

PARENTAL INVOLVEMENT IN END-OF-LIFE DECISIONS IN NEONATOLOGY: LEGAL CONSIDERATIONS WITH REGARD TO DUTCH MEDICAL PRACTICE

JOZEF H.H.M DORSCHIEDT*

University of Groningen, The Netherlands

EDUARD VERHAGEN**

University of Groningen, The Netherlands

PIETER J.J. SAUER***

University of Groningen, The Netherlands

JOEP H. HUBBEN****

University of Groningen, The Netherlands

ABSTRACT

Developments in legal and medical research regarding end-of-life decisions regarding severely suffering neonates in the Netherlands provide good cause for reflection on specific items of this issue. This article deals with the outcomes of the first national survey on end-of-life practice in Dutch Neonatal Intensive Care Units (NICUs) and examines the legal aspects of parental involvement in the decision making process. In this regard the authors reflect on the Dutch interpretation of ‘hopeless and unbearable suffering’, the medical-professional conduct in case of medical neonaticide, parental authority over an infant’s fundamental right to life and the role of parents in supervising legal-procedural aspects.

INTRODUCTION

The issue of end-of-life decisions regarding severely suffering newborn infants has been—and still is—widely discussed. In this debate, medical, ethical and legal aspects are thoroughly addressed and the importance of a multidisciplinary approach of the issue is generally acknowledged. Still, many aspects of the issue remain undecided, while apparent consensus regarding certain aspects are often overtaken by new casuistic nuances.

In the last two decades, the Netherlands has witnessed several developments regarding end-of-life decisions in neonatology. Developments that have shaped Dutch understanding include the statutory introduction of a reporting procedure, the acquittal of two physicians charged with the murder of a hopeless and unbearably suffering neonate, and the establishment of a national multidisciplinary expert committee serving as an advisory board to the Public Prosecutor. New research results on legal¹ and medical² aspects of neonatal end-of-life decisions in the Netherlands have vitalised the Dutch debate once more and provide good cause for further reflection on specific issues. These include the issue of how to judge parental involvement in the neonatal end-of-life decision making process and the way physicians deal with this involvement.

In this article this parental involvement is discussed from a legal perspective, partly as a response to current end-of-life practice in Dutch Neonatal Intensive Care Units (NICUs). An impression on the regulative state of the art and current neonatal end-of-life practice in the Netherlands is followed by an exposé concerning the parental influence on the decision making process and the characteristics of cases in which a conflict between the medical team and the parents occurred. A reflection on specific legal issues relating to parental involvement, such as the parental position in decisions regarding what counts as ‘hopeless and unbearable suffering’ (present suffering or predicted suffering as well?), their authority over their infant’s right to life and parental responsibilities in supervising legal-procedural aspects, concludes this article.

THE STATE OF THE ART IN THE NETHERLANDS

In the Netherlands, the wording ‘end-of-life decisions in neonatal practice’ is a collective noun for professional decisions in neonatal health care that lead to the death of a newborn patient. They involve decisions to withdraw or withhold medical treatment, to administer (or increase) sedative medication or—in extreme cases—to deliberately end a neonate’s life. Research has shown that the latter decisions are often preceded by a non-treatment decision.³ The physician in charge, in most cases a neonatologist, is responsible for these decisions. A non-treatment decision remains without legal consequences provided such a decision is based on admissible professional grounds, such as inability to realise the treatment’s goal and/or disproportionality between the ends and means of the treatment. If the grounds for a non-treatment decision are legally unsound or even negligent the physician in charge can be held accountable. In appropriate circumstances this may lead to disciplinary or even criminal charges

against the physician. To deliberately end a neonate's life counts as homicide or murder under Dutch criminal law. Physicians must report cases of medical neonaticide to a multidisciplinary expert committee. This committee reviews these cases against special requirements of due care and provides advice to the Public Prosecutor, who decides whether or not the physician in charge will be prosecuted.

Under Dutch civil law parents are responsible for taking care of their children and for raising them. Decisions regarding medical treatment are part of this responsibility. As a newborn child is too young to be competent to take part in decision making regarding medical treatment, the child's parents act as legal representatives of their child. They are to be informed about the child's health and their consent to the child's medical treatment is required. Parents may also refuse to consent to life-saving medical treatment or request a physician to withdraw or withhold such treatment. Dutch medical practice has revealed that they sometimes even ask a physician to end their child's life.

Parental involvement in neonatal end-of-life decision making raises questions concerning the legal limits of this involvement, how physicians should deal with conflict situations and how particular issues relate to the neonate's most fundamental right protected under international human rights law: the right to life. In the next sections these questions are investigated with reference to current Dutch medical practice, which is believed to be similar to practices in many other Western countries.

END-OF-LIFE DECISION MAKING IN DUTCH NEONATAL PRACTICE

In the Netherlands clinical care for severely suffering newborn infants is centralised in 10 level III NICUs. In all these NICUs, medical decisions are made by a multidisciplinary team, led by the attending neonatologist who is responsible for these decisions.

Survey 2005–2006

Verhagen et al. performed a retrospective descriptive study on Dutch end-of-life practice regarding severely suffering newborn infants.⁴ This study reviewed the medical files of 359 neonates who died in NICUs between October 2005 and September 2006. In 340 of these 359 cases a decision to withhold or withdraw treatment preceded death, while 19 infants died during cardiopulmonary resuscitation (CPR). The decision to withdraw life-sustaining treatment (mostly withdrawal from mechanical respiration) was taken in 294 cases.

Death resulting from withholding treatment occurred in 46 cases and deliberate ending of life officially took place in 1 case.

All cases where end-of-life decisions occurred, were classified in three groups: infants with no chance of survival (group I; 208 of 359 deaths => 58%), infants without terminal abnormalities but with a poor prognosis as to the child's future quality of life (group II; 150 deaths => 42%) and infants not dependent of NICU-care but with a poor prognosis and present severe suffering (group III; one child). In 147⁵ out of the 150 group II-cases the attending neonatologists (N=80) were interviewed by an experienced paediatrician (EV) in order to obtain detailed information about the decision making process. Several of these semi-structured interviews took place in the presence of a qualified legal scholar (JD).⁶ Here, the physicians were asked whether or not legal considerations influenced the decision making process. This also revealed whether such considerations influenced the physician's management of conflict situations with the parents.

