and Strategy on Palliative Care. Were that to be achieved, assisted death legislation would not be perceived as a mechanism to facilitate E or PAS as the only legitimate option in South Africa to alleviate deep suffering at the end of life.

In Chapter 8, I summarise the main points extracted from the body of work. Drawing on ethical and legal principles, I analyse the implications of E and PAS for end-of-life care and advance a framework towards an ethico-legal environment to assist doctors with end-of-life decision-making in South Africa.

8.2. SUMMARY OF THE MAIN POINTS EXTRACTED FROM THE CHAPTERS

Euthanasia in South Africa - hastening death – contradicts South Africa's deep-rooted communitarian history[1]. However, South Africa, too, must confront requests for assisted death through litigation by people who fear intractable suffering from terminal illness.

In countries where euthanasia has been legalised, the concept has been 'medicalised' because medical practitioners are asked to facilitate it.

The central value of this research is to offer an ethico-legal framework for South Africa to assist doctors in reaching decisions when dealing with patients who express intractable suffering and

a wish to have their death hastened.

In Chapter 1, I described the South African environment in terms of its medical and legal challenges in managing end-of-life care and gave a brief explanation of the introduction of euthanasia and physician-assisted suicide as an end-of-life option overseas. I laid out the process I would follow to analyse the ethico-legal environment of South Africa when dealing with end-of-life decision-making, with a view to offering a suitable ethico-legal framework for medical practitioners to apply to end-of-life decisions. I focused specifically on adults with full legal capacity to seek end-of-life options.

I mentioned that the founder of Hospice, Dame Cicely Saunders' views on what it meant to 'die well' underpinned the moral tradition of hospice. Dr Ira Byock, a palliative care physician, added that care of the dying included palliative care, symptom control, pain management and preserving 'human potential at life's end'. This approach was promoted as providing an alternative to physician-assisted suicide and euthanasia[2].

In 1983 the World Medical Association (WMA) released the Declaration of Venice on Terminal Illness, which considered it unethical for doctors to intentionally cause death. The WMA was concerned that vulnerable people would be placed at risk of abuse and that E and PAS would become an ethically acceptable precedent. Nonetheless, internationally, legalisation of E and PAS was gaining momentum. Although countries differed slightly in terms of the permissiveness of their laws, E and PAS was legalised or tolerated in several countries.

It was proposed in South Africa that legislation addressing end-of-life decision-making would assist the medical profession and society by facilitating E/PAS and eliminating legal uncertainty. One of the objections to legalising assisted death, however, was that government would then neglect to sustain and improve palliative care.

In 1997 the South African Law Reform Commission (SALRC) produced a Discussion Paper for public comment on *Euthanasia and the Artificial Preservation of Life*[3]. A draft bill was published as a result of this work, namely the End-of-Life Decisions Act of 1998. No progress has been made to date to enact the legislation.

I observed that, in 2005, the National Health Act 61 of 2003 clarified the right to refuse medical treatment, but that the right to refuse had not yet translated into the right to be assisted to die.

Allowing death by withdrawal or withholding of treatment, on the other hand, was relatively uncontroversial because case law had removed uncertainty. Wrongfulness was determined in the legal case of *Clarke v Hurst* to be based on the *boni mores* (good morals) of society, which the legal convictions of the community supported. Legal clarity eased moral discomfort. The judgment elucidated that intentionally causing death was not always considered wrong according to society's moral and legal convictions.

The Stransham-Ford case in 2015[4] - an urgent application to court to allow assisted suicide - brought no innovative law. A new action with different litigants was pending before the High Court at the date of this thesis.

With regard to considering ethical theories and bioethical principles surrounding E/PAS, the philosopher, McLean, wrote that there was no morally neutral attitude to life and death. The presumption was that life was good and that the physician's duty of care was to sustain life in accordance with Beauchamp and Childress's four biomedical moral principles: beneficence, non-maleficence, autonomy and justice. There was no moral duty to maintain life, however, where preserving life amounted to a greater harm, or suffering disproportionate to the good. The consequentialist moral argument supported the view that a person should be assisted to die where they had made that request to end their suffering. Indeed, the compassion of a virtuous doctor was also used by some as a persuasive argument in favour of E and PAS. The weakness of these arguments was that they did not answer the question of what action the doctor ought to take in such circumstances. This thesis supports Devettere's encouragement of exercising the virtue of prudence and applying prudential thinking to ethical problem-solving in healthcare on a case-by-case basis.

The South African Constitution[5], National Health Act[6] and HPCSA[7] endorsed the deontological philosophy that peoples' autonomy was of importance. However, I pointed out that the doctor, too, has autonomy and inherent dignity. If obliged to perform E/PAS against their will, they would themselves be used as a means to an end. Whether a doctor caused harm by refusing to perform E/PAS, however, was less obvious.

African philosophy promoted communitarianism and '*ubuntu*'. According to Dhai, the tenet of *Ubuntu* could be the basis for universally applicable bioethics in time to come[8].

In Chapter 2, I delivered an overview of the well-known moral philosophies that doctors could

apply when faced with end-of-life decision-making. Each ethical theory and bioethical principle had strengths and weaknesses, depending on how they were used. Reality was far more complex and theories too general to simply employ one theory for every ethical dilemma. The solution to problem-solving was found in a blend of several ethical approaches. Some examples were provided in Chapter 2.

To sharpen the ethical model and bring it closer to practical application, the method of prudential thinking was put forward. Approaches to ethical problem-solving were canvassed as tools towards the medical practitioner's framework for end-of-life decision-making.

I explained that several methods of inquiry were available for examining what it meant to live a moral life; but for an examination of medical ethics, it was appropriate to use a normative ethics approach. The better-known moral philosophies and bioethical principles that influenced the South African legal framework were presented in chronological order as they developed.

The case of *Clarke v Hurst* revealed the foundation of Natural Law in the South African legal system[9]. It was also recognised that universal human rights were required for people to lead a minimally good life.

I referred to the three main concepts of Aristotle's virtue ethics, which were summed up by Devettere as happiness, moral virtue, and prudence[10]. Because prudential reasoning was adjusted to situations and contexts[11], it was presented as a tool that doctors could use with end-of-life decision-making. I mentioned that virtue ethics, when applied to the doctor-patient relationship, highlighted that virtues displayed by doctors towards patients, such as integrity, honesty and compassion, resulted in a connection between doctor and patient which generated trust. Consequently, I suggested that, were a law to exist that permitted euthanasia as an end-of-life choice, consultation with a doctor within this relationship could be used to influence a patient in ways that would not have arisen if the law were not in place. I pointed out that various writers have warned that a sympathetic and passionate commitment to others can mislead, resulting in bias, irrationality and flawed judgment[12].

Instead of offering E/PAS, Devettere contended that, morally, terminal sedation may be the lesser of two evils to compassionately relieve suffering. He claimed that was better than encouraging private killings[13].

