

The Groningen Protocol — Euthanasia in Severely Ill Newborns

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Of the 200,000 children born in the Netherlands every year, about 1000 die during the first year of life. For approximately 600 of these infants, death is preceded by a medical decision regarding the end of life. Discussions about the initiation and continuation of treatment in newborns with serious medical conditions are one of the most difficult aspects of pediatric practice. Although technological developments have provided tools for dealing with many consequences of congenital anomalies and premature birth, decisions regarding when to start and when to withhold treatment in individual cases remain very difficult to make. Even more difficult are the decisions regarding newborns who have serious disorders or deformities associated with suffering that cannot be alleviated and for whom there is no hope of improvement.

Suffering is a subjective feeling that cannot be measured objectively, whether in adults or in infants. But we accept that adults can indicate when their suffering is unbearable. Infants cannot express their feelings through speech, but they do so through different types of crying, movements, and reactions to feeding. Pain scales for newborns, based on changes in vital signs (blood pressure, heart rate, and breathing pattern) and observed behavior, may be used to determine the degree of discomfort and pain. Experienced caregivers and parents are able to evaluate the degree of suffering in a newborn, as well as the degree of relief afforded by medication or other measures. In the Netherlands, euthanasia for competent persons older than 16 years of age has been legally accepted since 1985. The question under consideration now is whether deliberate life-ending procedures are also acceptable for newborns

and infants, despite the fact that these patients cannot express their own will. Or must infants with disorders associated with severe and sustained suffering be kept alive when their suffering cannot be adequately reduced?

In the Netherlands, as in all other countries, ending someone's life, except in extreme conditions, is considered murder. A life of suffering that cannot be alleviated by any means might be considered one of these extreme conditions. Legal control over euthanasia in newborns is based on physicians' own reports, followed by assessment by criminal prosecutors. To provide all the information needed for assessment and to prevent interrogations by police officers, we developed a protocol, known as the Groningen protocol, for cases in which a decision is made to actively end the life of a newborn. During the past few months, the international press has been full of blood-chilling accounts and misunderstandings concerning this protocol.

Infants and newborns for whom such end-of-life decisions might be made can be divided into three categories.¹ First, there are infants with no chance of survival. This group consists of infants who will die soon after birth, despite optimal care with the most current methods available locally. These infants have severe underlying disease, such as lung and kidney hypoplasia.

Infants in the second group have a very poor prognosis and are dependent on intensive care. These patients may survive after a period of intensive treatment, but expectations regarding their future condition are very grim. They are infants with severe brain abnormalities or extensive organ damage caused by extreme hypoxemia. When these infants can survive beyond the period of intensive care, they have an extremely poor prognosis and a poor quality of life.

Finally, there are infants with a hopeless prognosis who experience what parents and medical ex-

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perts deem to be unbearable suffering. Although it is difficult to define in the abstract, this group includes patients who are not dependent on intensive medical treatment but for whom a very poor quality of life, associated with sustained suffering, is predicted. For example, a child with the most serious form of spina bifida will have an extremely poor quality of life, even after many operations. This group also includes infants who have survived thanks to intensive care but for whom it becomes clear after intensive treatment has been completed that the quality of life will be very poor and for whom there is no hope of improvement.

Deciding not to initiate or to withdraw life-prolonging treatment in newborns with no chance of survival is considered good practice for physicians in Europe and is acceptable for physicians in the United States. Most such infants die immediately after treatment has been discontinued.

Neonatologists in the Netherlands and the majority of neonatologists in Europe are convinced that intensive care treatment is not a goal in itself. Its aim is not only survival of the infant, but also an acceptable quality of life. Forgoing or not initiating life-sustaining treatment in children in the second group is acceptable to these neonatologists if both the medical team and the parents are convinced that treatment is not in the best interest of the child because the outlook is extremely poor.

Confronted with a patient in the third category, it is vital for the medical team to have as accurate a prognosis as possible and to discuss it with the parents. All possible measures must be taken to alleviate severe pain and discomfort. There are, however, circumstances in which, despite all measures taken, suffering cannot be relieved and no improvement can be expected. When both the parents and the physicians are convinced that there is an extremely poor prognosis, they may concur that death would be more humane than continued life. Under similar conditions, a person in the Netherlands who is older than 16 years of age can ask for euthanasia. Newborns, however, cannot ask for euthanasia, and such a request by parents, acting as the representatives of their child, is invalid under Dutch law. Does this mean that euthanasia in a newborn is always prohibited? We are convinced that life-ending measures can be acceptable in these cases under very strict conditions: the parents must agree fully, on the basis of a thorough explanation of the condition and prognosis; a team of physicians, including at

Table 1. Considerations Used to Support the Decision to End the Life of a Newborn in 22 Cases.*

Consideration	No. of Cases (%)
Extremely poor quality of life (suffering) in terms of functional disability, pain, discomfort, poor prognosis, and hopelessness	22 (100)
Predicted lack of self-sufficiency	22 (100)
Predicted inability to communicate	18 (82)
Expected hospital dependency	17 (77)
Long life expectancy†	13 (59)

* Data are from Verhagen et al.³

† The burden of other considerations is greater when the life expectancy is long in a patient who is suffering.

least one who is not directly involved in the care of the patient, must agree; and the condition and prognosis must be very well defined. After the decision has been made and the child has died, an outside legal body should determine whether the decision was justified and all necessary procedures have been followed.