The analysis of the medical files showed that in 194 of the 208 group I-cases the parents agreed to an end-of-life decision. In the remaining 14 cases in this group parental involvement was not documented. In the 147 group II-cases the medical files and the interviews revealed that all parents were involved in the decision making process and that end-of-life decisions were never made without parental approval. End-of-life decisions in group II-cases were mostly initiated by the physician, who informed the parents of the medical team's considerations and final decision and who also asked for parental assent.

Conflicts between medical team and parents

A part of the survey was dedicated to determine frequency and characteristics of conflicts—defined as: disputes or disagreements about an end-of-life decision—between the medical team and the parents.⁷ Such conflicts were regarded as bearing relevant information as to the practice of neonatal end-of-life decision making and the legal aspects of parental involvement.

As the survey of Verhagen et al. particularly focused on group II-cases, no data concerning the incidence of conflicts in the 194 group I-cases were collected. This was due to the fact that no conflicts were expected in this group, as the infants' medical conditions in these type of cases are generally considered 'not compatible with life'. Similar circumstances played a role in the group III-case in which, according to the medical file and the interview, no conflict occurred. Yet, in view of several particularities in the decision making process, this case will be separately discussed in the next section.

In 18 of the 147 group II-cases conflicts between the medical team and the parents did occur.⁸ The general characteristics of these 18 cases have been published elsewhere.⁹

Tables 1 and 2 divide the 18 cases into 2 sub-categories. Table 1 shows characteristics of 4 cases in which the parents preferred to withdraw life-sustaining treatment (mostly withdrawal of mechanical ventilation) and the team favoured the continuation of treatment. Table 2 shows characteristics of 14 cases in which the parents preferred continuation of treatment while the team was in favour of withdrawal.

Both tables show that the differences of opinion between the medical team and the parents basically involve the decision to continue or to withdraw intensive treatment. The main consequence of such a difference of opinion is that the treatment decision is

Table 1. Cases in which parents prefer withdrawal: Team prefers continuation (N=4)

<i>No.</i>	<i>Cause of death</i>	<i>Source of conflict</i>	<i>Conflict within medical team</i>	<i>Parental involvement</i>	<i>Decision making influenced by parents*</i>
1	Extreme prematurity	Uncertain neurological prognosis	No	Prefer withdrawal long before team does.	Definitely no (1)
2	Extreme prematurity	Uncertain neurological prognosis	No	Prefer withdrawal treatment before team does.	Definitely no (1)
3	Sepsis/NEC	Uncertain neurological prognosis	Yes	Expect infant to die soon. Don't want their child to suffer, grant humane death.	Definitely no (1)
4	Asphyxia	Uncertain neurological prognosis	No	Relieved that infant is allowed to die, now that MRI confirmed diagnosis. Troubled by many diagnostics/ tests necessary to support end-of-life decision.	Definitely no (1)

* This section shows parental influence according to the interviewed physicians. The score is reflected in a 5-point Likert-like scale (definitely no (1); likely no (2); neutral (3); likely yes (4); definitely yes (5)).

Table 2. Parents prefer continuation: Team prefers withdrawal (N=14)

<i>No.</i>	<i>Cause of death</i>	<i>Source of conflict</i>	<i>Conflict within medical team</i>	<i>Parental involvement</i>	<i>Decision making influenced by parents*</i>
5	Sepsis/NEC	Uncertain neurological prognosis	No	Accept limited treatment, but reject withdrawal respiration on religious grounds. Need time to adjust.	Definitely no (1)
6	Extreme prematurity	Uncertain neurologic and pulmonary prognosis	No	Want to try everything to save child, team agrees for several days.	Definitely no (1)
7	Sepsis/NEC	Uncertain neurological prognosis	No	Hoped for surgery, but team believed this to be futile. In grief, but expected this to happen.	Definitely yes (5)
8	Sepsis/NEC	Uncertain neurological prognosis	No	Agreed to withdrawal after second opinion.	Definitely no (1)
9	Respiratory insufficiency	Uncertain pulmonary prognosis	Yes	Father cannot accept that infant will die. Accused team of waiting too long to act. Believed child was murdered.	Definitely yes (5)
10	Respiratory insufficiency	Uncertain neurological prognosis	No	At first no consent for withdrawal. Additional meeting to solve language barriers. Severe genetic history (3 previous infants died). Approval after one week.	Definitely no (1)
11	Congenital anomalies	Uncertain neurological prognosis	No	Denial of severity of infant's condition. Cannot let go. Demand second opinion. Approval after two weeks.	Definitely no (1)

Table 2 continued

<i>No.</i>	<i>Cause of death</i>	<i>Source of conflict</i>	<i>Conflict within medical team</i>	<i>Parental involvement</i>	<i>Decision making influenced by parents*</i>
12	Asphyxia	Uncertain neurological prognosis	No	Request second and third opinion in view of bereavement.	Definitely no (1)
13	Respiratory insufficiency	Uncertain neurological prognosis	No	At first no consent for limited treatment, but approval after second opinion.	Definitely yes (5)
14	Asphyxia	Uncertain neurological prognosis	No	No consent to withdrawal due to religious conviction.	Definitely no (1)
15	Asphyxia	Uncertain neurological prognosis	No	Religious father has difficulties to accept the inevitable.	Definitely yes (5)
16	Respiratory insufficiency	Uncertain neurological prognosis	No	Difficulties to accept poor prognosis, acceptance on insistence of team.	Definitely no (1)
17	Asphyxia	Uncertain neurological prognosis	Yes	No consent to withdrawal from respirator due to religious conviction. Afterwards father angry with gynaecologist	Definitely yes (5)
18	Congenital anomalies	Uncertain neurological prognosis	No	Medical file merely states "Language problem" and "Approval".	Definitely no (1)

* This section shows parental influence according to the interviewed physicians. The score is reflected in a 5-point Likert-like scale (definitely no (1); likely no (2); neutral (3); likely yes (4); definitely yes (5)).

postponed, while in the end both parties always reached consensus as to the discontinuation of the child's treatment. What remains unclear, however, is what happened after a decision to withdraw treatment was made. Although the decision to withdraw mechanical respiration was the decision most frequently taken, it is obvious that in most cases this decision did not result in the infant's death. After respiration was withdrawn other decisions were made as well, for instance decisions regarding medication. Yet, the survey holds no information as to the incidence of conflicts between parents and the medical team concerning decisions about an infant's medication.

