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DUTCH PROTOCOL FROM GRONINGEN
(THE SO-CALLED GRONINGEN PROTOCOL).
THE PROBLEM OF DELIBERATE CAUSING OF DEATH
IN NEWBORNS (“NEONATAL EUTHANASIA”)

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quality of life, autonomy, best interests of the child

Introduction

In the age of a very rapid development of medicine and the techniques and procedures associated with the life sustaining, the problem arises whether if a newborn is affected by a major disadvantage of a genetic or incurable disease you should save and prolong its life in every case. In what circumstances should you consider withholding therapy and in what circumstances

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should you withdraw from treatment, considering it futile or too burdensome for the patient?

One of the most controversial issues in today's bioethics is the active causing of death ("neonatal euthanasia") in newborns who have the ability to survive and even achieve adulthood, but because of the illness affecting them their future quality of life is being assessed as very poor. Whether it is a form of murder that is the complete opposite of the Hippocratic Oath's principle of not doing any harm (*Primum non nocere*), or an act of mercy when medicine no longer has much to offer. Very often it is a better alternative than dying in suffering. Proponents of such a solution emphasize that in fact there is no moral difference between actively causing death by administering a properly selected combination of drugs and withholding therapy or withdrawing from therapy, e.g. by disconnecting life-support apparatus (Cuttin et al., 2009, pp. 21–22; Voultsov, Chatzinikolaou, 2014, p. 199).

The problem of acceptance of "neonatal euthanasia" constitutes a separate issue in the debate on the admissibility of euthanasia and physician-assisted suicide in adults and raises doubts even in countries that have legalized procedures for medically assisted death.

"Neonatal euthanasia" or deliberate termination of life?

Although the term "neonatal euthanasia" is commonly used in the literature,¹ it is not correct for active shortening of life of children affected by incurable diseases or genetic defects (Barry, 2010, pp. 409–410). In the case of euthanasia in adults, the key condition is the consent of a patient who is conscious and free of pressure.² In turn when it concerns incompetent people,

¹ The term "neonatal euthanasia" issued in the text according to what is used in the literature on the subject. However, as explained this is meant to be deliberate causing of death and the relevant term used in this context should be: non-voluntary euthanasia. However, we are not dealing with euthanasia in the narrow sense, which is the medical causing of death at the pressure-free and conscious request (informed consent) of the patient. Therefore, the expression neonatal euthanasia has been included in quotation marks.

² It should be noted that in the case of the Dutch Act: *Termination of Life on Request and Assisted Suicide (Review Procedures)*, a person who has reached the age of 12 years after obtaining parental consent (section 2 point 3 and 4) may apply for euthanasia (Voultsov, Chatzinikolaou, 2014, p. 196 and Verhagen, 2014, p. 215), while the Belgian

i.e. unable to express their will independently, and such are children with serious illnesses, the fate of these children is decided by someone else on the basis of the assessment whether the continuation of life is in the best interest of the patient. This alternative decision is taken by doctors and parents. Thus, we are dealing here with deliberate ending of the life of newborns (Kon, 2007, p. 457; Kon, 2008 p. 27; Warnock Macdonald, 2008, pp. 35, 49; van der Westhuizen, 2017, p. 213; Tedesco, 2017, p. 254). Since there can be no voluntary euthanasia, the argument of autonomy cannot be invoked as a justification for medically assisted death. This changes the way in which the debate on this subject is viewed. Therefore, doubts arise whether referring to the poor quality of life of terminally ill children is a sufficient justification for exceeding one of the basic prohibitions in our culture, which is the prohibition of killing (Barry, 2010, p. 411).

The deliberate termination of life as an unofficial medical practice

Despite the lack of acceptance of euthanasia in neonates and children in most European countries, in some countries, such as France, Belgium and the Netherlands, the intentional interruption of the lives of seriously ill newborns in intensive care units is a fact.

Surveys conducted on the basis of anonymous questionnaires show that: 73% of neonatologists in France and 68% of doctors in this specialty in Flanders make decisions about “euthanasia” in order to stop the child’s suffering. In other European countries this percentage is much lower and amounts to 4% in Germany and the United Kingdom, 2%, in Sweden, Italy and Spain (Voultzos, Chatzinikolaou, 2014, p. 197; Cuttin et al., 2009, p. 21; cf. also Francis, 2016, p. 10 and Sauer, Verhagen, 2012, p. 300).

In France and the Netherlands, doctors also admitted to administering medication to interrupt the life of a patient, even if children were not dependent on intensive care, while their prognoses for the future were assessed as poor. Doctors decided to carry out “neonatal euthanasia” realizing that it was against the binding law (Cuttin et al., 2000, pp. 2114, 2116).

Act on Euthanasia of May 28th, 2002 does not mention the lower age limit, a minor may express his/her request for medical assistance in dying after obtaining parental consent (section 2, §2).

Therefore, despite the lack of legal regulations, such medical practices are applied. So one can put forward a thesis on the existence of “grey area”. The reason for this is the lack of criteria to distinguish between procedures related to withholding therapy or withdrawing from therapy and palliative care and deliberate acceleration of patient death (“neonatal euthanasia”). Some physicians may have reasonable doubt as to which of these procedures may be used without incurring criminal liability. On the other hand, it can be misrepresented in the documentation as the death occurred due to natural causes, e.g. after the withdrawing from therapy.

Not without significance is also the law in force in individual states. Thus, in Spain or Italy, a strong emphasis is placed on the protection of life and the prohibition of life interruption. The Netherlands has legalized euthanasia in adults and has clear guidelines for deliberate children’s life shortening procedures. In France, however, the number of cases of “neonatal euthanasia” is higher than in the Netherlands, despite the prohibition of medically assisted death. It results, among others, from the acceptance of this type of practice among the medical community (Cuttin et al., 2000, p. 2116). There is therefore a clear dissonance between the law in force and medical practice. So far, however, the Netherlands has been the only country that has adopted guidelines on causing deliberate death in children.

According to data provided by the Royal Dutch Medical Association (KNMG) in the Netherlands, out of 175,000 births per year, 650 children die as a result of serious birth defects shortly after birth. In 1995, out of 1041 child deaths in the first year after birth, 43% of infant deaths occurred without medical intervention, out of the remaining 57%: 26% of reported deaths were due to withdrawing from treatment or withholding therapy, 23% due to medication to eliminate suffering that could accelerate death, and 8% due to medication to accelerate death, and 1% of cases (15–20 per year) were administered to deliberately cause death in children whose condition did not require life-sustaining therapy (Vizcarrondo, 2014, p. 389 and Francis, 2016, p. 1).

In order to control the practice of shortening the lives of very young children in 2002, Eduard Verhagen and Pieter Sauer, pediatricians at the University Medical Center Groningen, after consultation with the Regional Public Prosecutor, developed guidelines related to “neonatal euthanasia”, which were accepted by the Dutch Pediatric Association. They were started

to be applied in 2005 under the name of the Groningen Protocol (Verhagen, Sauer, 2005, p. 959; Cuttin et al., 2009, p. 23 and Francis, 2016, p. 1; van der Westhuizen, 2017, p. 220).

The Prins and Kadijk cases

One of the key starting points for adopting the solutions contained in the Protocol were court trials in cases of deliberate causing death of seriously ill infants.