I discussed other philosophers' views such as Hume, who saw a strong connection between morality and human sociability because of the individual's ability to participate in others' beliefs, feelings and emotions[14.] Koenane[1] proposed that Utilitarianism would support E as a moral intervention. In his view, it would bring happiness to the greatest number of people who had no hope of recovery from terminal illness, intolerable pain and suffering. However, the amount of pleasure generated by the death compared with the unhappiness caused by the process, meant that E may not necessarily result in the greater happiness, taken as a whole.

I suggested that preference utilitarianism could be helpful as an ethical tool to assist doctors when weighing up end-of-life decisions with patients. Another theory I investigated was deontology, where deontologists concentrated on what the correct action was over the amount of good that could ensue. Kant, who was influenced by Hume, rejected out of hand the killing of innocent people, including committing suicide. He argued that human beings, as rational agents, had inherent dignity and intrinsic value[15]. This philosophy supported my argument that forcing Medical practitioners to perform E/PAS against their will would cause them harm, be disrespectful and would treat them simply as a means to an end.

Regarding bioethical principles, I introduced Beauchamp and Childress who distilled the popular model of four biomedical moral principles for ethical decision-making amongst medical practitioners[16] into autonomy, beneficence, nonmaleficence and justice. Principlism offered a fresh alternative to virtue ethics, utilitarianism, and deontology.

In respect of autonomy, I acknowledged that South African medical law promoted self-determination through the National Health Act's provision for informed consent, the right to refuse medical treatment, and the patient's right, regardless of their legal capacity, to participate in every decision related to their medical care[17]. In respect of non-maleficence, the Doctrine of Double Effect permitted the administration of higher dosages of medication to alleviate terminal discomfort, despite the fact that this could hasten death. In support of this proposition, I referred to the American authors, Quill *et al*, who stated that a medical practitioner's care of the dying patient was appropriately guided by the patient's level of suffering, their informed consent and the lack of any less harmful alternatives to the treatment. That approach was in line with traditional medicine and the expectations of society[18].

I viewed the issue then to be whether a valid request could be recognised in similar circumstances to a valid refusal. Death was perceived by the patient to be a benefit rather than

a setback, not a harm or a wrong. In contrast, the outcome of a doctor not assisting the patient could have been perceived as prolonging pain, discomfort, despair and indignity, which would have been a harm[19].

It was recognised that one could argue that there was no difference in principle between terminal sedation and E, except in the time it took for life to end. The end-of-life decisions made by the medical practitioner of withdrawing or withholding treatment, and terminal sedation, often in conjunction with the patient's family, amounted in both cases to an intentional and active process of achieving death[20].

Concerning beneficence, I accepted that ethical physicians would not cause harm to life unless they reached the conclusion from moral deliberation that there were substantial overriding reasons to do so. On the subject of justice, I listed several principles of justice based on different fundamental moral theories, including utilitarianism and communitarianism, John Rawls' egalitarian theory which embraced 'fair equality of opportunity'[21], and distributive justice. I concluded that if E and PAS became available as options in South Africa in end-of-life decision-making, the concern would be that the decision to accept E and PAS may be a quick and painless exit in place of offering improved palliative care interventions. Were end-of-life options not available to rural communities because of a lack of resources, the principle of justice would not be upheld. I also drew attention to the fact that Principlism was applied in the latest Health Professions Council of South Africa (HPCSA) Guidelines for Palliative Care[22] and the World Medical Association Medical Ethics Manual[23].

The last moral theory I examined was African philosophy, which promoted communitarianism and *ubuntu*[24] - an acknowledgment of one's interrelatedness with others[25]. This theory was in contrast to modern western thought which focused on autonomy (Kantianism)[26.] I also referred to the ethic of *Ubuntu* being applied in a number of Constitutional Court judgments, including *S v Makwanyane*[27], discussed further in Chapter 3. Accordingly, *Ubuntu* would be relevant when the judiciary and government deliberated on assisted death and the medical practitioner's support of patients in end-of -life decisions, in time to come.

Towards developing an ethical decision-making framework, I included a presentation of some models for solving ethical dilemmas, such as: prudential decision making, incorporating a 'rational choice' model and 'naturalistic decision-making'[28]; the WMA Medical Ethics Manual, which promoted compassion, competence, and autonomy within a combination of ethical

theories; and the HPCSA General Ethical Guidelines for the Health Professions, adapted from the WMA Medical Ethics Manual. It introduced prudential thinking by ensuring input from experienced colleagues and a measure of personal intuition, with cross-checks to confirm cautious application.

I concluded the chapter with the view that the philosophy of a society translated into society's public morality. I commented that in the future, the moral convictions of South African society would influence new legislation and, importantly, the ethico-legal environment in which medical doctors must function when helping patients to make the best end-of-life decisions.

In Chapter 3, I analysed the chronological progression of the South African law surrounding euthanasia and assisted suicide. I considered how ethical theories influenced legal reasoning to justify decisions that underpinned the South African courts' attitude towards hastened death. Legal cases were divided into a pre-constitutional period and a post-constitutional era to present day. The exercise established that South African courts have always applied virtue ethics in implementing the virtues of compassion and clemency when judging cases of 'mercy killing' and assisted suicide. Post-Constitution, South Africa was seen to be in an era of humanism, promoting individual human rights and humanity, modified to embrace the culture of respect for community through *Ubuntu.* That reinforced the idea that autonomy could be limited if a decision in favour of an individual would adversely affect the wider community. Therefore, E/PAS with its potential to adversely affect the wider community, as seen in Chapters 4, 5 and 7, was argued to be anathema to South African cultural values in terms of *ubuntu.*

In Chapter 4, as a comparison to the South African legal environment, I considered E/PAS legislation in foreign jurisdictions, and looked at how it has been integrated into different societies and their health systems. The philosophical themes were identified to try to understand what social reasons motivated people to choose a hastened death. This was in order to predict more accurately how South African courts and society might respond to similar E/PAS legislation in the future. Generally, the emphasis on autonomy and privacy were found to be paramount in the E countries. The right to equality successfully broadened the base of E/PAS law in most of these regions. It was established that some fundamental differences existed between South Africa and the foreign jurisdictions which embraced E/PAS. Besides the variation in moral philosophies, the stability and wealth of the E countries was a notable difference, compared to the multi-cultural and resource-poor environment of South Africa. Greater equality existed in general within E/PAS countries, supported by access to established

universal health systems, whereas South Africa was shown to be one of the most unequal societies in the world presently, with a fledgling universal health care system.

The palliative care offered as an alternative to E/PAS in countries where E/PAS was legalised, also came across in Chapter 4 as more accessible than the palliative care available in South Africa. Furthermore, South Africa does not yet have in place comparable social support to make E/PAS a suitable option for end-of-life medical care. With the inequality that dominated South Africa socially and economically, there was a danger that E/PAS as an end-of-life option could be exploited detrimentally, possibly at the expense of broader social access to universal health, and improved palliative care canvassed in Chapter 7.