Parental influence on decision making

According to the interviewed physicians in 16 out of the 147 group II-cases parents have substantially influenced the final end-of-life decision. In 5 of these 16 cases a conflict between the parents and the medical team occurred.¹⁰ This means that in 5 out of the 18 cases with a conflict between the parents and the medical team, the parents have directed the decision making process. Another finding of the survey shows that in 6 of the 147 group-II cases a conflict within the medical team occurred. In 3 of these 6 cases there was a conflict between the team and the parents as well. These 3 cases coincide with 3 cases as shown in Table 1 and 2.¹¹ In 2 of these 3 cases the conflict was overtaken by a deterioration of the child's condition. The remaining case coincides with case no. 17 in Table 2 and concerned a serotine infant, who died the day after birth, due to the effects of severe perinatal asphyxia. The infant's condition was probably of antenatal origin, because of the very serious cerebral abnormalities present shortly after birth and apparent from a shallow electroencephalogram. All conditions probably relate to a poor functioning placenta. The team believed that withdrawal of mechanical respiration was indicated.

REFLECTION

This section contains a legal response to the findings by Verhagen et al. as far as they are related to the issue of parental involvement. As the survey focused on issues apparent from the medical files and the interviews, some legal issues regarding parental involvement which are not covered by Verhagen et al. are identified and discussed as well.

Present vs. predicted suffering

In 92% (135) of the 147 deaths in group II the end-of-life decisions were based on the infant's expected future quality of life. In 76% (112) of these cases this concerned future suffering or expected inability to be engaged in some kind of verbal or non-verbal communication with others. In 48% (71) considerations regarding the infant's present quality of life were used, while in 44% (64) of the cases the expected quality of life was used in combination with considerations regarding the infant's present state. The infants' parents were always involved in all decisions in group II and consultation of other medical experts took place in almost all cases.¹²

These findings raise the question of the type of 'hopeless and unbearable suffering' which can justify an end-of-life decision: *present* pain and suffering or *future* pain and suffering as well? And if considering an infant's future pain and suffering in particular cases cannot be excluded, what about the pure expectancy of a child's pain and suffering? Is this a permissible basis for an end-of-life decision?

In November 2005 the Dutch Government stressed that present hopeless and unbearable suffering is the only admissible ground for decisions to deliberately end neonatal life. Future suffering—meaning: expected but not yet manifest suffering—is not mentioned to constitute such a ground.¹³ The Government's point of view is quite understandable and obviously demarcates the limited space at the disposal of a physician to perform lawful medical neonaticide. Yet, the question is whether it is plausible to exclude future suffering as a ground for neonatal end-of-life decisions in any case. We believe the Government's view needs further differentiation, as Verhagen et al. have shown that expected quality of life indeed plays a part in the end-of-life decision making process. It is striking that the Government's statement only refers to decisions regarding the deliberate ending of life. Non-treatment decisions or decisions regarding administering pain relief medication are not mentioned, although in these contexts future quality of life considerations are also used, particularly when discussing medical futility. Therefore, we believe there is reason to focus on the admissible content and weight of prospective suffering as an additional ground for a neonatal end-of-life decision and consider this approach to be preferable to an unconditional rejection of any use of this ground. Important in this regard is that the medical profession reaches a consensus on the interpretation of prospective suffering. For the present, however, such a consensus is still lacking. Besides, a generally accepted professional interpretation of prospective suffering does not provide a *carte blanche* for actions incompatible with the law.

This brings to mind the classification made by the Dutch Paediatric Association¹⁴ and the Royal Dutch Medical Association¹⁵ in their professional reports on non-treatment decisions in neonatology. The reports address the medical considerations on which decisions to forgo life-sustaining medical treatment are based as well as the exceptional circumstances under which deliberate ending of neonatal life is considered morally and professionally justified. Both reports argue that end-of-life decisions are at hand in relation to neonates with either a '*no-chance-of-survival*' prognosis or a '*poor-perspective-on-life*' prognosis. The first prognosis is rather unproblematic, as it applies to infants suffering from abnormalities which surely cause them to die shortly after birth. The use of available medical technology in these cases cannot prevent the child's inevitable death. The second prognosis, however, raises legal questions, as it applies to severely ill infants who, if treated, have a chance of survival but will have a poor prognosis with regard to a livable and endurable future life.¹⁶

The use of future pain and suffering as a basis for medical futility judgements is not undisputed, as it is argued that in particular circumstances non-treatment decisions based on expected pain and suffering can amount to medical discrimination of the disabled child. Medical practice in the United States of America¹⁷, the United Kingdom¹⁸, Germany¹⁹ but also the Netherlands²⁰ revealed that disabled neonates are at risk of being discriminated on the basis of disability in the enjoyment of their fundamental rights when end-of-life decisions—particularly non-treatment decisions—arise.²¹ Regular medical treatment (i.e. surgery) provided to a non-disabled child was sometimes considered medically futile and consequently withheld when the patient was an infant suffering from disabilities such as Down's syndrome, spina bifida, or anencephaly²²; conditions, which were often medically irrelevant for the decision to forgo treatment. With regard to American medical practice the United States Commission on Civil Rights concluded in 1989 that the discriminatory denial of medical treatment was based on ignorance and false stereotypes about the quality of life of persons with disabilities and, in others, on misconceptions about the nature of the particular disability the child would have if it were permitted to survive.²³

Yet, it is clear that infants suffering from these disabilities—as well as from additional health problems such as diaphragmatic hernia, bronchitis, duodenal atresia, kidney insufficiencies, acute respiratory distress, etc.—legally are to be considered as equal to infants who have no such disability, but suffer from the same 'additional' condition. Therefore, disabled infants are in principle entitled to the same correctional treatment as non-disabled children or other disabled infants who receive such treatment. To deviate from this line may violate a disabled infant's recognised legal interest in

substantive equal treatment.²⁴ A deviation can only be justified if a particular case is proved unequal to other cases. In that situation conduct in the particular case may differ from the one applied in other cases, provided the evidence for the difference to the other cases is sustainable. However, the principle of legal equality can also be violated by unjustified equal treatment of cases which are unequal.²⁵ Respect for the principle of non-discrimination then requires differentiation in treatment according to the needs of a particular disabled child.²⁶

