

The law related to end-of-life decisions concerning imperilled neonates in South Africa: Where angels fear to tread (1)*

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OPSOMMING

Die reg betreffende einde-van-lewe-besluite oor neonate in gevaar in Suid-Afrika: Waar engele bang is om te wandel

Met die vooruitgang van mediese tegnologie en die daaropvolgende toename in medici se vermoë om intensiewe indringende sorg aan neonate te voorsien, kom al hoe meer komplekse etiese dilemmas na vore. Baie lewens word dan ook geraak wanneer 'n neonaat gebore word aan die buitengrense van lewensvatbaarheid. Die neonaat ondergaan intensiewe, indringende behandeling en ondervind pyn en lyding terwyl daar geen sekerheid is dat haar toestand sal verbeter nie. Dit is ook 'n tydperk van lyding vir hul families. Die artikel ondersoek die reg en etiek met betrekking tot die besluitnemingsproses in 'n situasie waar 'n neonaat met 'n ernstige gebrek of terminale siekte gebore word, of aan die buitengrense van lewensvatbaarheid. Daar word spesifiek ondersoek ingestel daarna of die bestaande regsraamwerk wat die einde-van-lewe besluitnemingsproses oor neonate reguleer wel toereikend is, deur die Suid-Afrikaanse reg daaromtrent te ontleed. Die fokus is op die behandeling van neonate met ernstige siektes en gebreke en die regs-dilemmas wat met sodanige behandeling en besluitneming gepaard gaan. Ons bevind dat die ontwikkeling van behoorlike regulasies of 'n protokol kan bydra tot eties- en regs-korrekte besluite in Suid Afrikaanse hospitale en dat sodanige ontwikkeling deur die Grondwet, 1996 ondersteun word.

1 INTRODUCTION

Notwithstanding its tiny human subjects, paediatric medical law involves a multitude of difficult legal and ethical dilemmas. These dilemmas are felt most keenly when decisions have to be made regarding the care of imperilled neonates¹

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1 A "neonate" is a new-born child who is less than four weeks old. These neonates are considered "imperilled" as they are at risk of being harmed, injured or destroyed (*Oxford dictionary online*, available at <http://bit.ly/2IK6tTd>, accessed on 30-12-2016). For purposes of

continued on next page

– neonates born at the limits of viability or with severe illness or disability. Such neonates undergo intensive, invasive treatment and experience pain and suffering, sometimes without any certainty that their condition will improve. All of this happens while the neonate’s family suffers on many levels.

With the advancement of medical technology and our ever-increasing ability to provide intensive invasive treatment to imperilled neonates, the stage is set for new and complex legal and ethical dilemmas. These dilemmas include questions regarding whether treatment should be administered at all, what the extent of such treatment should be, whether and when treatment should be withdrawn and what the appropriate ethical and legal foundations for such treatment decisions are. In an emotionally-taxing and confusing place such as a Neonatal Intensive Care Unit (NICU), it is important that parents of patients are presented with care and guidance that uphold the law as well as the principles of medical ethics.

The article, then, examines the law related to the decision-making process in a situation where a neonate is born at the limits of viability or with a severe disability, with specific attention being paid to the rights enshrined in the Constitution of the Republic of South Africa, 1996 (the Constitution).² Specifically, the article examines whether the existing South African legal framework governing end-of-life decisions in neonates is adequate and whether it provides solutions to overcome ethical and legal dilemmas when such end-of-life decisions are made. Obstacles to optimum neonatal care in South Africa, and the differences in the nature of the decisions that are taken about the neonate in the private and public sectors, are explored. The article briefly mentions possible solutions to some of these dilemmas. Although reference is made to the British and Dutch legal systems in this regard, the focus is on South Africa.

We begin by sketching some of the circumstances in which a neonate may be considered “imperilled”, after which we highlight the importance in this context of the principle of the best interests of the child. We examine a few important British decisions in this regard.

2 CIRCUMSTANCES IN WHICH A NEONATE MAY BE CONSIDERED IMPERILLED AND THE BEST INTERESTS OF THE NEONATE

2.1 Imperilled neonates

Because of the hopelessness and pain it signals, the neonate’s family frequently considers the concept of medical futility unacceptable when applied to their neonate’s situation.³ Nevertheless, it is important for our purposes to identify situations in which neonates may be considered imperilled so that they qualify for end-of-life decision-making, as further medical treatment in their situation is considered futile. As any classification of this nature has the potential to elicit

this article the neonate is endangered due to being born with some form of terminal illness or severe disability that will cause her pain and suffering and may lead to her death.

2 “Viability” is “having attained such form and development as to be normally capable of surviving outside the mother’s womb”: *Merriam-Webster online*, available at <http://bit.ly/2kwGTvL>, accessed on 30 December 2016.

3 Anderson and Hall “Parents’ perceptions of decision making for children” 1995 *J of Law, Medicine and Ethics* 15.

discrimination on various grounds, when classifying neonates' situations it is important to keep in mind the principles of the Constitution, as discussed below.⁴

A decision regarding whether a neonate qualifies for end-of-life decision-making should not be based on medical or technical standards alone. Rather, the parties involved must base their decision on an accurate diagnosis and a complete and expert analysis of all the clinical and social realities of the situation, including an assessment of possible outcomes.⁵ We must emphasise that the views of the family are essential when trying to make a decision regarding what would be best for the neonate.