The Prins case of 1995 involved a child with a *spina bifida* and severe brain damage. The surgical intervention was deemed futile. The parents of the child, being convinced of his suffering and hopeless condition, demanded that the doctor terminate her life. Dr Prins administered a 4-day-old infant a combination of drugs that caused the baby's death. During the trial, the Alkmar court set out the criteria that a doctor should follow in similar cases in order to be able to defend himself/herself against a murder charge. They were:

1. Hopeless and unbearable suffering and lack of prospects for improvement of the patient's condition.
2. Parents' request to terminate their child's life.
3. The procedure must be performed in accordance with the accepted medical standard and medical ethics.

The court pointed out that the state of necessity in which the accused doctor found himself resulted from a conflict of duties. On the one hand, he had to deal with the obligation to save life, and on the other hand, with the duty to prevent and eliminate the suffering of the patient. In this case, fulfillment of one of the obligations shall preclude the other. The choice is justified by the fact that the doctor meets the conditions set out above to avoid prosecution.

A similar judgment was given by a court in the case of Kadijk in 1996, which concerned a girl born in 1994 who suffered from a genetic defect (trisomy 13) and a malformation of her body and abnormally functioning kidneys. The expected length of life of the child was set at one week to several months. Parents opposed the operation not wanting to deepen the child's suffering and asked for shortening of the girl's life. Doctor Kadijk, who gave a mixture of drugs causing the death of the child, was accused of

murder. Similarly to the previous case, the court acquitted the defendant by defining the criteria allowing to justify the doctor's actions in similar cases:

- the diagnosis and prognosis must be certain to a doctor and to parents,
- both parents must give their informed consent,
- consultations with independent specialist,
- the shortening of life procedure must be performed in accordance with the accepted standards,
- to report each case to the relevant authorities.

It should be noted that in both cases, the medical intervention was considered futile and the doctor had to choose between two incompatible duties (van der Westhuizen, 2017, pp. 215–217).

In both cases the deliberate causing of death occurred by the administering a mixture of drugs. The basis of the doctors' action was the demand of parents who claimed that their motive was to shorten the suffering of the child. Courts have formed a line of rulings based on the definition of criteria that should be met in order for a doctor to be released from criminal liability for one of the most serious crimes, which is murder. At the same time, these criteria have become the benchmark for appropriate medical practice in exceptional cases. Strict compliance with certain criteria, which were repeated in the subsequent Groningen Protocol, was intended to ensure adequate control of end-of-life procedures and to provide a transparent picture of such practices (Verhagen, 2014, pp. 296–297).

Both judgments issued several years before the drafting of the Protocol had a significant impact on the provisions contained therein.

Dutch protocol from Groningen (the so-called Groningen Protocol)

The development of the Protocol was preceded by the case of a girl suffering from *epidermolysis bulosa*, where a discontinuation of the therapy was not questioned, because the child was not dependent on life-supporting equipment. The doctors refused the parents' request to interrupt the child's life with medication. The child died a few months later (Verhagen, 2013, p. 293; van der Westhuizen, 2017, pp. 217–218).

The guidelines contained in the Protocol were aimed at establishing good practice in cases of “neonatal euthanasia”, making this practice more transparent and increasing trust in doctors. It was pointed out that the deliberate causing death in children is permitted only in exceptional cases (Verhagen, 2013, pp. 293–294; Verhagen, de Vries, 2008, p. 29).

The Protocol lists three groups of children:

- children who do not have a chance to survive despite intensive medical care,
- children who will survive on an ongoing intensive care basis but have very poor prospects for life,
- children who will survive without intensive care but who will suffer greatly and have a very poor quality of life.

In the case of the first group, death is the result of an incurable disease, e.g. undeveloped lungs or damaged kidneys, some doctors opt not to undertake treatment in these cases as an expression of good medical practice. In these cases, medicine can do nothing to improve the patient’s condition.

In the second group, physicians, in consultation with the parents, try to assess whether survival will be in the best interest of the child. In such cases, treatment is not continued, allowing the child to die. Appropriate medications are used so that the patient does not suffer after the end of therapy. The assessment shall take into account, *inter alia*, the following factors: the amount of pain and its degree, dependence on hospital care, length of therapy. If the parents still want to continue treatment, their will is respected.

The cases of children from the third group are the most controversial, as these patients’ therapies are not interrupted, but in order to accelerate death, medication must be administered, i.e. there is the deliberate ending of life. It is a question of determining the best interests of the child by assessing whether death is a better solution for these children (Verhagen, Sauer, 2005, pp. 959–960; Sauer, Verhagen, 2012, pp. 290–293).

The Groningen Protocol was created in order to avoid accusations against doctors and, at the same time, to ensure effective control over the procedure for accelerating death. It lists five criteria that must be met in order to carry out “neonatal euthanasia”:

- the diagnosis made must be certain and beyond question,
- the suffering felt is considered unbearable,
- an independent expert must be consulted,

- both parents must give their informed consent,
- procedure must be consistent with the medical standards.

The authors of the Protocol stressed the importance of respecting the conditions laid down in the Protocol when making end-of-life decisions (Verhagen, Sauer, 2005, p. 961; Sauer, Verhagen, 2012, pp. 290–292, 296).

Between October 2005 and September 2006, 359 deaths of newborn babies treated in 10 intensive care centers were investigated in the Netherlands – 95% of them were due to end-of-life medical decisions and only 5% of them continued to be treated until death. 58% of these cases concerned the first group of children listed in the Protocol, 42% of children belonged to the second group, with 92% of decisions in this group based on a quality of life assessment, while only one case concerned the third group. In 224 out of 340 cases (i.e. the aforementioned 95% of cases where death occurred as a result of medical decisions), analgesia and sedation were used. This number increased to 292 cases after the decision to end the life of children, in 55 cases neuromuscular blockers (NMB) were prescribed to prevent the occurrence of dyspnea after cessation of intubation. Parents were always involved in making decisions about their children.

According to Eduard Verhagen and Pieter Sauer, it is significant that there was only one case of the deliberate ending of life, which may indicate that it is practised only in exceptional cases (Sauer, Verhagen, 2012, pp. 298–299; Verhagen 2014, p. 297).

Amendments to the Protocol

In 2016, with the participation of the Royal Dutch Medical Association (KNMG) and the Netherlands Health Organization for Research and Development, the Protocol was revised. After the changes it has been renamed as the Regulation of the Minister of Security and Justice and the Minister of Health, Welfare and Sport of December 11, 2015, wherein 885614-145412-PG, establishing a commission for the assessment of reported cases of late abortion and euthanasia in newborns is given. Nevertheless, the name “the Groningen Protocol” is still used.

The original criteria were replaced by the following wording:

1. The doctor is convinced there is enduring and unbearable suffering [of the newborn]; there is no reasonable doubt about the diagnosis

and resulting prognosis. The medical treatment and applied intervention are futile, therefore discontinuation of such medical treatment is justified.

2. The doctor fully informs the parents of the diagnosis and the resulting prognosis. Both the doctor and parents believe that there is no reasonable alternative solution to the newborn's situation.
3. The parents have agreed to the procedure consisting in the termination of their child's life.
4. The doctor is obligated to consult at least one independent physician who provides a written judgement on the due diligence of the case, or, if an independent physician cannot reasonably be consulted, the doctor consults with the newborn's healthcare team who provide a written judgement as to the due diligence of the case.
5. The termination of life procedure is conducted with due medical care, according to the relevant standards.