Whether or not it is legally sound to use expected, but not yet manifest, pain and suffering as a ground for an end-of-life decision strongly depends on the specific circumstances of a case. To admit them as the sole ground for such decisions is highly improbable, as this would require assurance that the predicted pain and suffering will actually occur. Such guarantees are hard to give, although some medical predictions are quite substantiable by empirical data. Nevertheless, there is very limited data as to the survival rates and level of quality of life of infants with particular abnormalities, who have received every possible treatment in the past. Moreover, there is hardly any data as to the levels of suffering of such infants in case of their survival. Yet, such data could be a reference if one is to account for present decisions to withdraw or withhold treatment regarding infants with similar medical conditions and prognoses as the infants who were ultimately treated in the past.²⁷ To produce (more of) such data—provided this is possible without strong moral objections—would obviously contribute to better choices regarding the use of future pain and suffering as a basis for end-of-life decisions in neonatology.

Be this as it may, the Dutch Health Council holds it to be necessary to learn more about the requirement of present suffering, its criteria and how to determine whether it is at issue.²⁸ The Paediatric, Law and Ethics Commission of the Dutch Paediatric Association has encouraged the use of professional guidelines as an aid in establishing expected hopeless and unbearable suffering.²⁹

Deliberate end-of-life case

Group III holds a single case. In this case the neonate suffered from multiple fractures intra uterine and perinatal, suspecting osteogenesis imperfecta type 2 or 3. A conflict between the parents and the medical team was not documented in this case. During the interview the attending physician in this case did not address the parents' role in the decision making process. This provides good cause for reflection on two particular legal items in the decision making

process in this case. But first some remarks as to the diagnosis in this case.

Up to and including the time of Verhagen's survey, registered decisions to deliberately end a newborn infant's life in Dutch medical practice were only taken in connection with three medical diagnoses: severe spina bifida, trisomy 13 and epidermolysis bullosa. Osteogenesis imperfecta is a new³⁰ example of a medical condition that could give rise to a decision to terminate a neonate's life. It also implies that the decision to withdraw mechanical respiration in this case was not the final end-of-life decision, as the child does not die instantly as a result of this withdrawal. This conclusion is confirmed by the medical files. After the decision to withdraw respiration it was decided that—as apnoea would be accepted—no further respiration would be initiated. Moreover, several decisions with regard to the child's medication were taken. More specifically: as the infant was already on Dormicum (dose not documented) Morphine (40 mcg/kg/hour) was increased after detubation to 2400 mcg/kg for pain relief and to suppress gasping. Additionally, Midazolam (0.1 mg/kg/hour) was increased to 2 mg/kg/hour. The files mention 'relief of symptoms' as the core reason for these decisions and state that the parents agreed to this medication policy. Whether or not the parents were interviewed in the context of aftercare is not documented. In view of the particular increase of dosage, the obvious aim of this medicinal regimen was to hasten death; a situation which under Dutch law, in case death occurs, must be reported to the judicial authorities. Remarkably though, this case was not reported and remained unavailable for external or disciplinary review.

The child's right to life and the limits of parental authority

In the group III-case as well as in 6 of the 16 cases where parents substantially influenced the final end-of-life decision³¹ the parents explicitly informed the attending physician that they did not want their child to suffer any further. This gives rise to the question whether parents have a legal right to request their infant's death. And what about the legal responsibility of the physician who complies with such a request?

In Dutch literature, the first question is traditionally answered in the negative. A parental competency to decide about life and death of a child is considered incompatible with the child's right to life, protected under international human rights law.³² The core of the right to life is that it contains the basic legal prohibition of deprivation of life; a prohibition to be ensured by law. This prohibition includes arbitrary as well as intentional deprivation of life, being requirements

following from Article 6 of the International Covenant on Civil and Political Rights (ICCPR)³³ and Article 2 of the European Convention on Human Rights (ECHR).³⁴

The basic reason for the view that parents or any other legal representative of an incompetent child have no legal authority to choose for their child's death lies in a particular quality attributed to the right to life³⁵: its inalienable character. This inalienability holds that the exercise of this right is not transferable to others, that respect for this right cannot be suspended, annulled or made void and that the bearer of this right cannot waive it. In Article 6 of the UN-Convention on the Rights of the Child (CRC) the child's right to life is also characterised as 'inherent', meaning that the right is intrinsically linked to the human person. An inherent right is regarded as self-evident and for which Contracting States have positive as well as negative obligations under human rights law.³⁶ Moreover, authoritative commentators like Dinstein,³⁷ Redelbach³⁸ and Nowak³⁹ conceive the inherent right to life as part of *ius cogens*. Because an inalienable right is regarded to be non-transferable, a third person has no competency to exercise the right to life of another person on its behalf, even if this person is incompetent. In consequence, parents are not entitled to renounce their infant's legal protection of this fundamental right.⁴⁰

The meaning of the inalienability-doctrine when interpreting the right to life in the context of end-of-life decisions in neonatology is, yet, under debate. The same goes for the interpretation of the inherent quality of the right to life. The word 'inherent', which merely expresses the reason why a neonate bears the right to life, offers no specific direction for the assessment of questions related to the legal admissibility of neonatal end-of-life decisions. Whether a certain withdrawal or withholding of life-sustaining treatment, a particular medicinal regime or even medical neonaticide constitutes a violation of this inherency and/or inalienability isn't easy to establish, due to a lacking manifest and univocal standard for legal interpretation of these concepts. The absence of an authoritative point of reference for this interpretation also complicates attempts to justify views on whether these characteristics of the right to life excludes that third persons—parents, but physicians as well—supervise this right being respected for the purpose of observing a child's intrinsic human dignity, which underlies the right to life. A related issue is whether or not third persons can appeal to this dignity when doing so.

Apart from these rather theoretical deliberations on the essence of the right to life and the limits of its applicability, the survey of Verhagen et al. has revealed that parents in Dutch NICUs sometimes act contrary to the assumed nature of their infants' right to life.⁴¹ Physicians who are confronted with a parental request to end their

child's suffering are sometimes willing to satisfy such a request by changing the infant's medication in order to hasten death.⁴² So, how are we to understand this manifest difference between the nature of an applicable fundamental right and actual parental and medical conduct in the neonatal end-of-life decision making process? Is this apparent conduct unreservedly unacceptable—in our context: illegitimate—or do end-of-life decisions in neonatology come close to the limits of what application of the right to life can resolve?