Paediatricians are of the opinion that the most significant medical criteria for deciding about withholding or withdrawing treatment in neonates are extreme abnormality, disease, or damage to the central nervous system, specifically the brain.⁶ Conditions which meet this medical criterion include neonates born with severe neural tube defects,⁷ hydranencephaly,⁸ chromosomal disorders like trisomy 13 and 18,⁹ and gross hydrocephalus if complicated by infection.¹⁰

There are also disorders or conditions which are not as severe as those mentioned above and which therefore are surrounded by substantial disagreement or uncertainty about an appropriate course of action, such as Down's syndrome with complications.¹¹ Therefore, while occasionally the neonate's medical diagnosis may help the parties decide on a course of action or treatment option, often the issue remains complicated. Down's syndrome with complications, especially, raises a number of dilemmas. Some writers hold that the main argument for allowing a neonate born with Down's syndrome with complications to die is not to ease the burden that her life will have on her, but rather to prevent the burden that her life will place on her family and community.¹² This can develop into a spider-web of ethical dilemmas, because the interests of the family and the community in terms of financial and social aspects must be considered as well. Are there resources available to properly care for the child? Will her care be at the cost of other neonates or even of her siblings and may any of these factors even be considered against the right to life of the neonate?

The literature offers different opinions of what guidelines could aid in classifying a neonate as imperilled and thereby qualifying for end-of-life decision-making as different experts and physicians recommend different guidelines and

4 See para 3 2 below.

5 Campbell "Which infants should not receive intensive care" 1982 *Archives of Disease in Childhood* 569 ("Campbell").

6 *Idem* 570.

7 The infant is born with abnormalities in the spinal column, spine or brain. Spina bifida and anencephaly are examples of neural tube defects.

8 A congenital disorder in which the brain's cerebral hemispheres are absent and the remaining cavity is filled with cerebrospinal fluid.

9 Both chromosomal disorders. Trisomy 18, Edwards syndrome, is associated with severe mental disability and patient with this diagnosis has a possible life span of one week to one year. Trisomy 13, Patau syndrome, also is associated with mental disability as well as deformation of the features and patients normally die before reaching the age of one year.

10 The abnormal accumulation of cerebrospinal fluid in the ventricles and cavities of the brain; associated with severe physical and mental disability.

11 Campbell 570.

12 Raphael "Handicapped infants: Medical ethics and the law" 1988 *J of Medical Ethics* 6.

control mechanisms. The majority include the following as aspects to consider: the neonate's prognosis; the severity of the neonate's condition; and the quality of life that the neonate would have if the treatment is successful. The supreme factor that must be taken into consideration is no doubt the criterion of what would be in the neonate's best interests. Although these guidelines are still somewhat vague, they do offer some guidance.

The British Royal College of Paediatrics and Child Health (RCPCH) is responsible for one of the most influential and thorough guidelines for treatment decisions in imperilled neonates.¹³ The Royal College's Ethics Advisory Committee in 2004 published a revised framework for decisions concerning the withholding and withdrawing of life-sustaining treatment which recognises five situations in which it would be ethically and legally justifiable to withhold or withdraw life-sustaining treatment as further treatment is considered futile. They are the following: the brain-dead child; the permanent vegetative state; the "no chance" situation; the "no purpose" situation; and the "unbearable" situation.¹⁴ A brief discussion of each of these follows.

In the case of a brain-dead child, the patient is by definition dead once brain-stem death has been confirmed.¹⁵ In the second situation, a patient could be in a permanent vegetative state due to various causes such as possible cerebral abuse; examples include trauma to the head or hypoxia. The state the patient is in is only termed to be "persistent" after four weeks, and if it is confirmed that the patient will never recover awareness, then it is termed "permanent".¹⁶

The "no chance" situation is a situation where the treatment offered will only delay the patient's inevitable death. In this situation the quality of life of the patient is not improved nor is there a promise of possible improvement in the future. Thus, if further treatment is given, it will amount to futile treatment which is not in the best interests of the patient. It can be said that the deliberate continuing of such futile treatment could be an infringement of the patient's bodily integrity. An example would be where a child who suffers from a terminal cancer no longer derives any benefit from chemotherapy.

In the "no purpose" situation there is the possibility that the neonate will survive if treatment is continued, but it is established that such treatment will not be in the neonate's best interest. Here the impairment after the administration of treatment will be of such a severe degree that it would be irrational to expect the neonate to tolerate it.¹⁷ This situation often surfaces in cases where the child has an underlying neurological defect.

Lastly, the "unbearable situation" is where the family feels that the child cannot endure further treatment and then decides to withhold or withdraw the treatment, irrespective of whether the physician holds the opinion that the child may well benefit from the treatment.

13 Wilkinson *Death or disability: The 'Carmentis machine' and decision making for critically ill children* (2013) 51 ("Wilkinson").

14 Moodley *Medical ethics, law, and human rights: A South African perspective* (2011) 197 ("Moodley").

15 *Ibid.*

16 *Ibid.*

17 Pattinson *Medical law and ethics* (2006) 505 ("Pattinson").

When it comes to deciding whether prolonging treatment could be beneficial to the patient, the British Medical Association's guidelines, first published in 1999 and then revised in 2001 and 2007, are of assistance. The primary presumption here is that life-sustaining treatment should be commenced only where reasonable certainty exists as to its benefits. The guidelines also indicate that in a situation where the patient's wishes are unknown or unattainable, the surrogate in charge of the patient should make the ultimate decision, taking into account the patient's current and anticipated quality of life.¹⁸ We list those situations applicable to neonates:

- (a) What is the medical and clinical opinion regarding the possible success of the proposed treatment, which includes its possible harms and benefits?
- (b) Is there a possibility of the neonate having to endure extreme pain and suffering?
- (c) What is the chance and level of any degree of improvement in the neonate's condition in the event that treatment is provided?
- (d) Can the invasiveness of the proposed treatment be justified in the circumstances?
- (e) What are the parents' wishes?
- (f) What are the wishes of any other parties who are close to the neonate; such as other relatives or caregivers?¹⁹

These guidelines further recommend that the decision to withdraw or withhold nutrition and hydration be subject to independent review by an independent doctor not otherwise involved with the case, and that the reasons for the decision and the findings of the review should be properly recorded in the patient's file. It is also suggested that the family of the patient and the healthcare team should agree that further treatment would be inappropriate before nutrition and hydration are withdrawn.²⁰

It has been proposed by experts that intensive invasive treatment should not be allowed in any of the following circumstances:²¹

- (a) Where the neonate is incapable of surviving infancy;
- (b) Where the neonate is incapable of participating, even to a minimum extent, in "the human experience"; and
- (c) Where the neonate is incapable of living without extreme pain and suffering.