Reports on the procedure are sent to the Central Expert Commission Late Pregnancy Termination and Termination of Life in Newborns, which consists of a lawyer, an ethicist and four doctors. Its main task is to verify that the criteria laid down in the Protocol are met. This body also deals with the cases of late termination of pregnancy due to incurable foetal malformations. The Commission shall have an advisory role when investigation proceedings in these cases are conducted. If it is found that the procedure does not meet the required criteria, the Commission shall notify the State Inspectorate for Public Health, which may take appropriate measures in the form of using disciplinary consequences in relation to the doctor responsible for the shortening of life.

In addition, the report on the procedure is sent to the Board of Prosecutors General, which, with the support of the Commission, decides whether the procedure has been carried out in accordance with the applicable rules, which takes 6–12 weeks. The Protocol does not guarantee any automatic protection of doctors from prosecution. Only after the approval of the General Prosecutor's Office and the Ministry of Justice can it be concluded that the life termination procedure was carried out correctly (Francis, 2016, pp. 8–9).

Commission reports and related doubts

Since its establishment in 2006, the Commission has been drawing up reports on its activities. In the period from 2006 to 2014, there were 16 cases of late abortion and 2 cases of termination of life in newborn children. Both cases concerned children born with bullous epidermolysis (*Epidermolysis bulosa*) (Verhagen, 2014, p. 297; Francis, 2016, pp. 8–9). During nine years (1997–2005) before the introduction of the Protocol, 22 cases of “neonatal euthanasia” were reported, none of which ended with a bill of indictment (Verhagen, Sauer, 2005, p. 960; Verhagen 2014, p. 297; Francis, 2016, pp. 8–9). Prior to the implementation of the Protocol, the number of deliberate life shortening procedures was estimated between 15 and 20 cases per year and concerned children affected by *spina bifida* or *hydrocephalus* (Verhagen, Sauer, 2005, p. 961; Verhagen, 2014, p. 297; Francis, 2016, p. 10).

It should be noted that the number of cases reported to the Commission is very small.

The reason for this state of affairs is:

- the increasing number of lethal analgesias and sedations carried out in place of opiate administration,
- the decrease in the incidence of *spina bifida* by folic acid supplementation in pregnant women,
- the increasing number of abortion procedures with early detection of genetic defects of the fetus in ultrasound examinations,
- the administration of neuromuscular blockers (NMB).

In the latter case, there are doubts whether the administration of these drugs is not a deliberate causing of death. Most doctors believe that muscle relaxants are a part of palliative care, as they are prescribed for non-independent use and are a part of the extubation procedure. In its guidelines, the KNMG considers the use of these drugs, especially after the disconnection of artificial ventilation, to be in line with medical practice. It should be added that neuromuscular blockers (NMB) are also administered to children who are stable and do not depend on life-sustaining equipment. Because they experience unbearable suffering as a result of incurable disease, doctors, at the request of parents, administer these drugs together with a combination of opiates to speed up death. According to opponents of the Protocol, such action is in fact intentional causing of death in children and should therefore be reported to the Commission. On the other hand, according to opposite

views, this procedure is a part of palliative care appropriate when there is no other way to overcome suffering (Verhagen, 2014, p. 297).

In practice, however, the boundary between allowing a peaceful death without suffering and intentional causing of death is very blurred (Sauer, Verhagen, 2012, p. 299; Verhagen, 2013, pp. 294–295; Verhagen, 2014, p. 297; Francis, 2016, pp. 9–10). And therefore the question arises whether the guidelines proposed in the Protocol are indeed respected. It is possible to demonstrate in the report that the administration of drugs was a part of e.g. the withdrawal from therapy and not to go through the procedure of verification of the criteria specified in the Protocol.

One of the founders of the Protocol, Eduard Verhagen, a few years after its introduction, stressed that “neonatal euthanasia” is a rare procedure of an exceptional nature, suitable only if the methods used in palliative care are not sufficient to eliminate suffering. However, a sharp line needs to be drawn between “euthanasia” and palliative care. It is necessary to clearly define what “neonatal euthanasia”, i.e. intentional causing of death, is because until now, doctors who make decisions about the end of life of incurably ill children have had difficulty in determining whether their actions are intentional causing of death. They may therefore not report all cases to the Commission as required by the Protocol. According to Verhagen, transparency in end-of-life procedures and access to palliative care should be continuously improved. It is important that “neonatal euthanasia” is legalized as an option to relieve unbearable suffering, as it has been done for adult patients. As in the case of euthanasia in adults, the basis is judicial case law, medical practice and observation of how end-of-life procedures are applied. Legalization does not have to mean an open road to abuse in the form of launching a slippery slope. It is important that the practice of deliberately causing death is carried out in accordance with certain criteria and notified to the relevant authorities, in order to achieve transparency in the conduct of the procedure and effective control over its use (Verhagen, 2014, p. 298).

Should “neonatal euthanasia” be legal?

The solutions adopted in the Protocol have undergone a kind of transformation from internal guidelines applied in hospital intensive care units, approved by the KNMG, to official recommendations issued by the Minister of Security

and Justice and the Minister of Health, Welfare and Sport. Despite the existing social acceptance of “neonatal euthanasia” as a hospital practice, the Dutch legislator has so far not decided to legalize the deliberate causing of death of terminally ill children. The criteria for the implementation of this procedure are clearly defined and a control body is set up to verify whether they are met in a given case. Personnel responsible for decisions relating to the end of life of seriously ill infants may be liable to disciplinary action and to criminal prosecution, including charges of causing death or murder, if the requirements of the Protocol are not complied with.

The solutions presented above can be considered as an attempt to create effective control mechanisms to prevent possible abuses. “Neonatal euthanasia” should only be used in exceptional cases where doctors and parents believe that there is no other alternative to relieving the patient’s suffering. On the basis of currently available data, it cannot be determined to what extent these safeguards are effective and whether they really constitute protection against the occurrence of the slippery slope mechanism. This may be the reason why the Dutch Parliament has so far failed to pass the world’s first law legalizing “neonatal euthanasia”.

Proponents of legalization of medically assisted death in neonatology claim that it will help to avoid hypocrisy around this phenomenon. In many countries, it is unofficially practised, even though it is contrary to the law in force, such as that in Belgium or France. The criminalization of the deliberate causing of death leads to abuse and concealment of this fact, e.g. under the guise of palliative care or inaction or discontinuation of treatment. This encourages making arbitrary decisions by medical staff. We cannot talk about discussing and searching for a good solution when the facts of a child’s death are concealed in order to avoid criminal investigation and prosecution.

The Netherlands is the only country that openly practises deliberate hastening of death in terminally ill children whose prospects are considered hopeless, striving to maintain a balance between the authority and knowledge of the medical staff and the will of the parents of the sick child. Legalization of “neonatal euthanasia” in the opinion of advocates of its application will allow to reveal the scale of this phenomenon, enable its control and facilitate decisions about the fate of a child by parents and doctors, and thus will allow to better protect the interests of terminally ill children (Eijden, Martinovici, 2013, pp. 77–78).

