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Chapter 1

„But if the disease be not only incurable, but also full of continual pain and anguish, then the priests and the magistrates exhort the man (seeing that he is not able to do any duty of life, and by overliving his own death is noisome and irksome to others and grievous to himself) that he will determine with himself no longer to cherish that pestilent and painful disease; and either dispatch himself out of that painful life, as out of a prison or rack of torment, or else suffer himself to be willingly rid of it by another“.

Thomas More, *Utopia*¹

1.1 Introduction:

It is through the law that actions are regulated and the best course for all parties is made evident. When facing emotionally charged circumstances such as a mother giving birth to an impaired neonate, it can undoubtedly be said that the law should serve to create boundaries, provide a voice to the voiceless and set the standard for what the course of action should be.

While the law of South Africa provides that everyone has the right to life,² it is sometimes a step too far to create a double barrel right by entwining this with the right to die. Those who advocate the right to die bring great controversy to the table. A tug of war ensues between moral, social, religious, ethical and philosophical beliefs, however, if law stands firm we could see the end of this back and forth action which only greys this area unnecessarily so. The burning question here starts at the root of what course should be taken when there is a grey area in the law? Should the cracks in the system be filled by an individual's beliefs or will this raise the risk of the cracks becoming wider and as a result helpless infants fall through without being given a chance based on the reasoning of someone else? Or should we rather adopt approaches that have been taken in other parts of the world in an attempt to adhere to the tried and tested rather than venture too far off and form a path of our own?

Euthanasia in general stirs the pot so to speak. In England for example euthanasia is illegal.³ However, if we look to Switzerland we see cases where individuals travel from far and wide with

¹ T More *Utopia* (1951) 98.

² Section 11 of the Constitution of the Republic of South Africa, 1996 (the Constitution).

³ Darin Achilles „Examining the Groningen Protocol: Comparing the treatment of terminally-ill infants in the Netherlands with treatment given in the United States and England“ (2011) *Wisconsin International Law Journal* 795, 796.

the sole intention of utilizing their lenient euthanasia laws.⁴ From this it is submitted that where an individual cannot make do within their own legal system, they can, in the case of euthanasia, seek relief elsewhere. Instead of allowing this fragile topic to be left on the back burner it should be addressed, analyzed and steps should be taken to address the issues where such was not previously done.

1.2 Background

The birth of a child should be a joyous event. Sometimes however, it is a tragedy.⁵ In particular, this may be the case when the newborn infant suffers from such serious birth defects that it is not expected to live, even with aggressive and sophisticated medical intervention.⁶ When this is the case, it is up to the parents or other decision makers to make the appropriate choice: to use all available medical means to keep the infant alive for as long as possible; to let the child die, providing only comfort measures; or actively to terminate the suffering of the child by taking its life as quickly and painlessly as possible.⁷

Taking the first few steps into parenthood is a daunting task for many. Giving birth to a healthy newborn presents costs and an array of new responsibilities and obligations. The pressure of parenthood intensifies when the idea of a healthy child is replaced with a newborn who is premature or impaired in some way. Impaired neonates as well as their parents face a challenge. Either their condition was over looked during the amniocentesis or they were born with an impairment that was only made evident after birth. As harsh as it may seem, what waits in the wings for these infants is in a sense the “nip it in the bud” approach. Here, parents see the act of involuntary euthanasia as putting an end to an infant’s suffering by taking its life so that the pain and suffering ceases. What is a problem however, is that there is a blurring of whether the action is truly to bring an end to the so called misery that awaits the child, or is the real reason behind the final act to bring an end to the misery that a parent may feel stuck with as a result of having to raise a child with an impairment. Intention is everything and sometimes, a truly bad intention

⁴ Ibid.

⁵ E Henner & W Kluge „Severely Disabled Newborns“ in H Kuhse & P Singer (eds) *A Companion to Bioethics* (1998) 242.

⁶ Ibid.

⁷ Ibid.

may be masked to show remorse yet under layers of conflict between right and wrong the best course is taken from the view point of a parent for the parent, and not the child.

Adult euthanasia differs a great deal from neonatal euthanasia. The difference lies in the fact that infants are unable to make decisions regarding their futures and are thus not viewed as persons in the same way that adults are.⁸ Here the child does not participate at all in the decision making and the euthanasia is non voluntary with no element of consent or even effective assent from the child.⁹ Taking this one step further we see that adults are obviously autonomous agents and are thus capable of making their own decisions regarding all decisions that concern them. The same, however, cannot be said of neonates as they rely on their parents or guardians to act on their behalf.

While all eyes are on the infants, it must be kept in mind that this situation does not exist in a vacuum. The newborn is not the only party. While the newborn faces the challenge of fighting for its life and in some cases enduring tremendous amounts of pain to which no palliative care can be made available, it must also be born in mind that such circumstances will also have far reaching effects on the family.¹⁰ Medical expenses which were thought to be calculated for a healthy child increases at an alarming rate as a result of the special care and treatment that the now ill infant will have to receive without any guarantee that said treatment will even prove fruitful. While the family may have planned for a child, can they be forced to feed money into a cause that may sour very fast and even if the child is able to live a fairly normal life, is it justifiable to impose this heavy burden not only on the child but also on the unsuspecting family who may not have planned for such? In this regard, the ideals of society are not always unreasonable. Firstly, by condoning abortion to prevent the birth of a defective child society has made it clear that it is sympathetic to parents who are anxious to not have a baby if it suffers from a serious disability.¹¹ Secondly, cost-benefit studies have been published in the United

⁸ H. Tristram Engelhardt, Jr. „Ethical issues in aiding the death of young children“ in Mappes and DeGrazia (eds.) *Biomedical Ethics* (1996) 408-413.

⁹ S Wolf „Facing Assisted Suicide and Euthanasia in Children and Adolescents“ in L Emanuel (ed) *Regulating How We Die* (1998) 92, 105.

¹⁰ Catharina Susanna van der Westhuizen *A Proposed framework for the legal protection of premature and critically-ill neonates in the context of South African Child Law*. (Unpublished thesis, University of the Free State, 2012) 1.

¹¹ T Jenkins „Neonatal Euthanasia“ in G Oosthuizen, H Shapiro & S Strauss (eds) *Euthanasia* (1978) 173.

States which show what a financial burden such a child can be to the parents and to the state.¹² Thirdly, the achiever is undoubtedly more highly praised and valued in our society than is the non-achiever.¹³ It is with these considerations in mind that potential parents are encouraged to expect and in some cases demand physically and mentally normal children.¹⁴

As already established, the care of the child falls on the parents. It has been argued by Engelhardt that when treatment is very expensive and the chances of success are minimum there should exist no obligation on the parents to proceed with such treatment.¹⁵ What is suggested by this author is that a general notion exists where there is never a duty to engage in extraordinary treatment or treatment that is costly.¹⁶ This argument concerns children whose future quality of life is likely to be seriously compromised and whose present treatment would be very costly.¹⁷ It is thus up to the parent to make the final call because it is through the parents that the child exists until such time the child reached sufficient maturity to make their own decisions.¹⁸ It follows then that society can only intervene when the parents neglect the infant and the proposed treatment does not constitute a burden and it is likely that the child could enjoy a good quality of life, yet they are unjustifiably refusing such.¹⁹ Society must value mother-child and family-child relationships and they should only step in when neglect is unreasonable and would therefore undermine respect and care for children or where societal intervention would prevent children from suffering unnecessary pain.²⁰

A serious problem arises when the same condition that would have justified a mother having an abortion becomes known after birth.²¹ The argument here is that where an impairment arises that would have justified aborting a fetus, the same should apply to the killing of a newborn.²² The train of thought here is that killing a newborn should be ethically permissible in all circumstances where abortion would be.²³ It is submitted by Jenkins that if it is not feasible to

¹² Ibid.

¹³ Ibid 174.

¹⁴ Ibid.

¹⁵ Engelhardt (note 8 above)

¹⁶ Ibid 410.

¹⁷ Ibid.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Ibid 411.

²¹ Giubilini A and Minerva F „After-birth abortion: Why should the baby live?“ *J Med Ethics* (2012) 1.

²² Ibid.

²³ Ibid 2.

diagnose a certain disease in utero, which disease if it were diagnosable pre-natally would justify abortion, then the diagnosis of the condition at or soon after birth might, it could be argued, morally justify infanticide.²⁴ This standard of impairment is also extended to include cases where the newborn has the potential to have at the very least an acceptable life but the well-being of the family would suffer if the infant is allowed to live. It is also submitted by Giubilini and Minerva that the act of killing an infant should not be seen as a wrongful action because the infants has not yet developed any aims for its life and it thus has not been denied the opportunity to fulfill these aims simply because it has none.²⁵ The basis of this argument is provided as follows: The moral status of an infant is equivalent to that of a fetus, that is, neither can be considered as a person in a morally relevant sense and secondly it is not possible to damage a newborn by preventing her from developing the potentiality to become a person in the morally relevant sense.²⁶ The essence of the argument here is that a newborn is on the same level as a fetus as both are potential persons and human beings, but none of them are persons in a moral sense and they are incapable of exercising the rights that they have accrued. It follows then that if they are essentially the same then what is fit for a fetus should be fit for a newborn. The difference of in utero and being born alive does not provide sufficient changes to justify prolonging the life of one over the life of a fetus. This shows the slippery slope argument for what it really is. Allowing abortions to be done has led us to the point that is argued to be acceptable to take a defenseless life.²⁷

Those who escape the net of detection and abortion may be looked at as a second class or even lower citizen that is not entitled to first class medical care. With this, a seed of resentment is sown, it starts to grow between the parents who see their child as a burden and this extends to the child who may not have asked for their lives to be saved had they been in the position to do so.

While many neonates may be viewed as hopeless cases it is essential to note that medicine has come a long way. While previously nature would have been allowed to take its course purely on the basis that there were no alternatives due to the lack of medical progression, the same cannot

²⁴ Jenkins (note 11 above).

²⁵ Ibid

²⁶ Ibid.

²⁷ Ibid.

be said in this day and age.²⁸ Today there are options and with these options comes great ethical concerns that did not play a role in the past. As a result of this progression if an infant is born with an impediment, in previous years the infant may have died, but today, treatment may allow the infant to have a decent quality of life along with a longer life span. It is important to remember here that every life, at some point, will have a natural end and the duty of the healthcare professional does not extend to sustaining life artificially for many years for patients for whom there is little hope of recovery.²⁹ It is submitted with this in mind that a doctors obligation to treat extends only so far as such treatment can provide benefit. Surely it is acceptable to think that no infant should be put through excessive pain where results will only prolong the inevitable?

Some writers are of the view that where there is a hope, however dim, all must be done in order to give the infant a fighting chance.³⁰ Whilst other argue that by poking and prodding not only are doctors adding fuel to the fire and prolonging the pain but they are also wasting medical resources that could be used on an infant with a better prognosis.³¹ Engelhardt eloquently raises this progression in the well put question: “The quandaries are in a sense an embarrassment of riches; now that one *can* treat such defective children, *must* one treat them? And, if one need not treat such defective children, may one expedite their death?”³²

From this we establish the grey area in our law. Both the Children’s Act³³ and the National Health Act³⁴ have failed to address neonatal medical care. There are no set provisions that cater for the various age groups from birth to adulthood. Rather we see all children being placed in the same box and afforded the same protection. It is with this in mind that we proceed to unpack the ethical and legal implications of the involuntary euthanasia of impaired neonates from a South African perspective and then go on to look to other foreign jurisdictions in an attempt to establish a way forward.

²⁸ Van der Westhuizen (note 10 above).

²⁹ A Dhali & D McQuoid-Mason *Ethics, Human Rights and Health Law* (2011) 126.

³⁰ Members of the Hastings Center Research Project on the Care of Imperiled Newborns „Standards of Judgment for Treatment of Imperiled Newborns” in Mappes and DeGrazia (eds.) *Biomedical Ethics* (2001) 375.