These experts are of the opinion that to sustain the lives of neonates under such circumstances would be a violation of the ethical principle of non-maleficence, or "do no harm".²²

18 Mason and McLean *Legal and ethical aspects of healthcare* (2003) 167 ("Mason and McLean").

19 British Medical Association (2004) 356–357, as cited in Herring *Medical law and ethics* (2010) 540 ("Herring").

20 Mason and McLean 167.

21 Herring 540.

22 *Ibid.*

In 2006, a British non-governmental ethics body, the Nuffield Council on Bioethics, published a report that covers a range of considerations regarding decisions concerning extremely premature and pre-term neonates.²³ A determination of the best interests of the neonate where a decision must be made about possible withdrawal of treatment is considered paramount by the report. The report states that to insist on the furtherance of treatment, in order to prolong the life of a neonate, would not be in the best interests of that neonate if doing so will impose an “intolerable burden” upon her.²⁴

The authors of the report admit that it is both difficult to define the term “intolerable burden”, as well as to determine whether a particular neonate’s condition is intolerable. According to the report, to provide treatment that is considered burdensome to a neonate who is predicted to have a life “bereft of those features that give meaning and purpose to human life”, may impose an intolerable burden upon that neonate.²⁵ The report also discusses some potential benefits of treatment to be considered when the best interests of the child are to be determined. It suggests that the child’s capacity to establish relationships with others, her ability to experience pleasure, and her independence from life support must be considered.²⁶ The report differs from the Royal College’s guidelines in that it supports the notion that the interests of others, such as the neonate’s parents and society, must be taken into consideration as well, and not only the child’s interests. This could have the result that the interests of other parties would permit the withdrawal of treatment in certain situations, such as where uncertainty exists.²⁷ The report is unfortunately unclear about how this could be applied to the limitation of treatment for imperilled neonates as its focus is primarily on extremely preterm neonates.²⁸

2.2 Best interests of the neonate

The cornerstone of the above frameworks is a determination of the best interests of the child.²⁹ This determination is considered a very useful guide in decision-making where the possible futility of further treatment must be considered and weighed.³⁰ In the British case of *NHS Trust v D*,³¹ this determination was used and Cazalet J accepted that the neonate matched the “no chance” situation. He ruled that it would be lawful to refrain from resuscitation in the event of a future cardio-respiratory arrest.³² The judge also held that neither the neonate’s right to life nor its right to dignity was infringed as the course of action was in accordance with the best interests of the neonate and it involved the right to die with dignity.³³ Should a situation arise where the neonate’s condition does not fall into one of the above-mentioned categories, or where there is uncertainty about the

23 Nuffield Council on Bioethics *Critical care decisions in fetal and neonatal medicine: Ethical issues* (2006).

24 *Idem* 12.

25 *Idem* 12 para 12.13.

26 *Idem* 12 para 9.33.

27 Wilkinson 56.

28 *Ibid.*

29 *Idem* 52.

30 Moodley 198.

31 *NHS Trust v D* (2002) 2 FLR 677.

32 *Idem* 677–679. See also Pattinson 506.

33 *Ibid.*

neonate's degree of future impairment, the neonate's life should be protected in the best possible manner.³⁴

The following quotation from an interview with a neonatologist illustrates the extent to which the concept of the best interests of the child has penetrated into clinical practice:

"And if we actually concluded . . . [that] this baby is going to be very, very severely disabled, unable to sit up, very likely to have severe learning problems, and we are still ventilating . . . this is the point where we think that actually it is not in the baby's best interest [to continue]".³⁵

The concept of the best interest of the child forms an essential building block in the foundational wall of medical law and ethics. But what is its content and how is it applied in practical situations?

One could assume that there are various courses of action that are in the interest of the patient; however, the best interests concept invites us to search for that course which will *maximally* promote their interests on the whole, or the one that will promote their most important interests at stake.³⁶

As mentioned above, there are many ethical and legal dilemmas when end-of-life decisions regarding an imperilled neonate must be made. These dilemmas elicit different opinions and even disagreement amongst experts. However, all are of the opinion that the sole ethical criterion on which a morally acceptable decision must be based, is the neonate's best interest.³⁷

The term "best interest" has been criticised as too broad and vague in some instances.³⁸ The courts constantly emphasise that best interests include medical, emotional and all other welfare issues. Previously, the best interest concept was tied also to medical futility and quality of life predictions.³⁹ Today, however, the courts disapprove of attempts to use the best interests test by identifying the circumstances in which a child's quality of life might become intolerable.⁴⁰ In her judgement in *Re L*, Elizabeth Butler-Sloss expressed her disapproval about the concept of intolerability and instead found the concept of medical futility useful.⁴¹ She referred to presumptions in favour of preserving life, but not where treatment would be considered futile.⁴²

When saying that the best interest of the patient is paramount, it implies that the views of the doctor will be relevant, but will not be determinative.⁴³ It might seem simple to say that a doctor should do what is best for the patient, but what if it is not clear what would be best for that patient? What about the

34 Mason *et al* *Law and medical ethics* (2002) 491 ("Mason").

35 Wilkinson "We don't have a crystal ball: Neonatologists' views on prognosis, magnetic resonance imaging and treatment withdrawal for infants with birth asphyxia" 2010 *Monash Bioethics R* 5.9 ("Wilkinson").

