Neonatal Euthanasia and the Groningen Protocol

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Chapter 18
Neonatal Euthanasia and the Groningen Protocol

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Abstract Neonatal euthanasia has been legal in the Netherlands since 2005. Data indicate that neonatal euthanasia is practiced sub rosa by some clinicians in other countries as well; however, the true extent of neonatal euthanasia practice remains unknown. In this chapter, we review end-of-life options to describe the ethical background in the adult setting and how these translate into the neonatal setting. Further, the ethical arguments in favor and opposed to allowing euthanasia of infants, and those in favor and opposed to the use of paralytics in neonatal euthanasia, are presented.

Keywords Euthanasia · End-of-life · Neonatal ethics · Physician assisted dying · Life sustaining treatment

In 2002, experts in neonatology and bioethics from the University Medical Center Groningen, in collaboration with the Groningen district attorney's office, developed the Groningen Protocol that provides a systematic approach to decision-making regarding euthanizing infants (Verhagen and Sauer 2005a, b), which was adopted as a national guideline in 2005. The Protocol was spurred by data indicating that neonatal euthanasia was not uncommonly performed in The Netherlands (van der Heide et al. 1997); however, there were no standards for the practice. These findings raised significant concerns that some neonatologists may be euthanizing at least some infants without adequate oversight and without appropriate standards of practice.

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The goal of the Protocol is to allow parents and doctors to end the life of infants in cases where the infant is suffering unbearably[1] with no hope for improvement, but is neither actively dying nor dependent on medical technology (e.g., a ventilator) for life. Under the Protocol, physicians may administer substances to the infant to rapidly and painlessly end the infant's life[2] when specific criteria are met (Table 18.1).

In this chapter, we will review end-of-life options to describe the ethical background in the adult setting and how these translate into the neonatal setting. We will then present the ethical arguments in favor and opposed to allowing euthanasia of infants.[3] Finally, we will discuss the arguments in favor and opposed to the use of paralytics in neonatal euthanasia.

18.1 End-of-Life Options in Adult Medicine

In order to appreciate the ethical issues surrounding end-of-life (EOL) care in infants, it is imperative to understand these issues in the adult setting. Clearly, options that are not ethically permissible in the care of a competent adult patient would not be ethically permissible in the care of an infant. Although some have argued that infants are not

[1] NB: There is variability in the understanding of the term "unbearable suffering." In this chapter, we take it to mean subjective suffering to the extent that the patient herself feels that she can no longer bear it, and she believes that being dead would be better than being alive in her current state. That is, a degree of suffering that to the patient constitutes a fate worse than death.

[2] Note on terminology: Many clinicians, bioethicists, and authors use various terminology for similar acts. We have chosen to use terminology that is as unbiased and non-inflammatory as possible. Some authors, particularly those with strong moral objections to euthanasia, may use terminology such as "killing patients," "killing babies", "executing children," etc. We find such terminology to be overly biased and unhelpful when deep consideration of the ethical issues is appropriate.

[3] It should be noted that the Groningen Protocol has not been widely accepted. Indeed, neonatal euthanasia remains illegal in all countries except the Netherlands; however, as noted in this chapter, neonatal euthanasia is practiced to some extent widely. It should further be noted that two of the authors of this chapter have written extensively on this topic. E. Verhagen was the primary author of the protocol and has written extensively on the ethical justification of neonatal euthanasia (Brouwer et al. 2018; de Vries and Verhagen 2008; Dorscheidt et al. 2013; Sauer and Verhagen 2009; Verhagen 2013; Verhagen and Sauer 2005a, b, 2008; Verhagen et al. 2005; Verhagen 2006). A. Kon has written arguing that the protocol is not ethically justifiable and should be abandoned (Kon 2007, 2008, 2009). It should also be noted that many authors have argued strongly against the protocol based on ethical concerns and/or moral objections. We believe that this is an evolving area in health care. When withdrawal of life-sustaining treatment was first considered, many believed such an act to be immoral and equivalent to killing patients; however, such practice is now accepted in nearly all societies. When the discussion around allowing physicians to prescribe life-ending substances to terminally ill competent adults was first discussed, again many authors raised serious ethical and moral objections and stated that such acts are merely killing patients; however, Physician Assisted Dying is now widely accepted. Based on these historical occurrences, we believe that when considering novel end-of-life options, ethicists should attempt to approach topics in an unbiased and open fashion. As such, the current chapter is written to present a balanced consideration of the ethical arguments on both sides of this important issue.