Following on from the various foreign models investigated in Chapter 4, in Chapter 5 I dissected the South African draft End-of-Life Decisions Act (SA Bill) proposed for discussion in parliament in 1998. Using foreign E/PAS legislation as a guide, I constructed and motivated a revised version of the SA Bill as a legal framework for E/PAS in South Africa. The reworked and updated version of the SA Bill was offered as a template in the event that E/PAS legislation was considered further by the South African legislature. This end-of-life statute was proposed as the legal tool within the ethico-legal framework in which doctors could assist patients to reach appropriate end-of-life care decisions.

An alternative assisted death model was offered in Chapter 6. I proposed a PAS model more suited to South African conditions, which complemented the legal framework set out in the revised SA Bill presented in Chapter 5. It was premised on the stark reality of corruption, urban decay and disorder which confronted South African society at the time of this thesis, and the political leaders, and judicial officers who would decide on individual distressing cases who sought assisted death.

I contemplated the position in which doctors would find themselves as part of a strained public health sector if PAS law was enacted in South Africa. Specifically, I delved into the ethical and social concerns doctors would experience conducting E/PAS, and the impact that E/PAS law would have on the role of doctors in health services, as well as on their personal values. I concluded that, regardless of whether or not assisted death became a reality, it was evident that a statute providing legal guidance for end-of-life choices ought at the very least to reassure doctors and patients that end-of-life decisions were not only sound ethically, but also legally defensible.

With regard to introducing E/PAS legislation, I reached the firm decision that South Africa would not benefit from PAS at this stage. I suggested that such legislation may well cause harm to the country's social and moral fabric should people lacking the social determinants of health see it as the only escape from hardship and unbearable suffering. Also, the financial outlay to create an assisted death infrastructure could be better spent on improving palliative care and the national health infrastructure.

Bearing in mind the societal pressure for assisted death legislation witnessed overseas, in Chapter 7 I looked at the state of palliative care and good death models as preferred end-of-life care models for patients in South Africa. However, the South African palliative and end-of-life care options were found wanting, and in great need of focussed development and upgrading.

The opinions of foreign medical bodies and palliative care practitioners were shown to reflect their growing concern over the legalisation of E/PAS generally, and its impact on palliative care. Overall, the sentiment of the medical sector lacked support for assisted death and revealed an apprehension about the consequences of its introduction into society. I justified my settled view that, at present in South Africa, communities around the country would continue to bear the brunt of a lack of basic resources for effective and timely palliative care. It remained to be seen whether government-led decisions to improve conditions would ever reach fruition.

I emphasised that the National Health Department needed to urgently address wider access to good quality palliative care going forward, before E/PAS legislation was introduced. If it did not, the gap in services could have a devastating impact on everyone, but especially upon the poor, were E/PAS law ever to be introduced. On the other hand, I highlighted that without E/PAS legislation in place, depriving people of the opportunity to receive end-of-life palliative care was simply cruel and inhumane.

The ethico-legal framework offered drew its strength from the assumption that a high standard of palliative care would be available to all who needed it in the near future.

8.3. RECOMMENDATIONS

8.3.1 Creating an ethico-legal medical environment

What follows is a distillation from prior chapters of the South African ethico-legal factors that would create an environment within which the end-of-life decision-making models presented

in Chapters 5 to 7 establish a framework.

The external ethical setting in which medical practitioners find themselves in South Africa is a universal human rights-based consciousness: respect for self-determination, dignity, privacy, and equality are valued and legally reinforced through statutes such as the National Health Act, and case law.

The traditional communitarian culture of humanity and *Ubuntu* still resonate in the minds of the community, even if not always visible within society. These philosophies give insight into the expectations of patients and their families. Based on the description of patients' needs for a good quality death set out in chapter 7, a team of health professionals that caters to different aspects of the person's well-being should be provided.

Patients have an ethical right to adequate pain control and a legitimate anticipation that they will receive it, as stated in the WMA Declaration of Venice, referenced in Chapter 7. For palliative care to be effective, pain management, particularly, needs to be available and accessible. However, a biomedical model of palliative care that only focussed on physical symptoms would be insufficient to care for patients holistically at the end of life, as described in Chapter 7.

In Chapter 5, I mentioned that doctors felt ill-equipped to have difficult end-of-life conversations with people and did not feel comfortable managing the grief and bereavement of the extended family. To resolve this, Chapter 7 described end-of-life models that supported education of the palliative care health teams, with specialised training for the medical practitioner as leader. These would also be important for the creation of a conducive ethico-legal environment. Counselling during the end-of-life discussions should include culturally appropriate spiritual guidance, encouraging patients to make peace with family members if there had been conflict, and future care-planning. Advice on preparing advance directives, appointing a surrogate decision-maker, and possibly suggesting that their testament is up to date, which is often overlooked, would be valuable guidance. Talking about what the patient can expect and their preferences regarding care during their last days of life, including palliative sedation, if necessary, are relevant decisions that affect the medical team directly.

Compassion, benevolence, empathy, and kindness are all virtues associated with committed medical practitioners, even when time constraints and staff shortages caused them to be

compromised and exhausted by work. To ease the general burden on the health infrastructure, dedicated home-based palliative care teams would improve access to health care, free up hospital beds, and, at the same time, cater to the wish of patients who were still progressing towards the terminal phase of life, to remain functional and self-supporting for as long as possible.

The legal infrastructure supports the ethical environment by giving ethical rules the weight of law through legislation, making them enforceable if the health service falls short, and creating support and certainty through structure. Without law in place, physicians are hesitant to carry out certain palliative care practices, for instance continuous adequate pain management, for fear that they could be accused of some transgression, such as hastening death. Physicians who feel apprehension about causing death run the risk of under-treating patients who would then certainly prefer to die early than suffer through a prolonged death process. Therefore, an updated legal statute that incorporates end-of-life management would help to ensure that patients received suitable medication. It would also support medical practitioners in their endeavours to supply enough medication for those in need. Consequently, an End of Life Decisions Act that was suggested in Chapter 5, but without E/PAS legislation mixed into it, would go a long way to giving doctors peace of mind and make a big difference in facilitating an environment in which the ethical and legal tools could be used for end-of-life decision-making. As discussed in Chapter 3, legislation that specifically addressed the doctrine of double effect, withholding and withdrawing treatment such as ventilator support, nutrition and hydration, surrogate decision-making for incompetent patients and the recognition of advance directives, would be particularly helpful.

Palliative sedation, described in Chapter 7, is one of the most challenging areas of end-of-life decision-making. It affects all aspects of the person's being. It would probably fall under the provisions that deal with the doctrine of double effect, which would allay any professional discomfort about its administration. In addition, if the medical team were to be confronted with an unsolvable ethical conflict with the patient's family, knowledge of their legal recourse would also be built into the End-of-Life Decisions Act. These grey legal areas of end-of-life medical management are presently dependent on policies, guidelines, and limited case law, which provide inadequate reassurances for the profession.