According to Dutch jurisprudence⁴³ and applicable orders in council⁴⁴ parents must be consulted in case the physician considers to deliberately end the life of a hopeless and unbearably suffering newborn infant. In fact, parental consent for such a thanatic act constitutes one of the specific requirements of careful practice. This situation, however, seems to reveal an inconsistency in current Dutch legal understanding of parental involvement in neonatal end-of-life decision making in view of the neonate's right to life. But before we look closer at this inconsistency, it is important to understand the Dutch interpretation of the right to life's inalienable character. This interpretation is also the basis for our view on the position of parents in the decision making process.

During the genesis of the Euthanasia Act—which came into force in 2002 and does not involve end-of-life decisions regarding incompetent persons—the Dutch government stated that the right to life is inalienable provided a person has no reasonable interest in the possibility of waiving the right.⁴⁵ According to this interpretation, a neonate's right to life must be taken as inalienable as this child is not capable of expressing any reasonable interest in waiving the protection of this right. Be this as it may, in our view at least it seems rather unjust that a neonate cannot have a reasonable interest in abandoning his right to life, especially when the exercise of this right is accompanied by hopeless, unbearable and incurable pain and suffering. Accepting a neonate's reasonable interest in waiving, however, implies that a third party decides whether or not the legal protection of the neonate's right to life should be lifted. Besides, to justify this concession to the assumed non-transferability of the exercise of the right to life would require adequate arrangements to safeguard that in time this concession does not result in a thanatic practice where other interests than those of the child are an accepted motive for abandoning the legal protection of the child's right to life.⁴⁶

The Dutch government's view, expressed during the drafting of the Euthanasia Act, that one cannot be obliged to accept the protection of one's right to life against one's own free will⁴⁷ links the non-inalienable character of the right to life to the capability of the bearer of this right to express his will. The capacity to waive the protection

of the right as the cornerstone of the non-inalienability of the right to life leads to the conclusion that those who lack this capacity cannot ascribe a non-inalienable character to their right to life. We therefore believe that it is not the inalienable character of the right to life that stands in the way of (regulating) the deliberate ending of the life of a hopeless and unbearable suffering neonate, but the fact that this child is incapable of divesting its right to life of its inalienable nature. What follows, is a situation of legal inequality between the unbearable suffering competent person and the equally unbearable suffering incompetent newborn child regarding the possibility to prevent the exercise of one's right to life contrary to one's personal interest in avoiding a life of hopeless and unbearable suffering. In real neonatal practice situations occur in which it is unsound to hold on unconditionally to the idea of the inalienable right to life of a newborn child. To do this under any circumstance would mean to make a newborn child a prisoner of its inalienable right to life. This, we believe, distorts the fundamental aim of this elementary right.

An additional perspective in this regard can be found in Feinberg's analysis of the right to life's inalienability. Feinberg has stressed the need to distinguish between two interpretations of alienating: waiving and relinquishing. He wonders what exactly it is that cannot be alienated: life itself or the right to life? If it is life itself that cannot be voluntarily abandoned, transferred, surrendered, etc. then the right to life is a mandatory right which holds an obligation to (continue to) live. If it is the right to life which is inalienable, then that right is a discretionary right which can be exercised or even declined in every way the right's bearer chooses. To waive a discretionary right is a way to exercise that right. Omitting to exercise such a right is not to waive the right, but just another protected discretion to act as one chooses.⁴⁸

Feinberg's suggestion that the right to life is a discretionary right is appealing, although it does not provide all answers. Yet, it leaves room for further thought on how neonatologists must be able to act when seeking to comply with the essence of their incompetent patient's right to life and at the same time doing what they consider is best for the very ill child. As neonates are factually incapable to choose how to exercise their discretionary right to life, the question is whether transfer of this exercise can be justified, for instance by a best interest-reasoning. If we do not exclude the possibility of transfer, then our debate should focus on whether third persons, particularly and exclusively parents, can be allowed to exercise the neonate's right to life in the negative by choosing the child's death.

Let us now return to the above mentioned inconsistency. In this regard we notice on the one hand that, according to current Dutch

legal understanding, parents are obviously not entitled to ask for their infant's death, because of the inalienable character of their child's right to life. On the other hand, parents are not assumed to violate this right when they agree to a physician's well-considered proposal that leads to the same result. Furthermore, a physician who finally decides to deliberately end the life of a hopeless and unbearably suffering newborn infant due to the child's severe medical conditions, very poor prognosis and with reference to the ethical principle *primum non nocere*, at least in the Netherlands is not regarded to violate the infant's right to life, provided his conduct is based on indisputable professional and morally comprehensible grounds, a careful decision making process and proper performance.⁴⁹ The rationale of an inalienable right to life is considered not to forbid a thanatic performance under these circumstances. To accept this view, however, means to accept that the physician, who brings about the infant's death under these circumstances, decides that the infant's legal protection of its right to life must be abandoned. By doing so, this physician subrogates to the exercise of this right. Even though the inalienability-doctrine—at least to our knowledge—leaves no room for professionally motivated exceptions to the rule that transferral of the exercise of the right to life is not possible, we believe that the particular assessment of this physician's particular conduct can point out that indeed there *are* exceptions to the absolute bounds of the right to life's inalienability.

With reference to the issue of parental involvement the question is whether another exception to these bounds is imaginable. This new exception could concern the competency of parents to choose their infant's death when they, due to their child's severe medical conditions and very poor prognosis, are convinced this is in their child's best interest and the only merciful way to deal with their child's definite loss of intrinsic human dignity. In view of how medical professionals deal with parental concerns in Dutch NICU-practice and in awareness of the limitations of the inalienability-doctrine as a normative point of reference, we sympathise with such an exceptional parental competency in such severe cases. We also realise that such an exception needs further exploration and substantiation. To provide for this is beyond the scope of this article.

Procedural supervision a parental responsibility?

