

The law related to end-of-life decisions concerning imperilled neonates in South Africa: Where angels fear to tread (2)*

Christine van Aswegen

BA LLB LLM

Candidate attorney, MacRobert Incorporated Attorneys

Annelize Nienaber

BHons LLB LLM LLD

Professor of Public Law, University of Pretoria

3 3 Legislation

3 3 1 Children's Act 38 of 2005

The objects of the Children's Act are set out in section 2 of the Act, as to promote the preservation and strengthening of families and to give effect to the constitutional rights of children, especially the right that the best interests of a child are of paramount importance in every matter concerning the child. It also aims to give effect to the Republic's obligations concerning the well-being of children in terms of international instruments binding on the Republic, and to make provision for means of promoting and monitoring the sound development of children. Its goal is to protect children and to strengthen and develop community structures which can assist in such protection. It specifically aims to recognise the special needs of children with disabilities and, generally, to promote the protection, development and well-being of children.¹²⁵

The "best interests of the child" concept has been an element of South African law since the *Fletcher v Fletcher* case in 1948.¹²⁶ Subsequently, in 1994 in the case of *McCall v McCall*,¹²⁷ the High Court established a list of factors that must be considered by the courts when attempting to determine what would be in a child's best interest. The Children's Act now contains a list of similar factors in section 7.

Section 9 of the Act incorporates section 28(2) of the Constitution by stating that the standard that the child's best interests are of paramount importance in all matters regarding the care, well-being and protection of the child, must be applied.

The Act unfortunately does not refer to the child's right to basic health care, nor does it provide children with a right to a minimum standard of health care and, therefore, it offers only limited protection to the health care of children.¹²⁸

* See 2017 *THRHR* 432 for part 1.

125 S 2(a)-(i) Children's Act.

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

127 *McCall v McCall* 1994 3 SA 201 (C).

128 Buchner-Eveleigh and Nienaber 120.

The Act does, however, refer to the right to information on health care. Section 13 of the Act provides every child with the right to access to information regarding her own health status, the cause and treatment thereof as well as information on health promotion and the prevention and treatment of ill-health and disease, sexuality and reproduction. It also provides children with the right to confidentiality regarding their health status and the health status of a parent, care-giver or family member, except when maintaining such confidentiality is not in their best interests.¹²⁹ Section 13(2) states that any information provided to children in terms of that subsection must be relevant and must be in a format accessible to children. It goes on to emphasise that due consideration must be given to the needs of disabled children.

Section 129 of the Children's Act deals with consent to medical treatment and surgical procedures. Subsections 129(4) and (5) hold that a child under the age of 12 cannot give consent and that the child's parents, guardian or care-giver may consent to the medical treatment of and to a surgical operation on that child. Due to the imperilled neonate's lack of legal capacity, consent to treatment must be provided by the neonate's parents or care-givers or, in exceptional circumstances, by the superintendent, the person in charge of the hospital, or the Minister.¹³⁰ Once again, the best interests of the neonate must be seen as being of paramount importance when any end-of-life decision is made.¹³¹

3.3.2 *National Health Act 61 of 2003*

The Act provides a structure for a uniform health system in South Africa based on the obligations imposed by the Constitution and other laws relating to health care services. It ties together the provisions of the Constitution with health care legislation and with the acceptable ethical principles of medical practice.¹³²

In section 1 of the Act, health services are defined as (a) health care services, including reproductive health care and emergency medical treatment; (b) basic nutrition and basic health care services for children; (c) medical treatment for prisoners and detainees; and (d) municipal health services.¹³³ Section 2 sets out the objects of the Act and they are: to regulate national health and to provide consistency in respect of health services throughout the nation. It deals with the definitions of various terms, the rights and duties of both health care users and health care providers, informed consent and participation in decision-making, refusal of consent and emergency medical treatment, confidentiality and access to medical records, control of the use of human tissue and the control of national health research and information.