Table 18.1 The Groningen Protocol for Euthanasia in newborns

Requirements that must be fulfilled
The diagnosis and prognosis must be certain Hopeless and unbearable suffering must be present The diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor Both parents must give informed consent The procedure must be performed in accordance with the accepted medical standard
Information needed to support and clarify the decision about euthanasia
Diagnosis and prognosis Describe all relevant medical data and the results of diagnostic investigations used to establish the diagnosis List all the participants in the decision-making process, all opinions expressed, and the final consensus Describe how the prognosis regarding long-term health was assessed Describe how the degree of suffering and life expectancy were assessed Describe the availability of alternative treatments, alternative means of alleviating suffering, or both Describe treatments and the results of treatment preceding the decision about euthanasia
Euthanasia decision Describe who initiated the discussion about possible euthanasia and at what moment List the considerations that prompted the decision List all the participants in the decision-making process, all opinions expressed, and the final consensus Describe the way in which the parents were informed and their opinions
Consultation Describe the physician or physicians who gave a second opinion (name and qualifications) List the results of the examinations and the recommendations made by the consulting physician or physicians
Implementation Describe the actual euthanasia procedure (time, place, participants, and administration of drugs) Describe the reasons for the chosen method of euthanasia
Steps taken after death Describe the findings of the coroner Describe how the euthanasia was reported to the prosecuting authority Describe how the parents are being supported and counseled Describe planned follow-up, including case review, postmortem examination, and genetic counseling

Adapted from Verhagen and Sauer (2005b)

persons, and therefore are not entitled to protection (Giubilini and Minerva 2013), this view is shared by few and is not supported by major professional organizations nor statutes.

It is widely agreed that because they lack decision-making capacity and because they are entirely dependent on others for even basic care (e.g., feeding), infants enjoy special protections. Indeed, most jurisdictions globally afford special protections to infants and children, and when parents fail to meet these obligations, states have an obligation to provide for these minors. The doctrine of *parens patriae* requires states to assume responsibility for infants and children when they are subject to abuse or neglect; however, there is significant variability in the definition of abuse and neglect globally. Because infants and children enjoy special protections, EOL options that are not ethically permissible in competent adults would clearly be impermissible in the care of infants. At the same time, one could argue that denying infants EOL options that are ethically and legally accepted for competent adults in selected countries, seems unjust as well. We therefore present the range of EOL options in the adult setting, listed roughly in order of most widely accepted to least permissible, with brief discussion of each.

18.1.1 Limiting Life-Prolonging Interventions

In many cases, patients, families, and the care team decide that some life-prolonging interventions are not appropriate. For example, in some cases the patient, family, and care team determine that cardiopulmonary resuscitation is not appropriate should the patient suffer a cardiac arrest, and in such cases the doctor may write a Do Not Resuscitate (DNR) order (NB: Some use other terminology such as Do Not Attempt Resuscitation or Allow Natural Death; however, the ethical arguments are unchanged regardless of the terminology employed). Similarly, a decision may be made to not intubate the trachea of a patient should she develop respiratory failure. Such decisions to not initiate specific life-prolonging interventions are widely viewed as ethically permissible. Indeed, in some cultures (e.g., the United States) it is considered unethical and illegal to perform such interventions over the patient's objection even when failure to perform the interventions will lead to the patient's death.

18.1.2 Withdrawal of Life-Prolonging Interventions

In some cases, patients may already be receiving life-prolonging interventions and the patient, family, and care team determine that removal of such interventions is appropriate even when the team understands that removal of such interventions will most likely lead to the patient's death. In the famous 1976 American case of Karen Ann Quinlan, the parents of Ms. Quinlan, a 21-year-old woman in persistent vegetative state (PVS), wished to remove the breathing tube keeping their daughter alive

("In Re Quinlan, 355 A.2d 647" 1976). There was significant debate in the media and academic journals regarding the ethical appropriateness of what was then termed "passive euthanasia."[4] Ultimately, the New Jersey Supreme Court ruled that patients have a right to decline any medical intervention, including life-saving/prolonging interventions, based on a right to privacy; when patients lack decision-making capacity, their agents can make such decisions on their behalf; in such cases, physicians must remove the intervention(s) and they are not liable for such actions; and legal review is not required for subsequent cases ("In Re Quinlan, 355 A.2d 647" 1976). While withdrawal of life-prolonging interventions is not universally viewed as ethically permissible (e.g., in Japanese culture, such acts are widely considered a form of murder (Asai et al. 1997)), it is accepted as standard practice in most societies.