For and against the Protocol

The deliberate causing death vs palliative care

The essence of terminal sedation

According to the authors of the Protocol, the forms of palliative care provided to adults will not always be appropriate for very young children, due to the fact that the process of dying in children is different, e.g. the period between withdrawal from therapy and death is longer than in adults. Also suffering in children is more difficult to observe (Sauer, Verhagen, 2012, pp. 299–300). It seems that the way to eliminate suffering will be to use terminal sedation, i.e. to put the patient in a state of unconsciousness. Sedation can be of transient nature and be temporarily used in patients suffering from terminal disease. Deep continuous sedation is used in patients in the dying phase, usually in their last days and hours of life, and it lasts until death of the patient. This type of sedation is used only when death is inevitable, and sometimes it can be associated with the cessation of artificial hydration and nutrition. It should be remembered that this is a very radical solution and should be used only when other forms of palliative care are exhausted (Legemaate, Verkerk, van Wijlick, de Graeff, 2007, pp. 62, 67; Badarau, de Clercq, Elger, 2019, p. 51). According to the guidelines of medical and hospice associations, the recommended period of use for terminal sedation is 14 days (Badarau, de Clercq, Elger, 2019, pp. 52–56).

It is important to exercise particular caution, the therapy must be adequate to the patient's condition. Supporters of the use of sedation emphasize that if used correctly, it does not contribute to hastening the patient's death and may be considered an alternative to medically assisted death. It is possible to draw boundaries between the two procedures. The purpose of terminal sedation is to relieve the patient's suffering, it does not shorten the patient's life, and it is also a reversible procedure. Other drugs are used in this case, whose dose is not exceeded as in the case of medically assisted death. Sedation is considered to be a radical albeit normal procedure in palliative medicine, but the intention to shorten life cannot be a part of it. The patient's informed consent is crucial, but in the case of young children, the authorisation for the procedure is transferred to the parents. The decision to use sedation should be made by the parents and the medical team in agreement on what is best for the young patient, and its sole purpose should be to

alleviate the child's suffering (Legemaate, Verkerk, van Wijlick, de Graeff, 2007, pp. 64–70; Cherny, Radbruch, 2009, pp. 585–586). Taking into account the specificity of neonatal cases, sedation does not deal with the problem of exclusion of consciousness as in adults (which is sometimes perceived as unacceptable because it prevents patients from leaving on their own terms) because in such small children, consciousness is not developed yet. What is meant here is the elimination of physical pain.

Doubts related to the use of sedation

According to opponents of deep continuous sedation, the boundary between this procedure and medically assisted dying is very difficult to establish. One of the problems is the lack of evidence that correctly applied sedation does not affect time of death. It may not therefore be presented as an alternative to the use of euthanasia or “neonatal euthanasia”. It is not possible to state unequivocally that the use of sedation will eliminate symptoms of suffering that are difficult to control by other methods (Badarau, de Clercq, Elger, 2019, pp. 59–60, 62).

Sedation is presented by its supporters as a procedure that restores comfort to the patient and gives the illusion of “natural” death – because the patient dies in their sleep. This removes responsibility from the medical personnel making this procedure acceptable. However, this is not the case because we are dealing with a coma pharmacologically induced by a doctor. Sedation also has effects difficult or even impossible to predict, such as respiratory depression or aspiration pneumonia, which can hasten death of the patient. Thus, it cannot be said in this case that the patient died as a result of illness, whereas as in the case of euthanasia or “neonatal euthanasia” the cause of death is the administration of medicines (Badarau, de Clercq, Elger, 2019, p. 60).

Another very important problem is that it is not always clear whether the purpose of sedation was to relieve suffering or whether the real intention was to speed up death of the patient. It is not possible to state unequivocally that the acceleration of death was only predicted. On the one hand, medical staff may not want to use sedation because they will have doubts about how to morally assess this procedure and will not want to be accused of causing death of the patient (Cherny, Radbruch, 2009, p. 582). On the other hand,

since this procedure does not require formal rigors such as those laid down in the Protocol, sedation can be given in the documentation instead of medically assisted death of the patient, which is a field for abuse. Therefore, it can be said that it is a kind of “euthanasia” in disguise, and this poses a greater threat to patients than a deliberate shortening of life in accordance with the requirements set out in the Protocol (Cherny, Radbruch, 2009, p. 582; Raus, Sterckx, Mortimer 2012, pp. 45–52).

The principle of double effect in palliative care

Proponents of the use of sedation argue that the goal of sedation should always be to overcome symptoms that are especially troublesome for the patient, and never to cause their death. Such a position has been adopted by medical associations such as the American Medical Association, Norwegian Medical Association, nursing associations or hospices in their guidelines, emphasizing that the sole purpose of sedation is to bring relief from suffering (Matersvedt, Bosshard, 2009, p. 622). French Code of Medical Ethics precludes the intention to shorten life as an objective of the palliative care (Baumann, Claudot, Audibert, Mertes, Puybasset, 2011, p. 5). The principle of dual effect is cited as the moral justification for the risk of accelerating death in some palliative care procedures. It means that an action which causes both good and bad results, in this case the bad result being the hastening of death of the sick person, is morally justified if it is taken with the intention of achieving the good result, which is to relieve suffering by sedation. Bad result cannot be intentional but only expected (Sykes, 2009, p. 49; Dangel 2011, p. 59). The dual effect principle allows palliative therapy to be conducted in a legitimate manner, justifying the risk of hastening the patient’s death associated with the dosing of analgesics and sedatives. Resignation from this principle would have to lead to the deliberate acceleration of death as a morally justifiable act or result in the prohibition of pain relief and sedation (Jansen, 2010, pp. 20–21; Sykes, 2009, p. 49).

At the same time the principle of double effect is very strongly criticized. The main charge is the ambiguity of the intention. How to determine which effect of the action taken was intended and which was only anticipated. It is very difficult to determine the relationship between actions, effects and intentions. As already mentioned, this may give rise to legitimate concerns

for doctors and health professionals as to their responsibility for the effects of the treatment administered. Very often, medical staff caring for terminally ill people do not notice the difference between pain control and euthanasia, or are afraid to administer large doses of analgesics and sedatives in order not to be accused of abuse or misconduct contrary to medical ethics (Sykes, 2009, p. 49; Jansen, 2010, pp. 21–22; Warnock, Macdonald, 2008, p. 111). On the other hand, the defenders of the application of the dual effect principle claim that, despite the doubts, it should take place in decisions related to palliative care. The doctor's activities may well determine the doctor's intentions, e.g. by planning the administration of medicines and monitoring the doses administered. The documentation of the pharmacological agents used is very important (Sykes, 2009, p. 49).

The risks associated with the possibility of shortening life must be very well justified (McStay, 2003, p. 76) and the principle of dual effect alone cannot be the only premise in assessing the use of sedation. However, the doctor who conducts the procedure should always be guided by the relief provided to the terminally ill patient. Determining the intention of a physician is very important in clinical practice, even if we question the usefulness of the double effect principle (Jansen, 2010, p. 30).

Is sedation an alternative to “neonatal euthanasia”?

Sedation, although an acceptable form of palliative care, is not, according to the authors of the Protocol, an alternative to the deliberate causing of death. Sedation should be used approximately two weeks before the expected death of the patient. In the case of children, there are diseases that are different from those of adults who suffer most often from cancer. And so death as a result of e.g. a *spina bifida* or hydrocephalus is expected within a few weeks or months, so it is difficult to say that the use of sedation until death is a good medical practice. Therefore, the application of the procedures laid down in the Protocol may be the only alternative to eliminating suffering in terminally ill children (Sauer, Verhagen, 2012, pp. 299–300; Legemaate, Verkerk, van Wijlick, de Graeff, 2007, p. 71).