³¹ *Ibid* 376.

³² *Ibid* 409.

³³ The Children’s Act 38 of 2005.

³⁴ The National Health Act 61 of 2003.

When looking at the policy that exists in South Africa it is established that in terms of public hospital policy, an infant who weighs below 1000g is deemed to be incapable of surviving in a public hospital or ambulance and as such is not given any form of advanced care.³⁵ Private hospitals at the very least exercise discretion. South African policy places significant emphasis on the weight of the infant in order to determine a way forward. This is helpful in the cases involving premature babies. The child is provided with basic health care to establish if it can survive on its own. Whilst such policy exists with regards to premature babies, there is little mention of what should happen when there is some underlying factor far more serious than just weight. The fact that these babies that are born with impairment may be denied medical care in itself raises several questions. Some individuals may see a certain condition as a bad omen and as a result decide to have their infant euthanized. On the one hand euthanasia allows for the pain to be brought to an end. On the other, pain is subjective and thus it is submitted that if a child is brought into the world in pain then that is all that they know, in a sense it is all they have felt and thus they do not know what it is like to be healthy, so all should be done to save such an infant without the fear of not bringing the pain to an end. However, this notion is rejected by Eduard Verhagen who agrees that suffering is a subjective feeling that cannot be measured objectively, whether in adults or in infants, but it is accepted that adults can indicate when their suffering is unbearable.³⁶ Infants cannot express their feelings through speech, but they do so through different types of crying, movements, and reactions to feeding.³⁷ Pain scales for newborns, based on changes in vital signs (blood pressure, heart rate, and breathing pattern) and observed behavior, may be used to determine the degree of discomfort and pain.³⁸ Experienced caregivers and parents are able to evaluate the degree of suffering in a newborn, as well as the degree of relief afforded by medication or other measures and it is through these means that the true degree of suffering can be determined and accordingly dealt with.³⁹ Another approach is adopted by those who deem sanctity of life as the be all and end all.⁴⁰ This group places all value on life and the invaluable experiences that the infant has in its future that we should not have a hand in taking away. The other side to this coin is based on the quality of life argument which places

³⁵ Van der Westhuizen (note 10 above) 2.

³⁶ Eduard Verhagen „The Groningen Protocol – Euthanasia in Severely Ill Newborns“ *NEJM* 2005 1.

³⁷ *Ibid.*

³⁸ *Ibid.*

³⁹ *Ibid.*

⁴⁰ Giubilini (note 21 above).

emphasis on the type of life that the infant will have should he/she survive and if such circumstances would pose more positives than negatives and if life entails more pain than the infant should rather be allowed to die with dignity.⁴¹

1.3 Terminology

According to the law an action is either legal or illegal. However, the line gets blurred when there are compelling arguments presented for both sides. What adds to this blurring is that there are several types of euthanasia, some appear to be acceptable whilst others are prohibited.

Murder is the unlawful and intentional killing of another person, while euthanasia or „mercy killing“ is aimed at allowing hopelessly ill or injured people to die in dignity in order to prevent further suffering.⁴²

Euthanasia refers to an act or omission that brings about an easy and painless death for persons suffering from an incurable or painful terminal disease.⁴³ When an autonomous, hopelessly ill patient decides that death is preferable to a continually painful or otherwise intolerable existence and requests that he be killed, the subsequent intentional killing of the patient by reasons of mercy by the attending physician (or someone else) is voluntary euthanasia.⁴⁴ The second form of Euthanasia applies to permanently unconscious or otherwise non autonomous patients who have never expressed preferences regarding the technological preservation of their lives.⁴⁵ If and when such non autonomous patients are intentionally killed for reasons of mercy, the causation of their deaths is correctly described as non-voluntary euthanasia or involuntary euthanasia because they were unable to express their desire or preference concerning the continuation or termination of their lives.⁴⁶ When autonomous patients express a desire to continue living, or when a now non autonomous patient previously expressed such a desire in a clear fashion when thinking about the possibility of medical circumstances similar to the circumstances that now exist, any subsequent killing of such patients by someone else is involuntary euthanasia (in moral

⁴¹ John A. Robertson „Involuntary Euthanasia of defective newborns“ in Mappes and DeGrazia (eds.) *Biomedical Ethics* (2001) 369-374.

⁴² SA Strauss *Doctor, Patient and the Law* 3 ed (1993) 336.

⁴³ DJ McQuoid-Mason & MA Dada *A-Z of Medical Law* (2011) 185.

⁴⁴ R Weir *Abating Treatment with Critically Ill Patients* (1989) 303.

⁴⁵ *Ibid.*

⁴⁶ *Ibid.*

terms) or murder (in legal terms).⁴⁷ Thus, voluntary euthanasia takes place where the patient brings about his death or requests another person to bring about such end whereas involuntary euthanasia occurs where there is no consent that is given by the patient and another person proceeds to take steps to hasten the patient's death.⁴⁸

Euthanasia can further be broken into two forms, namely passive or active. Active euthanasia refers to a situation where a person intentionally or actively participates in causing the death of a terminally ill patient to end pain and suffering which can take the form of administering a fatal injection or dose of medicine as seen in the *S v Hartman*⁴⁹ case.⁵⁰ Passive euthanasia occurs when a person withdraws or withholds treatment from a terminally ill patient or a patient suffering from unbearable pain by switching off a ventilator or turning down a pacemaker⁵¹ which was shown in the case of *Clarke v Hurst*.⁵² There is a further division namely Voluntary and involuntary euthanasia and is determined by the individuals competency to consent.

These forms of euthanasia often differ in terms of the seriousness of the patient's medical condition, the patient's decision making capacity, the patient's motivation, the patient's intention, and the consequences of an act of treatment abatement or euthanasia on the patient's continued life or likelihood of death.⁵³

Euthanasia is governed by the common law which provides that active euthanasia is unlawful and constitutes murder whereas passive euthanasia is lawful where it involves terminating treatment in hopeless cases after all possible procedure have failed and as such the patient is allowed to die naturally.⁵⁴ Thus where passive euthanasia has been done, doctors would generally not be held liable for murder if they withhold or withdraw treatment or provide

⁴⁷ Ibid.

⁴⁸ DJ McQuoid-Mason „Recent Developments Concerning Euthanasia in South Africa“ (1995) 1 *Law and Medicine* 7.

⁴⁹ *S v Hartman* 1975 (3) SA 532 (C).

⁵⁰ Mason and Dada (note 43 above) 186.

⁵¹ Ibid.

⁵² *Clarke v Hurst NO* 1992 (4) SA 630 (D).

⁵³ Weir (note 44 above) 303.

⁵⁴ Verhagen (note 36 above).

palliative treatment that hastens death where treatment is futile because the intention here is not to kill and it is at the hand of nature taking its course that the life ceases.⁵⁵

Active euthanasia can then further be broken up into active voluntary and active involuntary euthanasia. Active voluntary euthanasia is when a mentally competent patient asks for their death whereas active involuntary euthanasia is the action on the part of the physician that hastens the patient's death without their informed consent.⁵⁶ With these definitions in mind it is evident that a neonate is incapable of providing consent due to lacking capacity. Thus on the part of the neonate the type of euthanasia will always be involuntary. Some argue that the lack of capacity places all decisions in the hands of the parent and thus euthanasia can in a sense be voluntary because the required consent will be sought from the infants parents who have the required capacity as long as such action is in the best interest of the child.⁵⁷

This dissertation aims to unpack the legal and ethical implications of involuntary euthanasia of impaired neonates in order to create a solid foundation, eradicate any uncertainty that exists from a legal perspective and recommend a way forward in order for more protection to be afforded to those who truly need it. The system is bound to fail if the final say is being made by a mother who may be suffering from depression after the birth of her child and as such may not necessarily have the best interest of her child at heart. The focus should perhaps be on giving an impaired neonate a fighting chance instead of pulling the plug and denying a can be miracle.

1.4 Research Methodology

This dissertation takes the form of a literature study involving only desk top research. It will rely on the Constitution, legislation, guidelines, journal articles, case law and other academic works. A comparative study will also be used to show the grey area in South African law as opposed to foreign jurisdictions. I will look at the Groningen Protocol and how that could begin a wave of change when compared with England. It is worthy to note here that these foreign jurisdictions have been chosen as not only have they too ratified the Convention on the Rights of the Child, but there is also a binding link through Roman Dutch law.

⁵⁵ DJ McQuoid-Mason „Withholding or withdrawal of treatment and palliative treatment hastening death: The real reason why doctors are not held legally liable for murder“ (2014) 104 *SAMJ* 102.

⁵⁶ Achilles (note 3 above) 800.

⁵⁷ Ibid.

Chapter 2 – Ethics

2.1 Introduction

Ethics differs a great deal from law. While law is set in stone and actions are either lawful or unlawful, ethics sets a different standard. What is unlawful is not necessarily frowned upon in ethics.⁵⁸ One such example is refraining from telling a critical patient that her family has passed away in a motor vehicle accident and instead providing reassurance that they are in separate wards. This action is not unlawful but from an ethical stand point it violates the principle of full disclosure. Closer to the topic at hand, it can be said from a legal perspective taking a life would constitute murder or culpable homicide. However, ethically it can be argued that the practitioner has acted in the best interest of the patient.

2.1.1 What is Ethics?

Ethics is the outcome of reflection on the meaning of the concepts “good” and “bad” or “right” and “wrong”, as well as on a range of ideas about what confers value or disvalue on human action.⁵⁹ It is a form of reflection born from our universal discernment that human action is not simply something that happens beyond the conscious control and choices of the actors.⁶⁰ We as humans not only know what we do when we act, but we, universally, submit our actions to the measure or criterion of obligation.⁶¹ From this stems the idea that when faced with a situation we as humans are programmed to ask questions: What ought I to do? Is this course of action the right course to take? Thus, ethics is a theory or a system of moral values, the study of the general nature of morals and of the specific moral choices to be made by a person and the rules or standards governing the conduct of a person or the members of a profession.⁶²

When an individual is faced with making an ethical decision there are three important factors that will need their consideration.⁶³ Firstly, the moral agent must look at all of the possible

⁵⁸ A. A Van Niekerk *Medical Ethics, Law and Human Rights. A South African Perspective* (2011) 11.

⁵⁹ A Van Niekerk, „Ethics and Philosophy” in K Moodley (ed) *Medical Ethics, Law and Human Rights. A South African Perspective*. (2011) 7, 10.

⁶⁰ Ibid.

⁶¹ Ibid.

⁶² Ibid.

⁶³ J. A. Singh „Ethical Decision-making” in MA Dada and DJ McQuoid-Mason (eds.) *Introduction to Medico-Legal Practice* (2010) 35.

choices that are available to them.⁶⁴ This can be through a course of medication, new trial procedures, surgery or even withdrawal or withholding of treatment. Secondly, the consequences of the choices need to be analyzed.⁶⁵ Here the moral agent looks at what the outcome will be. The last aspect that must be taken into account is the context or setting of the health care dilemma.⁶⁶ Here one can look at whether the situation involves emergency medical care, or whether the institution providing aid is public or private.

Every individual develops the ability to distinguish between right and wrong and from a very young age, regardless of whether a law is in place to aid this ability, we know what we ought to do and what we ought not to do.⁶⁷ However, at a more intense level there are various ethical theories and principles that have been developed in order to move the decision making process along.

Before the development of biomedical ethics an impaired neonate would have been killed. The same approach cannot be used today because not only has the neonate taken its first breath and acquired legal personhood, but ethics steps in and reinforces the wrongfulness of the act. This chapter will look at deontology, utilitarianism and virtue ethics as the three main ethical theories. This will be followed by a discussion of the four principles of biomedical ethics namely, autonomy, beneficence, non-maleficence and justice. Lastly the principles of sanctity of life and quality of life will be weighed against each other. In this chapter law will take a step back and the various ethical principles and theories will be discussed.