The last contributor extracted from this thesis towards generating an ethical setting influencing end-of-life decision-making, is the principle of justice, as expressed in chapter 2. The WMA's

four attitudes to justice are listed here once more, bearing in mind that whichever attitude is chosen to apply to the context depends on the doctor's personal morality and the socio-political environment of the country in which they practise: i) a libertarian approach, which promotes resources being distributed in line with market principles; ii) a utilitarian approach, where resources are to be distributed to achieve the greatest benefit for all; iii) an egalitarian approach, when resources are distributed only according to need; and iv) a restorative approach, which requires resources to be distributed such that the historically disadvantaged are favoured. A few approaches are commonly identified as being present simultaneously, and would affect what resources would be available to individual patients.

8.3.2 The Ethico-Legal Framework

The ethico-legal framework consists of palliative care models to support the dying process, a range of ethical tools that can be applied to solve ethical dilemmas, and legal tools that can support end-of-life decision-making.

8.3.2.1 Palliative care models for managing death

A summary of the models is presented here as a guide towards frameworks of care. The details were provided in Chapter 7.

8.3.2.1.1. Biopsychosocial and clinical model of care

The original biomedical model of care, which focuses on problem-solving after a diagnosis, followed by treatment of the medical condition, is expanded to incorporate support of the psychological, social and spiritual domains as well. Attention is given to preparation of the patient and family for death, the nature of health care provided, and life completion. Important factors specific to the individual patient must be borne in mind such as being culturally aware, and sensitive and knowledgeable about cultural differences and traditions related to death. All of these interventions aim to improve the patient's quality of end-of-life in a holistic manner.

Table 6 lays out the relevant steps to apply the biopsychosocial and clinical model of care.

Table 6: Biopsychosocial and clinical model of care

1) Apply the biomedical model of care to manage the physical symptoms.
2) Support the psychological, social, and spiritual domains through a multi-disciplinary team.
   - Psychological and social domain: maintain functionality and independence of the patient within their own location for as long as possible.
   - Spiritual domain: encourage personal reflection, spiritual rituals, or practices. This is central to the quality of end-of-life experience, and becomes more pronounced the closer to death, and could be an opportunity for personal growth.
3) Bear in mind the appropriate timeframes to adjust treatment and therapy interventions in line with disease progression.
4) Check the nature of health care the person wants to receive, or not receive any longer. Provide good communication between patient, family, and doctor's palliative care team.
5) Give attention to preparation of the patient and family for death.
6) Help facilitate the patient's process of life completion.

8.3.2.1.2. Goal-based model of care

The medical practitioner helps the patient and their family to define and reach goals they set for themselves as the illness progresses towards death.

Table 7 indicates the points to bear in mind using the goal-based model of care.

Table 7: Goal-based model of care

1) Assist the patient and family to define their goals as participants in the treatment.
2) Re-assess the goals over time with continuous communication and negotiation as the disease progresses and circumstances change.
3) Encourage ongoing contributions towards the goals, being sensitive to the patient's feelings of any pressure or distress.
4) Reassure the patient that medical help is readily available.
5) Listen intensively to understand the patient's context and ongoing needs.

8.3.2.2. Ethical tools

When confronted with an ethical dilemma, the proposed starting point is for the medical practitioner to apply prudential reasoning, looking at the reality of the problem from the different perspectives of each person involved in the situation. The framework in which to resolve ethical dilemmas was laid out in Chapter 7 in both the international WMA Ethics Manual and the national HPCSA ethical guidelines. They blend the ethical theories and bioethical principles of Chapter 2 in such a way that, depending on the problem, the relevant theories and principles are automatically identified and associated with the situation in one's mind.

Table 8 illustrates an approach to an ethical dilemma.

Table 8: Use of ethical tools to solve an ethical dilemma

1)	Utilise prudential thinking to assess the particular circumstances by gaining insight into the specific problems at hand. To do this, the perspective of each person involved is considered and a first rapid assessment is made. Often the solution is recognised almost immediately and intuitively, but it needs to be tested against other physicians' experience of similar problems, ethical guidelines, and legal boundaries.
2)	Choose the person or group of people who would be of greatest assistance to help solve the particular problem through their expertise and advice; in discussion weigh-up the few fitting alternative solutions to achieve the intended goal.
3)	Apply either the international WMA Ethics Manual guidelines or the national HPCSA ethical guidelines of problem-solving depending on preference and personal skill in problem-solving. The guidelines are very similar to each other because the HPCSA model is based on the WMA model. The HPCSA model is well-suited to inexperienced professionals because it takes the practitioner through a rigorous step-by-step assessment of the situation. (A combination of both is summarised in Table 8)
4)	Ensure that spiritual and emotional support for the patient is built into the solution.
5)	Implement the solution.
6)	Re-assess the decision as time passes to ensure it continues to be the best fit for the problem.
7)	Counsel and include all the person's loved ones who are involved with the patient's wellbeing.
8)	Bereavement counselling and support of the family after death should be facilitated.

The details of the ethical tools are explained in chapter 2.

8.3.2.2.1. General Ethical Guidelines for problem-solving (HPCSA and WMA)

Table 9 also offers a summary of the steps that can be taken to resolve ethical problems.

Table 9: General Ethical Guidelines for problem-solving (HPCSA and WMA)

1)	Establish whether the problem is an ethical dilemma and formulate the problem.
2)	Gather information: clinical, personal, social data. Consult authoritative sources and colleagues, considering how others have dealt with similar situations.
3)	List options: examine alternative solutions.
4)	Make a moral assessment: weigh up the ethical content of each option by asking:
	a. What are the likely consequences of each option?
	b. What are the most important values, duties and rights? Which weighs the heaviest?
	c. What are the weaknesses of the Medical practitioner's personal view concerning the correct option?
	d. How would the Medical practitioner personally want to be treated under similar circumstances?
	e. How does the Medical practitioner think that the patient would want to be treated in a particular circumstance?
5)	Discuss the proposed solution with those whom it will affect.
6)	Act on the decision with sensitivity to those affected by it.
7)	Evaluate the decision and be prepared to change the approach in future.

8.3.2.2.2. Other ethical tools

At a national level, the HPCSA palliative care guidelines, Booklet 18, as well as the guidelines for withholding and withdrawing treatment, Booklet 7, referred to in chapter 6, are readily available to offer further guidance to physicians.

To check what the international standards of medical care are, the following international instruments mentioned in Chapter 7 are available for medical practitioners: the WMA Declaration of Venice on End of Life Medical Care, the Resolution on Access to Adequate Pain Treatment, the EAPC approach to palliative sedation, the WMA Declaration of Sydney on the

Determination of Death and the Recovery of Organs, the WMA Statement on Organ and Tissue Donation and the Lisbon Declaration on the Rights of the Patient.