An additional consideration relating to parental involvement is whether parents, who more or less ask the physician to end the life of their hopeless and unbearably suffering newborn infant, also have a responsibility to supervise that the case is properly settled in legal-

procedural terms. When a newborn infant's life has deliberately been ended by the physician, Dutch law, as already mentioned, requires the case to be reported to the judicial authorities for review by a multidisciplinary expert committee. This committee investigates whether the physician complied with special requirements of due care and sends its conclusions as advice to the Public Prosecutor, who will decide whether to start criminal pre-investigations or whether prosecution is appropriate.

If decisive parental influence on a physician's decision to end a neonate's life is to be regarded as legally excusable because of the exceptional circumstances and the fundamental responsibility of parents for the well-being of their child, isn't it arguable that the proper legal-procedural settlement of such a case is not just a physician's concern, but requires some kind of parental involvement as well? To us it seems quite appropriate that parents are at least informed about the fact that the local coroner is adequately notified by the physician and that the expert committee is informed as well. The fact that parents were provided with this kind of information should also be documented in their child's medical file. A physician's responsibility to keep parents posted might stimulate parents to become acquainted with the different phases of the legal-procedural settlement in case of medical neonaticide. Growth of procedural knowledge among parents could also contribute to an increased awareness within society as to the importance of careful decision making in this regard, as this might bring about a better understanding of the professional and normative elements of well-founded thanatic decisions. Accepting such a parental involvement would stress that carefully deciding to end a neonate's life in essence is a shared responsibility of those primarily involved, rather than a single physician's burden. It might even contribute to a decrease in the number of non-reported cases of medical neonaticide.

FINAL REMARKS

The survey by Verhagen et al. shows that parents were involved in almost all end-of-life decisions and that in all investigated cases consensus was reached between the parents and the team. Conflicts between the parents and the team occurred in 12% of all cases of end-of-life decision making. Yet, all these conflicts were resolved by postponing the particular decision.

The survey also makes it clear that sound legal reflection on specific aspects of end-of-life decision making in neonatology depends much on insights in actual medical practice and particular bottlenecks neonatologists are confronted with. Such insights offer

the opportunity to check whether the legal approach of dealing with a very ill young child's hopeless and unbearable suffering reasonably reflects what honest professionals and careful parents believe to be a humane and righteous response. Of course, this does not mean that the sole views of medical professionals and parents can prescribe the content of the law in this matter. Yet, the authority of the law also depends on its validity, i.e. the extent to which it is recognised as prudent law by its subjects. To ensure this to be so an ongoing process of re-evaluation of (current interpretations of) fundamental rights and values is required as well as a continuing contemplation within medical practice as to whether a preferred professional conduct still lives up to the rules of the law.

While parents become involuntarily involved in this process and the importance of their input is beyond dispute, the issue of parental involvement definitely deserves more systematic legal reflection.

NOTES

* LL.M., Ph.D. Section of Health Law, University Medical Centre Groningen, University of Groningen, The Netherlands.

** LL.M., M.D., Ph.D. Department of Paediatrics, University Medical Centre Groningen, University of Groningen, The Netherlands.

*** M.D., Ph.D. Department of Paediatrics, University Medical Centre Groningen, University of Groningen, The Netherlands.

**** LL.M., Ph.D. Section of Health Law, University Medical Centre Groningen, University of Groningen, The Netherlands.

- 1 J.H.H.M. Dorscheidt: *Levensbeëindiging bij gehandicapte pasgeborenen, Strijdig met het non-discriminatiebeginsel?* (Medical ending of disabled neonatal life. Compatible with the principle of non-discrimination?), (diss.) Sdu: Den Haag, 2006.
- 2 Eduard Verhagen: *End-of-life decisions in Dutch neonatal intensive care units*, (diss.) Zutphen: Paris Legal Publishers, 2008.
- 3 A. van der Heide, P.J. van der Maas, G. van der Wal, C.L. de Graaff, J.G. Kester, L.A. Kollee, et al.: Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet* 350, 1997, (9073), pp. 251-255; A.M. Vrakking, A. van der Heide, W.F. Arts, R. Pieters, E. van der Voort, J.A. Rietjens, et al.: Medical end-of-life decisions for children in the Netherlands, *Archives of Pediatrics & Adolescent Medicine* 159, 2005, No. 9, pp. 802–809.
- 4 A.A.E. Verhagen, J.H.H.M. Dorscheidt, B. Engels, J.H. Hubben, P.J.J. Sauer: End-of-life decisions in Dutch Neonatal Intensive Care Units, *Archives of Pediatrics & Adolescent Medicine* 163 (2009), no. 10, pp. 895–901.
- 5 The data of 3 deaths were missing as Verhagen et al. were unable to trace the responsible physicians.
- 6 Verhagen et al., n. 4, p. 896.
- 7 A.A.E. Verhagen, M. de Vos, J.H.H.M. Dorscheidt, B. Engels, J.H. Hubben, P.J.J. Sauer: Conflicts about End-of-life decisions in NICUs in the Netherlands, *Pediatrics* 124 (2009) 1, e-112-119.
- 8 Notice that the 18 conflict-cases were identified by physicians. Parental views to confirm or contest the medical estimation of these cases—for instance, with