Section 5 of the Act provides for emergency treatment by stating that a health care provider, health worker or health establishment may not refuse a person emergency medical treatment. However, the Act does not provide a definition of emergency treatment and so it is uncertain whether life-sustaining treatment for an imperilled neonate would qualify as emergency treatment in terms of the National Health Act. It may be argued that neonatal intensive care can amount to

129 S 13(a)–(d) Children's Act.

130 S 129(6) Children's Act.

131 See below.

132 McQuoid-Mason 285.

133 S 1 National Health Act.

emergency medical treatment as it is general practice to perform manual resuscitation on an imperilled neonate who has just been born and whose life appears to be in danger.¹³⁴

McQuoid-Mason and Dhai define emergency treatment as referring to cases where medical intervention is required due to a person's life or health being in grave danger as a result of disease, injury or poor health,¹³⁵ while Liebenberg argues that the purpose of this right is to ensure that every individual has the opportunity to get the necessary medical treatment during an emergency.¹³⁶ She emphasises that this right, however, is a limited right due to it being subject to the availability of resources.¹³⁷ Although we support the definition provided by McQuoid-Mason and Dhai, there are interpretational difficulties. The term "emergency" is defined by the Oxford dictionary as: "a serious, unexpected, and often dangerous situation requiring immediate action".¹³⁸ It is often associated with a limited amount of time available to help someone or to do what needs to be done. A person who just suffered a gunshot would be in need of emergency medical treatment and in terms of section 5 he would be entitled thereto. But what if one considers a person suffering from renal failure?¹³⁹ In such a case McQuoid-Mason and Dhai's definition will still be applicable because medical intervention will be required due to a person's life or health being in grave danger as a result of disease. However, this person will not merely need a single immediate intervention to save her life or her health, but will require multiple sessions of renal dialysis. It is unlikely that this treatment will constitute emergency medical treatment.

Sections 7 and 8 of the Act uphold the principle of patient autonomy by requiring a patient's informed consent,¹⁴⁰ and requiring the patient's participation in the decision-making process - even if the patient does not have legal capacity to give consent.¹⁴¹ This would apply to small children who are able to express their feelings, but who are unable to give proper consent. In the case of neonates, of course, this is not possible, and proxy consent to treatment should be given, in the best interest of the neonate.

134 Van der Westhuizen *A proposed framework for the legal protection of premature and critically-ill neonates in the context of South African child law* (LLD thesis UFS 2012) 160.

135 Dhai 75.

136 Liebenberg *Socio-economic rights: Adjudication under a transformative Constitution* (2010) 138.

137 *Ibid.*

138 *Oxford dictionaries*, available at <http://bit.ly/2liTXJo>, accessed on 30 December 2016.

139 See *Soobramoney v Minister of Health* 1998 1 SA 765 (CC) where the Constitutional Court held that the right not to be refused emergency medical treatment meant that a person who suffers a sudden catastrophe requiring immediate medical attention should not be denied ambulance or other emergency services which are available and should not be turned away from a hospital which can provide the necessary treatment. However, as Mr Soobramoney required on-going renal dialysis, the Constitutional Court did not consider this emergency medical treatment in terms of s 27 of the Constitution.

140 S 7 National Health Act; s 129(4) and (5) Children's Act; cf para 3 2 2 above.

141 S 8 National Health Act.

3 4 Conclusion

From the above analysis it should be clear that there is an overarching system in place, in the form of the Constitution and legislation, which protects the rights of neonates in situations where end-of-life decisions have to be made regarding their care. It is also clear that the principle of the best interest of the child should be paramount in all decisions regarding these neonates' care. However, it is also evident that there is no specific law or protocol in place that deals appropriately with neonates' situations. Unfortunately, this defect can have tragic consequences for neonates and their families because, by failing to have a proper protocol in place to regulate these decision-making situations, we fail to uphold the basic human rights of our children. Even though such a protocol will be aimed specifically at neonates, the implementation thereof will be to the benefit of children of all ages.

In the next section we briefly examine the different courses of action that are available when end-of-life decisions have to be made regarding the care of imperilled neonates in an effort to highlight the necessity for a specific protocol or set of guidelines to govern end-of-life decisions in imperilled neonates.