36 *Idem* 48.

37 Fost "Counselling families who have a child with a severe congenital anomaly" 1981 *Pediatrics* 321–324.

38 Herring 200.

39 Fortin *Children's rights and the developing law* (2009) 378 ("Fortin").

40 *Ibid.*

41 *Re L* (*Medical treatment: benefit*) [2004] EWHC 2713 (Fam), [2005] 1 FLR 491 12 ("*Re L*").

42 *Ibid.*

43 Herring 538.

doctors, other patients, or even the families of the patients? Is it such a good idea to hold both doctors and parents to a standard where they should always make the very best choice for the child involved?

The case of *Re J*⁴⁴ provides some guidance as it supports the idea that a doctor is not obliged to provide futile treatment if it is against the child's best interests.⁴⁵ Baby J was born prematurely at 27 weeks gestation with severe brain damage which caused epileptic fits. He also seemed to be blind, mute and deaf and neonatologists agreed that he would probably develop serious spastic quadriplegia. It unfortunately also seemed as though he was able to experience pain. He suffered from episodes where his breathing would cease and then he would require artificial ventilation. It was certain that with artificial ventilation he could be rescued every time and it was just as certain that the withholding of this treatment of artificial ventilation would be fatal to the neonate.⁴⁶ The doctors' opinion was that it would be in the best interest of Baby J to refrain from providing artificial ventilation in the future. But was this really in the best interests of the neonate, Baby J?

In his decision about Baby J's best interests, Taylor LJ identified three important factors. He stated, firstly, that the best interests of the child must be the court's "prime and paramount" consideration. Secondly, he explained the importance of the sanctity of life and that it imposes a presumption in favour of taking all reasonable steps to preserve life, except in exceptional circumstances. The court similarly commented on the difficulty of defining what those exceptional circumstances are. The third issue raised was that the court "never sanctions steps to terminate life".

Having underlined these three principles, the court had to consider the quality of life that this imperilled neonate would enjoy if life-sustaining treatment was not withdrawn. Taylor LJ held that the test must be whether the child in question, if capable of making a sound decision, would consider the life tolerable.⁴⁷ The court concluded that it would not be in Baby J's best interest to be artificially ventilated as it would result in a deterioration of his condition and the consequent treatment would lead to further distress and suffering, ultimately resulting in an intolerable quality of life.

It should be noted that, even though Baby J's condition was dire, he was not dying at the time when a decision had to be made about his treatment and that there was a clear acknowledgement that he might survive into late childhood or adolescence. The decision in *Re J* was explicitly related to the concept of intolerability and the court held that if the child's future life could be considered as intolerable to him, the court, acting on his behalf, may properly elect a course of action which "did not prevent his death".⁴⁸ This case, then, emphasises that a neonate need not necessarily be dying before a decision can be made to withhold treatment.⁴⁹

44 *Re J (a minor) (wardship: medical treatment)* [1991] Fam 33 ("*Re J*").

45 Mason and McLean 168.

46 Mason 480.

47 *Re J* 55F.

48 *Re J* 33 34 para C.

49 Fortin 377.

Another case of treatment limitation for a neonate with severe impairment was the British case of *Re C*,⁵⁰ where the court decided that a dying neonate's life does not have to be artificially prolonged irrespective of the circumstances. Baby C was a four-month-old, severely-disabled and terminally-ill infant. The court ordered that the medical staff were not required to provide life-sustaining treatment; they were allowed to care for her in a manner which would relieve her suffering and allow her to die peacefully and with dignity. The Court of Appeal based their decision on what they considered to be in her best interests. They held that to ease her suffering and to prevent her life from being prolonged by medical treatment would be in her best interests. Baby C's situation was terminal and she was suffering and therefore the court did not have such a difficult time deciding what would be in her best interests. This situation is different to that of *Re J*;⁵¹ in the case of Baby J the neonate was not dying, but the court still held that it was in the neonate's best interest to withdraw treatment.

The following case illustrates the courts' preference for making a judgment based on what the court considers would be in the best interests of the neonate, rather than what the neonate's parents consider would be in her best interests. *Re B*⁵² dealt with a new-born diagnosed with Down's syndrome complicated by an intestinal blockage which would have killed her within a few days if it were not surgically removed. It was estimated that with the surgery, she would have a life expectancy of 20–30 years. Her parents, however, refused to consent to the surgery on Baby B's behalf. They were of the opinion that it would be more merciful to let her die than let her live with learning disabilities. The local authorities sought an order from the courts to have the operation carried out despite the parent's refusal to consent. At first, the parent's views were respected and the order was refused. On appeal, however, the focus shifted from the wishes of the parents to what would be in Baby B's best interests and the parents' refusal was overruled by the Supreme Court of Appeal. Templeman LJ stated that the test was "whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die" and held that undergoing the surgery would be in the best interest of the neonate. One can take note that the parents' opinion was rather that the refusal of the surgery was in the best interest of their baby.⁵³ The court allowed the order on the basis that, with the surgery, the baby could survive for many years. The court did take into account that she would be permanently disabled, but concluded that her life would be neither "intolerable" nor "awful" if she carried on living. Had the court decided differently, it would have condemned all those living with Down's syndrome as having lives that are intolerable and not worth living.⁵⁴

The cases discussed above illustrate that, regardless of the severity of the neonate's condition or the parents' wishes with regard to the treatment of their child, the courts' approach is to decide what would be in the best interests of the child and to act accordingly.⁵⁵ These cases may be factually specific, but the following may be observed: Determining what was in the best interest of the neonate was a

50 *Re C (a minor) (wardship: medical treatment)* (1989) 2 All ER 782 787 ("*Re C*").