2.2 Ethical Theories

An ethical theory provides the moral agent with a set of moral standards that is to be used to determine what is morally right and morally wrong. These ethical theories provide guidance in serious situations that may not have immediate obvious answers.⁶⁸

⁶⁴ Ibid.

⁶⁵ Ibid.

⁶⁶ Ibid.

⁶⁷ Ibid.

⁶⁸ Singh (note 63 above).

2.2.1 Deontology

This ethical theory provides that the action that is taken must always be in the best interest of the individual concerned. Here the determination of right and wrong stems from the intrinsic property of the action.⁶⁹ Deontologists are firm in the belief that only if the action in question is in line with a morally acceptable principle will such an action be deemed acceptable.⁷⁰ What this means is that an action will be acceptable if it would be permissible for everyone else to do it and as such confirms to the dictates of morality and is thus the correct approach to adopt in the given circumstance.

In terms of medical care, deontologists believe that each and every patient has rights and the practitioner has a duty to their patients in return. From this approach these duties and obligations must not be breached irrespective of what the situation is because the patients have rights and their rights cannot be infringed.

Emanuel Kant states that everyone should be treated as an end and not a means to an end. Here one cannot argue that denying treatment to an impaired neonate should be done in order to provide treatment to an infant with a better prognosis.

From a deontological perspective we can conclude that taking a life is wrong. We should not allow individuals, regardless of their experience, to take the life of a neonate based on an impairment nor can the situation be justified purely because it aids another. Instead, the rights of the neonate must be respected and the practitioner must perform his duties irrespective of any existing impairments simply because the neonate has the right to life, dignity and medical care.

2.2.2 Utilitarianism

The main constituents of any utilitarian theory may be called „consequentialism“, „welfarism“ and „aggregationism“.⁷¹ Consequentialism focuses on the end result of the action.⁷² Good consequences denote good actions and bad consequences denote bad actions.⁷³ According to this

⁶⁹ Ibid.

⁷⁰ Ibid.

⁷¹ R Hare „A Utilitarian Approach“ in H Kuhse & P Singer (ed) *A Companion to Bioethics* (1998) 80.

⁷² Ibid.

⁷³ Ibid.

theory the moral agent must look at which action brings about the greatest good for the greatest number of people.

The second constituent implies that Utilitarians believe that the consequences that are relevant to the morality of actions are consequences that increase or diminish welfare of all those affected.⁷⁴ Welfare in this regard is defined by Hare as the obtaining to a high or at least reasonable degree of a quality of life which on the whole a person wants, or prefers to have.⁷⁵ This means that the consequences that we have to attend to are those that conduce to the welfare of those affected or the opposite.

The last constituent that makes up the utilitarian approach is a view about the distribution of this welfare.⁷⁶ It is the view of a utilitarian that when we have a choice between the welfare of one lot of people and the welfare of another lot, we should choose the action which maximizes the welfare (maximally promotes the interests) of all in sum or in aggregate.⁷⁷ If a utilitarian faced an ethical dilemma they would have to examine the possible long and short term consequences of the action and weigh those results against the number of individuals that will be helped or harmed and the degree of each.⁷⁸ After such deliberation the action that is found to bring about the greatest benefit or the least harm for the majority would be deemed as the correct course of action to take.

Thus the utilitarian approach differs from the deontological approach in that it moves away from looking at the action and focuses more on the consequences. While deontology focuses on the individual, utilitarianism encompasses the majority and what course of action would be best for them.

What is best for an impaired neonate will not stand with the utilitarian's. According to this theory money, resources and time should not be wasted on a futile case but rather the resources should be used to help other infants with a better chance of survival. A utilitarian would look at the end result. From this approach a child born with a severe impairment receiving precious resources like medical treatment and access to scarce incubators is not a good action because the

⁷⁴ Hare (note 71 above) 80.

⁷⁵ Ibid 81.

⁷⁶ Ibid 82.

⁷⁷ Ibid.

⁷⁸ Ibid.

consequence is that the agent is being wasteful on a futile case when what could and should rather be done (from a utilitarian perspective) is the saving of more lives with the use of the available resources instead of pumping the little that the public sectors have into someone who will die anyway.

2.2.3 Virtue Ethics

This ethical theory provides that the answer to an ethical dilemma rests not in the action or the consequences of said action but rather in the moral character of the agent (in this case the health practitioner).⁷⁹ This reasoning stems from the idea that if a morally sensitive and skilled individual makes a decision then that decision will be morally correct. Here the moral agents education, skills and development are looked at.⁸⁰

It is submitted by Justin Oakley that there are six key claims which are essential to modern forms of virtue ethics.⁸¹

- a) An action is right if and only if it is what an agent with a virtuous character would do in the circumstances.
- b) Goodness is prior to rightness.
- c) The virtues are irreducibly plural intrinsic goods.
- d) The virtues are objectively good.
- e) Some intrinsic goods are agent-relative.
- f) Acting rightly does not require that we maximize the good.

In terms of neonatal care and virtue ethics the character of the neonates parents as well as the health care practitioner are important because both parties will play a role in determining what will be in the best interest of the child.

2.3 Principles of Biomedical Ethics

Ethical principles were shaped predominantly by the Belmont Report and Beauchamp Childress' "Principles of Biomedical Ethics."⁸²

⁷⁹ Singh (note 63 above) 37.

⁸⁰ Ibid.

⁸¹ J Oakley „A Virtue Ethics Approach“ in H Kuhse & P Singer (ed) *A Companion to Bioethics* (1998) 88.

The Belmont Report defines „basic ethical principles“ as those general judgments that serve a basic justification for the many particular ethical prescriptions and evaluations of human actions.⁸³ It goes on to say that there are three main principles that are relevant to medical ethics that involve human subjects. These three principles are: respect for persons (Autonomy), Beneficence and Justice.⁸⁴ Beauchamp and Childress suggest a fourth principle that stems from Beneficence but can be viewed as a separate principle namely non-maleficence.⁸⁵ When dealing with ethical dilemmas there are several avenues to take depending on one’s beliefs and morals. These four principles are not always in harmony with each other. When facing a situation where an individual has the capacity and competency to make their own decisions and understand the nature and consequences in such case the principle of autonomy will dominate.⁸⁶

2.3.1 Autonomy

Autonomy at a very basic level means that there must be respect for persons.⁸⁷ This definition encompasses two rules. Firstly, that all individuals should be treated in such a manner that allows them to make their own decisions, it follows then that these decisions should be respected.⁸⁸ Secondly, individuals with diminished autonomy should be protected to ensure that no harm comes to them or anyone else.⁸⁹

An autonomous individual is one who has the capacity to deliberate about their goals and they are also capable of acting to achieve such goals.⁹⁰ Respecting ones autonomy would mean accepting such a person’s decision unless they pose harm. It follows then that in instances where the patient is a child and cannot exercise autonomy then the medical practitioner will act in the best interest of the child.

It is clear that in order to act autonomously there needs to be capacity, which a neonate lacks. It is important to note that although a neonate may not be in the position to make their own

⁸² Singh (note 63 above).

⁸³ Ibid.

⁸⁴ Ibid.

⁸⁵ Ibid.

⁸⁶ K Moodley (ed.) *Medical Ethics, Law and Human Rights. A South African Perspective* (2011) 41.

⁸⁷ Ibid.

⁸⁸ Ibid.

⁸⁹ Ibid.

⁹⁰ Ibid.

decisions, autonomy cannot be ruled out. Instead, and decisions regarding the medical care of the neonate would be made by the parents or guardians.

Parents or guardians are under a negative duty.⁹¹ They must act in the best interest of their child.⁹² This however, may be difficult because during the decision making process the parent may be influenced by their own economic, emotional or other circumstances and thus make a decision that is more beneficial to them rather than to the neonate.

Thus there are restrictions placed on parental autonomy. When a parent has to make a decision regarding what treatment to consent to or whether treatment should cease, such decision must be taken in the best interest of the child and further from the child's perspective. The child is of paramount importance here regardless of their capacity. This was evidenced in the case of *Hay v B and Others*.⁹³ In this case the respondents, who were the parents of an infant, opposed an urgent application by doctor Hay to administer a blood transfusion in order to save the infants life. The parents opposed the application on the grounds that such procedure was against their religious beliefs and further, they were concerned about possible infection. In this case, the court held that the child's best interest were of paramount importance in all matters concerning the child and further that the child's right to life outweighed and possible religious beliefs.⁹⁴

By this case, it is made evident that cases do exist where autonomy cannot be blindly followed. It is because of this that beneficence will come in. The Children's Act provides that no parent shall be allowed to refuse medical treatment and justify such action on the grounds of religious beliefs.⁹⁵

Thus such cases will no longer occur because the Children's Act prohibits it and in such cases beneficence will be dominant.

⁹¹ Van der Westhuizen (note 10 above) 97.

⁹² Ibid.

⁹³ *Hay v B* 2003 (3) SA 492(W).

⁹⁴ *Hay v B* 2003 (3) SA 492 (W) 495-496.

⁹⁵ Section 129.

2.3.2 Beneficence

All patients are to be treated in an ethical manner. This is done by not only respecting decisions that they make and protecting those who cannot act appropriately (as seen in the Autonomy section) but there is also an ethical duty imposed on health care practitioners to ensure the wellbeing of their patients.⁹⁶ This is in line with beneficence which is an act of kindness that goes beyond strict obligation.⁹⁷

All doctors have the responsibility to provide their patients with treatment and to do everything in their power to minimize harm.⁹⁸ The rules of beneficence guide health care practitioners to:⁹⁹

- Protect and defend the rights of others;
- Prevent harm from coming to others;
- Remove conditions that will cause harm to others;
- Help persons with disabilities and;
- Rescue persons in danger.

Putting this principle into practice we see that a medical practitioner must not only act in the best interest of their patient and contribute to their health and well being but they must also protect individuals, such as a neonate, and prevent harm from coming to such. In a scenario where a mother gives birth to an impaired baby, it is up to the medical practitioner to provide all care and treatment possible to the neonate and provide protection to the neonate should the parents or guardians oppose treatment. Further, a health care practitioner should not do anything to harm the newborn. Thus neonatal euthanasia would not stand with Beneficence because a medical practitioner has a duty to save lives, and not to take lives.

2.3.3 Non-Maleficence

One of the fundamental principles of medical ethics is “do no harm”. This principle requires medical practitioners not to deliberately harm others.¹⁰⁰

⁹⁶ Singh (note 63 above) 36.

⁹⁷ Ibid.

⁹⁸ Moodley K (ed.) *Medical Ethics, Law and Human Rights. A South African Perspective* (2011) 57.

⁹⁹ Ibid.

¹⁰⁰ Singh (note 63 above) 36, 37.

Just like beneficence there are rules of Non-Maleficence:¹⁰¹

- Do not kill;
- Do not cause pain and suffering to others;
- Do not incapacitate others and;
- Do not deprive others of a good life.

What needs to be done by the medical practitioner here is a thorough analysis of the possible risks versus the possible benefits.¹⁰² If the risk outweighs the benefit, then the action should not be done as it would violate the *primum non nocere* principle.

While benefits are being analyzed, it must be remembered that the benefit applies to the patient only. One patient should not undergo harm for the benefit of another patient. This “do no harm” principle is also entrenched in the Hippocratic Oath which states – “I will keep them from harm and injustice”.

It follows then that this principle does not include all types of harm as a doctor may have to perform surgery which even though it constitutes harm cannot be prohibited through the application of non-maleficence. The correct application of this principle would be seen as follows: In any given situation where the planned course of treatment for the applicable condition would not help the patient and reap no benefit but will instead cause harm and suffering in a situation where death would be unavoidable, then the practitioner should not proceed with the treatment because the harm or risk of harm outweighs the possible benefit. This sets the standard that there is no duty to treat if no benefit shall come from such treatment. This was proven in the *Airedale Trust v Bland*¹⁰³ case.