4 A FEW NOTES ON APPROPRIATE COURSES OF ACTION

4 1 Introduction

End-of-life decisions are decisions that will certainly or most likely cause or hasten the death of a neonatal patient.¹⁴² This includes the decision to withhold or withdraw a neonatal patient's life-sustaining treatment (ie passive euthanasia), as well as the decision to actively administer lethal drugs to the patient with the intention of ending her life (ie active euthanasia).¹⁴³

The word euthanasia, meaning "good death" in Greek, is defined also to mean "mercy killing of the hopelessly ill, injured or incapacitated", and "the ending as painlessly as possible of life of the person who is fatally ill and suffering".¹⁴⁴ Medical advances in neonatology have led to a sharp decrease in the mortality of extremely preterm neonates; however, this has been at the expense of an increase in the number of survivors with poor health and disabilities.¹⁴⁵ There is therefore controversy over what course of action would be in the neonate's best interests.¹⁴⁶ Although withholding and withdrawing life-sustaining treatment from imperilled neonates has been practiced since the start of modern neonatology,¹⁴⁷ it is still wrought with ethical, legal as well as emotional challenges.

142 Verhagen *et al* "End-of-life decisions in Dutch neonatal intensive care units" 2009 *Archives of Pediatrics and Adolescent Medicine* 895.

143 *Ibid*.

144 Carstens and Pearmain 200.

145 Walther "Withholding treatment, withdrawing treatment, and palliative care in the neonatal intensive care unit" 2005 *Early Human Development* 965.

146 Singh *et al* "End-of-life after birth: Death and dying in a neonatal intensive care unit" 2004 *Pediatrics* 1620 ("Singh *et al*").

147 Doyal and Wilsher "Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine" 1994 *Archives of Disease in Childhood* 66 ("Doyal and Wilsher").

End-of-life decision-making for terminal patients has become accepted into modern health care.¹⁴⁸ In some countries the practice of actively hastening the death of a patient by administration of lethal drugs is legal; however, its prevalence is rare and is most frequently made use of at the explicit request of the terminal patient.¹⁴⁹ More frequent practices include the withholding or withdrawing of life-sustaining treatments as well as the alleviation of severe pain and symptoms through the administration of high doses of sedatives or drugs with similar effects while considering the possibility of hastening death, although this is not the primary purpose of the practice.¹⁵⁰

One of the first publications that described end-of-life practices reported that only 14 per cent of neonatal deaths were related to withholding life-sustaining treatment.¹⁵¹ Between the years of 1988 and 1999, there were two studies that investigated changes in end-of-life decision-making in NICUs.¹⁵² These studies found that the proportion of deaths as a consequence of decisions to withhold or withdraw life-sustaining treatment have increased significantly over the ten-year study period.¹⁵³ More recent studies show that most neonatal deaths in first world countries are a consequence of a decision to withhold or withdraw life-sustaining treatment.¹⁵⁴

4.2 Passive euthanasia

Withholding or withdrawing life-sustaining treatment at birth or in the NICU has been practiced frequently for many years.¹⁵⁵ However, this is but one step in a sequence of treatment options. According to Walther, the process begins with an accurate diagnosis and prognosis.¹⁵⁶ After that has been determined, a process of decision-making, based on futility of treatment and quality of life issues, follows. Next Walther recommends counselling of the family and only once this is done, does he recommend the actual withholding or withdrawing of intensive care.¹⁵⁷

Withholding or withdrawing of life-sustaining treatment may be separated into two groups of treatment options. The first group is where treatment is not initiated at birth because of the non-viability of an extremely preterm neonate; and the second group is where treatment is not initiated because it is considered futile in a terminal neonate who has been admitted to the NICU. In both groups passive euthanasia is performed by withholding CPR for the dying neonate in accordance with do-not-resuscitate (DNR) orders.¹⁵⁸ Withdrawal of life-sustaining

148 Onwuteaka-Philipsen *et al* "Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001" 2003 *The Lancet* 395 ("Onwuteaka-Philipsen").

149 *Ibid.*

150 *Ibid.*

151 Campbell and Duff "Moral and ethical dilemmas in the special-care nursery" 1973 *New England J of Medicine* 890.

152 Lantos *et al* 1620–1626; Hagen *et al* "Deaths in a neonatal intensive care unit: A 10-year perspective" 2010 *Pediatric Critical Care Medicine* 5 463–468.