- regard to their causes or characteristics—were not investigated. See Verhagen et al., n. 7, e117.
- 9 Verhagen et al., n. 7, e115, Table 2. Furthermore, the interviewed physicians mentioned four categories of factors possibly responsible for a conflict with parents: factors related to the parents, the neonate, the physician/medical team or other factors. The majority of physicians (63%) indicated that strong religious convictions that forbid parents to agree to withdrawal of life-sustaining treatment and poor communication between parents and the team are main causes for conflict situations. See e116, Table 3.
 - 10 Verhagen, n. 2, p. 70. Verhagen et al., n. 7, p. e115 adds that in these 5 cases the neonate died while being on the ventilator after it was decided to withhold treatment.
 - 11 Verhagen et al., n. 7, op. cit., e114–e115, Tables 2 and 3.
 - 12 Verhagen et al., n. 6, op. cit., p. 898.
 - 13 Kamerstukken II (Parliamentary Papers) 2005–2006, 30300 XVI, nr. 90, p. 4; *Regeling centrale deskundigencommissie late zwangerschapsafbreking in een categorie 2-geval en levensbeëindiging bij pasgeborenen* (Regulation central expert committee on late abortion in category 2-cases and termination of neonatal life) *Staatscourant* (Government Gazette) 13 March 2007, nr. 51, p. 8 under ‘Toelichting’ (p. 3).
 - 14 Nederlandse Vereniging voor Kindergeneeskunde (NVK): *Doen of laten? Grenzen van het medisch handelen in de neonatologie* (To act or to omit? Limits of medical conduct in neonatology), Utrecht, 1992.
 - 15 Commissie Aanvaardbaarheid Levensbeëindigend handelen KNMG, *Medisch handelen rond het levenseinde bij wilsonbekwame patiënten*, Eindrapport (RDMA: Medical conduct at the end of life of incompetent patients, Final report), Bohn Stafleu Van Loghum: Houten/Diegem, 1997.
 - 16 Since the publication of these reports European paediatricians have distinguished a third category of infants. These infants can stay alive without intensive medical treatment, but live in view of a future of unbearable pain and suffering, as they suffer from—for instance—severe spina bifida or epidermolysis bullosa. After the decision to forego medical treatment has been effectuated the severely suffering child usually continues to live. Most Dutch physicians, however, regard it to be unacceptable to wait for nature to take its course in such cases and raise the issue as to whether hastening of the infant’s death must be considered. See P.J.J. Sauer et al.: Ethical dilemmas in neonatology: recommendations of the Ethics Working Group of the CESP (Confederation of European Specialists in Paediatrics), *European Journal of Paediatrics* 160, (2001), no. 6, pp. 364–368.
 - 17 *In re Infant Doe*, No. GU8204-00, Indiana Circuit Court, Monroe County, 12 April 1982
 - 18 *R. v. Arthur* (1981) 12 B.M.L.R. 1, Leicester CC 5 November 1981, discussed in H. Kuhse, P. Singer, *Should the baby live?* The problem of handicapped infants, Oxford/New York: Oxford University Press, 1985, pp. 1–11. See also *Re B* [1990] All E.R. 927, 927-930 (CA).
 - 19 See a decision by the Schwurgericht Hamburg in 1970 mentioned by A. Kaufmann: Zur ethischen und strafrechtlichen Beurteilung der sogenannten Früheuthanasie, *Juristenzeitung* 37 (1982) no. 14, p. 481. See also Landgericht München I, 29 January 1982, Ks 122 Js 4226/81.
 - 20 *Baby Ross*, Dutch Supreme Court 28 April 1989, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1989/51, pp. 391–398. This case is extensively discussed in Dorscheidt, n. 1, pp. 216–241.
 - 21 The relevance of this approach was argued in the debate concerning the Baby Doe–Regulations in the US in the mid-1980ties. For an overview, see M.A. Gardell, H. Tristram Engelhardt: *The Baby Doe Controversy: an outline*

of some points in its development, in: R.C. McMillan, H. Tristram Engelhardt Jr., St.F. Spicker (eds.): *Euthanasia and the Newborn*. Conflicts regarding saving lives, Dordrecht: Reidel Publ. Comp. 1987, pp. 293–299 and A. Meisel, K.L. Cerminara: *The Right to Die: The Law of End-of-Life Decisionmaking*, third edition, New York: Aspen Publ., 2004, par. 10.02(B), pp. 10.8–10.14. An opposite view is argued by R. Merkel: *Früheuthanasie*, Rechtsethische und strafrechtliche Grundlagen ärztlicher Entscheidungen über Leben und Tod in der Neonatalmedizin, Baden-Baden: Nomos Verlagsgesellschaft, 2001, 544–549.

- 22 A remarkable example in that matter is *In re Baby K*, 832 F. Supp. 1022, ED Va 1993, 1993 US Dist. LEXIS 12574 and *In re Baby K*, aff'd 16 F.3d 590 (4th Cir. 1994), 1994 US App. LEXIS 2215, to be found at www.lexis.com.
- 23 United States Commission on Civil Rights: *Medical Discrimination against Children with Disabilities*, Washington D.C., 1989, pp. 26–47 and pp. 103–110. See also United States Commission on Civil Rights: *Hearing on the protection of handicapped newborns*. Washington D.C., June 12–14, 1985, pp. 58–78 and *Hearing on the protection of handicapped newborns*, Vol. II, Washington D.C., June 26–27, 1986, Open Sessions.
- 24 See M. Nowak, *UN Covenant on Civil and Political Rights. CCPR Commentary*, 2nd revised edition, Kehl: Engel Publisher, pp. 546–550, who stresses the need for statutory measures by the State to protect children against sexual abuse, assault, severe neglect while being raised and infanticide. In this regard he refers to Article 24 (1) ICCPR as well. See also *CCPR General Comment No. 17: Rights of the Child* (art. 24), 7 April 1989, para. 5.
- 25 E.W. Vierdag: *The concept of discrimination in international law*, The Hague: Martinus Nijhoff, 1973, pp. 7–18.
- 26 See Dorscheidt, n. 1, pp. 505–515.
- 27 Lorenz et al. and Kosho et al. examined the outcomes of aggressive use of intensive care in extremely premature newborns and in newborns with trisomy 18. In similar infants in other centers, the generally recommended approach would be restricted use of intensive care, because of the infant's poor prognosis. (J.M. Lorentz, N. Paneth, J.R. Jetton, L. den Ouden, J.E. Tyson: Comparison of management strategies for extreme prematurity in New Jersey and the Netherlands: outcomes and resource expenditure, *Pediatrics* 108, (2001), nr. 6, pp. 1269–1274 and T. Kosho, T. Nakamura, H. Kawame, A. Baba, M. Tamura, Y. Fukushima: Neonatal management of trisomy 18: clinical details of 24 patients receiving intensive treatment. *American Journal of Medical Genetics A* 140, (2006) nr. 9, pp. 937–944). Both studies, however, focused on mortality and morbidity, not on quality of life or levels of suffering.
- 28 Gezondheidsraad (Dutch Health Council: Center for Ethics and Health): *Overwegingen bij het beëindigen van het leven van pasgeborenen (Considerations as to the ending of the life of neonates)*, Signalering ethiek en gezondheid 2007/1, Den Haag: Centrum voor ethiek en gezondheid, 2007, pp. 35–36.
- 29 A.A.E. Verhagen, M.A. Van der Hoeven, J.B. van Goudoever, M.C. De Vries, A.Y. Schouten–Van Meeteren, M.J. Albers: Uitzichtloos en ondraaglijk lijden en actieve levensbeëindiging bij pasgeborenen (Hopeless and unbearable suffering and active ending of neonatal life), *Nederlands Tijdschrift voor Geneeskunde (Dutch Journal of Medicine)* 151, 2007, no. 26, pp. 1474–1477.
- 30 See Dorscheidt, n. 1, pp. 95–96.
- 31 Verhagen et al., n. 7, e115.
- 32 H.J.J. Leenen: Actieve levensbeëindiging bij een ernstig gehandicapte baby, *Nederlands Juristenblad (Dutch Law Journal)* 70, 1995, no. 23, pp. 851/852; H.J.J. Leenen, Artikel 2, in J.K.M. Gevers (ed.): *Het EVRM en de gezondheidszorg (The ECHR and health care)*, Nijmegen: Ars Aequi Libri, 1994, pp. 27–40,