When dealing with an impaired neonate, a health care practitioner has a duty not to cause harm, however this is not absolute as discussed above. What needs to be done is an analysis of whether making a sick newborn undergo, sometimes, aggressive treatment will in fact be in its best interest. A practitioner cannot say that they have done no harm if the neonates’ prognosis is still critical, if the pain still persists and the chances of living a normal and fruitful life is practically

¹⁰¹ K Moodley (ed.) *Medical Ethics, Law and Human Rights. A South African Perspective* (2011) 63.

¹⁰² *Ibid.*

¹⁰³ *Airedale NHS Trust v Bland* [1993] 1 All ER 858 (HL).

non existent. What this means is that harm does not necessarily mean terminating a futile life, or giving treatment that causes more pain than actual benefit. This notion of do no harm extends to the neonates future. Practitioners should not aim to preserve a life for a day and provide treatment with the goal of prolonging a life. Instead it is submitted that the future condition of the neonate should be looked at. What also does not stand here is the notion that by harming one you can save the lives of many. Do no harm refers to one patient and does not put one patient up against another. It may stand on Utilitarian grounds to sacrifice one for the greater good, but non maleficence does not require the doctor to look at a group of patients but instead he must look only at his patient and what he can do to save that particular life.

Prolonging the inevitable is prohibited, but what must also be taken into consideration is the advancement of medicine. In the past a child born with a severe impairment may have been seen as a hopeless case. However, in todays world medicine has come leaps and bounds and many previously incurable conditions are incurable no more. Thus, another aspect that is important to look at when deciding whether to treat or not is whether there is hope.

2.3.4 Justice

Justice asks who ought to receive the benefits and who ought to bear the burdens.¹⁰⁴ An injustice occurs when a benefit is not given to someone who is entitled to such or a burden is unduly imposed on someone.¹⁰⁵ This principle dictates that everyone should be treated equally and that everyone should share in the good and the bad alike.¹⁰⁶

In the context of medical ethics the principle of justice requires that treatment of patients should be fair, equitable and impartial for all persons who have the same needs. All impaired neonates shall be treated in the same manner and one should not be favoured over another.

2.4 Quality of Life versus Sanctity of Life

The sanctity of life doctrine provides that life should be preserved at all costs.¹⁰⁷ This doctrine has strong roots in religion and thus its followers are of the belief that all human beings,

¹⁰⁴ Singh (note 63 above) 37.

¹⁰⁵ Ibid.

¹⁰⁶ Ibid.

¹⁰⁷ Van der Westhuizen (note 10 above) 112.

regardless of whatever illness or disability they may have, are creatures of god and should be seen as very sacred.¹⁰⁸ It follows then that god created life so only god should be the one to take it away. As a result, medical practitioners should provide treatment no matter how futile a case is deemed to be, because everything possible should be done to save a life.

On the other hand, the Quality of Life doctrine dictates that life is not absolute.¹⁰⁹ Here one must look at the quality of life that the neonate is likely to have and from this it will be determined if it is worthy of preservation. In the case of *S v De Bellocq*¹¹⁰ the mother in question was a medical student. After birth, the baby was found to have toxoplasmosis. The mother, with her medical background, decided that her child would not have a decent quality of life, subsequently she decided it would be best to end the child's life by drowning it. She was charged with murder. The judge stated that she was in a higher emotional state and that "she was in a puerperal state when a woman is inclined to be more emotional than the normal person". He went on to say however, that "the law does not allow any person to be killed whether that person is an imbecile or very ill. The killing of such a person is an unlawful act and it amounts to murder in law." However the court held that there would be no object in sending De Bellocq to prison nor would a suspended sentence be appropriate. The accused was never called upon for sentence and thus in a manner of speaking got away with murder. This leans towards the idea that in certain circumstances the law is lenient with the repercussions that go with the crime.

Quality of life is highly subjective. The assessor of such is not in the same position as the impaired neonate; all that can be done is based on pure speculation as future developments of medicine is still unclear. Another point to consider here is the idea that an impaired neonate is born into pain. All they have experienced from birth is pain, it can be argued from this that they may not be aware of what other feelings exist. We cannot deny care on the basis that an impaired neonate is suffering pain and we call for that to cease at all costs including taking a life, when in actuality, it is all the infants knows and instead treatment should be offered. Here it is also worthy to note that quality of life will not remain the same, medicine is advancing and through this advancement we could see a steady increase in treatment for various illnesses. Pain

¹⁰⁸ Ibid.

¹⁰⁹ Van der Westhuizen (note 10 above) 114.

¹¹⁰ *S v De Bellocq* 1975 (3) SA 538 (T).

is manageable; treatment should not be refused on the basis of the neonate eventually living a bad life quite simply because the future is anything but certain.

From this we see that quality of life is not as certain as it may seem. One cannot plan for something that you have not experienced nor can we favour the life of another over an impaired neonate just because of the hurdles placed in that very moment. However, the quality of life debate also raises the point that withholding treatment can in fact be justified because death is the lessor of two evils.

Some writers take a step further to say that quality of life should not only focus on the neonate, but also the quality of life that the family will live through with their impaired child.¹¹¹ Children who are born with an impairment are viewed by some as burdens or second rate citizens that are not worthy of first class medical care. Parents may grow to resent their child and the child in turn may begin to resent the life that it has. Not only is the quality of life of the child diminished but the parents are also left to face growing hospital bills and costs of treatment that may continue until the child eventually passes on. Non treatment is justified here by saying that the continuation of such a child's life has a far reaching negative impact on all concerned and thus death should be the course pursued not just in the interest of the child but also in the interest of the immediate family. This argument however it is put, appears to be twisted. One cannot equate suffering of parents to a new life.

Infants that are born with certain impairments require severe treatment, sometimes not to cure but rather to merely sustain life. This treatment offers a longer life compared to cases that were faced in the past. Although these infants will not have the same human experiences as a healthy child, they are still treated and their interest in life is accordingly preserved. Some parents make the decision to cease any treatment and such action results in the infants death.

2.4.1 Sanctity of Life

As discussed briefly above this standard requires that treatment be given and medical practitioners should do all that they can to preserve life which is of the highest value. One of the positions under the sanctity of life standard is Vitalism.¹¹² This holds that as long as a child is

¹¹¹ Members of the Hastings Center (note 30 above) 371.

¹¹² Members of the Hastings Center (note 30 above) 375.

alive and fighting a medical practitioner must provide treatment because where there is even a shadow of life, however weak, there is still hope. A child's life should be saved regardless of impairment. A heartbeat, respiration or brain activity are all signs that treatment should be given because life still exists and this hope only ceases upon death.¹¹³ By a medical practitioner withholding or withdrawing treatment he commits an unethical act. This principle is noticeably extreme in its approach. While a positive prognosis would demand further treatment, it is questionable whether an infant in severe pain on the brink of death should be put through aggressive treatments which may be futile purely based on the existence of a weak heartbeat or shallow breathing. It is a pointless attempt to preserve a life that is no longer strong enough to continue. If medical practitioners are agreed that the neonate will soon die and further treatment will not change the condition, then treatment should not be allowed. If a vitalist still stands firm in their belief that treatment should be provided regardless then they are protecting life only and not what would be in the best interest of the neonate. What should be done is not found in pumping a neonate with medication and causing more pain but rather letting die with dignity.

2.4.1.1 Medical Indications Policy

Paul Ramsey proposes a more reasonable sanctity of life position in the form of the Baby Doe Rules.¹¹⁴ According to his standard, each infant/child should be viewed equally in terms of dignity and intrinsic worth. That being said, no child should be denied treatment purely based on their impairment or the future quality of life that they are presumed to have. All infants should be treated unless such falls into the following two groups:¹¹⁵

- When Doctors agree that the infant is already in the process of dying;
- When the course of treatment is deemed to be medically contradicted.

Ramsey is of the view that the only comparison that should exist is between the different forms of medication and their beneficial nature.¹¹⁶ At no time is it acceptable to compare impaired and normal children in order to determine who should live.

¹¹³ Ibid.

¹¹⁴ Members of the Hastings Center (note 30 above) 376.

¹¹⁵ Ibid.

¹¹⁶ Ibid.

2.4.2 Quality of Life

It is generally agreed that if the quality of life of a newborn infant will be exceedingly low because of his disabilities, then the infant need not be kept alive but may be either made or allowed to die.¹¹⁷ This phrase is ambiguous and raises more questions than it does provide answers. For instance, some define quality of life objectively by focusing on the ability of the individual to function materially in society; others use a subjective approach and focus on the experiences of the individual and on his life satisfaction.¹¹⁸ It in essence is used to denote how much of social worth an individual has. This social worth is measured by balancing the burdens and benefits that said individual will have on other people like their family members.

When dealing with severe impairment many parents and physicians may feel that subjecting a newborn to intense treatment will cause more harm than good and it is on this premise that withholding treatment is justified.¹¹⁹ Through their eyes, the pain and suffering that the child will go through only to end up living a less than satisfactory quality of life is in no way worth the social and economic cost of treatment.¹²⁰ It would appear that this train of thought has been adopted based on its common sense approach but what is of concern here is that these individuals make the assumption that the quality and utility of ones life can be weighed up against that of another and that resources should only be given to those who prove to be the most useful. While there may be merit in saying that quality of life is diminished when impairment rears its head, it is submitted that in no way should it be acceptable for medical treatment to be given based on who is more useful and whose life will be of a higher standard. Pain should never be used as the benchmark for who should live and who should die. Pain alone, if not totally unmanageable, does not sufficiently show that a life is so worthless that death is preferable.¹²¹ Although many may argue that this line of thinking is wasteful of precious resources, we must not forget the human rights that all acquire upon taking a first breath.

This notion of looking at benefits and burdens raises more than a few eyebrows. One cannot measure the worth of a life based on utility, more so when an infant was helpless in choosing to

¹¹⁷ Van der Westhuizen (note 10 above) 243.

¹¹⁸ Ibid.

¹¹⁹ John A. Robertson "Involuntary Euthanasia of defective newborns" in Mappes and DeGrazia (eds.) *Biomedical Ethics* (2001) 369-374.

¹²⁰ Ibid 370.

¹²¹ Ibid.

be born with an impairment.¹²² It is granted that external factors do play a role in the infants quality of life as their parents will be affected by the situation, but the standard should not be judged externally but rather focus on the infants well being and not how useful they will be.

Quality of life can also be measure by a comparison of the life the impaired neonate will live versus what is regarded as the „acceptable“ life.¹²³ This is clearly highly subjective as we are all very different people with different preferences. What may be acceptable to one person may not necessarily be acceptable to another.

A subset of the quality of life standard is the Best Interest of the Child. The Medical Indication Policy as previously discussed, fails to take into account quality of life which the Best Interest of the Child standard does. This standard maintains that infants should be given live sustaining therapy with the exception of:¹²⁴

- The infant already facing death;
- Treatment is medically contradicted or;
- Continued life would be worse for the infant than an early death.

With this third consideration we see quality of life being brought in from the infants perspective and not societies. This allows for the course of action that truly is in the best interest of the child without over treatment as seen by the Sanctity of Life standard or under treatment which may be influenced by the parents circumstances or the burdens outweighing the benefits.

2.5 Conclusion

Everyone has a sense of what is right and what is wrong. Medical practitioners dealing with end of life decisions of impaired neonates may not necessarily jump to ethical theories in order to reach their decision, however, they still have the sense to determine what should and what should not be done. Thus, ethics are not extensively followed but merely provide a framework for what is already developed in our minds as different moral views can still lead a practitioner to the same decision.

¹²² Ibid.

¹²³ Ibid.

¹²⁴ Ibid.

Chapter 3 – The Law

3.1 Introduction

Human rights are protected not only at a national level but also at an international level. The provisions that are found in International Human Rights Instruments are given effect to in South African legislation. Thus, the starting point for an analysis of the law will commence with International law. Here the standard of protection afforded to neonates will be analysed in order to determine if South Africa has truly done all that it can in protecting this vulnerable group and in so doing risen to the promises made at an international level.