51 *Re J* 33.

52 *Re B (A Minor) (wardship: medical treatment)* [1990] 3 All ER 927 ("*Re B*").

53 Raphael 6.

54 Carr *Unlocking medical law and ethics* (2012) 356.

55 *Idem* 355.

balancing act which should be viewed from the assumed or estimated perspective of the neonate and should find application in a way that shows preference to options that will extend the neonate's life.⁵⁶ According to Taylor LJ, "the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment, and decide whether in all the circumstances, such a life would be so afflicted as to be intolerable to that child".

Where a decision has to be made on behalf of a non-competent person, the correct approach is to use the best interests test.⁵⁷ This is an acknowledgement of the complexities of human life and human nature and their many different aspects. Decision-makers are encouraged by the courts to take into account all the different elements involved and to consider the particular person at the centre of the decision-making process to establish and ultimately decide what is best for them.⁵⁸ Therefore, in order to decide what is best for such a neonate, the decision should be based on an accurate diagnosis and a complete and expert analysis of all the clinical and social realities which include an assessment of possible outcomes.⁵⁹

It remains important to take into account the views of the family and they should be guided through the decision-making process. Unfortunately, for many families concepts such as the best interests of the neonate or medical futility remain vague and theoretical if there are no adequate frameworks in place to make them practically applicable. In the light of this, the next section turns the focus to South Africa in order to explore the applicable legal rules pertaining to end-of-life decisions concerning imperilled neonates.

3 APPLICABLE SOUTH AFRICAN LEGAL FRAMEWORK

3.1 Introduction

South Africa does not have an all-inclusive piece of legislation governing the rights of children in healthcare.⁶⁰ Currently, the health of children in South Africa is governed by a number of statutes; namely, the Children's Act;⁶¹ the National Health Act;⁶² and the Mental Health Care Act.⁶³ The Sterilization Act,⁶⁴ as well as the Choice on Termination of Pregnancy Act,⁶⁵ provide for appropriate reproductive health services for children. We restrict our examination to the Children's Act and the National Health Act as the other acts do not have specific application to the rights of imperilled neonates.

We commence with a discussion of the Constitution and its regulation of children's health care rights, specifically the rights of imperilled neonates.

56 Pattinson 505.

57 Foster *et al* *The law and ethics of dementia* (2014) 309.

58 *Ibid.*

59 Campbell 569.

60 Büchner-Eveleigh and Nienaber "Gesondheidsorg vir kinders: Voldoen Suid-Afrikaanse wetgewing aan die land se verpligtinge ingevolge die Konvensie oor die Regte van die Kind en die Grondwet?" 2012 *PER* 113 ("Buchner-Eveleigh and Nienaber").

61 38 of 2005.

62 61 of 2003.

63 17 of 2002.

64 44 of 1998.

65 92 of 1996.

3 2 Constitution, 1996

When dealing with end-of-life decisions concerning imperilled neonates in South Africa, the starting point must be an examination of the Constitution.⁶⁶ The following discussion focusses specifically on the rights and duties relating to the protection of imperilled neonates that are enshrined in the Bill of Rights.⁶⁷ Note that the rights contained in the Bill of Rights are not unconditional, and that heed must be paid to their limitation by way of the limitation clause and through a balancing of rights.⁶⁸

3 2 1 Right to life

The first important provision is the right to life, provided for in section 11 of the Constitution. The right to life is textually unqualified⁶⁹ as it is, according to Justice O'Regan, a predecessor to all the other rights in the Bill of Rights. She makes a powerful statement about the right to life in *S v Makwanyane*:⁷⁰

“[T]he right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes, but the right to human life . . . the right to share in the experience of humanity.”⁷¹

The right to life is accorded only to living persons who are recognised as such by law.⁷² A foetus is not recognised as a living person under South African law and, therefore, is not afforded the right to life.⁷³ The same, however, cannot be said in the case of a neonate who is born alive. The neonate is entitled to full protection in terms of the Bill of Rights in the Constitution, regardless of the degree of prematurity or impairment it was born with. This is in accordance with the words of Chaskalson P in *S v Makwanyane*: “[Constitutional] rights vest in every person.”⁷⁴ Nevertheless, many will argue that if further intervention will not be beneficial to a neonate, then a dying neonate has a right to die with dignity.⁷⁵

From a constitutional perspective, the matter of passive and active euthanasia pleads for a resolution of the conflict between the right to freedom and bodily integrity and the state's duty to protect life;⁷⁶ even dying life as in the case of a terminally-ill neonate. In this context the Constitutional Court observed that dying is a part of life and that there is no meaningful way in which the right to life can be extended to encompass the right to evade death.⁷⁷ Thus, when dealing with imperilled neonates who are already dying it is challenging, but necessary, to accept that the right to life cannot be extended indefinitely to evade death.

⁶⁶ S 2 Constitution.

⁶⁷ Ss 9–28.

⁶⁸ S 36.

⁶⁹ Currie and De Waal *The Bill of Rights handbook* (2005) 281 (“Currie and De Waal”) and *S v Makwanyane* 1995 3 SA 391 (CC) (“*Makwanyane*”).

⁷⁰ *Makwanyane* 506.

⁷¹ *Ibid.*

⁷² Carstens and Pearmain *Foundational principles of South African medical law* (2007) 27 (“Carstens and Pearmain”).

⁷³ *Ibid.*

⁷⁴ *Makwanyane* para 137.

⁷⁵ Fortin 376.

⁷⁶ Currie and De Waal 288. See para 4 below.

⁷⁷ *Soobramoney v Minister of Health, Kwazulu-Natal* 1998 1 SA 765 (CC) 784.