Because five years after the Protocol was introduced, two cases of intentional causing of death were officially recorded, and both concerned children with *epidermolysis bullosa*, opponents of “neonatal euthanasia” presented

a case of submission of a several-month-old child with this condition to palliative sedation. It is possible not only to save the lives of children with EB, but also to increase the comfort of their lives or at least to let them die without suffering. When using analgesia and sedation at the end of life, and with very good cooperation between doctors, pharmacists and parents, the patient died 5 days after sedation. Previously, analgesia was administered along with adequate palliative care, resulting in a significant improvement in the quality of life of the child who spent part of its life at home. Therefore, appropriate therapeutic solutions can be sought and “neonatal euthanasia” does not have to be the only option for patients with this disease (Pasichov, Frizolla, Miller, 2018, pp. 1–2).

Opponents of the Protocol’s solutions stress the need for comprehensive education of medical personnel in the use of appropriate analgesic therapy and sedation. It is becoming necessary to establish and comply with strict criteria for the application of these procedures, taking into account the specific nature of neonatal cases. The procedure itself should be exceptional and used when there is no other way to alleviate the suffering of the sick. In the specific case it is necessary to assess the burdens and benefits for the patient. If sedation is used in the last phase of a terminal disease, there is very little risk of hastening death. There is no question that sedation is a hidden form of euthanasia. This appropriate action in relation to palliative care is the opposite of “neonatal euthanasia”. It is also important not to call it terminal but rather palliative sedation, otherwise there is a suggestion that this procedure speeds up death. The correct and proportionate use of sedation to serve the good of the patient and to be the best way to care for patients at the end of life can be a response to the use of “neonatal euthanasia” (Cherny, Radbruch, 2009, p. 582; Carr, Mohr, 2008, p. 79; Rietjens, van Delden, van der Heide, 2018, p. 2; Warnock, Macdonald, 2008, pp. 108, 111).

The deliberate termination of life as an alternative to withholding and withdrawal from therapy

In considering whether it is acceptable to deliberately shorten children’s lives, the same problem arises as in the case of adults. For some of the patients listed in the Protocol, withholding therapy or withdrawing from therapy shall apply. The question therefore arises as to what these procedures stand for.

Why are they considered morally acceptable even though they result in death of the patient and the deliberate shortening of life because treatment is withheld/withdrawn? The distinction is necessary in order to set a limit for withdrawing from treatment and not to expose patients to treatment that is not beneficial to them and that can place a heavy burden on them. In ethics and medical law, it has been assumed that when a patient resigns from therapy, he dies as a result of the disease, whereas in the case of medically assisted death, including “neonatal euthanasia”, the cause of death is the administration of drugs (Callahan, 2000, p. 99; Brock, 2004, p. 73). Withholding therapy or withdrawing from therapy occurs when from the medical or moral point of view it no longer makes sense. The reason for withdrawing from medical intervention is its inconvenience and inability to overcome the disease both in children and adults. However, the use of further treatment can only be prolongation of the agony. Withholding therapy as well as withdrawing from therapy in the last stage of the disease allows the patient to die (Aszyk, 2006, p. 144).

Withdrawal from life-sustaining therapy or life-saving measures shall not be considered a homicide. The cause of death is the removal of technical measures that delay death, and so, e.g. disconnection of the respirator is consent to death that would have occurred had the respirator not been used. The basis for decisions in such situations is judgement about the limits of treatment, not about the patient’s life.

Withdrawing from treatment is considered to be a part of a medical practice, whereas administering a pharmacological agent with the intention of causing death cannot be allowed, and therefore “neonatal euthanasia” is the murder of the patient. There is a difference between artificially sustaining life and artificially shortening it (cf. Urofsky, p. 135). Assuming that withholding or withdrawing from the therapy is the killing of a sick child, we will become a hostage of modern technologies. It is therefore very important to establish transparent procedures for the withdrawing from treatment in terminally ill children (Callahan, 2000, pp. 174–177).

It should be added that in the era of current neonatal intensive care units, it becomes very difficult to answer the question of what natural death really is. Is it dying, which occurs after all available means of prolonging life have been exhausted, sometimes at the cost of the enormous burden that this entails for the patient, or a peaceful death without technological extravagance?

The active shortening of the lives of newborn babies should be considered controversial, especially as the child cannot express his or her wishes and the decision is made on the basis of an assessment of the quality of his or her life. The purpose of the procedure is to relieve the suffering of a terminally ill child. Supporters of the Protocol shall adopt the assumption that death is not always evil. There is no moral difference between switching off the respirator and giving the patient a lethal dose of medication, in both cases the patient is allowed to die. Therefore, drawing a distinction between causing death and letting die is simply hypocritical.

“Euthanasia” can be a better option than withdrawing from therapy in some cases. The child is at risk of suffering from malnutrition and dehydration while waiting for death, which cannot always be minimized by palliative care. Sometimes parents may prefer deliberate causing of death to withdrawal from therapy, as the child dies quicker (Woien, 2008, p. 31; Verhagen, 2013, p. 295; cf. Kon, 2008, p. 27). If there is nothing but pain and suffering in a child’s life and medicine has nothing to offer, then early death will be an expression of the child’s best interest. Therefore, euthanasia in this case will be a more humane alternative than withholding therapy or withdrawing from therapy. The procedures in the Protocol are designed to protect children with no future prospects (Manninen, 2006, pp. 644–645; Manninen, 2008, p. 33). Naturally, the best interests of the child must always be a primary consideration when making end-of-life decisions (Verhagen, Sauer, 2005, p. 960; Verhagen, de Vries, 2008, p. 29; Manninen, 2006, p. 644).

Opponents of the Protocol criticize the concept of the best interests of the child on the grounds of a lack of prospects, a hopeless situation and an unbearable suffering. It should be noted that the argument that there is no moral difference between withdrawal from therapy and euthanasia cannot be applied because the most controversial cases concern children who are not dependent on intensive care and can survive from a few months to an adult age depending on the disease (e.g. in the case of *spina bifida*). The Protocol poses a major risk because it concerns children who are not affected by terminal illness (Kon, 2007, p. 457).

Criticism of quality of life

The criteria used by proponents of the Groningen Protocol, i.e. quality of life and poor prospects for the future or unbearable suffering, lack clinical and ethical precision (Chervenak, Arabian, 2006, p. 31; Lindemaan, Verkerk, 2008, p. 47).

The Protocol does not define what the term “quality of life” means. This assessment is made by doctors. The Dutch Pediatric Association agrees that the evaluation of the quality of life is very difficult, but gives some reference criteria: perceptible pain and discomfort, dependence on third parties, low communication capacity, dependence on hospital care and the expected length of therapy (Sauer, Verhagen, 2012, p. 292; Barry, 2010, p. 409). According to opponents of the Protocol, poor biological quality does not necessarily mean poor quality of life at all. This criterion is very subjective – we evaluate the quality of life best from our own perspective; infants cannot do this. Here, the decision for children is made by someone else. Is it not the case, then, that quality of life assessment is an assessment of the burden that sick children place on parents and society? (Chervenak, McCullough, Arabian, 2006, p. 31; Chervenak, McCullough, Arabian, 2009, p. 202).