3.2 International Human Rights Instruments

The International Covenant on Economic, Social and Cultural Rights¹²⁵ (hereinafter referred to as the ICESCR) of 1996 guarantees that everyone has the right to life. All states that are party to the ICESCR are required to have a high standard of health care. The right to life is further protected in the International Covenant on Civil and Political Rights of 1996¹²⁶ (hereinafter referred to as the ICCPR) of 1996 as well as the African Charter on Human and Peoples Rights of 1981.¹²⁷

The Universal Declaration of Human Rights, although not legally binding, echoes the right to life in Article 3. All of these instruments protect the rights of all individuals who are party to it. However, special protection is needed when children are involved. The Convention on the Rights of the Child (hereinafter CRC) of 1989 provides such protection. It is the first International Instrument that acknowledges the difference in age groups and as a result does not place everyone in the same box. Instead, it recognizes that children are not like adults and therefore require different degrees of protection. The CRC places an obligation on state parties to ensure protection of children. This document was ratified by South Africa on 16 June 1995. The CRC provides that a child is a human being that is below the age of eighteen. It further provides that children need protection both before and after birth. Article 3 introduces the best interest of the child standard and Article 6 guarantees a child's right to life.

¹²⁵ Article 12(1) of the International Covenant on Economic, Social and Cultural Rights of 1966.

¹²⁶ Article 6 of the International Covenant on Civil and Political Rights of 1996.

¹²⁷ Article 4 of the African Charter on Human and Peoples Rights of 1981.

On 7 January 2000 the African Charter on the Rights and Welfare of the Child was ratified into South African Law. Article 4(1) also makes reference to the best interest of the child standard which is set as a primary consideration. Article 5(1) entrenches the right to life by imposing a duty on states parties to ensure as far as possible the survival, protection and development of the child. Article 14(1) and 14(2) provide that every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health. It also imposes on states parties the obligation to reduce infant and child mortality rate.

All of these instruments provide a blueprint for the protection and preservation of life with particular focus on infants. The burden lies on South Africa to give effect to the above provisions.

3.3 The Constitution of the Republic of South Africa, 1996

3.3.1 Introduction

This chapter seeks to determine if South African legislation has followed through with its international obligations and in so doing assess whether sufficient protection is afforded to neonates.

It is important to note from this point that not all rights are absolute. In this regard section 36 of the Constitution is of particular relevance. The general limitations clause allows for rights in the Bill of Rights to be limited. The Constitution reads as follows:

The rights in the Bill of Rights may be limited in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all the relevant factors, including –

- a) Nature of the right;
- b) The importance of the purpose of the limitation;
- c) The nature and extent of the limitation;
- d) The relation between the limitation and its purpose; and

e) Less restrictive means to achieve the purpose¹²⁸

The limitations clause essentially provides for the rights entrenched in the Bill of Rights to be limited as long as the above mentioned criteria are met. If the criteria are met then it follows that the restriction will not be unconstitutional. A two stage approach has been developed. The first stage is to ask whether there has been an infringement of a right by law or conduct. The second stage is to ask whether such infringement is indeed justifiable in an open and democratic society.

3.3.2 The Right to Life

The right to life is entrenched in Section 11 of the Constitution. This right is bestowed on legal persons. A fetus is not a legal person and thus acquires no rights until a first breath is taken. A neonate has been born alive and thus is afforded protection and rights that a fetus does not have. There is a negative duty not to take a life, however, making the wrong decisions with regard to treatment could result in the neonates life being endangered or the pain and suffering being prolonged. It is unlawful to take a life, but the suffering imposed on a neonate may also be too great a burden to bear. The right to life is a right that forms part of the Bill of Rights and can thus also be limited under section 36.

In *S v Makwanyane*,¹²⁹ Justice O'Regan explained that the right to life is imperative because without it, it would not be possible for a person to have these rights and to exercise them.¹³⁰ O'Regan went on to say that the right to life forms part of the Bill of Rights not just to enshrine the right that individuals have to an existence. This right does not mean that organic matter is protected but rather the right to human life in the sense that individuals have the right to live as a human being, to be part of a broader community as well as to share in the experiences of humanity.

S v Makwanyane and the above interpretation of the right to life given by O'Regan, we see that a neonate has been born alive and as such has acquired legal personhood. This acquisition is essential to the „what next“ process. Being born alive and taking a first breath is the beginning of greater protection that a fetus does not enjoy purely because it is still in utero. The neonate is

¹²⁸ Section 36 of the Constitution.

¹²⁹ *S v Makwanyane* 1995 (3) SA 391 (CC).

¹³⁰ *Ibid.*

now entitled to protection in terms of the Bill of Rights which includes the right to life. This would mean in practice that regardless of the impairment that the neonate is entitled to receive treatment and to be kept alive. The other side to the right to life debate stems from the right to dignity. It can be argued that although a neonate has the right to life, if they will not be in a condition that allows them to participate in activities, interaction, living a normal life and medicine or treatment will only prolong the inevitable then the neonate has the right to die with dignity. This notion was found in the Soobramoney case which showed that the right to life does not go so far as to include the right to evade death.

*Soobramoney v Minister of Health (KwaZulu-Natal)*¹³¹ dealt with the right to life and how far this right can be used and protected. The patient required dialysis twice a week in order to stay alive. He sought to claim this right under section 27 of the Constitution which entitles everyone access to health care service provided by the state. The court acknowledged that the state has a constitutional obligation to provide health care but found that this extends only so far as it is able to within its available resources. The court held that if treatment were to be provided to the patient then it would have to be allowed for all in the same position as him. This would obviously deplete state resources and prove to be highly expensive given the form of treatment and duration of such.

The Constitutional Court held that the right not to be refused emergency medical treatment means that a person who suffers a sudden catastrophe which calls for immediate medical attention should not be denied ambulance or other medical services which are available and further a person in such situation should not be turned away from a hospital that is able to provide the treatment that is needed. The court accordingly decided that this situation did not classify as an emergency. The court further held that the right not to be refused emergency medical treatment is separate from the right to life and needs to be looked at with reference to the availability of health resources.

This case leans towards the idea that death is a natural part of life and the state cannot be expected to fund treatment for all that prolong the life of an individual whose condition is such that there is no hope for recovery. The justification given for this is simply that there are

¹³¹ *Soobramoney v Minister of Health (KwaZulu-Natal)* 1998 (1) SA 765 (CC).

insufficient resources and the little that there is should rather be used on those individuals who have a better chance of recovery.

The law cannot be extended to evade death. “The state has to manage its limited resources in order to address all these claims. There will be times when this requires it to adopt a holistic approach to the larger needs of society rather than focus on the specific needs of particular individuals within society”.¹³² This view raises two new debates. On the one hand it raises concerns largely because when treating an impaired neonate one cannot ascertain whether the course of treatment will have the opposite effect and merely serve to prolong the life. What should instead be done is state hospitals should follow in the steps of private hospitals and first allow the neonate a chance to fight and overcome before providing aggressive treatment instead of just disregarding the value of that life and moving on to the next newborn.

On the other hand, the case provides that if treatment is futile then it can be withheld. We see in the *Soobramoney* case, that the treatment was needed to keep him alive and further that the cost played an important role in what the state is allowed to provide and where it is acceptable for the to draw the line. The same applies to a neonate. Where treatment is used purely to keep a newborn alive and such treatment is out of the primary health care scope, then withdrawal or withholding of such treatment would be justified in the same way that it was justified in the *Soobramoney* case. Patients are only entitled to free primary health care, this excludes the time spent in an intensive care unit.

The Children’s Act and the National Health Act do not state the prescribed standard of health care that is expected when treating an impaired neonate or any infant for that matter. The Children’s Act further fails to address a child’s right to primary health care and does not set a minimum standard for what is required when treating a child.

What this means is that private hospitals will provide treatment as long as payment is being made. State hospitals differ in that where there is little hope, resources will not be wasted on a sick neonate. Here an element of discrimination needs to be addressed. Strauss makes references of an apt quote seen at a graveyard in England - „If life were merchandise that med

¹³² Ibid.

could buy, the rich would live and none but poor would die.”¹³³ The only difference between saving the life of a neonate here is that the one finds itself in a private hospital being born to parents who have deeper pockets than the one who was born at a state hospital and is denied the opportunity to prove whether he will be able to survive.

3.3.3 The Right to Dignity

The Constitution provides that everyone has inherent dignity and the right to have their dignity respected and protected.¹³⁴ Dignity is one of the most important rights as a founding value of our Constitution. When a person is ill and they are dependent on someone else to do activities that some may take for granted, it is obvious that their sense of dignity will gradually get eaten away. This stretches as far as vegetative conditions or even a child that will grow up to depend more and more on someone else to bath, feed, change and do other tasks that one should be able to do for oneself.

Thus it is submitted that where a person’s dignity is diminished, they no longer enjoy a decent quality of life.

3.3.4 The Best Interest of the Child

The Constitution states that a child’s best interests are of paramount importance in every matter concerning the child.¹³⁵ This principle finds its roots in the case of *Fletcher v Fletcher*.¹³⁶ From this case we see that there was a shift from parental rights to the rights that every child has from the time they take their first breath. The protection of the child’s interests is taken further in the Children’s Act which will be discussed later on. What is worthy to note here is that this standard is deemed to be effective in divorce matters and over the issue of who the child would be better off with. However the Act clearly states that in all matters concerning the care, protection and well-being of a child the standard that the child’s best interest is of paramount importance, must

¹³³ SA Strauss *Doctor, Patient and the Law* 3rd ed (1992) 336.

¹³⁴ Section 10 of the Constitution.

¹³⁵ Section 28(2) of the Constitution.

¹³⁶ *Fletcher v Fletcher* 1948 (1) SA 130 (A).

be applied.¹³⁷ This means that the standard extends beyond the scope of divorce and family law and neonates are offered protection by this standard even with medical matters.

When an adult makes a decision such is made on the basis of autonomous choice or, in cases where they are no longer competent but their views on the matter were known, by substituted judgment.¹³⁸ It is clear from this that the position for newborns is different because they cannot act as autonomous agents as they are not competent and therefore the parents step in as proxy or at a higher level the High Court will step in as upper guardian of all minors. The standard used by all parties in this regard is the best interest of the child. This is a beneficence standard, and reflects an attempt to weight up different competing interests, or to adjudicate which course of action will lead to the best balance of net benefits and burdens for the child.¹³⁹ According to Wilkinson, in practice the key task for parents and doctors treating these neonates is to look to the future and imagine what the life of that infant will be like and the key question is whether the life in question will be of sufficient quality for that individual, to justify the act of sustaining it.¹⁴⁰

While we know that this standard exists and that its purpose is to afford protection to all children, this standard may not be used correctly in many cases. What is supposed to be done requires the parent, guardian or medical practitioner to put themselves in the position of the neonate in order to determine what would be in their best interest. While this seems easy enough, this is not always the case. One needs to remember that although the parents or medical practitioner are attempting to look at the situation through the eyes of the child, they will never truly be in the child's position and never really understand or see how the future life could possibly play out. Another issue worthy of noting here is that there will always be differing views and opinions as to what would be in the best interest of the child. As upper guardian of all minors, the High Court would step in to make a decision that are in the best interests of the neonate and not necessarily in line with the thinking of parents or guardians who may be swayed by the economic and emotional hardship that they feel awaits if life is allowed to continue. In the case of *Hay v*

¹³⁷Section 9 of the Constitution.

¹³⁸ D Wilkinson *Is it in the best interests of an intellectually disabled infants to die* J Med Ethics 2006; 32: 454-459.

¹³⁹ Ibid 455.

¹⁴⁰ Ibid.