18.1.3 Voluntary Stopping of Eating and Drinking

In some cases, patients choose to stop eating and drinking as a means to hasten their death when they view their life as unbearable. There remains some debate as to the ethical permissibility of such action; however, because this is an individual choice that does not require the participation of the health care team, most agree that the voluntary stopping of eating and drinking (VSED) does not violate health care ethics norms, although in many cultures it does violate social norms. In some cases, however, VSED can itself be very distressing to patients, particularly as they suffer severe hunger and thirst. In some cases, clinicians may use palliative sedation (sometimes called terminal sedation) to ease the suffering of such patients. Research shows that palliative sedation does not hasten death (Maltoni et al. 2009; Mercadante et al. 2009); however, there remains ethical debate as to the appropriateness of palliative sedation as many view such action as participating in suicide (Quill et al. 1997, 2009). In the United States, palliative sedation in the care of patients who opt for VSED is generally considered ethically supportable and is practiced openly; however, in many other countries it remains taboo.

18.1.4 Withholding Medically Provided Nutrition and Hydration

In some cases, patients are not dependent on a ventilator or other medical technology to maintain basic physiologic functions, therefore withdrawal of life-prolonging

[4] As noted above, many authors use different terminology. In the Quinlan case, many referred to the option of removing her breathing tube as "killing" her. It is important to note that some continue to view withdrawal of life-sustaining interventions as killing patients and therefore morally unacceptable.

interventions is not an option; however, the burdens of treatment may be viewed as outweighing the benefits. In some such cases, patients, families, and care teams may determine that medically provided nutrition and hydration (MPNH) is not indicated. In the United States, removing MPNH was deemed permissible in the 1990 case of Nancy Cruzan ("Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261" 1990), Ms. Cruzan was a 25-year-old woman in PVS. Her parents wished to remove her gastrostomy tube and stop all MPNH. The case was adjudicated by the United States Supreme Court, and ultimately it was determined that stopping MPNH was both legally supported and ethically justifiable. Since that case, stopping MPNH has been widely accepted in the United States. Such practices are more controversial in other countries. Indeed, in many jurisdictions (Japan (Aita et al. 2008), many Islamic countries (Alsolamy 2014), Israel (Shalev 2009), etc.) stopping MPNH is generally considered illegal or unethical.

18.1.5 Physician-Assisted Dying

In some jurisdictions, physicians are allowed to prescribe substances to patients that will allow the patient to end her life quickly and painlessly. Some use the term "physician-assisted suicide"; however, because the term "suicide" has significant negative connotations, most prefer one of the more neutral terms: "death with dignity," "physician aid in dying," or "physician-assisted dying" (PAD). PAD is legal in The Netherlands, Belgium, Luxembourg, Colombia, Canada, Australia, and parts of the United States (in 2020, approximately one-third of Americans live in jurisdictions that allow PAD). PAD remains controversial, and many argue that it is unethical and should be illegal. Indeed, in most countries PAD is illegal.

18.1.6 Voluntary Active Euthanasia

Euthanasia (from the Greek "good death") is the deliberate termination of life, generally understood to be an act of mercy, with a goal of painlessly ending a person's life and suffering. Euthanasia may also be referred to as "mercy killing." The term "voluntary" indicates that the patient herself chooses life termination. Further, the term "active" indicates that there is an affirmative act (e.g., administration of life-ending substances) to terminate the patient's life, in contrast to "passive" (described above) in which life-prolonging interventions are removed and the patient is allowed to die from her underlying disease process.

Some jurisdictions allow not only PAD, but also voluntary active euthanasia (VAE). In such cases, patients wish to have their life ended quickly and painlessly in order to relieve their suffering. VAE is less accepted than PAD because physicians play an active role in administering the life-ending substances (Quill et al. 1997). It has been argued, however, that if we allow PAD, then we must allow VAE

because some patients lack the physical ability to self-administer the life-ending substances, and to deny such individuals the option of PAD while allowing others who are more physically able to access this option is not ethically supportable (Brock 1992). Currently, VAE is practiced legally in only a few jurisdictions (The Netherlands, Belgium, Luxembourg, Colombia, and Canada). In all of these jurisdictions, patients must be actively involved in the choice to end their life. There is evidence, however, that VAE is practiced sub rosa in the United States, Australia, the United Kingdom, and elsewhere (Back et al. 1996; Brahams 1992; Maitra et al. 2005; Meier et al. 1998).

18.1.7 Nonvoluntary Active Euthanasia

VAE requires the voluntary choice of the patient herself. Clearly, some patients (e.g., infants) lack the decision-making capacity to make such a choice. In very few jurisdictions, families and care providers may choose to end the patient's life without the express consent of the patient herself. Such practice is termed "nonvoluntary active euthanasia" (NVAE) or "active life ending without consent."[5] Because others choose on behalf of the patient, active life ending without consent is legally permissible only in The Netherlands; however, there is some evidence that NVAE may be administered to adult patients clandestinely in Australia (Stevens and Hassan 1994), the United States (Meier et al. 1998), and potentially elsewhere.