8.3.3. Legal tools

The proposed tools for the legal framework in which doctors can assist patients to reach appropriate decisions for their end-of-life care would include legislation that confirms the legal status of advance directives. It would also confirm the lawfulness of acting on difficult end-of-life decisions such as accepting the doctrine of double effect, administering palliative sedation, implementing a person's Advance Directive, withdrawal of hydration and nutrition and removal of medical equipment that is futile and simply prolonging death. Where there is no surrogate decision-maker, or there is uncertainty with regard to the next step in medical management, clear instructions are required to approach a court for legal assistance. An example of a legal statute covering these more controversial areas of end-of-life decisions is attached as Annexure 2: the updated draft *End of Life Decisions Act of 1998.* However, a version of the amended End of Life Decisions Act must exclude the section that pertains to E and PAS, even if it becomes legalised.

If E and/or PAS were to be introduced into South African law, an entirely separate Act must be dedicated to that subject alone, so that no confusion with palliative care can arise. Furthermore, the alternative model that I proposed in Chapter 6, which only allows PAS, and utilises non-government organisations to facilitate assisted death in place of the public health sector, is recommended.

It should be emphasised that E and PAS are not medical treatments for a disorder and are not, in my view, an extension of the medical role of doctors. E and PAS are purely social responses to a request to die initiated by the patient, and the procedure should not be offered by medical practitioners as if it is another medical option to deal with the terminal phase of life, which I submit it is not.

8.3.4. Summary

In summary, the following recommendations are made to facilitate the development of the framework:

i) Enact end-of-life legislation to clarify what are acceptable end of life choices in medical

care so that the patient, doctor, and family are reassured and guided in their palliative care decisions.

ii) Educate doctors on how to counsel patients and family about terminal illness, including the value of advance directives, future care that would be needed as the disease progresses, and, if necessary, particularly in South Africa, also teach the family how to care for the dying patient. Bereavement counselling would be a worthwhile skill to have for the family during the preparation of their loss and after the patient's death.

iii) Another area of focus for doctors is knowledge of how to withdraw life sustaining treatments.

iv) Basic formal training is suggested for all doctors and specialised training for palliative care teams.

v) Form palliative care teams which can become mobile.

8.4. LIMITATIONS

A limitation of this research was that it primarily addressed the problem of end-of-life decisions for adults without a discussion about children, infants or other vulnerable groups. Also, the extraction and choice of all information presented was gathered only by the author which introduces bias. No empirical data was prepared. In addition, the research was performed mostly using available English literature, and a few translations, although a number of foreign countries published their research or commentaries in other languages, such as French. In those instances, depth of insight may have been lost. Consequently, some inaccuracy and bias could have influenced the opinions expressed and developed in the comparative law chapter. A further limitation was that this thesis has covered a wide range of topics related to end-of-life decisions, as well as the medical-practitioner's role in helping to medically manage those decisions. This has resulted in a more superficial examination of each overall than would otherwise have been warranted had they been treated as individual research topics.

Much more research can be done to understand some of the individual challenges better: research into health services to develop the best organisational structure and practices to offer dying patients optimal care, for example, and establishing what South African patients'

requirements would be to experience a better quality of their end-of-life phase as they progress towards death, would both benefit from further research.

8.5. CONCLUSION

I conclude this thesis by establishing that the ethical and legal enquiry has resulted in finding clarity surrounding the end-of-life options best suited for South African society at present. Both ethical palliative care and end-of-life legislation are put forward as possibilities for assisting doctors and their patients with managing end-of-life decisions. To this end an ethico-legal framework has been provided for medical practitioners with suggestions towards further improvement.

It is evident, according to this thesis, that South Africa is not a suitable environment for E/PAS legislation to be introduced at this stage. Rather, there is a need to focus on expanding palliative care and promulgating legislation that supports end of life decisions. The law would reinforce a minimum standard of care such as ensuring the human right to adequate pain control. That would remove the opportunity for government to avoid the responsibility of supplying it by attempting to argue that such a health service utilises scarce resources.

A priority for the country is to broaden the base of palliative care and to improve the social determinants of health for everyone. Social determinants are the conditions in the environment that affect health, including advancing economic stability, access to good quality education and health care and improved community relationships between people so that they receive social support from one another[29]. In that way, people with chronic terminal conditions, such as neurological diseases, and not only those with just a few months left to live, can easily access the benefits of palliative care, too.

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42. Western Australia. Voluntary Assisted Dying Act No, 27 of 2019

ANNEXURE 1 : (SALRC) End of Life Decisions Bill of 1998

To regulate end of life decisions and to provide for matters incidental thereto.
To be introduced by the Minister of Justice

BE IT ENACTED by the Parliament of the Republic of South Africa, as follows:

Editorial note: Now Act 132 of 1998 assented to 11 December 1998, date of commencement to be proclaimed.

Definitions

1. (1) In this Act, unless the context otherwise indicates-

'competent witness' means a person of the age of 18 years or over who at the time he witnesses the directive or power of attorney is not incompetent to give evidence in a court of law and for whom the death of the maker of the directive or power of attorney holds no benefit;

'court' means a provincial or local division of the High Court of South Africa within whose jurisdiction the matter falls;

'family member' in relation to any person, means that person's spouse, parent, child, brother or sister;

'intractable and unbearable illness' means an illness, injury or other physical or mental condition, but excluding a terminal illness, that-

(a) offers no reasonable prospect of being cured; and

(b) causes severe physical or mental suffering of a nature and degree not reasonable to be endured.

'lawyer' means an attorney as defined in section 1 of the Attorney's Act, 1979 (Act 53 of 1979) and an advocate as defined in section 1 of the Admission of Advocates Act, 1964 (Act 74 of 1964);

'life-sustaining medical treatment' includes the maintenance of artificial feeding;

'medical practitioner' means a medical practitioner registered as such in terms of the Medical, Dental and Supplementary Health Service Professions Act, 1974 (Act 56 of 1974);

'nurse' means a nurse registered as such in terms of the Nursing Act 50 of 1978 and authorised as a prescriber in terms of section 31(14)(b) of the proposed [South African Medicines and Medical Devices Regulatory Authority Bill][683];

'palliative care' means treatment and care of a terminally ill patient with the object of relieving physical, emotional and psycho-social suffering and of maintaining personal hygiene;

'spouse' includes a person with whom one lives as if they were married or with whom one habitually cohabits;

'terminal illness' means an illness, injury or other physical or mental condition that-

(a) in reasonable medical judgement, will inevitably cause the untimely death of the patient concerned and which is causing the patient extreme suffering; or

(b) causes a persistent and irreversible vegetative condition with the result that no meaningful existence is possible for the patient.