*B*¹⁴¹ an infant was in need of a blood transfusion, failure to receive such would result in its death. The infant's parents rejected the transfusion stating that a blood transfusion was against their religious beliefs and secondly, they were concerned about the risk of infection. The pediatrician applied to the High Court as upper guardian for permission to do the blood transfusion. The court granted the required permission on the grounds that the child's best interests are of paramount importance, the child's life is protected by the Constitution¹⁴² and any action to end this would be a violation. The court found that whilst the right to freedom of religion is protected under section 15(1) of the Constitution, refusing a lifesaving blood transfusion in favour of religious beliefs is in no way reasonable and justifiable in an open and democratic society. The court also found that the High Court as upper guardian can overrule the decisions that a parent may make and can order for medical treatment to be given if such decision is inconsistent with what is deemed to be in the best interest of the child. The court provided that the parents' religious beliefs could be overridden by the best interest of the child and the child's right to life.¹⁴³

While the best interest of the child is of paramount importance, like any other right in the Bill of rights can be limited via the s36. This was recognized in *S v M*¹⁴⁴ which emphasized that one still needs to take into consideration other rights and in so doing the right may be limited. While a neonate takes its first breath and is accordingly entitled to protection, these rights are affected by circumstance. A neonate born to a wealthy family enjoys peace of mind of knowing that as long as their pockets are deep or it can be covered by medical aid, all shall be done to save the life of their infant. However, the story is very different for those who walk into the doors of the public sector where the end is bleak for those with empty pockets, no medical aid and a hospital that may lack facilities or be over booked. It goes without saying that what can be done in the private sector cannot always be done in the public sector. Thus, the best interest of the child can be limited in the sense that the treatment that is given is done within the means of what the parents or the hospital can afford. One cannot make demands on the public sector because of the limited resource available as seen in the *Soobramoney* case.

¹⁴¹ *Hay v B* 2003 (3) SA 492 (W).

¹⁴² Section 11 of the Constitution of the Republic of South Africa.

¹⁴³ *Hay v B*: 495.

¹⁴⁴ *S v M* (Centre for Child Law as Amicus Curiae): 26.

3.4 South African Legislation

3.4.1 The National Health Act 61 of 2003

Section 27 of the Constitution deals with Health care and as such there was a need to enact legislation dealing with this. The National Health Act gives effect to s27 of the Constitution and aims to protect, respect, promote and fulfill the right of vulnerable groups such as women, children the elderly as well as persons with disabilities.¹⁴⁵ One thing is clear from this: Neonates that are impaired would fall under this Act and receive the necessary protection. What is of concern however, is that the Act makes no reference to neonates and neither does it provide a definition of what a neonate is or what procedure should be followed in order to provide the required protection.

S 4(3)(a) states that:

Subject to any condition prescribed by the Minister, the State and clinics and community health centers funded by the state must provide pregnant and lactating women and children below the age of six years, who are not members or beneficiaries of medical aid schemes, with free health services.

This raises many questions. Does the free health services that the Act makes reference to include specialized care that a neonate would need or does this free care end at primary care? Does this apply to public hospitals only or can a less wealthy woman give birth in a private hospital and lay claim to intensive care treatment if her child is impaired and claim this right under section 4(3)(a)?

From this it is clear that there is a need for these issues to be addressed. Extending treatment and taking the above mentioned right at face value would impose a heavy burden on the public sector and the demand is not one that our health care system would be able to keep up with. As previously discussed, there are limitations that can be imposed on all rights in the Bill of Rights as no right is absolute. The Act needs to make these limits clear instead of stating rights broadly and the standard of medical service needs to be defined so all parties know where they stand.

¹⁴⁵ Section 2(c) of the National Health Act 61 of 2003.

3.4.2 The Children's Act 38 of 2005

The Children's Act aims to give effect to certain rights of children as contained in the Constitution as well as to set out principles relating to the care and protection of children whilst also to define parental responsibilities and rights.

Section 1 of the Act defines a child as a person under the age of 18 years.

This means that all individuals who are below the age of 18 years will be deemed to be children. What this essentially does is place all children in the same little box and fails to take into account that children of different ages require different levels of protection. Surely it is not a hard concept to digest that a child who is just born and has no voice should be granted a higher degree of protection than a child who is 17 years old and has full knowledge and understanding of his rights and is accordingly able to voice his opinions more effectively than a child who is younger and thus less knowledgeable. Just like a fetus is afforded more and more protection as the pregnancy progresses the opposite is needed after birth. There needs to be a distinction that is drawn between different age groups in order to protect those who are not in a position to protect themselves and may find themselves at the mercy of a parent or guardian who did not want an impaired child or finds themselves in a state of post partem depression and as such decides to withdraw or refuse treatment with the goal of getting rid of the problem.

Before an operation can be done or treatment can be administered there needs to be consent. In the case of *Stoffberg v Elliot*¹⁴⁶ an operation was found to be a wrongful act because it was done without the necessary consent. Further, in *Castell v De Greef*¹⁴⁷ the consent was provided but the doctor failed to bring the material risks of the procedure to the patients' attention and thus the consent was not informed.

Such consent can be implied by conduct or can be written or oral.¹⁴⁸ It is evident that a neonate cannot consent and cannot provide any direction as to treatment because it does not have the necessary capacity to consent. The Children's Act provides that before a child can undergo

¹⁴⁶ *Stoffberg v Elliot* 1923 CPD 148.

¹⁴⁷ *Castell v De Greef* 1994(4) SA 408.

¹⁴⁸ Carstens and Pearmain 2007 898.

surgery or be given treatment the element of consent must be fulfilled.¹⁴⁹ This is done through the parent or guardian.

Chapter 4 - The Position in England and the Netherlands

4.1 Introduction

From the previous chapter it is evident that the current position in South African law fails to address neonatal protection in any sufficient detail. This grey area in our law, if not dealt with properly, not only violates the right of innocent babies but can also lead to innocent lives being lost because our law has failed to provide adequate protection to infants who really need it.

One thing is strikingly obvious. There is need for change. Law cannot remain static. Once the needs of the people change and develop so too should the National Health Act as well as the Children's Act. It is evident from the previous chapter that these Acts do not provide definitions, groups all minors together and does not even hint at procedures to follow when dealing with impaired neonates. What is done in these Acts is rather a brushing over of terms and the granting of protection without stating how to go about implementing anything. The answer is obviously that these gaps need to be filled.

This Chapter will look to other parts of the world (England and the Netherlands) in the hopes of unpacking tried and tested methods that can be adopted into South African law to bridge the distance between protection and its implementation. Here the focus will be on how each jurisdiction embraces or shuns euthanasia of neonates and what South Africa stands to learn from each.

4.2 Euthanasia in England

Neonates are not in a position to make their decisions known and thus they are dependent on their parents or guardians to act in their best interest.¹⁵⁰ It is only when a first breath is taken does the newborn acquire all the rights that are set out in the United Nations Convention on the Rights of the child, 1989 (CRC) which was ratified by the British government in 1991.¹⁵¹ The

¹⁴⁹ Section 129.

¹⁵⁰ J Bridgeman *Because we Care? The Medical Treatment of Children?* (2007) 8.

¹⁵¹ Van der Westhuizen (note 10 above) 196.

CRC is not binding in court, but still serves to guide on how the law should be developed.¹⁵² Article 3 places obligations on States Parties that in all actions concerning children the best interest of the child shall be a primary consideration. Article 6 goes on to protect a child's right to life and Article 24 requires States Parties to recognize the right of the child to the enjoyment of the highest attainable standard of health and facilities for the treatment of illness and rehabilitation of health.¹⁵³

Under the Children and Young Persons Act of 1933 young children are afforded the right to health care¹⁵⁴ and this was further developed in the Children's Act 1989.

When the Children's Act came into effect England saw a shift from the norm of parental rights to parental responsibilities and as such, there was a move away from the thinking that children were property of their parents but there was now an acknowledgement that parents have the responsibility to protect their children and their interests.¹⁵⁵ The Children's Act further imposes a duty on the holder of parental responsibilities to ensure that their children receive appropriate medical care. If there is a failure to act accordingly when it is necessary then such is deemed to be a criminal offence in terms of the Children and Young Persons Act 1933.¹⁵⁶

From the above we can see at the very outset that England has made more progress than South Africa in dealing with Children. Not only is there a Children's Act but there is also a Children and Young Persons Act which doubles the protection and makes failure on the part of the parents a criminal offence. Such repercussions should be extended into South African law to allow neonates a fighting chance to the health care it needs and should this be denied or the parents refuse for whatever reason this should not be the end of it.

We see that England is very similar to South Africa in the chain of informed consent, parental responsibilities and in allowing the court to act should there be a dispute between medical practitioners and parents. But, how do they fair in issues regarding withdrawal and withholding of treatment or letting a neonate die?

¹⁵² Ibid.

¹⁵³ Ibid.

¹⁵⁴ Section 1(2).

¹⁵⁵ Van der Westhuizen (note 10 above) 197.

¹⁵⁶ Section 1(1) and 1(2).

Similar to the South African case of *Hay v B, In re O*¹⁵⁷ dealt with a 12 week premature baby girl who suffered from respiratory distress syndrome who needed a blood transfusion to survive. The Doctors all agreed that a failure to provide this emergency medical treatment would result in her death. The baby's parents opposed the treatment as they were devout Jehovah's Witnesses. The court was asked to intervene. The court acted in favour of the best interest of the baby and as such over ruled the parents' right to religious freedom.

In *NHS Trust v MB*¹⁵⁸ the father of Baby M was a practicing muslim and thus did not support the idea of withholding or withdrawing mechanical life support from his child. He argued that it is only gods place to decide who should live and who should die. The court however held that the best interest of the child needed to be taken into account and accordingly ordered for ventilation to be removed.

*In re A*¹⁵⁹ the issue of surgical separation of conjoined twins was discussed. The twins shared a common artery and the parents who were Roman Catholics did not wish to proceed with surgery on the basis that the weaker twin would die. The hospital brought an action to the High Court to order the operation to go forward. Here what was sought was confirmation that no prosecution would follow as a result of the death of one twin. The court reasoned here that by not doing the surgery a few months later neither of the twins would survive. Thus the court held that the surgery should proceed.

From the above three cases it is clear that saving a child's life takes preference over the parents religious beliefs, and where a life can be saved it must be done. The European Convention on Human Rights¹⁶⁰ (hereinafter the ECHR) protects the individual's right to life, regardless of how old the person is. Thus, if a person who has parental responsibilities towards a child and withholds treatment which causes death then such a person will be charged with murder.¹⁶¹ However that is not to say that all must be done to prolong life at all costs and in all circumstances. Parents and health care professionals must take the course of action that is in the

¹⁵⁷ *In re O* [1993] 2 FLR 149.

¹⁵⁸ *NHS Trust v MB* [2006] EWHC 507 (Fam): [49].

¹⁵⁹ *In re A* [2001] 2 WLR 480.

¹⁶⁰ Article 2.

¹⁶¹ Van der Westhuizen (note 10 above) 215.

best interest of the patient and it is through this action and way of thinking that their duty is fulfilled.¹⁶²

It seems clear that where there is hope, a medical practitioner must treat however this does not mean that life must be prolonged above all else. Article 2 of the ECHR removes the obligation to treat where the case is futile. This is evidenced in the case of *In re J*¹⁶³ where Baby J was born 27 weeks premature. Doctors agreed that he would develop serious spastic quadriplegia further her was blind and deaf. The issue before the court was whether Baby J should be mechanically ventilated should he stop breathing on his own. Lord Donaldson emphasized that the best interest of the child must be weighed against the opinions of the family members as well as the medical experts. This shows that the answer does not always lie in isolation but rather should be taken jointly by the court, the parents and the doctors. After looking at the benefits that treatment promised and the burdens that would continue if this life was prolonged, the court held that it would not be in Baby J's best interest to prolong his life.¹⁶⁴

Lord Donaldson and the approach adopted by England teaches us two things. Firstly that one need not wait for an infant to be on a ventilator before such decisions can be made and secondly, the pain and suffering that the child will experience if their life is prolonged needs to be given the adequate attention from the view of the infant before making any decisions.¹⁶⁵

4.3 Euthanasia in the Netherlands

We have seen that the South African as well as the English approach to euthanasia is anything but liberal. There is a common fear that euthanasia may bring forward murder charges and thus medical practitioners are wary to stay within their limits and as such would rather prolong life than hasten death. What will follow in this chapter is a discussion of a more liberal stance that is found in the Netherlands.