18.1.8 Involuntary Active Euthanasia

In some cases, providers may end the life of persons against that person's expressed wishes; so-called "involuntary active euthanasia" (IVAE). Most notably, IVAE was carried out in Nazi Germany as part of the eugenics movement. The atrocities of the Nazis lead to the eugenics movement being widely discredited and abandoned, and IVAE is illegal universally and globally considered inconsistent with bioethical principles. Indeed, IVAE is ethically and legally simply murder.

[5] Those who are strongly opposed to such practices often refer to NVAE as "killing patients." Here, we use less pejorative terminology to allow the reader to weigh the arguments of both sides of this controversy; however, it is important to note that many clinicians and ethicists believe that such acts are merely killing and have strong moral objections to use of any other terminology.

18.2 End-of-Life Options in Neonates

Because neonates cannot participate in decision-making, any EOL decisions are necessarily nonvoluntary. In general, parents and care providers work collaboratively to determine the option or options that are in the infant's best interest. At times, it may be appropriate to consider the interest of others in decision-making for neonates and children; however, in general, the interests of the infant herself must be of primary concern (Katz et al. 2016).

Several EOL options are well-accepted in neonatal care. For example, limiting or withdrawing life-prolonging interventions is widely accepted and practiced when doing so is deemed consistent with the infant's best interest. There is significant variability, however, regarding when and in which cases life-prolonging interventions can or should be limited or withdrawn. Further, there is variability regarding who holds the authority to make such decisions (Lago et al. 2008; Liu et al. 2020; McHaffie et al. 1999; National Institute for Health and Care Excellence 2016 (updated 2019); Weise et al. 2017).

Clearly, infants cannot voluntarily stop eating and drinking, therefore VSED is not relevant to neonatal medicine; however, withholding MPNH is relevant and raises special ethical issues. Unlike most adults, neonates are incapable of feeding themselves. Indeed, feeding a baby is widely viewed as a primary obligation of parents and care providers, and withholding oral feeds from a baby who can bottle or breast feed and who is hungry is widely considered unethical and cruel. Because all infant feeding is provided by others, withholding MPNH raises special ethical issues that do not exist in the care of adult patients for whom being fed is not "normal." Because many view the obligation to feed an infant as paramount, and because MPNH (through a nasogastric tube, percutaneous gastrostomy tube, or other enteral tube feeding devices) may be viewed as feeding the baby, some argue that withholding MPNH is never ethically permissible in infants. Withholding MPNH in the neonatal setting is practiced openly in the United States and Europe (Bucher et al. 2018; Diekema et al. 2009; Kuhn et al. 2017; Moreno Villares 2015; National Institute for Health and Care Excellence 2016 (updated 2019); Weise et al. 2017); however, it is unclear the extent to which this practice is accepted elsewhere, and there remains significant debate regarding the ethical permissibility of withholding MPNH in the neonatal setting.

Due to the infant's inability to participate in decision-making, PAD, VAE, and IVAE are also irrelevant in the neonatal setting. Any hastening of death in the neonatal period would necessarily be a form of NVAE. In such cases, the ethical implications of NVAE in an infant would be similar to those in an adult patient who lacks the ability to participate in decision-making or the ability to have or express her wishes and preferences.

Research shows that neonatal euthanasia is practiced openly or sub rosa[6] in many countries. In 2000, the EURONIC Study Group reported that among survey respondents, 73% of French neonatologist, 47% of Dutch neonatologists, and several German, British, Swedish, Italian, and Spanish neonatologists reported personally administering drugs with the purpose of ending the life of an infant (Cuttini et al. 2000). Further, a 2004 study showed that a significant proportion of physicians in Lithuania had been personally involved in at least one case of neonatal euthanasia (Cuttini et al. 2004). In a 2020 study of Greek neonatologists, one subject indicated that they had performed neonatal euthanasia in one case (Dagla et al. 2020). Further, in a study of French doctors, nurses, and lay public, the overwhelming majority in each group favored neonatal euthanasia at least in some cases (Teisseyre et al. 2010). A similar attitude among nurse and doctors working in Flanders, Belgium was reported in a nationwide study in 2020 (Dombrecht et al. 2020). While the above references demonstrate health care professionals have reported euthanizing infants in many countries, it is likely that neonatal euthanasia is practiced even more widely than has been reported. Due to the criminal nature of such acts in many jurisdictions, and wide condemnation of such practices, however, it is likely that those who have euthanized infants would not report such activity.

18.3 Neonatal Euthanasia: Pro and Con Arguments

18.3.1 Arguments in Favor of Allowing Neonatal Euthanasia

The arguments supporting acceptability of neonatal euthanasia, and ultimately the endorsement of the Groningen Protocol in the Netherlands can probably best be understood in the context of the developments in the adult setting.