In terms of South African law and in accordance with the laws of many other countries, life needs not be artificially sustained after a person has been diagnosed clinically dead.⁷⁸ Further, a competent person may refuse the administration of life-sustaining treatment and a person can also set out her wishes not to be kept alive artificially by means of a living will.⁷⁹ Thus, the practice of passive euthanasia is not unlawful in South Africa, whereas the practice of active euthanasia is unlawful in terms of the common law and amounts to the offence of murder: "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."⁸⁰

3.2.2 Right to dignity

The right to dignity is enshrined in section 10 of the Constitution and has been identified as equally central by the Constitutional Court: "The importance of dignity as a founding value of the new Constitution cannot be overemphasised."⁸¹ Although the fundamental importance of the right to human dignity is assured in the Constitution, the meaning of the concept is less sure.⁸² It is a challenging task to clearly define human dignity, but it is evident that the constitutional protection of dignity asks of us to recognise the significance and worth of all individuals as members of South African society.⁸³

Health is vital for human life and dignity. Therefore, there is a *nexus* between health and the right to life as well as the right to dignity.⁸⁴ If a person is suffering from poor health it is reasonable to accept that they are incapable of fully enjoying and participating in their rights to life and dignity. Carstens and Pearmain correctly argue that a person's dignity is diminished when he or she no longer is able to enjoy quality of life.⁸⁵ Labuschagne argues that, as a person is still alive when in the process of dying, it follows that a death that lacks dignity is essentially also a life that lacks dignity.⁸⁶ It is his opinion that the present system relies on abstract and merciless regulations that require the sustaining of life at all costs, and that this may compel people to die in an undignified manner.⁸⁷

In *Clarke v Hurst*,⁸⁸ Thirion J stated:

"As it was put in 58 *US Law Week* 4936: 'Medical advances have altered the physiological conditions of death in ways that may be alarming: highly invasive treatment may perpetuate human existence through a merger of body and machine that some might reasonably regard as an insult to life rather than its continuation'."

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

79 *Clark v Hurst* 1992 4 SA 630 (D).

80 *S v De Bellocq* 1975 3 SA 538 (T) 539; *S v Hartmann* 1975 (3) SA 532 (C).

81 *Makwanyane* 451.

82 Currie and De Waal 273.

83 *Ibid* referring to *National Coalition for Gay and Lesbian Equality v Minister of Justice* 1999 1 SA 6 (CC).

84 Carstens and Pearmain 29.

85 *Ibid*.

86 Labuschagne "Aktiewe eutanase; mediese prerogatief of strafregtelike verweer?" 1996 *SALJ* 411.

87 *Ibid*.

88 *Clark v Hurst* 653.

In the case of imperilled neonates, the right to dignity may be used to shelter them from dying in a manner which their parents or proxy decision-makers consider to be undignified.

3 2 3 *Right to bodily and psychological integrity*

In *Ex Parte Minister of Safety and Security: In Re S v Walters*, Kriegler J observed:

“What looms large in both the threshold and the limitation phases of the exercise in the present case is that the right to life, to human dignity and to bodily integrity are individually essential and collectively foundational to the value system prescribed by the Constitution. Compromise them and the society to which we aspire becomes illusory. It therefore follows that any significant limitation of any of these rights would for its justification demand a very compelling countervailing public interest.”⁸⁹

Section 12 of the Constitution provides for the right to bodily and psychological integrity. Specifically, section 12(1) provides the right to freedom and security of the person, which includes freedom from all forms of violence; and section 12(2)(b) provides for the right to bodily and psychological integrity. The first-mentioned section is important in the context of prolonging treatment in a neonate which will result in that neonate’s continued suffering. The last-mentioned section supports the principle of patient autonomy in that a person has the right to make decisions regarding their own body. In the case of imperilled neonates, it is the duty of parents or guardians to uphold the neonate’s rights in terms of this section.

Section 12(1)(c) places a positive duty on the state to protect individuals against violations of their physical integrity by others,⁹⁰ and 12(1)(e) upholds a person’s right not to be treated in a cruel, inhumane or degrading way. One could argue that subjecting a terminally-ill new-born to extensive invasive treatments and procedures, which could be considered futile, could amount to an infringement of that neonate’s rights in terms of section 12(1)(e), and a failure by the state to protect that neonate in terms of their obligation to do so in section 12(1)(c). This is based on the notion that it could be considered cruel, degrading or even inhumane to subject a terminally-ill neonate to extensive invasive treatments and procedures which can offer her no hope of relief or recovery. Relying on section 12(1)(c) it can also be said that, if a neonate is being subjected to such extensive treatment, the state is failing in its obligation to protect that neonate from a certain form of violence.

Section 12(2) defines the ambit of the right to security of one’s person to include the protection of a person’s physical as well as psychological integrity. The principles of necessity and proportionality both should be taken into consideration and an infringement must not inflict unnecessary pain or anxiety or run the risk of disfigurement or injury to health.⁹¹

The right to bodily and psychological integrity entitles an individual to the right not to be forced to receive medical treatment against her will.⁹² In the case

⁸⁹ *Ex Parte Minister of Safety and Security: In Re S v Walters* 2002 4 SA 613 (CC) para 28.

⁹⁰ Currie and De Waal 304.

⁹¹ *Idem* 309 referring to *Winston v Lee* 470 US 753 (1985).