153 Lantos *et al* 1620.

154 Bos *et al* "Dutch neonatologists have adopted a more interventionist approach to neonatal care" 2015 *Acta Paediatrica* 888.

155 Partridge and Wall "Death in the intensive care nursery: Physician practice of withdrawing and withholding life support" 1997 *Pediatrics* 64 (Partridge and Wall).

156 Walther "Withholding treatment, withdrawing treatment, and palliative care in the neonatal intensive care unit" 2005 *Early Human Development* 965 ("Walther").

157 Walther 966.

158 Singh *et al* 1621.

treatment takes place in the context of physiologically stable infants whose life-sustaining treatment, such as mechanical ventilation, is actively removed for quality-of-life concerns.¹⁵⁹

It seems that most people are morally more troubled by withdrawing treatment from a patient than not providing or withholding that treatment in the first place. Many feel that ceasing treatment directly causes the patient's death, whereas never initiating the treatment does not have such a direct causal role.¹⁶⁰ Even though one can comprehend the feeling of hesitancy about withdrawing treatment, the distinction between withdrawing and withholding treatment is both irrelevant and dangerous.¹⁶¹ Even if there existed a clear distinction, both stopping and not starting treatment may potentially cause the patient's death.¹⁶² This could result in many potentially successful treatments being withheld from patients for fear of the delayed burden of failure in some cases.¹⁶³

However, that said, one is able in selected cases to fruitfully distinguish between the effects of the withdrawal and the withholding of treatment. On the one hand, there is the withholding or withdrawing of treatments from a terminal patient that are considered futile. In these cases, there are very few people who raise an objection to the withholding or withdrawing.¹⁶⁴ Some even argue that no party other than the patient has the right to object in such a case.¹⁶⁵ On the other hand, there are treatments that can successfully alleviate pain and stabilise some neonates, but neurologically those neonates have such a hopeless chance that the burdens of prolonged life-sustaining treatment outweigh the benefits of sustained life.¹⁶⁶ These treatments would then rather be withheld or withdrawn due to concerns for the neonate's quality of life.¹⁶⁷

The only adequate ethical and legal validation for not acting in accordance with the general obligation of providing or sustaining life-saving treatment is that it is in the neonate's best interest.¹⁶⁸ This statement is vital because, in practice, physicians sometimes raise other arguments to validate withdrawal of treatment such as "we are allowing nature to take its course".¹⁶⁹ The problem comes in where omitting to provide treatment for a neonate with the expected consequence of hastening death potentially amounts to the criminal offence of murder. Likewise, the parents who provided informed consent to such omission may be considered co-conspirators.¹⁷⁰ Thus, it is of great importance to clarify the circumstances under which the withholding or withdrawal of treatment will be in the neonate's best interest. The British courts emphasise that human life is precious and should be safeguarded, but they stress that there is no obligation to

159 Walther 970.

160 Beauchamp and Childress *Principles of biomedical ethics* (2001) 120.

161 *Idem* 121.

162 *Ibid.*

163 *Ibid.*

164 *Ibid.*

165 Partridge and Wall 64.

166 Beauchamp and Childress 121.

167 Partridge and Wall 69.

168 Doyal and Wilsher 66.

169 *Ibid.*

170 Kennedy and Grubb *Medical law: Text and materials* (1990) 936–941.

endorse an absolute sanctity of life-doctrine, and so medical professionals are not required to use all medical means possible to save or prolong life.¹⁷¹

This raises the question – what kind of treatment may be withdrawn without crossing the line of what would be ethical? After the decision has been made to withdraw or withhold treatment, there arise new obligations and considerations. When death is inevitable for the neonate, the main concern regarding its care is to provide pain relief and comfort.¹⁷² Now the doctor's duty is to "treat for dying". This normally entails that the necessary analgesia and nursing care must be provided for the neonate.¹⁷³ However, what is more controversial is the question of how far the duty to provide the neonate with nutrition and artificial hydration stretches. If the neonate was born prematurely, it is likely that it will require nasogastric feeding for extended periods. In the case of *Bland*,¹⁷⁴ where the patient was in a permanent vegetative state, the court held that artificial feeding amounts to medical treatment and, thus, if the physicians conclude that it will not benefit the patient it could be withheld.