The majority of the population in the Netherlands has always been in favor of euthanasia, defined as deliberate medical life ending on the patients' own request, since 1966 in public opinion polls (Griffiths et al. 1998). Surveys among doctors have consistently shown their willingness to perform euthanasia for patients with unbearable suffering. Reports in the 1980s and 1990s from professional organizations and governmental institutions examined Dutch EOL care and made suggestions for practical ways to allow euthanasia and monitor and review these cases. During these years, several doctors were prosecuted after reporting they had ended the life of a patient who suffered unbearably, at the patient's request.

[6] The term "sub rosa" is defined by the Merriam-Webster dictionary as: in confidence; secretly. However, the term has a connotation of something carried out undercover, in confidence, privately, or with discretion whereas the term "secretly" has a connotation of being specifically designed to escape notice. See https://www.merriam-webster.com/dictionary/sub%20rosa, https://www.urbandictionary.com/define.php?term=sub%20rosa, https://www.dictionary.com/browse/sub-rosa, and https://www.dictionary.com/browse/secret?s=t.

In 1984, in a landmark Dutch Supreme Court decision, the concept of necessity resulting from a conflict of duties was formulated as a potential legal justification for not prosecuting doctors who perform euthanasia. The conflict was between the duty to alleviate the patient's hopeless suffering and the duties to obey the law and to preserve the patient's life. Ultimately, this court's verdict resulted in the enactment of the Dutch Termination of Life on Request and Assisted Suicide Act ('Euthanasia Law') in 2002. This law stipulated that physicians may perform euthanasia if they are convinced that the patient: (a) made a voluntary and well-considered request; (b) suffers unbearably with no prospect of improvement, and there's no reasonable alternative to relieve the suffering; (c) understands the situation and prognosis. Additionally, an independent physician is consulted who must visit the patient and the physician performs the act with due care and reports the case to the regional review committee. Patients over the age of 16 years may request and consent to euthanasia. Patients aged 12–15 years may request euthanasia; however, parental participation in the decision-making process is also required.

The ethical justification of VAE for the Dutch originates in the principles: self-determination, beneficence, responsibility, and compassion (Widdershoven 2002). Politically, legalization of VAE as an option (not an obligation) in end-of-life care was justified by the broad acceptance of euthanasia in the population.

Similar to the developments for adults, a national debate started in the 1980's about end-of-life decision-making for severely ill newborns (Griffiths et al. 2008; Verhagen and Sauer 2005a, b). Influential reports from various professional organizations on the medical and ethical acceptability of EOL decisions in newborns, including neonatal euthanasia were published (Nederlandse Vereniging voor Kindergeneeskunde 1992). In two landmark cases against physicians who ended the life of a sick newborn in the 1990's, the high courts accepted necessity resulting from a conflict of interests as defense, identical to the justification in the rulings on the adult cases mentioned above.

Based on these verdicts, the 2005 Groningen Protocol was created and accepted by Dutch pediatricians (Verhagen and Sauer 2005a, b). Two years later, the Protocol became a legal governmental regulation which included the establishment of a multidisciplinary advisory committee that publicly reviews all neonatal euthanasia cases.

Clearly, the ethical justification for neonatal euthanasia differs in part from adult euthanasia especially where it concerns self-determination. The Groningen Protocol requires the agreement of both parents, which provides specific extension of the notion of self-determination that Brouwer et al. have called 'parental determination' (Brouwer et al. 2018). This parental determination is a bridge between self-determination and beneficence, which is another justifying principle. This view is based on the presumption that parents are the appropriate surrogate decision makers, and that parents give primacy to the best interests of their child. For a doctor to act beneficently, he needs to have sufficient understanding of the child's suffering. The parents provide a specific and necessary perspective on the child's suffering, informed by family values, intimate knowledge of the child, and their view on the child's quality

of life. This parental determination prevents euthanasia for incompetent children from becoming an out-of-balance decision based only on beneficence.

From this brief comparative overview, it becomes apparent that the main arguments in favor of allowing neonatal euthanasia in the Netherlands are closely tied to the rationale employed in justification of adult euthanasia. Specifically, adult euthanasia was deemed permissible in order to improve the quality of dying for patients who were suffering unbearably. From the Dutch perspective, to deny loving parents the possibility to end unbearable and hopeless suffering for the newborn for whom they are responsible and whom they love feels unjust. Further, the majority of the Dutch medical community has always supported this argument. At the same time, physicians have underlined the need for procedural safeguards to prevent misuse and to protect the responsible physicians from unjust prosecution for murder. Hence the formal regulation with an obligation to report each case for review by a multidisciplinary advisory committee. In the view of most Dutch stakeholders in the debate, this set of provisions is the best way to make a complex medical practice transparent and open to review. The committee's annual reports are published as open-access documents (Committee Late Termination of Pregnancy and Termination of Life in Newborns (Commissie Late Zwangerschapsafbreking en levensbeeindiging bij pasgeborenen) 2020). Between 2007 and the writing of this chapter (2020), only 3 cases (2 with epidermolysis bullosa, 1 with progressive neurodegenerative disease) were reported and reviewed, and none was prosecuted.