⁹² Pearmain *A critical analysis of the law on health service delivery in South Africa* (LLD thesis UP 2012) 123 (“Pearmain Thesis”).

of *Minister of Safety and Security and Another v Xaba*,⁹³ the court refused to grant an order which would allow a bullet to be surgically removed from a prisoner's leg against his will. The order was refused on the basis that his section 12 rights would clearly be infringed if the proposed surgery were to take place without his consent in the absence of a law limiting these rights as contemplated in section 36 of the Constitution.⁹⁴

In light of this and in the context of imperilled neonates, one would have to reconsider administering treatment to a neonate if that treatment would cause an infringement as explained above. Section 12(2)(b) and 12(2)(c) also provide a person with the right to security in and control over their body. In the context of medicine, if a physician does an invasive procedure on a patient without the necessary consent, her actions will amount to assault.⁹⁵

3 2 4 *Right to equality*

Another right that comes into play is the right to equality,⁹⁶ in that "everyone is equal before the law and has the right to equal protection and benefit of the law".⁹⁷ Specifically, a neonate may not be discriminated against based on age, gender, race or, especially, disability.⁹⁸ Because of these constitutional guarantees, there must be clear guidelines as to which neonates qualify for which course of action and such a decision may not be based solely on the neonate's disability – other factors must also be taken into consideration.

Gestational age is a potential ground of discrimination that could be applied to imperilled neonates. Imperilled neonates may be referred to as one group; however, the group consists of neonates of different ages. According to section 9(3) of the Constitution, a neonate has the right to be treated equally regardless of her age. This would mean that a neonate who is born at 28 weeks gestation must receive the same resources and attention as a neonate born at, say, 32 weeks gestation, as both neonates are premature and require special attention. This is in conflict with many protocols and guidelines around the world that use the gestational age of the neonate to dictate that neonate's treatment. Empirical data from the United States suggests variation of resuscitation practices at 24 weeks of gestation, but at less than 23 completed weeks, physicians consider resuscitation to be of insignificant benefit.⁹⁹

In their suggested guidelines for the treatment of imperilled neonates, the Nuffield Council on Bioethics also uses the gestational age of a neonate to indicate

93 *Minister of Safety and Security v Xaba* 2003 2 SA 703 (D).

94 *Ibid.* See also Pearmain *Thesis* 123 and, for an in-depth discussion of the right to refuse medical treatment, Nienaber and Bailey "The right to physical integrity and informed refusal: Just how far does a patient's right to refuse medical treatment go?" 2016 *SA J on Bioethics and L* 73–77.

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

96 S 9 Constitution.

97 S 9(1) Constitution.

98 S 9(3) Constitution.

99 Baer Gerri *et al* "A review of ethical issues involved in premature birth" (2007) Annexure C in Behrman *et al Preterm birth: Causes, consequences and prevention* (2007) Committee on Understanding Premature Birth and Assuring Healthy Outcomes 658, available at <http://bit.ly/2kS3NkP22> (accessed on 30 December 2016).

what type of treatment should be provided.¹⁰⁰ As will be seen below, the protocol followed in South African state hospitals dictates that any neonate weighing less than 1 kg at birth may not be ventilated.¹⁰¹ Thus, they do not generally base their decision on the gestational age of the neonate, but rather on her weight. However, the doctor still has discretion to decide, along with the parents, what would be in the neonate's best interests. As section 9 of the Constitution prohibits *unfair* discrimination, it will be adequate to say that discrimination based on *fair* grounds may be considered acceptable. It is submitted that a neonate's weight, as well as gestational age, are good indications of her possible treatment outcome and, therefore, may justifiably be considered in determining her treatment options.¹⁰²

3.2.5 *Right to privacy*

The association between the right to privacy and end-of-life decision-making in imperilled neonates rests on the idea that nothing could be more intimately connected with how a person lived their life than their right to privately and autonomously decide the manner and timing of their death. This association was recognised by the European Court of Human Rights in 2013 when it held that Switzerland had violated the right to decide when and how to die included in the right to respect for private and family life under article 8 of the European Convention on Human Rights.¹⁰³ It may be argued that section 14 of the South African Constitution, similarly, protects the individual's right to privacy in end-of-life decision-making.

Section 14 of the Constitution further guarantees the individual's right to respect for the privacy of their medical information, and is supported in this context by sections 14 and 15 of the National Health Act. Section 13 of the National Health Act creates an obligation on the person in charge of the health establishment to keep record of certain information pertaining to the treatment of a patient,¹⁰⁴ such as consultation information about imperilled neonates and end-of-life decisions concerning them. Information as to a patient's health status is personal as well as highly confidential. Such information is indistinguishably linked to the patient's right to privacy and, if disclosed without permission, could lead to adverse effects. This is similarly recognised in the Promotion of Access to Information Act.¹⁰⁵ Section 1(a), (b) and (d) of the Act defines personal information as including information relating to "pregnancy", "physical or mental health, well-being, disability" and "blood type". Unreasonable disclosure of such personal information to a third party is forbidden in terms of sections 34 and 63 of the Act. The neonate's medical records, therefore, must remain confidential.¹⁰⁶

When making decisions about the medical treatment of a neonate, that neonate's right to privacy is central to the decision-making process as it is her basic

100 *Nuffield Council on Bioethics Critical care decisions in fetal and neonatal medicine* (2006).

101 Interview with Dr Ilse Els at George Regional Hospital on 8 April 2016. Recording of the interview is on file with the authors. Also see para 5 below.

102 See fn 100 above.

103 *Gross v Switzerland* [2013] ECHR 67810/10.

104 S 13 National Health Act.

105 2 of 2002.