Conduct of a medical practitioner in the event of clinical death

2.(1) For the purposes of this Act, a person is considered to be dead when two medical practitioners agree and confirm in writing that a person is clinically dead according to the following criteria for determining death, namely –

(a) the irreversible absence of spontaneous respiratory and circulatory functions; or

(b) the persistent clinical absence of brain-stem function.

(2) Should a person be considered to be dead according to the provisions of sub-section (1), the medical practitioner responsible for the treatment of such person may withdraw or order the withdrawal of all forms of treatment.

Mentally competent person may refuse treatment

3.(1) Every person –

(a) above the age of 18 years and of sound mind, or

(b) above the age of 14 years, of sound mind and assisted by his or her parents or guardian, is competent to refuse any life-sustaining medical treatment or the continuation of such treatment with regard to any specific illness from which he or she may be suffering.

(2) Should it be clear to the medical practitioner under whose treatment or care the person who is refusing treatment as contemplated in subsection (1) is, that such a person's refusal is based on the free and considered exercise of his or her own will, he or she shall give effect to

such a person's refusal even though it may cause the death or the hastening of death of such a person.

(3) Care should be taken when taking a decision as to the competency of a person, that an individual who is not able to express him or herself verbally or adequately, should not be classified as incompetent unless expert attempts have been made to communicate with that person whose responses may be by means other than verbal.

(4) Where a medical practitioner as contemplated in subsection (2) does not share or understand the first language of the patient, an interpreter fluent in the language used by the patient must be present in order to facilitate discussion when decisions regarding the treatment of the patient are made.

Conduct of medical practitioner in relieving distress

4.(1) Should it be clear to a medical practitioner or a nurse responsible for the treatment of a patient who has been diagnosed by a medical practitioner as suffering from a terminal illness that the dosage of medication that the patient is currently receiving is not adequately alleviating the patient's pain or distress, he or she shall -

(a) with the object to provide relief of severe pain or distress; and

(b) with no intention to kill

increase the dosage of medication (whether analgesics or sedatives) to be given to the patient until relief is obtained, even if the secondary effect of this action may be to shorten the life of the patient.

(2) A medical practitioner or nurse who treats a patient as contemplated in subsection (1) shall record in writing his or her findings regarding the condition of the patient and his or her conduct in treating the patient, which record will be documented and filed in and become part of the medical record of the patient concerned.

Active voluntary euthanasia
Option 1:

No legislative enactment

Option 2:
Cessation of life

5.(1) Should a medical practitioner be requested by a patient to make an end to the patient's suffering, or to enable the patient to make an end to his or her suffering by way of administering or providing some or other lethal agent, the medical practitioner shall give effect to the request if he or she is satisfied that-

(a) the patient is suffering from a terminal or intractable and unbearable illness ;

(b) the patient is over the age of 18 years and mentally competent;

(c) the patient has been adequately informed in regard to the illness from which he or she is suffering, the prognosis of his or her condition and of any treatment or care that may be available;

(d) the request of the patient is based on a free and considered decision;

(e) the request has been repeated without self-contradiction by the patient on two separate occasions at least seven days apart, the last of which is no more that 72 hours before the medical practitioner gives effect to the request;

(f) the patient, or a person acting on the patient's behalf in accordance with subsection (6), has signed a completed certificate of request asking the medical practitioner to assist the patient to end the patient's life;

(g) the medical practitioner has witnessed the patient's signature on the certificate of request or that of the person who signed on behalf of the patient;

(h) an interpreter fluent in the language used by the patient is present in order to facilitate communication when decisions regarding the treatment of the patient are made where the medical practitioner as contemplated in this section does not share or understand the first language of the patient;

(i) ending the life of the patient or assisting the patient to end his or her life is the only way for the patient to be released from his or her suffering.

(2) No medical practitioner to whom the request to make an end to a patient's suffering is addressed as contemplated in subsection (1), shall give effect to such a request, even though he or she may be convinced of the facts as stated in that subsection, unless he or she has conferred with an independent medical practitioner who is knowledgeable with regard to the terminal illness from which the patient is suffering and who has personally checked the patient's medical history and examined the patient and who has confirmed the facts as contemplated in subsection (1)(a), (b) and (i).

(3) A medical practitioner who gives effect to a request as contemplated in sub-section (1), shall record in writing his or her findings regarding the facts as contemplated in that subsection and the name and address of the medical practitioner with whom he or she has conferred as contemplated in subsection (2) and the last-mentioned medical practitioner shall record in writing his or her findings regarding the facts as contemplated in subsection (2).

(4) The termination of a patient's life on his or her request in order to release him or her from suffering may not be effected by any person other than a medical practitioner.

(5) A medical practitioner who gives effect to a patient's request to be released from suffering as contemplated in this section shall not suffer any civil, criminal or disciplinary liability with regard to such an act provided that all due procedural measures have been complied with.

(6) If a patient who has orally requested his or her medical practitioner to assist the patient to end the patient's life is physically unable to sign the certificate of request, any person who has attained the age of 18 years, other than the medical practitioner referred to in subsection (2) above may, at the patient's request and in the presence of the patient and both the medical practitioners, sign the certificate on behalf of the patient.

(7) (a) Notwithstanding anything in this Act, a patient may rescind a request for assistance under this Act at any time and in any manner without regard to his or her mental state.
(b) Where a patient rescinds a request, the patient's medical practitioner shall, as soon as practicable, destroy the certificate of request and note that fact on the patient's medical record.

(8) The following shall be documented and filed in and become part of the medical record of the patient who has been assisted under this Act:

(a) a note of the oral request of the patient for such assistance;

(b) the certificate of request;

(c) a record of the opinion of the patient's medical practitioner that the patient's decision to end his or her life was made freely, voluntarily and after due consideration;

(d) the report of the medical practitioner referred to in subsection (2) above;

(e) a note by the patient's medical practitioner indicating that all requirements under this Act have been met and indicating the steps taken to carry out the request, including a notation of the substance prescribed.

Option 3: Decision by panel or committee
Cessation of life

5.(1) Euthanasia may be performed by a medical practitioner only, and then only where the request for the euthanasia of the patient has been approved by an ethics committee constituted for
that purpose and consisting of five persons as follows:

a) two medical practitioners other than the practitioner attending to the patient;

b) one lawyer;

c) one member sharing the home language of the patient;

d) one member from the multi-disciplinary team; and

e) one family member.

(2) In considering and in order to approve a request as contemplated in subsection (1) the Committee has to certify in writing that:

a) in its opinion the request for euthanasia by the patient is a free, considered and sustained request;

b) the patient is suffering from a terminal or intractable and unbearable illness;
is the only way for the patient to be released from his or her suffering.

(3) A request for euthanasia must be heard within three weeks of it being received by the Committee.