- particularly p. 39 and 40; H.D.C Roscam Abbing, *Levensbeëindigend handelen bij zwaar defecte pasgeborenen*, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1988, pp. 467–475.
- 33 S. Joseph, J. Schultz, M. Castan, *The International Covenant on Civil and Political Rights*. Cases, Materials, and Commentary, Second edition, Oxford/New York: Oxford University Press, 2004, pp. 156–166 and pp. 181–187.
- 34 Jacobs & White, *European Convention on Human Rights*, fourth edition. (C. Ovey & R.C.A. White), Oxford/New York: Oxford University Press, 2006, pp. 56–73.
- 35 Thomas Jefferson (1743–1826), the third president of the United States of America, is believed to be the first to have expressed the right to life’s inalienable character. In the American Declaration of Independence he incorporated that the Creator has gifted all men with ‘...certain unalienable rights, that among these are life, liberty and the pursuit of happiness.’. See A. Reidelbach: Protection of the right to life by law and by other means, in B.G. Ramcharan (ed.): *The right to life in international law*, Dordrecht: Martinus Nijhoff, 1985, p. 199. The concept of this inalienability has been explored by F. Przetacznik: The right to life as a basic human right, *Revue des droits de l’homme/Human Rights Journal. Droit international et Droit comparei: International and Comparative Law IX*, 1976, pp. 589–590, who discusses whether the right to life is an inalienable or an infeasible right.
- 36 Dorscheidt, n. 1, pp. 293–297.
- 37 Y. Dinstein, The right to life, physical integrity, and liberty, in L. Henkin (ed.): *The International Bill of Rights: The Covenant on Civil and Political Rights*, New York: Columbia University Press, 1981, pp. 114–116.
- 38 Reidelbach, n. 35, pp. 186–187.
- 39 Nowak, n. 24, p. 122.
- 40 J.H.H.M. Dorscheidt: End of life-decisions in neonatology and the right to life of the disabled newborn child: impressions from the Netherlands, in L. Clements, J. Read (eds.): *Disabled people and the right to life*, The Protection and Violation of Disabled People’s Most Basic Human Right, Oxford: Routledge, 2008, pp. 176–194, in particular pp. 182–184.
- 41 This occurred in the Prins-case as well. See District Court Alkmaar 26 April 1995, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1995/41. The parents in this case explicitly asked doctor Prins to end the life of their child, as the child suffered from severe and inoperable spina bifida. In the trial of Prins the District Court qualified the parental request as a necessary condition for the physician’s careful practice. In view of the child’s right to life, however, this qualification was generally regarded as disputable.
- 42 A.A.E Verhagen, J.H.H.M. Dorscheidt, B. Engels, J.H. Hubben, P.J.J. Sauer: Analgesics, sedatives and neuromuscular blockers as part of end-of-life decisions in Dutch NICUs, *Archives of Disease in Childhood, Fetal and Neonatal Edition* 94, 2009, no. 6, F434–438.
- 43 Amsterdam Court of Appeals 7 November 1995, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1996/1; District Court Groningen 13 November 1995, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1996/2; Leeuwarden Court of Appeals 4 April 1996, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1996/35.
- 44 Kamerstukken II (Parliamentary Papers) 2005–2006, 30300 XVI, nr. 90; *Regeling centrale deskundigencommissie late zwangerschapsafbreking in een categorie 2-geval en levensbeëindiging bij pasgeborenen* (Regulation central expert committee on late abortion in category 2-cases and termination of neonatal life) *Staatscourant* (Government Gazette) 13 March 2007, nr. 51, p. 8, under ‘Toelichting’ (page 3).

- 45 Parliamentary Papers I 2000–2001, 26691, no. 137a, p. 15; Parliamentary Papers I 2000–2001, 26691, no. 137e, p. 6; Plenary Notes II 2000–2001, 27 (23 November 2000), p. 2247.
- 46 J.H.H.M. Dorscheidt, in L. Clements, J. Read (eds.), op. cit., pp. 185–186.
- 47 On this ground the Dutch government holds that the content of the Euthanasia Act is not contrary to the right to life set forth in Article 2 ECHR. This viewpoint was provided by the *Rapport van de Staatscommissie Euthanasie* (Report of the State's Commission on Euthanasia), Deel 1: Advies. Staatsuitgeverij 's-Gravenhage 1985, pp. 36–39. See also J. Rummelink: The legal position on euthanasia in the Netherlands in the light of article 2 of the ECHR, in P. Mahoney et al. (eds.): *Protecting Human Rights: The European Perspective*, Studies in memory of Rolv Ryssdal, Köln: Carl Heymanns Verlag, 2000, pp. 1157–1171 *Pretty v. UK* (Appl.nr. 2346/02; 29 April 2002, (2002) 35 *EHRR* 1) did not alter this view.
- 48 J. Feinberg: *Rights, Justice and the Bounds of Liberty*, Essays in Social Philosophy, Princeton/New Jersey: Princeton University Press, 1980, pp. 221–251.
- 49 This can be derived from the decisions in the Prins-case and the Kadijk-case. See District Court Alkmaar 26 April 1995, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1995/41; Amsterdam Court of Appeal 7 November 1995, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1996/1; District Court Groningen 13 November 1995, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1996/2; Leeuwarden Court of Appeal 4 April 1996, *Tijdschrift voor Gezondheidsrecht* (Journal of Health Law) 1996/35.