It is also very dangerous to say that the patient has no future prospects (Jotkowitz, Glick, Gesundheit, 2008, p. 24). We cannot really know that. Individuals with a *spina bifida* live to an adult age and can lead a very satisfying life. Many medical prognoses are sometimes misleading. Account should also be taken of the continuing development of medicine, which contributes to the well-being of many of those who until recently were considered to be in a hopeless condition (Barry S., 2010, pp. 412–413; Voultsov, Chatzinikolaou, 2014, p. 200). The question is whether, in the case of children with genetic diseases, poor biological quality of life makes them less valuable than others. Or maybe it is rather a question of financial issues related to treating children who will never be fit (Vizcarrondo, 2014, p. 391). The question also arises whether the solutions adopted in the Protocol will not promote discrimination against poorer families who cannot afford expensive childcare (Voultsov, Chatzinikolaou, 2014, p. 199). Thus, the issue of quality of life can easily turn into an economic one.

In view of the above doubts, we should consider whether quality of life can be considered a proper justification of decisions related to ending the life of terminally ill children (Warnock, Macdonald, 2008, p. 40). Are poor

prognoses and a lack of a future not the same as “a life unworthy of living?” Thus, under the pretext of a poor quality of life, an economic calculation is made (Jotkowitz, Glick, Gesundheit, 2008, p. 25). “Neonatal euthanasia” may be a cheaper solution than keeping terminally ill children alive. Why should we cure someone who will never be fit, and in many cases throughout life will be dependent on the care of others? It is easy to estimate the costs of treatment in intensive care units or of other life-sustaining procedures. In addition, there is the burden on parents of caring for a child with disabilities on a permanent basis. There were cases where parents could not cope with the child’s care and the child was returned to the hospital ward, where it stayed until its death. Why should society bear the burden of caring for terminally ill children who, according to medical prognoses, are likely to die anyway? Is “neonatal euthanasia”, which is not only a quick and painless release from suffering, easier and simply cheaper option at the same time? These are open-ended questions, but they are not answered directly.

In the Groningen Protocol, the quality of life category is used to assess whether the lives of seriously ill children are worth continuing with and whether they can be interrupted. It shall be assessed in this way: whether life in the cases listed in the Protocol is of value to these children or whether it remains only a burden. Illness and the unbearable suffering it causes can mean that life is not of good quality, so one can conclude that it is not worth living and pass judgment on whether or not to prolong it. A shorter life can mean protection from the evil of living with the disease and therefore justifies its interruption. The assessment of the quality of life of young children was reflected in clinical decisions in neonatology. On the basis of the premises of unbearable suffering and poor predictions for the future, a “neonatal euthanasia” is carried out.

The opponents of such arguments believe that the evaluation of the quality of life should be combined with the improvement of the patient’s health. Children suffering from incurable diseases should be cared for appropriately and their pain and suffering caused by the disease should be minimized. It is an expression of concern for those of us who cannot speak for themselves. And it does not necessarily mean vitalism, which says that life must be saved at all costs (cf. Paterson, 2003, pp. 2, 11, 15–16; Warnock, Maconald, 2007, p. 40).

The quality of life argument, which was used as one of the arguments for the admissibility of euthanasia in adults, is not a sufficient justification

for the decision to deliberately interrupt life in young children. According to opponents of the Protocol, quality of life is a blurred category and it serves to make often arbitrary assessments by third parties. Parents, doctors and composition of judges are not entitled to assess the quality of life of a particular child, and even less to conclude whether it is worth continuing, as they can only assess the situation from their own perspective. It is not enough to decide about death of another human being.

Criticism of the concept of unbearable suffering

Further doubts have been raised over a vague concept of the patient's suffering felt by the patient as one of the conditions for the admissibility of deliberate causing of death. This is one of the key arguments for justifying life termination. The Protocol does not define or explain what unbearable suffering is (Westhuizen, 2017, p. 219; Chervenak, McCullough, Arabian, 2008, p. 6). In the case of adults, they can themselves evaluate both their physical and psychological suffering. Since very small children cannot communicate whether they suffer unbearably, it is estimated on their behalf (Kodish, 2008, p. 893; Chervenak, McCullough, Arabian, 2009, p. 202; Lindemaan, Verkerk, 2008, p. 47; Eijden, Martinovici, 2013, pp. 76–77).

Proponents of the Protocol claim that it is possible to assess the pain experienced by a child through observation and analysis of vital parameters (e.g. crying, pressure, breathing) (Verhagen, Sauer, 2005, p. 959). It is obvious that children can feel pain and sometimes it causes terrible suffering. Moreover, not every pain is treatable and the only way to stop it is to make a decision about ending a child's life. That is why it is so important to follow the guidelines of the Protocol (Sauer, Verhagen, 2012, p. 295; Tedesco, 2017, p. 255). The aim of the Protocol is to protect children who have the prospect of a future life full of suffering and then a long and painful agony. In certain situations, death is the only option for reducing suffering (Manninen, 2006, pp. 645–646).

However, as with quality of life, the assessment of suffering comes from third parties. In fact, when parents ask for their child's life to be shortened, they talk about their suffering and their sense of hopelessness. For example, neuromuscular blockers (NMB) are administered when artificial ventilation is disconnected. Parents do not want to witness the child's agonal respiration

and ask for NMB. Then whose suffering is at stake? Do they assess their own situation or do they consider what is in the best interests of their child? (Verhagen, 2014, p. 297; Voultsov, Chatzinikolau, 2014, pp. 197, 199).

Opponents of the Groningen Protocol claim that suffering is a psychological phenomenon, and in the case of very young children, we can only talk about the physical symptoms that are observed. An assessment carried out in this way cannot be effective. It is impossible to estimate what unbearable suffering is and as such it cannot be accepted as a premise in the argument justifying medically assisted termination of life (Chervenak, McCullough, Arabian, 2006, p. 32). For example, children with *spina bifida* (and precisely 21 out of 22 registered cases of “neonatal euthanasia” were affected by this disease before the entry into force of the Protocol) do not suffer from chronic pain, and as a result, most people affected are able to lead a normal life (Kon, 2007, p. 458; Chervenak, McCullough, Arabian, 2006, p. 31).

Why, then, was a controversial category included in the Protocol as one of the key criteria for justifying the use of “neonatal euthanasia”? According to Serge Van den Eijden and Dana Martinovici, it happened because in the Netherlands euthanasia of adults was accepted and legalized. In the law, one of the prerequisites for medically assisted death is that the patient suffers unbearable suffering. This premise has been explicitly transferred to the Protocol from the norms of the Termination of Life on *Request and Assisted Suicide (Review Procedures) Act* for adults who can evaluate their suffering both physically and mentally and base on an assessment of their quality of life to request euthanasia or assisted suicide. Causing death becomes the only acceptable way out of a hopeless situation. However, in the case of “neonatal euthanasia” there is a projection of values and ideas about the suffering of adults. This is a very weak and even inadequate reference to the real state of the child. Therefore, it is very difficult to translate the premise of unbearable suffering into the situation of neonatal patients and to make it legally binding (Eijden, Martinovici, 2013, pp. 76–77).

Indeed, the Groningen Protocol according to its opponents, proposes the abolition of suffering through the acceptance of infanticide, which is incompatible with medical ethics (Kodish, 2008, p. 893). Response to the suffering in children is love and sympathy. If it is not possible to restore health, hospital and hospice care and support for patients staying at home should be provided. Nowadays, medicine provides a lot of tools for pain relief. It is palliative care that should serve the purpose of reducing or

eliminating suffering, not the consent to killing (Vizcarrondo, 2014, p. 391 and Jotkowitz, Glick, 2006, p. 158).