106 Carstens and Pearmain 32.

human rights that can be affected by the decision at hand and therefore it is important that the neonate's diagnosis, prognosis, as well as any treatment decisions regarding the neonate remain confidential throughout the decision-making process. We submit that this is also important to prevent more parties than necessary from becoming involved in the neonate's case. The last thing that is needed in such a difficult decision-making process is the public eye watching and criticising the decisions made on behalf of the neonate. An example of a case where a neonate's best interests were not upheld when the public got involved was the case of *Neonate Doe*.¹⁰⁷

3 2 6 Children's rights

The Constitution recognises that children have specific rights and interests that are especially vulnerable to violation¹⁰⁸ and, thus, affords special protection to children's rights and interests. Section 28 provides children with special protection of the rights that are unique to them. Section 28 goes on to afford children with the right to family or parental care,¹⁰⁹ as well as to basic nutrition, shelter and healthcare services.¹¹⁰ Even though it does not define what basic healthcare services entail, one can draw the inference that children with disabilities and special requirements, such as neonates, cannot be denied the right to appropriate healthcare.¹¹¹

The Constitution provides children with the right to protection from maltreatment, neglect and abuse or degradation.¹¹² This is also relevant when end-of-life decisions need to be made on behalf of a neonate and, thus, the process must be executed without infringing any of these rights. In instances where a neonate's suffering is prolonged or when end-of-life decisions are taken inappropriately, this may amount to forms of maltreatment, abuse and degradation of the neonate.

The Constitution emphasises the importance of the protection of children's rights in providing that in every matter that concerns a child, that child's best interests are of paramount importance.¹¹³ The best interests of the child refer to the norm that physicians, parents and other laypeople dealing with children should

107 Pless "The story of Baby Doe" 1983 *New England J of Medicine* 664. In this case a neonate was born with Down's syndrome and also had oesophageal atresia with associated tracheoesophageal fistula. The treating doctors disagreed about whether to limit treatment or not. The parents were presented with two courses of action and they decided that the neonate should not undergo surgery and should not be administered intravenous feeding. The hospital administrators sought legal advice on the possibility of obtaining a court order to overrule the parents' decision and to perform the surgery. This led to a long and gruelling process that involved the public and the courts in a highly personal matter between a family and their physician. The outcome was that the Indiana Supreme Court held that it was the parents' right to decide on the infant's treatment according to the physician's recommendations. This case was taken on appeal to the United States Supreme Court, but the appeal was never heard as the infant had passed away.

108 Bekink *et al* "Constitutional protection of children" in Davel (ed) *Introduction to child law in South Africa* (2000) 178 ("Bekink").

109 S 28(1)(b) Constitution.

110 S 28(1)(c) Constitution.

111 Moodley 185.

112 S 28(1)(d) Constitution.

113 S 28(2) Constitution.

always safeguard that the child's interests are of priority above the interests of other persons involved.¹¹⁴

In *Minister of Welfare and Population Development v Fitzpatrick*,¹¹⁵ the Constitutional Court explained that the principle of the 'best interest' of children recognised in section 28(2) of the Constitution extends beyond the rights enumerated in section 28(1) and creates a right of its own which, as a matter of necessity, must always be considered in issues involving children.¹¹⁶ In commenting on the use of the "best interest" principle to determine cases before the courts, Davel and Skelton stress that the factors which need to be taken into consideration would vary depending on the facts of each case before the court.¹¹⁷ In their opinion the court has a duty not only to carefully balance issues in reaching a conclusion that can be viewed as being in the best interest of children, but must also ensure that child-centred approaches are adopted in reaching their decision.¹¹⁸

Consequently, in certain instances it may be in keeping with the Constitution to withhold or withdraw an imperilled neonate's life-sustaining treatment if it would be in the best interest of that neonate. It can be argued that in order to make a reasonable and justified decision, the interests of other persons involved should be considered as well but that, in keeping with section 28 of the Constitution, the neonate's interests should be of paramount importance. We submit that, for example, the neonate's right to be protected from the maltreatment and degradation that she would suffer from undergoing further extensive and invasive treatment would take priority over the parents' interests of wanting their child to be kept alive for a few hours longer.

3 2 7 Right of access to health care

Section 27 of the Constitution provides for various rights, including the right to have access to health care and the right not to be refused emergency medical treatment. Access to health care entails that a person should be able to receive healthcare services and that these services should be effective and available.¹¹⁹ Carstens and Pearmain argue that the right to health care may also be found in various other rights in the Constitution, such as the rights discussed above.¹²⁰ Section 27 specifically provides these rights for "everyone": thus, no distinction is made based on age, race or the type of health care treatment that a specific person requires. Presently in South Africa, pregnant women and children below the age of 6 years have the right to access free health care services;¹²¹ however, having the right of access and actually having access are entirely different concepts.

The right to health care and other socio-economic rights in the Constitution are subject to the availability of resources.¹²² However, children's rights, including the right of children to basic health care, are unqualified by the limitation of

114 McQuoid-Mason *et al A-Z of medical law* (2011) 42 ("McQuoid-Mason").

115 *Minister of Welfare and Population Development v Fitzpatrick* 2000 3 SA 422 (CC).

116 *Idem* para 17.

117 *Commentary on the Children's Act* (2012) 2–9.

118 *Idem* 2–12 2–14.

119 McQuoid-Mason 6.

120 Carstens and Pearmain 26.

121 S 4(3)(a) National Health Act.

122 Dhai *et al Bioethics, human rights and health law: Principles and practice* (2011) 146.

“availability of resources” contained in section 27(2).¹²³ We submit that children’s right to basic health care services includes those health care services required by imperilled neonates when their parents are reliant on the public health sector and that, thus, such a neonate should be provided with the necessary nutrition, hydration and pain medication. The state is obliged to ensure that imperilled neonates, whose parents are impoverished, are provided with the necessary health care services. However, it is uncertain what exactly is included in the term “basic health care services” for imperilled neonates, as these babies often require more than basic care.

The sections of the Constitution discussed above in some circumstances support the practice of withholding or withdrawing an imperilled neonate’s treatment, however, such withholding or withdrawing will have the effect that some of the neonate’s constitutional rights are limited. It is submitted that, if such limitation may be justified in terms of the limitation clause in section 36 of the Constitution,¹²⁴ the limitation-causing conduct will be deemed constitutional.

(to be continued)

123 S 28(1)(c) Constitution.

124 S 36 Constitution.