At present, though, nasogastric feeding is still regarded as standard care and neonatal intensive care staff are hesitant to consider withdrawal thereof.¹⁷⁵ However, it is at least possible to ethically and legally justify the withdrawal of nasogastric feeding if it meets the best interest criteria as this perspective was held in the *Bland*¹⁷⁶ case. An example would be a case where a neonate had a severe congenital malformation and it is certain that an early death is imminent.

4.3 Active euthanasia

In a situation where it has been decided that further treatment would not be in the best interest of the neonate and that the neonate should be allowed to die with dignity, it could be argued that a better way to achieve this would be by taking positive steps to hasten death, rather than by withdrawal or withholding treatment.¹⁷⁷ This is prohibited by criminal law in almost all countries, including South Africa, but it may be possible to argue that it is fundamentally more dignified to die as a result of a lethal dose of sedative rather than because of an untreated opportunistic infection.¹⁷⁸ The act of extubating a neonate's trachea or withdrawing vaso-active medications and, in so doing, causing the neonate to die, is now an accepted practice that may also be ethically justifiable.¹⁷⁹ By utilising advanced palliative treatments, neonates generally may be made comfortable throughout the dying process.¹⁸⁰

171 Elliston *The best interests of the child in healthcare* (2009) 189 ("Elliston"). Cf para 2 above.

172 Walden Sudia-Robinson and Carrier "Comfort care for infants in the neonatal intensive care unit at end of life" 2001 *Newborn and Infant Nursing Reviews* 97.

173 Doyal and Wilsher 69.

174 *Airedale NHS Trust v Bland* (1993) 1 All ER 858 (HL) ("*Bland*").

175 Doyal and Wilsher 69.

176 *Bland* 858.

177 Elliston 188.

178 *Ibid.*

179 Diekema *et al Clinical ethics in pediatrics: A case-based textbook* (2011) 124 ("Diekema *et al*").

180 Catlin and Carter "Creation of a neonatal end-of-life palliative care protocol" 2002 *J of Perinatology* 184.

Each neonate is different and therefore some neonates die shortly after the withdrawal of life-sustaining treatment, whereas others can carry on living for hours and even days. Then there are also cases where the neonate survives without any medical technology. A child or neonate can suffer considerably during a lingering death and, therefore, some have advocated actively accelerating death in order to alleviate suffering.¹⁸¹ In cases of a lingering death after withdrawal of life-sustaining treatment, the parents of the neonate often feel that the doctor should administer something to the neonate to end life sooner.¹⁸² They feel that the doctor should, in that manner, ease the neonate's suffering as well as their own anguish and they see no value in extending the neonate's or the family's misery in such situations.¹⁸³ They plead for active euthanasia.

Active euthanasia is met with much resistance throughout the world, but three arguments may be made in its favour. The first is to alleviate the unyielding pain and suffering of a patient; the second is to respect a patient's right of autonomy; and, third, to ease the fear of loss of dignity often due to a loss of autonomy.¹⁸⁴ The growing acceptance of passive euthanasia as a result of a respect for the principle of autonomy has raised questions regarding the legal and ethical objections to active euthanasia.¹⁸⁵

Statistics suggest that many children who are terminally ill suffer from untreatable pain, exhaustion, difficulty in breathing and other distressful symptoms.¹⁸⁶ Protocols that regulate and dictate the use of palliative sedation in children exist in some health care facilities, and research has proven that when such sedation is used at the end of life, it does not itself speed up death.¹⁸⁷

However, this form of therapy is often unable to adequately alleviate the suffering of each and every patient.¹⁸⁸ The dilemma is whether it will be in the neonate's best interest to either alleviate her suffering by ending her life quickly, or to allow the dying process to take its natural course.¹⁸⁹ The desire to minimise the neonate's suffering is the primary argument in support of non-voluntary euthanasia. If it is inevitable that the neonate will die and she is experiencing unbearable pain and suffering, despite medical intervention, then it may be ethically permissible to hasten death for the purpose of alleviating suffering. However, without knowledge about the neonate's experience of pain and suffering, one cannot say for certain that the suffering is indeed unbearable. External signals are looked at, such as facial expressions and vital signs, to make assumptions about the level of comfort or discomfort the neonate is experiencing, but one cannot truly know what they are feeling.¹⁹⁰

181 Diekema *et al* 124.

182 McHaffie *et al* "Lingering death after treatment withdrawal in the neonatal intensive care unit" 2001 85 *Archives of Disease in Childhood Fetal and Neonatal Edition* 8 11.