The problem of autonomy

As mentioned earlier, the most important argument used in the debate on the legalization of medically assisted death in adults – autonomy – cannot be raised in the discussion on the admissibility of the solutions proposed by the Protocol. In the case of very young children who cannot make and communicate their decisions, it is up to someone else to decide (cf. Kon, 2007, p. 455; Kon, 2008, pp. 27–28 and Gusendheit, Steinberg, Blazer, Jotkowitz, 2009, p. 6).

In the past, the decision on the fate of a newborn child with a genetic defect, incurable disease or disability was made by a doctor or a midwife, especially if the birth took place at home. Today, parents are involved in the decision-making process (Warnock, Macdonald, 2008, pp. 42–43). For example, in the Netherlands they decide on the fate of their child, in the UK their vote is co-decisive, and in the event of a dispute between parents and doctors, the final decision is taken by the court. In France, doctors decide who do not have to take into account the opinions of parents. The principle is to avoid a therapy that is too burdensome for the patient and does not bring him benefits and irrational obstinacy (Cuttin et al., 2009, pp. 23–24; Voultsov, Chatz Nikolau, 2014, p. 200)

In the case of the procedures laid down in the Groningen Protocol, the fate of the child shall be decided by the parents. Initially, their decision was referred to in the Protocol as *informed consent*, but this term can be used only if it is a patient herself/himself, who makes her/his own decisions. In such a situation, it is only possible to speak of surrogate decisions on behalf of the child or simply *permission*. The parents in this case act as his/her trustees, whose task is to protect the best interests of the child (Verhagen, Sauer, 2005, p. 960; Vizcarrondo, 2014, pp. 389–390; Chervenak, McCullough, Arabian, 2008, p. 203; Chervenak, McCullough, Arabian, 2006, p. 30; van der Westhuizen, 2017, p. 219).

The solutions adopted in the Protocol provide for a double authorization of this interest: a reasonable assessment of doctors who act as experts on the one hand, and parents who agree to the procedures laid down in the

Protocol on the other hand could be regarded as safeguards to protect the interest of the child. A prerequisite for this is that there is an agreement and unanimity between the two parties, as the child cannot speak for himself or herself. This solution, according to its supporters, is characterized by great caution and balance. The intentional causing of death procedure allowed by the Protocol applies only to exceptional cases where medicine has nothing else to offer. The Groningen Protocol remains consistent with the interests of the child in a situation where death remains tragic but the only choice. Such a construction is as acceptable as possible. There is nothing special about this since decisions to end therapy are made on the same basis and are acceptable. Therefore, why not accept the intentional causing of death, in both cases the ending is the same – the termination of a child's life (Tedesco, 2017, pp. 253–256). It should be up to parents to resolve the conflict between alleviating suffering and prolonging a child's life, as they bear the burden of care and upbringing. Their opinion should be final. It should be added that if the parents do not agree with the doctors' assessment and want to continue the treatment, their will is respected (Sauer, Verhagen, 2012, p. 292; Lindemaan, Verkerk, 2008, pp. 49–50).

Opponents of such a solution claim that since consent is a key element in the dispute over the admissibility of medically assisted death, it is doubtful whether parental consent can replace the child's consent. In this case the reference to the concept of *informed consent* is dangerous and vague. Children are not the property of their parents. After all, they can make a decision being terrified or at least afraid, that they will not be able to bear the burden of caring for a seriously ill child, and they are also influenced by the opinion of doctors. It is therefore necessary to protect those who are the weakest and who cannot speak for themselves. And therefore the Protocol should be rejected, it may not become a part of the paediatric practice (Chervenak, McCullough, Arabian, 2006, p. 32; Kodish, 2008, p. 893; Voultsov, Chatzinikolaou, 2014, p. 200; Chervenak, McCullough, Arabian, 2009, p. 202; Jotkowitz, Glick, 2006 p. 157).

Groningen Protocol and medical ethics

According to its critics, the Groningen Protocol is a violation of one of the fundamental principles of medical ethics, which is not to harm the

patient. The provisions of the Protocol are, in fact, an acceptance of the active ending of the lives of seriously ill children. It contradicts the Hippocratic Oath. The deliberate termination of life (“neonatal euthanasia”) may not become a determinant of a good medical practice (cf. Gusendheit, Steinberg, Blazer, Jotkowitz, 2009, p. 7 and Voultsos, Chatzinikolaou, 2014, p. 200). The role of the doctor is to protect and prolong life, and when it is impossible to do so, to minimize suffering, but never to kill the patient. We have a duty to care for the chronically ill and incurable patients (Kon, 2007, p. 456 and Jotkowitz, Glick, Gesundheit, 2008, pp. 25–26). We need an absolute ban on the deliberate shortening of life in incompetent people. The protection of the weakest should become the rule in this case (Kodish, 2008, p. 893).

In Belgium, despite the amendment of the Belgian Act on Euthanasia, in which the minimum age limit from which the child may express its request to shorten life was legally deleted, it is still forbidden to intentionally shorten the life of infants.

According to a representative of the American hospice movement, Brian S. Carter, it is important that medical art and related technology are used for the benefit of patients, including children with congenital malformations. Even in such a complicated situation as the decision on the fate of an incurably ill child, it is impossible to take the shortcut of reducing suffering by deliberately shortening the life of the patient. If this life is never perfect can you just get rid of it? Why does life, even in the cases listed in the Protocol, not deserve to be protected and preserved? Hospice care is proposed as an alternative to the provisions of the Protocol where treatment cannot be offered but it is possible to minimize suffering and to surround the child and its family with kindness and compassion (Carter, 2016, pp. 5–7).

It should be remembered that in discussions on the provisions of the Groningen Protocol, the decisions taken by doctors working with terminally ill children determine the direction of evolution of contemporary European civilization and are an important voice in the dispute over the attitude of society towards the weakest and most vulnerable individuals. For ethical considerations, clinical and legal decision-making, it is important to make clear distinctions between:

- life prolonging treatment when there is a real chance of a cure or remission (intensive therapy),
- life prolonging treatment when the chance of a cure or remission is negligible (persistent therapy),

- withdrawal from life prolonging treatment and deciding on palliative care, when the chance of cure is negligible,
- purposeful ending of life motivated by compassion.

According to the critics of the Protocol, withholding therapy or withdrawing from therapy when the benefits for the patient are negligible is morally justified. The right way to deal with this situation is to use palliative care and provide comfort in the last period of life. This makes it possible to avoid extremes: on the one hand to deliberately accelerate death (“neonatal euthanasia”) and on the other hand to use aggressive and burdensome treatment (persistent therapy). It is in accordance with both the doctor’s duties to provide the relief of suffering and the prohibition of intentional hastening of the patient’s death. The attitude of the physician is aimed at providing palliative care and decent dying conditions for sick children (Dangel, 2011, pp. 54, 59–60).

The solution, proposed by opponents of the Protocol, permits to avoid the conflict of duties pointed out by the Dutch courts in the Prins and Kadijk cases, where the relief of a seriously ill patient’s suffering is burdened with the risk of shortening his/her life. Palliative care permits to avoid taking shortcuts in form of “neonatal euthanasia”. However, it should be widely available to all those in need.

Conclusions

It should be noted that the provisions contained in the Protocol are not binding legal norms. These are merely the guidelines to help doctors make decisions in specific and difficult cases. However, there is a detailed procedure for documenting and verifying doctors’ activities. So far, the Dutch legislator has not decided to legalize the procedures ending life in neonatology.