The approach adopted here is analysis of the quality of life that the infant will have and it is from this analysis that the decision to terminate life support treatment is made. What the medical

¹⁶² Van der Westhuizen (note 20 above) 216.

¹⁶³ *In re J* [1991] 2 WLR 140.

¹⁶⁴ *Ibid.*

¹⁶⁵ *In re J* 149.

practitioners do here is withdraw or withhold life sustaining treatment to the infant, there is no deliberate ending of the neonate's life and thus no consequences are attached to this action.

Article 11 of the Dutch Constitution requires a physician to obtain consent before any treatment is provided. Further, a physician who imposes treatment on the patient without the patient's consent, purely because they believe that that is what is truly in the best interest of the patient can be prosecuted for a criminal offence and further opens the door for civil action.¹⁶⁶ It is obvious from a neonatal perspective that an infant is not capable of consenting to anything because it lacks capacity and is not of the right age. The parents thus step in and it is their consent that is necessary before a medical practitioner can provide medical treatment. With the issue of consent out the way, what needs to be looked at now is the actual process that follows the birth of an impaired neonate up to the stage where the decision is made regarding end of life issues.

There is little to go by with regards to when one should prolong life and when the suffering should be allowed to come to an end through withdrawal or withholding of life-sustaining treatment. While it may seem like an act of kindness to end the pain, this issue is not black and white after all, a life is at stake and medical miracles do occur. The Netherlands has established three categories of end of life decisions in the case of neonates.¹⁶⁷ Firstly there is the withholding of medical treatment. This is done by withholding or withdrawing ventilation or feeding tubes. The second category is where the medical practitioner provides the patient with painkillers and sedatives that will hasten death. The last category is the deliberate ending of the competent patient's life upon their request. This last category from a neonatal point is illegal and one cannot kill a neonate as obviously a neonate is not competent to consent to such nor ask for such.

Before an end of life decision can be made there needs to be consults with another doctor and the decision to end the infant's life must be discussed with the health care team. Thus it is clear that in the Netherlands it is not illegal to withhold or withdraw medical treatment from an impaired infant whose quality of life brings no joy and the prospects of recovery are futile. It is thus possible to bring an end to life sustaining treatment so long as the parents provide the necessary consent.

¹⁶⁶ Van der Westhuizen (note 10 above) 229.

¹⁶⁷ Van der Westhuizen (note 10 above) 231.

While England and South Africa appear to be lagging behind, the Netherlands have gone beyond empty Acts that sit on the fence and provide no clarity. The Netherlands instead takes a proactive approach and through The Dutch Association of Pediatrics formed a Perinatology Section which led to the establishment of a Working Group whose function was to draft guidelines that could be followed when dealing with end of life issues in Neonatology.¹⁶⁸ This group came to the conclusion that ending a life of a child when the advised treatment will not have a positive effect is the responsibility of all Neonatologist.¹⁶⁹ He group further clarified that there is no ethical difference between the withholding of treatment versus the withdrawal of treatment. A further distinction was drawn between what is termed “kansloos” medical treatment where death is inevitable and “zinloos” medical treatment where the treatment would be futile.¹⁷⁰

With the establishment of two types of medical treatment, the logical step that the Working Group progressed to is laying down criteria that would aid a medical practitioner in determining when medical treatment would be deemed futile. This is as follows:¹⁷¹

- Suffering and pain;
- Permanent functional impairments;
- Anxiety;
- Bleak prospects for the future;
- Life expectancy;
- Capacity to communicate – verbally and non-verbally;
- Possibilities for personal development – Learning to read, write, work;
- Self-sufficiency – capacity to sit, walk, live and care for oneself and
- Dependency on medical care – how many times will they have to be hospitalized.

The Working group went on to make it clear that these rules should not be looked at in a rigid manner. What needs to be kept in mind is the fact that the neonates circumstances are subjective but their future should be looked at objectively.¹⁷²

¹⁶⁸ Van der Westhuizen (note 10 above) 233.

¹⁶⁹ Ibid.

¹⁷⁰ Ibid.

¹⁷¹ S Moratti „End of Life Decisions in Dutch Neonatology“ (2010) *Medical Law Review* 18:477, 489.

¹⁷² Strauss (note 133 above) 477.

With that being said we note that there is no duty that is imposed on medical practitioners to treat neonates where such treatment would be futile. This decision is shown through several cases that will now be discussed.

In the *Baby Ross* case¹⁷³ the infant had down's syndrome and duodenal atresia. The pediatrician chose not to operate on the basis that the infant's parents would not provide consent for such. The pediatrician instead administered a sedative and the infant eventually passed on. Later a charge of murder was brought forward, the pediatrician was acquitted. On review the decision was confirmed on the basis that the parents had not consented and thus no obligation on the pediatrician existed.

The *Prins* case¹⁷⁴ dealt with a neonate who was born with spina bifida, hydrocephalus, a spinal cord lesion as well as brain damage. The Baby was four days old when Prins ended her life on the basis that her prognosis was such that according to medical opinion any surgery would not be beneficial.¹⁷⁵ The parents also asked the medical practitioner to end their infant's life because of the severe pain the infant was going through as evidenced by the screaming and crying. The District Court at Alkmaar acquitted Prins.

In the *Kadijk* case¹⁷⁶ the infant was diagnosed with Trisomy 13 as well as other congenital malformations. The Doctor discussed the state of affairs with the parents and advised them that the infant had between a week and a few months of life. The parents then took the infant home. Later complications arose and the pain was so great that painkillers did nothing to alleviate it. The Doctor, with the consent of the parents, administered a high dose of two lethal drugs which resulted in the infant's death. The court acquitted Kadijk on the following grounds:¹⁷⁷

- The diagnosis as well as the prognosis was clear to all parties.
- Kadijk had consulted with another experienced general practitioner as well as a pediatrician and,
- The death was brought about according to acceptable medical practice.

¹⁷³ Nr. 46. Hoge Raad (Strafkamer) DD89.398. *Nederlandse Jurisprudentie. Uitspraken in burgerlijke en strafzaken* 1990:200.

¹⁷⁴ Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41.

¹⁷⁵ Van der Westhuizen (note 10 above) 236.

¹⁷⁶ This case is reported in *Tijdschrift voor Gezondheidsrecht*, No 5/1996:284-291.

¹⁷⁷ Van der Westhuizen (note 20 above) 237.

These cases show that under Dutch law namely Article 40 of the Dutch Penal Code the Doctors are able to raise the defense of necessity when facing murder charges. The basis of the argument was that “the responsible doctor had been confronted with a conflict of duties between the two ethical imperatives that characterize the medical profession; saving life and relieving suffering”.¹⁷⁸ The Doctors did not merely take the decision into their own hands. What was done is a consult with another independent doctor who also came to the same conclusion – medical treatment would be futile. It is here that the Netherlands stakes a step beyond what England and South Africa has done and they deal with the issue head on without skirting the issue. It is at this point that there is a shift from saving a life to ending the pain and this shift, if regulated properly like the Netherlands proposes, can be ethically sound and in the best interest of the neonate. It is this very line of thinking that led to the birth of the Groningen Protocol.

The Groningen Protocol was developed with the idea that Doctors would be able to terminate the life of an infant in exceptional circumstances and if the correct criteria are met to escape the net of any resulting charges.¹⁷⁹ Although this Protocol does not formally form part of Dutch law it is still a step forward with regards to euthanizing neonates.

The Protocol makes reference to three categories: First, where there is no chance of survival even if the best medical treatment is administered. Here withdrawal or withholding of treatment would not be frowned upon because all attempts at saving the life will be futile. Second, where there is a poor prognosis and the neonate may survive if they are given life-preserving treatment but their prognosis is still very bleak. It is here that quality of life debates ensue and the best interest of the child standard steps in to tip the scales. The last category is where there is a hopeless prognosis. The neonate is not dependent on Neonatal ICU’s for survival but despite any surgery their quality of life remains poor. If the decision to end a life is not made here and a doctor simply lets nature take its course the neonate will eventually die from insufficient hydration or nutrition and not from the impairment itself.

While there is heated debate over these end of life decisions we must not lose sight of the objective of the Groningen Protocol. A medical practitioner has tough choices to make. On the one hand an oath has been taken to the effect that they will save lives and not taken them, but on

¹⁷⁸ Strauss (note 133 above) 483.

¹⁷⁹ Van der Westhuizen (note 10 above) 239.

the other hand the principle of „do no harm“ also has value. A medical practitioner thus stands to gain nothing by taking the life of a neonate but rather does so with the intention of bringing an end to the suffering. This is not done for all cases but rather for those who are in critical conditions and meet the set requirements. It is through Protocols like these that a situation can be regulated and infants are granted a humane death that is in line with accepted medical practices. It is evident that this situation is well regulated and does not happen purely because the Doctor holds it to be best. The infant's doctor is not the only role player in the decision making process. The position must be discussed with the parents and the information that they receive must be an accurate assessment of the child's condition and future life.¹⁸⁰ It is then left to the parents to decide if death would be better than dragging out the child's pain and suffering. Further, an independent physician must confirm the prognosis given by the initial doctor and must be of the opinion¹⁸¹ that such condition is untreatable and that the child is suffering unbearably. Once this has been established and all parties have come to the same conclusion that Euthanasia is the best route to take then high doses of an opiate is administered to the neonate to gently ease the child into death. Here the best route medication wise is also taken for the infant as immediate lethal injections are not used.¹⁸² Once the neonate has died the death must then be reported to the coroner and after such a committee consisting of five members and including an ethicist and a lawyer is called upon to analyze the decision to ensure that that the treatment provided adhered to the conditions set out in the Protocol.¹⁸³

The above shows just how well monitored the situation is in the Netherlands when compared with England or even South Africa. Euthanasia is being embraced for good of neonates who are impaired and meet the requirements however the deliberate killing of a neonate who does not meet the requirements remains a criminal offence. Thus, the Protocol sets out set criteria and a failure to adhere to this will result in a risk that no doctor would chance by acting unlawfully. The requirements that must be adhered to are as follows:¹⁸⁴

- There is a high degree of certainty over the diagnosis and prognosis.

¹⁸⁰ Van der Westhuizen (note 10 above) 241.

¹⁸¹ Van der Westhuizen (note 20 above) 242.

¹⁸² Ibid.

¹⁸³ Ibid.

¹⁸⁴ Strauss (note 133 above) 487.

- The baby is suffering unbearably and without prospects of improvement, and there is no medically responsible means to relieve the suffering.
- The condition of the baby is so severe that life-prolonging treatment would be deemed futile according to the criteria laid down in the 1992 Report of the Association of Pediatrics.
- The doctor informs both parent extensively about the diagnosis and the prognosis and both parents agree that there is no acceptable solution for relieving the baby's suffering.
- At least one independent doctor or multidisciplinary team is consulted, examines the baby in person, and agrees with the findings of the doctor who has treated the baby.
- Deliberate ending of life is performed in accordance with state of the art medical standards.