183 *Ibid.*

184 Clarke and Egan "Euthanasia – Is there a case?" 2009 *SA J of Bioethics and L* 24 25 ("Clarke and Egan").

185 *Ibid.*

186 Heath *et al* "Symptoms and suffering at the end of life in children with cancer: An Australian perspective" 2010 *Medical J of Australia* 71.

187 Maltoni *et al* "Palliative sedation therapy does not hasten death: Results from a prospective multicenter study" 2009 *Annals of Oncology* 1163.

188 Davis "Does palliative sedation always relieve symptoms?" 2009 *J of Palliative Medicine* 876.

189 Diekema *et al* 126.

190 *Ibid.*

In the Netherlands, the Groningen Protocol for neonatal end-of-life decision-making has been implemented successfully.¹⁹¹ The Groningen Protocol allows for active euthanasia of neonates, but only in very specific and clearly-defined circumstances.¹⁹²

However, active euthanasia is unlawful in South Africa despite a 2015 High Court judgment which granted an order to the applicant, a terminally-ill, mentally competent adult, allowing a willing medical practitioner to assist him in committing suicide by the supply or administration of a lethal substance without being prosecuted.¹⁹³ The judgment was subsequently overturned on appeal,¹⁹⁴ and active euthanasia therefore is not a treatment option available to South African neonates.

Next, in the penultimate section of the article, we turn to a brief examination of factors influencing end-of-life decisions concerning neonates in South African private and public healthcare sectors.

5 WHERE ANGELS FEAR TO TREAD: END-OF-LIFE DECISIONS CONCERNING IMPERILLED NEONATES IN SOUTH AFRICA

5.1 Public sector

Many challenges exist in caring for imperilled neonates in South African public hospitals.¹⁹⁵ The primary challenge that all developing countries face is a lack of resources. The number of patients admitted to public hospitals in South Africa far outnumbers the availability of hospital staff, medicine and medical products, hospital beds and healthcare professionals. The World Health Organisation recommends an average ratio of eight doctors to every 10 000 people; this is about three times more than the current number of doctors in South Africa.¹⁹⁶ The list of resource shortages in South African hospitals is endless and remains a factor that carries a lot of weight in the decision-making process about appropriate care of adults and neonates.¹⁹⁷

191 The Groningen Protocol for Euthanasia in Newborns; see Verhagen “The Groningen Protocol for newborn euthanasia, which way did the slippery slope tilt?” 2013 *J of Medical Ethics* 293. See also Van Aswegen and Nienaber “End-of-life decisions regarding the care of imperilled neonates: Lessons for South Africa from the Dutch and other legal systems” 2017 *CILSA* (forthcoming) for a full discussion of the usefulness of the Groningen Protocol in a South African setting.

192 See Van Aswegen “End-of-life decisions concerning imperilled neonates: Proposals for reform” (LLM diss UP 2016) ch 6.

193 See *Stranham-Ford v Minister of Justice and Correctional Services* 2015 4 SA 50 (GP).

194 *Minister of Justice and Correctional Services v Estate Late James Stranham-Ford* (531/2015) [2016] ZASCA 197 (6 December 2016). The Supreme Court of Appeal upheld the appeal and set aside the order of the North Gauteng High Court.

195 Bulletin of the World Health Organisation *Bridging the gap in South Africa* (2010), available at <http://bit.ly/2l7xPzg>, accessed on 30 December 2016.

196 See *Mail and Guardian* “SA state hospitals in crisis” (2009), available at <http://bit.ly/2lgAb1y>, accessed on 30 December 2016.