18.3.2 Arguments Against Allowing Neonatal Euthanasia

Many authors have raised serious moral objection to any form of neonatal euthanasia (Jotkowitz and Glick 2006; Kodish 2008). Such moral objections are similar to those raised by opponents of VAE. Specifically, they argue that actively ending the life of another human is morally corrupt in all cases and is contrary to the obligations of a physician. Further, because infants are a vulnerable class, unable to express their wishes or advocate for their interests, actively killing an infant is even more abhorrent than killing an adult. Such an argument is persuasive to those who agree with the fundamental moral position that physicians should not kill patients; however, it is unpersuasive to those who hold a different moral belief. For those who hold this moral belief, no further argument is necessary. However, for those whose moral beliefs allow for euthanasia when doing so is consistent with bioethical principles, the patient's interests, and good medical practice, more scrutiny is required. As such, the following arguments are based on an assumption that VAE is ethically permissible; not because the acceptance of VAE is universal, but rather because neonatal euthanasia could be justified only if VAE is considered justifiable. However, as described below and as discussed by multiple authors, even if one posits that VAE is justifiable and consistent with good medical practice (in some cases), neonatal euthanasia is not justifiable

(Chervenak et al. 2006, 2008, 2009; Jotkowitz et al. 2008; Jotkowitz and Glick 2006; Kon 2007, 2008, 2009).[7]

In general, the ethical arguments against allowing neonatal euthanasia are the same as the arguments against all forms of NVAE. To best understand these arguments, a clear understand of the arguments in favor of PAD and VAE are necessary in order to then understand why they do not apply in the NVAE scenario.

The primary ethical support for PAD and VAE are two-fold: (1) The principle of respect for patient autonomy, and (2) The principle of beneficence. Many have argued that patients have a right to determine their own destiny. If a patient believes that her life is unbearable, or if she has significant concern regarding the progression of her disease with impending suffering and potentially loss of decision-making capacity, then, it is argued, she has a right to end her suffering (Quill 1991). Under this logic, if the patient chooses to end her life (either by taking a substance herself (PAD) or by having the physician administer a substance (VAE)), then the principle of respect for patient autonomy could be viewed as allowing the physician to participate. Alternatively, however, it can be argued that although the patient may have a right to request PAD or VAE, unless there is a medical indication for this intervention (e.g., the goal of treatment is to alleviate the patient's suffering, all reasonable interventions have failed to alleviate her suffering, and the patient and physician agree that the only reasonable option to end her suffering is the end her life; then it can be argued that PAD or VAE is medically indicated) the physician should not participate. It has been argued by many that PAD and VAE are contrary to the physician's duty to do no harm; however, others have argued that if the patient and physician agree that PAD or VAE is consistent with the patient's best interests, then the physician is not harming the patient by participating.

Alternatively, some point to the principle of beneficence as the primary support for PAD and VAE. If a patient is suffering unbearably, has exhausted all reasonable medical options without alleviation of her suffering, and believes that her suffering is a fate worse than death, then the patient's death may be viewed as therapeutic (Kon and Ablin 2010). That is, if the goal of treatment is to end the patient's suffering, and if all other treatments have failed to achieve this goal, and if the patient's suffering will end upon her death, then PAD or VAE may be seen as therapeutic, consistent with the principle of beneficence, and consistent with good medical practice.

In order to be ethically supportable under the principle of respect for patient autonomy, the patient must be able to make her own decisions. Clearly, in the case of infants, this is not possible. There is some measure of parental autonomy; however,

[7] NB: Several authors have written about ethical problems with the Groningen Protocol specific to how it has been implemented and the infants who have been euthanized under the protocol (Barry 2010; Callahan 2008; Van Der Maas et al. 1991). Here, we discuss only the broader ethical concerns with any form of nonvoluntary euthanasia, including neonatal euthanasia. We do this to focus on any form of such practice beyond the Groningen Protocol and its use. Readers should be aware, however, that even if they find the ethical arguments in favor or neonatal euthanasia compelling, there are deeper concerns with the clinical applications of the Groningen Protocol specifically as it was connected to infants with myelomeningocele.

there are significant limits to this autonomy and the state has an obligation to supersede parental authority when parents make choices that are contrary to the infant's best interests. As such, the principle of respect for patient autonomy cannot be the ethical basis for any form of NVAE, including neonatal euthanasia.