These requirements serve to set the standard of which cases would be suitable and which would not. The Protocol further imposes the obligation to report the death and this stands to prevent individuals from abusing the process and performing euthanasia in an unjustified manner. This means that the Protocol only allows the euthanasia of hopeless cases and by no means allows the termination of life for a minor defect and as such will not pass the requirements. The aim is to deal with and manage terminally ill neonates. One needs to go through the requirements before the decision to end the life can be reached and thus not all cases will pass the criteria set out in the Protocol. While this is certainly a step in the right direction to some extent, there are those who criticize the Protocol stating that the wording used is not properly defined and thus is left open to various interpretations and is sometimes too vague. The automatic response here when compared to other parts of the world is that the Netherlands have done a great task that ends the misery of the most vulnerable group. It is through this Protocol that a step has been taken in the acceptance of death when life is no longer of sufficient quality. Legislation in South Africa leaves much to be desired in terms of wording as well as classing all minors together without setting any requirement whatsoever. Regardless of the shortcomings it is submitted that the Protocol, if used correctly and the set procedures are followed, should be welcomed in other parts of the world in order to regulate what is being done by Doctors on a regular basis. Instead of allowing these medical practitioners to act on their own accord, the solution is rather to adopt legislation and regulate what is already underway.

Chapter 5 – The Way Forward

5.1 Introduction

While it is evident that the human rights movement has made great progress there is certainly room for improvement. Medicine too has made great progress that much is undeniable. Marcia Angell states that now we have become aware that modern medicine is a two-edged sword, capable of dramatically rescuing some people from death, while damning others to prolonged suffering.¹⁸⁵ This chapter will deal with the ability of medicine to prolong suffering and the need for law to be enacted to regulate end of life decisions in a manner that maintains the right to dignity as enshrined in the Constitution.

In the past, infants born with impairment were not afforded the same standard of medical care that is enjoyed today. This progression has made the once incurable curable, the pain experienced by patients can now be managed and life can be prolonged instead of allowing nature to take its course. Thus, the stone age train of thought has been noted, acknowledged as backward and a swift move away has led to steady progress in the change of attitude to the extent that taking a life is now a crime. It is here that one must bear in mind the difference between a lost cause and those who have a fighting chance. It is this very difference that should determine whether life be brought to a merciful end or not.

The law is silent on the exact steps that should be taken when dealing with end of life decisions of a neonate. Avoiding these pediatrics issues is a mistake.¹⁸⁶ It risks having the practices occur among children and adolescents with no applicable justification, no consideration of the special dangers, and no specific safeguards.¹⁸⁷ It is through such actions that the rights and interests of minors are minimized.¹⁸⁸

This chapter will examine how South Africa has neglected the issue of neonatal euthanasia and will conclude with suggestions for the way forward.

¹⁸⁵ M Angell „Helping Desperately Ill People Die“ in L L Emanuel (ed) *Regulating How We Die* (1998) 3, 5.

¹⁸⁶ S Wolf „Facing Assisted Suicide and Euthanasia in Children and Adolescents“ in L L Emanuel (ed) *Regulating How We Die* (1998) 92, 93.

¹⁸⁷ Ibid.

¹⁸⁸ Ibid.

5.2 Critique

The right to health care and for all action to be in accordance with the best interest of the child standard forms the foundation of the CRC which has been ratified by South Africa, England and the Netherlands.¹⁸⁹ While South Africa has ratified International Law and given effect to such in the Constitution, the National Health Act and the Children's act fail to do justice to the situation. It is submitted that South African law is vague, generalized and does not distinguish between the different levels of protection that should be afforded across the different age groups particularly with neonates.

As previously discussed Article 2 of the ECHR removes the obligation to treat where the case is futile. Thus it is evident that the English stand firm in the belief that all cases other than futile cases deserve the attention, resources and assistance that can be made available. The case of *In re J* also showed that no decision should ever be made in isolation, but rather the parents, medical experts as well as the courts should be used in order to attain the best action for the infant.

The Netherlands on the other hand takes a much more active approach. As seen above, the Netherlands has been proactive in dealing with neonatal end of life decisions and in this regard have the Groningen Protocol as a starting point. It is thus no surprise that the adopted approach has attracted great controversy.

Wolf suggests that forgoing life-sustaining treatment can be justified and assigned to parental discretion within certain limits, as long as the practice is in the best interests of the child.¹⁹⁰ Analysis of euthanasia must thus proceed from that starting point. In many cases it is felt by parents that after treatment was foregone, the child did not die quickly enough.¹⁹¹ These children who do not die immediately endure a poor quality of life, they face great pain and the duration is uncertain, it could be hours, days or even weeks. Wolf submits that it is from these cases that we must be very wary of taking a step too far, what was once merely foregoing treatment can lead to a change in intention.¹⁹² One may commence, in these cases, by stopping treatment to allow the

¹⁸⁹ Van der Westhuizen (note 10 above) 251.

¹⁹⁰ Wolf (note 186 above) 114.

¹⁹¹ Wolf (note 186 above) 114.

¹⁹² Wolf (note 186 above) 114.

disease to take its course but there is a switch when facing such hopelessness that leads to the action to intentionally and directly take the infant's life in a bid to bring an end to the pain faster than nature allows. Wolf goes on to critique those in favour of neonatal euthanasia by bringing forward the idea that if one has opted for terminating treatment then once palliative care or sedatives have been administered there is no reason to take the final step towards ending a life when death is imminent and through the use of medication pain can be minimized or eradicated completely.¹⁹³ Given these options Wolf contends that given these options, it is hard to see how the child's best interests might dictate going further to euthanasia.¹⁹⁴ The rule for euthanasia cannot be laxer; if anything, direct killing should demand more strictly child-centered standards.¹⁹⁵ To permit euthanasia rather than insisting on and relying upon good pain relief, palliative care, and terminal care for young children is thus to give up on a child-centered standard.¹⁹⁶ Taking the step toward euthanasia of impaired neonates returns us to an era in which parents could consign a child to death for their own convenience and it is through this that the best interest of the child standard loses relevance.¹⁹⁷

It is from cases like these that we become aware of how under regulated neonatal issues truly are. Neonatal euthanasia occurs all over the world regardless of whether it is legal or illegal. While it can be argued that no one has the right to take life and where there is hope, however dismal, all must be done, it is submitted that this is nowhere near practical. Regardless of what is said, one cannot deny the fact that there will be a neonate who is in tremendous amounts of pain, a futile prognosis is determined and there are healthier newborns that could truly benefit from the resources that may be wasted on such a hopeless case.

From a practical point of view the current state of affairs cannot remain. It is submitted that there needs to be a change in South African law in order to allow for a standard to be set and cast in stone instead of allowing morals and ethics to cloud the minds of medical practitioners who currently do not have concrete law to follow in order to determine what steps should be followed.

¹⁹³ Wolf (note 186 above) 116.

¹⁹⁴ Wolf (note 186 above) 116.

¹⁹⁵ Wolf (note 186 above) 116.

¹⁹⁶ Wolf (note 186 above) 116.

¹⁹⁷ Wolf (note 186 above) 116.

5.3 Recommendations

When faced with end of life decisions alternate dispute resolution could play a significant role before the matter is taken to court.¹⁹⁸ Parents or guardians are not always as well informed as they could be and a decision could be made if experts are brought in to clarify certain aspects that may be challenging for a lay person to grapple with and understand. This mediation process was used in England where there was disagreement between the parents and the health care practitioner regarding what the next logical step should be when treating a critically ill neonate. During this mediation process an impartial mediator will aid the parties to reach an agreement that they are all comfortable with. This method is advantageous as it is an informal meeting as opposed to a rigid court case which ensures that all parties are able to speak their mind freely without any tension or stress that comes from court rooms. Further, it is less time consuming as well as less expensive. Once understanding has been reached then a “memorandum of understanding” or settlement agreement should be drafted.

Another way forward could be through the drafting of Guidelines.¹⁹⁹ The current law has a document drafted by the Health Professions Council of South Africa (HPCSA) which is very general and does not pay specific attention to neonates only. While it is acknowledged that this document has taken a step forward, progress should not stop here. An ethics committee could also be established in order to hear matters and determine if the child should be given palliative care and nature should be allowed to take its course or if the child should be euthanized because palliative care will not be beneficial, pain is far too great and the end may be further out of reach.

The last recommendation is court intervention.²⁰⁰ This should be utilized as a last port of call or when there is limited time to argue over differing opinions. Here the best interest of the child standard should always be applied. We see from an ethical perspective that under beneficence a doctor has the duty to step in for those with diminished autonomy and they must ensure the well being of their patients. Thus, as seen in the case of *Hay v B*, the doctor patient relationship is such that where a parent refuses to commence with treatment where there is hope that the infant will survive, it is in the hands of the medical practitioner to apply to the court and fight for the

¹⁹⁸ Van der Westhuizen (note 10 above) 260.

¹⁹⁹ Van der Westhuizen (note 10 above) 261.

²⁰⁰ Van der Westhuizen (note 10 above) 263.

infants life. Granted, the same should not be done where the chances of survival are not in favour of the infant and rather steps should be enforced to allow a medical practitioner to deal with this in a structured and regulated manner. But the court can step in as upper guardian to overrule the parents decision and grant an order allowing the medical practitioner to proceed and as such save a child's life where a quick remedy is needed in a short space of time.

From the above it is evident that South African Law has a grey area that need to be filled. Under South African law, euthanasia is illegal, and actively killing a neonate, no matter how severe an impairment is, would undoubtedly lead to criminal repercussions. Like most situations, there are always exceptions to the rule based on necessity. It seems unwise to hide behind a law stating all acts of this nature are illegal when these practices are in full effect in both the public and the private sector. It is not to say that South Africa has not taken the first step towards progress. The Law Commissions Proposed Act²⁰¹ shows that progress will be accepted. This Bill aims to provide for the determination of a terminal illness, power of attorney authorizing a person to make decisions concerning medical treatment in cases of terminal illness, power of attorney authorizing a person to make decisions regarding medical treatment or cessation thereof as well as other areas that arise in end of life decision making.

In the Pearson cases a child in England was born with Downs syndrome. The child's mother no longer wanted the child and it was decided by one Doctor Leonard Arthur after examination of the child to sedate Baby Pearson with painkillers and he should be given water by no food. The infants died within 3 days.²⁰² Arthur was initially charged with murder but the court allowed an attempted murder charge to go the jury.²⁰³ Ultimately the jury acquitted him on the attempted murder charge. We see from this that the Groningen has its advantages. This Protocol does not allow for children who have full quality lives ahead of them to slip through the cracks. The current system has done a great injustice to Baby Pearson in England and several other children who are given the axe instead of a helping hand. If the Groningen Protocol was applied in the Pearson case, baby Pearson would not have met the criteria for Euthanasia. This shows us that there is a lot to be learnt from the Netherlands. Granted there is the need for less drastic measures

²⁰¹ South African Law commission Euthanasia and the Artificial Preservation of Life Working Paper 53, Project 86 (1994).

²⁰² Achilles (note 3 above) 813.

²⁰³ Ibid.

but one thing remains clear, the law must change and develop as the circumstances change and warrant protection for those who truly need it.

What should instead be done is the bridging of all of these different Bills and Protocols that meet the needs of South Africans. Whilst we see that all of the Acts including the Proposed Bill focus on those who have already attained majority status, it becomes glaring obvious that there is a need for legislation that deals specifically with neonates. Such would be able to regulate the situation by providing doctors with a set structure. Requirements that must be fulfilled could follow that of the Groningen Protocol:

- The diagnosis and prognosis must be certain,
- Hopeless and unbearable suffering must be present,
- The diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctors,
- Both parents must give informed consent and
- The procedure must be performed in accordance with the accepted medical standard.²⁰⁴

This will enable doctors to follow set procedures in addition to court intervention or dispute resolution in order to truly act in the best interest of the infant and determine if proceeding with medical treatment would be beneficial or not.

5.4 Conclusion

Euthanasia is a topic that has been debated ad nauseum and yet there are still gaps in our law that do not serve the people in the most efficient way. The stance that should be adopted is a removal of the blinkers that we have that blanket prohibitions brings an end to the story. This way of thinking should be replaced with acceptance that, if done correctly, can lead to proper regulation in the form of enactment of legislation, the birth of ethics committees and the use of the court system, and thus brings the best interest of the child standard full circle.

²⁰⁴ Verhagen (note 36 above).

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