197 See Gordon, Allorto and Wise “Analysis of referrals and triage patterns in a South African metropolitan adult intensive care service” 2015 *SAMJ* 491–495 and Scribant and Bhagwanjee “National audit of critical care resources in South Africa – Open versus closed intensive and high care units” 2007 *SAMJ* 1319–1322.

In South African public NICUs, there is a desperate need for incubators, medicine, clean breast-milk and qualified medical personnel.¹⁹⁸ The shortage in health care professionals is particularly calamitous in rural areas.¹⁹⁹ In 2002 it was found that there were at least 29 200 vacant health care professional posts in public hospitals throughout South Africa;²⁰⁰ and by 2010, the Department of Health estimated that South Africa was short of over 44 700 nurses.²⁰¹ These shortages are mostly associated with poor conditions of service and inadequate support structures in public hospitals, which make working there difficult and, consequently, hamper efforts to attract and retain competent professionals.²⁰²

Unfortunately, in some cases limited resources may even be the primary factor taken into account when a decision must be made whether a neonate should receive intensive invasive treatment or not. In a hospital that is severely understaffed and over-crowded with patients, the primary consideration might not be what is in the particular neonate's best interests but, rather, what is in the best interest of all the other patients who are also in need of the resources required by that one imperilled neonate. One can simply not be guaranteed the best optimal care in a facility where resources are limited and, therefore, the ideals of medical ethics often have to take a back-seat to the practical challenges faced during the practice of medicine.

While a lack of resources is the most challenging problem that South Africa's healthcare system faces, the importance of other socio-economic factors must be considered if we wish to improve the situation in South African public hospitals. A problem often faced at public hospitals is the fact that many of the patients, if not the majority of them, are uneducated or educated to a very low level of formal schooling. The consequences of this are vast. The Saving Babies 2010–2011 Report reflects the early neonatal death rate as high as 21 per 1000 live births. Deaths due to prematurity had avoidable patient-associated factors in 30 per cent of cases with the top 5 factors identified as being: delay in seeking medical attention during labour; non-initiation of antenatal care; booking late in pregnancy; infrequent visits to antenatal clinics; and inappropriate responses to rupture of membranes.²⁰³ It is a sad reality that a less-educated pregnant mother is more likely to commit the errors listed above than a mother who is well-educated and versed in the requirements that she needs to meet in order to give birth to and to raise a healthy baby. This has important implications for neonatal health care in the public sector: the high premature birth rate because of avoidable patient-associated factors places a heavy burden on the country's already-stretched neonatal health care resources.

Another important socio-economic factor that must be taken into account is that of poverty. In a community where the majority of residents are uneducated and impoverished, this will inevitably breed other challenges such as teenage

198 Nmutandani *et al* "Community service doctors in Limpopo province" 2006 *SAMJ* 180 ("Nmutandani *et al*").

199 *Ibid.*

200 Hlangani "Brain drain: Health systems on life support" *The Star* 22 October 2002.

201 Cullinan "SA Health Review 2015: Nursing in crisis" (2015), available at <http://bit.ly/2npDofT>, accessed on 20 March 2017.

202 Nmutandani *et al* 180.

203 Georgi and De Witt "Neonatal mortality in South Africa: How are we doing and can we do better?" 2013 *SAMJ* 518.

pregnancies, alcohol and drug abuse and a high crime rate. The effect this has on South African NICUs is, firstly, an increase in the number of neonates to be delivered and cared for; secondly, an increase in the number of imperilled neonates due to the pregnant mother's abuse of alcohol and drugs. This increase then puts a further strain on the available resources in the NICUs and inevitably prevents neonates from receiving the healthcare that is considered to be in their best interests.²⁰⁴

Another sad reality is that many neonates receiving treatment in public hospitals' NICUs are not visited by their mothers or by both their parents.²⁰⁵ Consequently, the hospital staff "adopt" these neonates as their own as they have unavoidably become attached to them.²⁰⁶ This attachment by the staff to the neonate may eventually start to influence their capacity to make objective decisions concerning the neonate.²⁰⁷