The principle of beneficence is more conducive for consideration as the ethical basis for NVAE. If the patient is suffering unbearably, and if death is the only therapeutic option that will alleviate that suffering, then NVAE could be ethically supportable. The problem here, however, is the judgement of whether the infant's suffering is *unbearable*. Through caring for adults and older children, it is clear that there is significant variability regarding what patients view as *unbearable* suffering. While many patients suffer, only the patient herself can judge whether that suffering is unbearable and whether living in her condition is worse than death. Clearly, we can judge whether a patient, even an infant, is suffering by regarding their face, listening for crying, seeing how they react to stimuli, and looking at their condition over time. We cannot, however, accurately judge whether the patient's suffering is unbearable. Many patients with severe unrelenting pain judge their suffering to be unbearable; however, other patients with the same degree of pain judge their suffering to be horrible but still better than being dead (i.e., not unbearable). The judgement of whether suffering is *unbearable* is wholly subjective and can be determined only by the patient herself (Jotkowitz and Glick 2006; Kodish 2008; Kon 2007).

Further, data suggest that health care providers, and even parents, are poor judges of the extent of children's suffering. Data suggest that when asked to self-assess their own quality of life, children with disabilities and "normal" children generally provide similar assessments (Saigal et al. 1996). Unfortunately, however, physicians generally rate the subjective quality of life of children with disabilities significantly lower than those children rate their own subjective quality of life (Janse et al. 2004). Further, in general, significant others of patients also generally underestimate patients' subjective quality of life (Sprangers and Aaronson 1992). These findings are critical because they demonstrate that physicians and parents are highly likely to overestimate the burdens to an infant and overestimate the infant's suffering (see Chapter DEVEREAUX). As such, empirical research suggests that many infants who suffer, but whose suffering is not unbearable, will be judged to have unbearable suffering by physicians and parents. This would necessarily lead to euthanizing infants who are not suffering unbearably.

Based on the above discussion, if we forbid NVAE, there will be some infants who suffer unbearably who are kept alive with unbearable suffering. Alternatively, if we allow NVAE, there will certainly be infants whose suffering is significant but not unbearable, and for whom being alive would be preferable to being dead, who will be euthanized. The question we must answer, therefore, is: Is it better to keep some patients with unbearable suffering alive, or to euthanize some patients who are not suffering unbearably?

One of the foundational tenets of medicine is *do no harm* (Hippocrates 400 B.C.E.). Clearly, there are times when physicians must harm patients in order to further their best interests. For example, cutting a person open is harming them; however, if doing so is the most appropriate treatment for their perforated appendix,

then such harm is justified. Similarly, it may be argued that euthanizing a patient is harming them; however, if doing so is the most appropriate treatment for their unbearable suffering, then such harm may be ethically permissible. Because we cannot accurately judge the *unbearableness* of an infant's suffering, and because research shows that doctors and parents are highly likely to overestimate the burdens of disease and disability, it is clear that allowing neonatal euthanasia would lead to the killing of some infants whose suffering is not unbearable. We use the term "killing" here because in such cases, life-termination is not euthanasia, it is simply killing a baby. Because killing some babies whose suffering is not unbearable is widely considered worse than keeping some babies alive who are suffering unbearably, the only conclusion can be that neonatal euthanasia is unsupportable.

18.4 Use of Paralytics and Neonatal Euthanasia: Pro and Con Arguments

18.4.1 Arguments in Favor of Using Paralytics

In the last 15 years, several studies were carried out in the Netherlands to monitor end-of-life practice in the Dutch Neonatal Intensive Care Units (NICUs) (Verhagen et al. 2009, 2010, 2007). In up to 16% of NICU deaths, providers administered paralytic agents (also referred to as neuromuscular blockade) at the time of withdrawal of mechanical ventilation. The main argument from these studies was that the patients already received these agents to support respiratory treatments at the time life-sustaining treatment was withheld or withdrawn, and discontinuing these medications would likely contribute to suffering. A second argument was to stop or prevent gasping in the final phase of dying babies on parental request. Paralytic agents were always combined with the administration of opioids and/or sedatives as comfort providing medication. The main reason for the use of paralytics instead of other medications was that they simply work well for both indications. Interestingly, physicians had different rationales for using paralytics in dying newborns: some viewed it as palliative care, while others viewed it as deliberate hastening of death, which needed to be reported as neonatal euthanasia and reviewed.