(4) (a) The Committee which, under subsection (2), grants authority for euthanasia must, in the prescribed manner and within the prescribed period after euthanasia has been performed, report confidentially to the Director-General of Health, by registered post, the granting of such authority and set forth –

(i) the personal particulars of the patient concerned;

(ii) the place and date where the euthanasia was performed and the reasons therefore;

(iii) the names and qualifications of the members of the committee who issued the certificates in terms of the above sections; and

(iv) the name of the medical practitioner who performed the euthanasia.

(b) The Director-General may call upon the members of the Committee required to make a report in terms of subsection (4) or a medical practitioner referred to in subsection (1) to furnish such additional information as he may require.

(5) The following shall be documented and filed and become part of the medical record of the patient who has been assisted under this Act:

(a) full particulars regarding the request made by the patient;

(b) a copy of the certificate issued in terms of subsection (2);

(c) a copy of the report made in terms of subsection (4).

Directives as to the treatment of a terminally ill person

6.(1) Every person above the age of 18 years who is of sound mind shall be competent to issue a written directive declaring that if he or she should ever suffer from a terminal illness and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, medical treatment should not be instituted or any medical treatment which he or she may receive should be discontinued and that only palliative care should be administered.

(2) A person as contemplated in subsection (1) shall be competent to entrust any decision-making regarding the treatment as contemplated in that subsection or the cessation of such treatment to a competent agent by way of a written power of attorney, and such power of attorney shall take effect and remain in force if the principal becomes terminally ill and as a result is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof.

(3) A directive contemplated in subsection (1) and a power of attorney contemplated in subsection (2) and any amendment thereof, shall be signed by the person giving the directive or power of attorney in the presence of two competent witnesses who shall sign the document in the presence of the said person and in each other's presence.

(4) When a person who is under guardianship, or in respect of whom a curator of the person has been appointed, becomes terminally ill and no instructions as contemplated in subsection (1) or (2) regarding his medical treatment or the cessation thereof have been issued, the decision-making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator.

Conduct in compliance with directives by or on behalf of terminally ill persons

7.(1) No medical practitioner shall give effect to a directive regarding the refusal or cessation of medical treatment or the administering of palliative care which may contribute to the hastening of a patient's death, unless-

(a) the medical practitioner is satisfied that the patient concerned is suffering from a terminal illness and is therefore unable to make or communicate considered decisions concerning his or her medical treatment or the cessation thereof; and

(b) the condition of the patient concerned, as contemplated in paragraph (a), has been confirmed by at least one other medical practitioner who is not directly involved in the treatment of the patient concerned, but who is competent to express a professional opinion on the patient's condition because of his expert knowledge of the patient's illness and his or her examination of the patient concerned.

(2) Before a medical practitioner gives effect to a directive as contemplated in subsection (1) he shall satisfy himself, in so far as this is reasonably possible, of the authenticity of the directive and of the competency of the person issuing the directive.

(3) Before giving effect to a directive as contemplated in subsection (1), a medical practitioner shall inform the interested family members of the patient of his or her findings, that of the other medical practitioner contemplated in paragraph (b) of subsection (1), and of the existence and content of the directive of the patient concerned.

(4) If a medical practitioner is uncertain as to the authenticity as regard to the directive or its legality, he shall treat the patient concerned in accordance with the provisions set out in section 8 below.

(5) (a) A medical practitioner who gives effect to a directive as contemplated in subsection (1) shall record in writing his or her findings regarding the condition of the patient and the manner in which he or she implemented the directive.

(b) A medical practitioner as contemplated in paragraph (b) of subsection (1) shall record in writing his or her findings regarding the condition of the patient concerned.

(6) A directive concerning the refusal or cessation of medical treatment as contemplated in sub-section (1) and (2) shall not be invalid and the withholding or cessation of medical treatment in accordance with such a directive, shall, in so far as it is performed in accordance with this Act, not be unlawful even though performance of the directive might hasten the moment of death of the patient concerned.

Conduct of a medical practitioner in the absence of a directive

8.(1) If a medical practitioner responsible for the treatment of a patient in a hospital, clinic or similar institution where a patient is being cared for, is of the opinion that the patient is in a state of terminal illness as contemplated in this Act and unable to make or communicate decisions concerning his or her medical treatment or its cessation, and his or her opinion is confirmed in writing by at least one other medical practitioner who has not treated the person concerned as a patient, but who has examined him or her and who is competent to submit a professional opinion regarding the patient's condition on account of his or her expertise regarding the illness of the patient concerned, the first-mentioned medical practitioner may, in the absence of any directive as contemplated in section 6(1) and (2) or a court order as contemplated in section 9, grant written authorisation for the cessation of all further life-sustaining medical treatment and the administering of palliative care only.

(2) A medical practitioner as contemplated in subsection (1) shall not act as contemplated in subsection (1) if such conduct would be contrary to the wishes of the interested family members of the patient, unless authorised thereto by a court order.

(3) A medical practitioner as contemplated in subsection (1) shall record in writing his or her findings regarding the patient's condition and any steps taken by him or her in respect thereof.

(4) The cessation of medical treatment as contemplated in subsection (1) shall not be unlawful merely because it contributes to causing the patient's death.

Powers of the court

9.(1) In the absence of a directive by or on behalf of a terminally ill person as contemplated in section 6, a court may, if satisfied that a patient is in a state of terminal illness and unable to make or communicate decisions concerning his or her medical treatment or its cessation, on application by any interested person, order the cessation of medical treatment.

(2) A court shall not make an order as contemplated in subsection (1) without the interested family members having been given the opportunity to be heard by the court.

(3) A court shall not make an order as contemplated in subsection (1) unless it is convinced of the facts as contemplated in that subsection on the evidence of at least two medical practitioners who have expert knowledge of the patient's condition and who have treated the patient personally or have informed themselves of the patient's medical history and have personally examined the patient.

(4) A medical practitioner who gives effect to an order of court as contemplated in this section shall not thereby incur any civil, criminal or other liability whatsoever.

Interpretation

10. The provisions of this Act shall not be interpreted so as to oblige a medical practitioner to do anything that would be in conflict with his or her conscience or any ethical code to which he or she feels himself or herself bound.

Short title

11. This Act shall be called the End of Life Decisions Act 1999

ANNEXURE 2 : WMA DECLARATION OF VENICE ON END OF LIFE MEDICAL CARE

Adopted by the 35th World Medical Assembly, Venice, Italy, 1983.
Revised by the 57th WMA General Assembly, Pilanesburg, South Africa, 2006 and by the 73rd WMA General Assembly, Berlin, Germany, October 2022.

PREAMBLE

When a patient is seriously ill and e restoration of health may not be possible, the physician and the patient are often faced with a complex set of decisions regarding treatment.

The end of life must be recognised and respected as an important part of a person's life.

Advances in medical science have improved the ability of physicians to address many issues associated with end-of-life care. While the priority of research to cure disease should not be compromised, more attention must be paid to developing palliative treatments and improving assessment and response to the physical, psychological, social and spiritual or existential components of terminal illnesses and other conditions at the end of life.