In public hospitals, doctors often have to deal with parents who are very young or uneducated or even disinterested in the neonate's treatment.²⁰⁸ The neonate's parents may live far away from the hospital and may be unable to arrange transport to visit their neonate regularly.²⁰⁹ In some cases the mother of the neonate is mentally incompetent, addicted to drugs or even deceased and no guardian has been appointed to make decisions on behalf of the neonate.²¹⁰ It is not uncommon for doctors in these circumstances to merely reach the decisions on their own and to simply inform the neonate's parents of what will be happening to the neonate.²¹¹ This course of action is entirely in conflict with the principle of patient autonomy; however, under such circumstances the doctors believe that it is best that they, and not the parents, decide what is best for the neonate.²¹² Of course, one must remember that there are parents who have imperilled neonates in public hospitals who are very involved in the decision-making processes, but unfortunately these parents appear to be in the minority.²¹³

5.2 Private sector

In the private sector, patients are required to pay for their medical treatment; either out of their own pockets or out of their medical aid scheme. This financial reality has the effect that South African private hospitals attract better healthcare professionals, have better equipment and resources, as well as generally offering better health care services to patients.²¹⁴ Thus, imperilled neonates in private hospitals have a better chance of receiving treatment that is considered to be in their best interests.²¹⁵ In public hospitals, the decision-making process has to include factors such as limited resources and challenging socio-economic factors, all of which are largely absent from consideration in private hospitals.²¹⁶

204 See fn 101 above.

205 *Ibid.*

206 *Ibid.*

207 *Ibid.*

208 *Ibid.*

209 *Ibid.*

210 *Ibid.*

211 *Ibid.*

212 *Ibid.*

213 *Ibid.*

214 Young "Private vs Public healthcare in South Africa" (2015), available at <http://bit.ly/2nTRpjJ>, accessed on 20 March 2017.

215 See fn 101 above.

216 *Ibid.*

As a consequence, in private hospitals the neonate's parents on the whole are involved in the decision-making process as the treating doctors deem them to be competent individuals capable of making decisions on behalf of their neonate.²¹⁷ This means that parents generally take part in the end-of-life decision-making process on behalf of their neonate, and in doing so they exercise their right to autonomous decision-making. The private sector, generally, is a milieu where doctors can thoroughly explain the imperilled neonate's circumstances to his/her parents and where all the parties involved are able to reach agreement on what course of treatment would be in the neonate's best interest. Again, this is the situation in general and may not be true in every individual instance.²¹⁸

6 CONCLUSION

Neonatology is a rapidly-developing area of medicine. Advances in medical technology and a better understanding of normal neonatal physiology have resulted in a greater number of neonates surviving and living longer. With advances in neonatal care came changes: changes in attitudes and approaches towards end-of-life decision-making, specifically where imperilled neonates are concerned. These changes in attitudes and approaches all involve challenges that are amplified in a setting such as South Africa where, on the whole, resources are limited.

Although neonates' rights are guaranteed broadly in the Constitution and in legislation, there exists no specific set of regulations or protocols dealing with the highly-complex situations in which imperilled neonates, their doctors, and their parents find themselves. As illustrated above in our discussion of British case law, the best interest of the child concept rarely provides optimal solutions in a clinical context. Because of these uncertainties, health care professionals need to be provided with appropriate guidelines, or a protocol, so that imperilled neonates and their parents are not met with confusion and crises in the NICU which could expose neonates to the potential infringement of their rights as well as unethical and illegal treatment.

It must be stressed that the treatment of imperilled neonates should be regarded as the provisioning of clinical, medical care within an ethically and legally justifiable framework. The concept of the neonate's best interests should underscore clinicians' consideration of the burden of intensive or invasive care and futility weighed against possible outcomes.²¹⁹ An appropriate protocol or guideline as to how the decision-making process should be managed will serve as immensely helpful in South African hospitals. Such a protocol will be able to offer some assistance to parents who are involved in the decision-making process and will be able to offer assistance to doctors who, sadly, sometimes have to make these difficult decisions without the participation from the neonate's parents.

217 *Ibid.*

218 *Ibid.*

219 Chiswick "Infants of borderline viability: Ethical and clinical considerations" 2008 *Seminars in Fetal & Neonatal Medicine* 14.