When it became clear that health care providers used different definitions of newborn euthanasia and palliative care, a multidisciplinary group of experts was created to address this controversy (Willems et al. 2014). According to this expert group, administration of paralytics is permitted if the aim is to stop prolonged gasping during ventilator withdrawal and to end a dying process presumed to take several hours or more, which only adds to the suffering of the parents. This uncommon situation may occur when even state-of-the-art palliative sedation is insufficient to relief pain and suffering and despite the medical team's careful preparation of the parents. The experts ultimately concluded that administering paralytics in these circumstances should be regarded as "good medical practice," but they recommend that, in view of

the ongoing debate about its legality, all cases must be reported for review to maintain full transparency and accountability.

Most of the group's recommendations were adopted in the evidence-based Guidelines for Pediatric Palliative Care that was issued by the Dutch Pediatric Association in 2013 and updated a few years later. Interestingly, the debate about use of paralytic agents in newborns has faded since 2018, and our 2020 informal survey confirmed that paralytics are no longer used in end-of-life care and that most units have removed paralytics from their EOL care protocols and palliative plans.

So, thanks to the thorough and repetitive studies of EOL care in the Dutch NICU's we know exactly how and why paralytics are administered in some severely ill babies. These data helped health care professionals and parents to reflect on this issue, rethink EOL care strategies, and find ways to control/regulate paralytic use to prevent misuse as covert euthanasia. Experts have indicated that probably as a result of data analysis and multidisciplinary debate, paralytics are no longer part of Dutch NICU care.

18.4.2 Arguments Against Using Paralytics

The primary reason to use paralytics in euthanasia is for the comfort of those seeing the patient die. Paralytics mask any signs of pain or discomfort, air hunger, anxiety, or other evidence of suffering. Indeed, one survey demonstrated that when physicians use paralytics during neonatal euthanasia, they generally do so to mask gasping, a sign of air hunger and suffering (Dorscheidt et al. 2013). To be clear, paralytics do not decrease air hunger or the patient's suffering, they merely mask the signs of such suffering so that others are less uncomfortable with the infant's demise.

Although seeing a patient suffer air hunger, anxiety, etc. while she is being euthanized can be very unsettling, it is imperative that care teams not mask such symptoms. If a patient exhibits signs of suffering while being euthanized, then providers have an obligation to aggressively treat that suffering. If all suffering is fully treated, then the patient will not show signs of anxiety, air hunger, pain, etc. and therefore paralytics would not be required. If the goal of NVAE is to relieve the patient's suffering, then masking her suffering during dying is contraindicated and ethically unsupportable.

Further, the use of paralytics has a high likelihood of harming the patient. Because paralyzed patients cannot be assessed for distress, air hunger, pain, etc., there is a high likelihood that such suffering will go untreated in the dying infant. Paralytics harm the infant, provide no benefit to the infant, and are used solely so that parents and members of the care team do not see signs of suffering during the dying process. As such, use of paralytics in any form of euthanasia is unethical and inconsistent with good medical practice.

18.5 Conclusion

Neonatal euthanasia has been practiced legally in the Netherlands since 2005. Outside of the Netherlands, neonatal euthanasia remains illegal; however, data suggest that it is practiced sub rosa by some clinicians in other countries. The true extent of neonatal euthanasia practice remains unknown. The ethical support for neonatal euthanasia stems from the duty of health care professionals to treat patient suffering. If the only intervention that can alleviate the patient's suffering is death, then death may be seen as therapeutic and hastening death may be ethically appropriate. In contrast, the ethical arguments against neonatal euthanasia stem from the ethical principle of do no harm and the belief that only the patient herself can judge whether her suffering is truly unbearable. Further discourse on this subject should illuminate these and other ethical arguments for and against NVAE.

Guiding Principles in Neonatal Euthanasia

• Neonatal euthanasia is illegal in all countries except The Netherlands
• Data suggest that neonatal euthanasia occurs occasionally in many countries in which it is illegal. The true extent of clandestine neonatal euthanasia is unknown
• In The Netherlands, neonatal euthanasia is performed legally using a detailed protocol (the Groningen Protocol). The protocol aims to ensure that only infants who face a life of unbearable suffering are euthanized. All cases undergo thorough post hoc review to ensure they were conducted appropriately
• Critics of the protocol argue that the safeguards are not sufficient to ensure that infants who suffer, but whose suffering is not unbearable, will not be euthanized. Many critics point to the use of the protocol in patients with myelomeningocele as evidence that the protocol is not ethically supportable
• Critics of neonatal euthanasia further argue that no protocol could be devised that would provide adequate protection for neonates and therefore neonatal euthanasia in all forms in not ethically supportable
• Like all areas of end-of-life care, this is an evolving field

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