The Groningen Protocol was created to make decisions to shorten life of children with serious defects, and whose suffering and pain cannot be reduced in any other way more transparent. Its supporters claim that the Dutch experience is not unique, but what is unique, is the open discussion held on the subject in the Netherlands for more than 20 years (Verhagen, de Vries, 2008, p. 29; Sauer, Verhagen, 2012, pp. 299–300; Verhagen, 2013, p. 294). The provisions of the Protocol have become a guide for doctors. Clear rules have been established for end-of-life decisions: such as withholding

therapy, withdrawing from therapy and the most controversial deliberate termination of life in terminally ill newborn children.

Supporters of the solutions contained in the Protocol stress that “neonatal euthanasia” is a fact and it is practised in many European countries despite the formal prohibition and lack of social acceptance. In the Netherlands, the deliberate causing of death can only be tolerated in exceptional cases if palliative care is not effective and the only way to alleviate the suffering of a seriously ill child is to terminate his or her life. The Protocol sets out very strict criteria to be used as the last and only option in such cases (Sauer, Verhagen, 2012, p. 299; Francis, 2016, pp. 10, 15). It has nothing to do with eugenic practices and it is used in cases where medicine cannot do anything more for the patient. The only goal is that the child does not suffer any more. This is considered more humane than withholding or withdrawing from treatment (Manninen, 2006, p. 651; Sauer, Verhagen, 2012, p. 297). It should be emphasized that the procedures of the Groningen Protocol, involving deliberate causing of death, are intended only for extreme and rare cases. The primary objective of medical action remains the well-being of the patient when nothing more can be proposed than the maintenance of biological life. Therefore, opponents’ objections cannot apply (Tedesco, 2017, pp. 256–258; van der Westhuizen, 2017, p. 223). The way the Groningen Protocol has been practised so far and the small number of reported cases show that the procedures developed in the Protocol do not constitute a general consent to killing, therefore no slippery slope phenomenon has been proven (Verhagen, 2013, pp. 294–295 and Tedesco, 2017, p. 256). On the contrary, it is claimed that the Protocol should be considered a safeguard against the uncontrolled and unjustified euthanasia of young children (van der Westhuizen, 2017, p. 219).

Opponents of the Groningen Protocol, on the other hand, call for its complete rejection as the one contrary to the principle of non-harming present in all codes of medical ethics, while postulating at the same time a ban on deliberate shortening of life (“neonatal euthanasia”) in neonatology (Gusendheit, Steinberg, Blazer, Jotkowitz, 2009, pp. 7, 9). In their opinion it is the duty of society to care for children, and the provisions of the Protocol contradict this obligation (Kodish, 2008, p. 892).

The transparency of the practice of terminating life in newborn children, which is referred to by the authors of the Protocol, does not mean that

it is ethical (Chervenak, McCullough, Arabian, 2009, p. 204; cf. Voultsov, Chatzinikolaou, 2014, p. 201).

The low number of cases reported to the Commission also raises legitimate doubts. This does not mean that there are fewer procedures associated with deliberate termination of life. They could be treated as a part of palliative care and documented as, e.g. lethal analgesia (administration of morphine) or withdrawing from therapy (cf. Verhagen, 2013, p. 294; Francis, 2016, p. 10). It means that there is a justified doubt about the reliability of reports and the actual number of cases of deliberate shortening of life. Therefore, it gives rise to a suspicion of intentional causing of death of children that exceeds the criteria laid down in the Protocol.

According to some critics, the Protocol is, by definition, crossing the border between allowing people to die and actively causing death, and thus it is the next step (after the legalization of euthanasia and assisted suicide in adults in the Netherlands) towards allowing the killing of vulnerable and unable to make decisions people such as newborn children (Jotkowitz, Glick, 2006, pp. 157–158).

It should be stressed that there is no clear limit when a seriously ill person's life can be ended and when it is unacceptable. The Groningen Protocol is a very radical solution, as it applies to people who are not terminally ill.

The arguments in favor of legalizing the deliberate causing of death in children refer to the principle of respect for autonomy as in the case of adults, whereas in the case of newborns this principle cannot be applied. It is also a misunderstanding to categorize children according to their expected quality of life, because it is based only on the ideas of the doctors or the parents of the children. This is clearly not enough to accept its provisions (cf. Kon, 2007, p. 458; Lindemaan, Verkerk, 2008, p. 46; Barry, 2010, p. 413; Dangel, 2011, p. 54).

Legalizing the provisions of the Protocol could in fact mean a “up-heaval” in the legal system, undermining the fundamental human right to life (as expressed in constitutional law and international law at both regional and universal levels). In fact, it would be the legalization of a murder in the form of medically assisted death. It should be remembered that in the continental and Anglo-Saxon legal culture, a child at birth acquires the ability to be a subject of rights and obligations (although the decisions on its behalf will be made by parents or guardians), and therefore the decision to terminate its life is, by law, something other than abortion. In some cases,

the homicide of a child as someone who is vulnerable could be treated more severely by the courts than the murder of an adult. That is why it is so important to distinguish between withdrawing from therapy and the deliberate termination of life.

In the case of applications of the Protocol, the doubts are all the greater because the previous practice shows that the diseases suffered by the patients under the procedure were not terminal (*spina bifida* and *epidermolysis bullosa*) and the patients could have survived with them for many years. Taking decisions based on an assessment of the expected quality of life, which in addition is made by other people does not seem to be sufficient justification for the intended termination of life.

Even in a liberal Dutch society, at least in the nearest future, a law legalizing deliberate termination of life will not be proceeded. Nevertheless, some regulations are attempted to be carried out through the back door, as in Belgium, where there is no legal age limit for assisted death (in the Netherlands it is 12 years). It should be remembered, however, that we are talking here about consenting to the acceleration of death, which cannot be said in the case of the Protocol.

The practice itself is not new, at this point it should be reminded of the so-called therapeutic withdrawal in cases of “thalidomide children” who were born with deformed limbs. For example, in Great Britain, without asking parents for their consent, in some cases doctors made decisions in the delivery room based on the expected quality of life, which in their opinion was not worth continuing. This was done by leaving the newborn baby in a cold room to die. In some people’s opinions, this protocol is a more civilized form of such practice. A clear procedure, the need for parental consent, rapid causing of death by administering the right mix of medicines. The doubts and arguments of opponents and supporters of the deliberate termination of life (perhaps only the euphemism used so as not to talk about murder) remain the same despite the passage of time. The problem, however, remains topical all the more because it concerns the fate of terminally ill children who, depending on the decisions of others, remain ones of the weakest members of society. Doubts associated with the Protocol are very difficult to remove. According to its opponents, it should be rejected.

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Abstract

The problem of euthanasia in countries where this procedure is legal concerns patients who are capable of deciding on their own death. Consent to medically assisted acceleration of death is essential. However, the situation is different in the case of people who do not have the capacity to make decisions, such as patients who are mentally ill, mentally disabled, unaware or very young children. In the Netherlands, guidelines have been adopted for infants affected by incurable diseases, the so-called Groningen Protocol. The provisions of the Protocol concern both the resignation from therapy and active termination of life (“neonatal euthanasia”). It should be noted that this document is not a binding legal act.

Doubts arise as to whether the provisions of the Protocol are merely a permitted abandonment of resignation from therapy or a consent to homicide, which may go unpunished under liberal Dutch policy. The question remains open as to whether this is an act of mercy in the form of putting an end to the suffering of terminally ill patients or a convenient pretext for getting rid of terminally ill children under the guise of poor quality of life.