WMA remains firmly opposed to euthanasia and physician-assisted suicide, as set forth in the WMA Declaration on Euthanasia and Physician-Assisted Suicide.

Ethically-appropriate care at the end of life should routinely promote patient autonomy and shared decision-making, and be respectful of the values of the patient, his or her family or intimate associates, and surrogate(s). The WMA recognises that attitudes and beliefs toward death and dying vary widely from culture to culture and among different religions, and palliative care resources are unevenly distributed. The approach to medical care at the end of life will be influenced significantly by these factors, and thus attempting o develop detailed universal guidelines on terminal care is neither practical nor wise.

Therefore, the WMA articulates the following:

RECOMMENDATIONS

Pain and Symptom Management

1. Palliative care at the end of life is part of good medical care. The objective of palliative care is to maintain dignity and freedom from distressing symptoms, Care plans should emphasize keeping a patient as comfortable as possible and the patient's pain controlled while recognizing the importance of attention to the social, psychological and spiritual needs of the patient, and his or her family and intimate associates.

2. The clinical management of pain in patients at the end of life is of paramount importance in terms of alleviating suffering. The WMA Resolution on Access to Adequate Pain Treatment (2020) makes recommendations for physicians and governments that

optimize treatment of pain and other distressing symptoms. Physicians and National Medical Associations should promote the dissemination and sharing of information regarding pain management to ensure that all physicians involved in end-of-life care have access to best practice guidelines and the most current treatments and methods available. National Medical Associations should oppose laws or regulations that unduly inhibit physicians from providing intensive, clinically appropriate symptoms management for patients at the end of life in keeping with recognized best practices.

3. When a patient at the end of life experiences severe pain or other distressing clinical symptoms that do not respond to intensive, symptom-specific palliation, it can be appropriate to offer sedation to unconsciousness as an intervention of last resort. Sedation to unconsciousness must never be used to intentionally cause a patient's death and should be restricted to patients in the final stages of life. Thorough efforts should be made obtain consent of the patient or the patient's surrogate(s).

4. Palliative care is often provided by multidisciplinary healthcare teams. When possible, the physician should be the leader of the team, being responsible, amongst other obligations, for diagnosis and medical treatment plans. A carefully kept medical record s of the utmost importance. The rationale for all symptom management interventions, including medications for symptom relief, should be documented in the medical record, including the degree and length of sedation and specific expectations for continuing, withdrawing, or withholding future life-sustaining treatments.

5. The health care team should promote collaborative care of the patient and offer bereavement support after the patient's death. The needs of children and families or intimate associates may require special attention and competence, both when children are patients and when they are dependents of patients.

Education and research

6. Education of healthcare professionals should include the teaching of end-of-life medical care. Where it does not exist, the establishment of palliative medicine as a medical specialty should be considered. In countries where palliative medicine is not a recognised medical specialty, post-graduate training in palliative medicine can nevertheless improve the quality of palliative care provided.

7. Physician education should help to develop the skills necessary to increase the prevalence and quality of meaningful patient advance care planning for patients with life-threatening illness and the right of patients to use written advance directives that describe their wishes and goals regarding care in the event that they are unable to communicate. Physicians should receive education to encourage their patients to formally document their goals, values and treatment preferences and to appoint a substitute health care decision maker with whom the patient can discuss in advance his or her values regarding health care and treatment.

8. Governments and research institutions are encouraged to invest additional resources in developing treatments to improve end-of-life care. This includes, but is not limited to, supporting research on general medical care, specific treatments, psychological implications and organization to improve end-of-life care.

9. When employing treatments, the physician must carefully consider the balance between the intended benefits to the patient and the potential harm. National Medical Associations should support the formulation of palliative treatment guidelines.

10. The physician must also communicate to the patient a willingness to discuss at any time the natural course of the disease and what to expect during the dying process, while also providing guidance about treatments and alternatives that could ease the patient's suffering, including palliative care or psychotherapy. If a patient indicates a desire to die or expresses suicidal thoughts, the physician has a duty to engage in open and confidential discussions with the patient to understand the motives and reasoning behind these thoughts.

11. Physicians should assist the dying patient in maintaining an optimal quality of life by controlling symptoms and addressing psychosocial and spiritual needs, to enable the patient to die with dignity and in comfort. Physicians should inform patients of the availability, benefits and other aspects of palliative care. Discussions about patient preferences should be initiated early, routinely offered to all patients and should be revisited regularly to explore any changes patients may have in their wishes, especially as their clinical condition changes. Information and communication among the patient, his or her family or intimate associates, surrogates and members of the health care team are one of the fundamental pillars of quality care at the end of life.

12. Physicians should endeavor to identify, understand and address the psychosocial and spiritual needs of their patients, especially as they relate to patient's physical symptoms. Physicians should try to ensure that psychological, social and spiritual resources are available to patients, their families and intimate associates, to help them deal with the anxiety, fear and grief associated with the end of life.

13. Physicians should encourage patients to designate a substitute decision-maker/surrogate to make decisions that are not expressed in an advance directive. In particular, physicians should discuss the patient's wishes regarding the approach to life-sustaining interventions as well as palliative measures that might have the additional effect of accelerating death. Because documented advance directives are sometimes not available in emergency situations, physicians should emphasise to patients the importance of discussing treatment preferences with individuals who are likely to act as substitute health care decision-makers/surrogates. Whenever possible and consented to by the patient, the patient's substitute decision-makers/surrogates should be included in these conversations.

14. If a patient has decision-making capacity, his or her autonomous right to refuse any medical treatments or interventions must be respected even if the patient's life may be

shortened. Physicians should make sure that the patient is adequately treated for pain and discomfort before consent for end-of-life care is obtained in order to ensure that unnecessary physical and mental suffering do not interfere with decision-making. Laws regarding the decision-making capacity of minor patients vary greatly, but discussions with the family and child, if possible, are encouraged.

15. Upon a patient's death, physicians may apply such means as are necessary to keep organs viable, for transplantation, provided that they act in accordance with the ethical guidelines established in the WMA Declaration of Sydney on the Determination of Death and the Recovery of Organs. In addition, any transplantation must be in accordance with the principles in the WMA Statement on Organ and Tissue Donation.

ANNEXURE 3 : RESEARCH ETHICS COMMITTEE WAIVER

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Innovation)

28/03/2023

Ref: W-CBP-230328-02

TO WHOM IT MAY CONCERN

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical)

Investigator: Mrs Y Guidozzi
Student No. (if appropriate): 81 3756 8
Staff No. (if appropriate):

Supervisor: Professor A Dhai

Department: Steve Biko Centre for Bioethics
Medical School
University

Project title: *Euthanasia and physician-assisted suicide in South Africa: towards an ethico-legal framework to assist medical practitioners with end-of-life decision making*

Reason: Review of information in the public domain
No human participants will be involved in the study

CB Penny

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