A national survey of neonatologists in the Netherlands has shown that each year there are 15 to 20 cases of euthanasia in newborn infants who would be categorized in the third group.² According to Dutch law, it is a doctor's duty to file a death certificate when a patient has died from natural causes. If a death is due to euthanasia, it cannot be certified as "natural." The doctor must inform the coroner, who inspects the body and, in turn, informs the district attorney, whose office reviews each case in light of the applicable laws or jurisprudence. The district attorney presents the case, together with his or her own opinion, to the College of Attorneys General, whose four members manage the national public prosecution department and provisionally decide whether or not to prosecute. The final decision is made by the minister of justice.

Two court cases, decided in the mid-1990s, regarding euthanasia in infants in the Netherlands provide some guidance for both judges and physicians. In the first case, a physician ended the life of a newborn who had an extreme form of spina bifida. In the second case, a physician ended the life of a newborn who had trisomy 13. Both cases involved a very limited life expectancy and extreme suffering that could not be alleviated. In their verdicts, the courts approved the procedures as meeting the re-

Table 2. 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	

quirements for good medical practice. Although these rulings have given some guidance, many organizations have repeatedly pleaded for clearer guidelines, arguing that a committee with multidisciplinary

(medical, legal, and ethical) expertise would be more capable than judges of assessing such cases. Physicians would be expected to be much more willing to report procedures to such a committee than they are to report to a district attorney. The Dutch government, however, has neither created a committee nor offered other guidance, despite having promised repeatedly, since 1997, to do so.

Twenty-two cases of euthanasia in newborns have been reported to district attorneys' offices in the Netherlands during the past seven years. Recently, we were allowed to review these cases.³ They all involved infants with very severe forms of spina bifida. In most cases (17 of the 22), a multidisciplinary spina bifida team was consulted. In the remaining five cases, at least two other independent medical experts were consulted. The physicians based their decisions on the presence of severe suffering without hope of improvement (see Table 1). The decisions were always made in collaboration with, and were fully approved by, both parents. The prosecutor used four criteria to assess each case: the presence of hopeless and unbearable suffering and a very poor quality of life, parental consent, consultation with an independent physician and his or her agreement with the treating physicians, and the carrying out of the procedure in accordance with the accepted medical standard. The conclusion in all 22 cases was that the requirements of careful practice were fulfilled. None of the physicians were prosecuted.

Given that the national survey indicated that such procedures are performed in 15 to 20 newborns per year, the fact that an average of three cases were reported annually suggests that most cases are simply not being reported. We believe that all cases must be reported if the country is to prevent uncontrolled and unjustified euthanasia and if we are to discuss the issue publicly and thus further develop norms regarding euthanasia in newborns. With that aim, we developed a protocol in 2002, in close collaboration with a district attorney. The protocol contains general guidelines and specific requirements related to the decision about euthanasia and its implementation. Five medical requirements must be fulfilled; other criteria are supportive, designed to clarify the decision and facilitate assessment (see Table 2). Following the protocol does not guarantee that the physician will not be prosecuted. Since implementing this protocol, our group has reported four cases in which we performed a deliberate life-ending pro-

cedure in a newborn. None have resulted in prosecution.

Dilemmas regarding end-of-life decisions for newborns with a very poor quality of life and presumably unbearable suffering and no hope of improvement are shared by physicians throughout the world. In the Netherlands, obligatory reporting with the aid of a protocol and subsequent assessment of euthanasia in newborns help us to clarify the decision-making process. This approach suits

our legal and social culture, but it is unclear to what extent it would be transferable to other countries.

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Tsunami in Thailand — Disaster Management in a District Hospital

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On the morning of December 26, 2004, a magnitude 9.0 earthquake occurred off the west coast of Sumatra. The tsunami that followed swept across the Indian Ocean, devastating areas of Indonesia, affecting the Indian Ocean islands, Thailand, Sri Lanka, India, Bangladesh, Myanmar, Malaysia, and parts of Africa, and resulting in more casualties than any other tsunami in recorded history. All told, as of mid-February, an estimated 214,000 people had been killed, at least 142,000 were missing, and more than 34,000 were injured.¹

In Thailand, 5395 people are confirmed dead, 2998 are missing, and 8457 have been injured.² The most severely affected provinces were Phangnga, Krabi, Phuket, and Ranong, with the greatest damage in Phangnga, on the southwest coast.² Before the tsunami, this primarily agricultural area had a population of 234,188.³ Tourism is an important source of its revenue: the province had nearly 100 hotels, many of them on or near the beach in the now-shattered resort area of Khao Lak (see photographs and map). December being peak tourist season, the resorts were full. Khao Lak is a tropical paradise with beautiful cliffs, hills, beaches, estuaries, and mangroves, but the tsunami devastated

it, turning most buildings to rubble. The fishing village of Ban Nam Khem was hit particularly hard; many of its people died, and all its houses and most of its fishing fleet were destroyed.

One of the principal referral centers for people injured in the tsunami was Takuapa Hospital, a general hospital in Phangnga with 177 beds, a 6-bed intensive care unit, 4 operating rooms, an emergency department, and medical, surgical, and pediatric wards. The staff includes 118 nurses, 5 junior doctors, 1 general surgeon, 2 orthopedic surgeons, 2 general physicians, 3 pediatricians, and 1 ophthalmologist. The hospital has four ambulances and on-site radiology, biochemistry, and microbiology laboratories. The emergency department consists of one large, open room, normally staffed by one physician, two nurses, and one assistant.

At around 10:30 a.m. on December 26, an unidentified caller informed the hospital that a large wave had swept across Ban Nam Khem, leaving many casualties. An ambulance dispatched to investigate found a large area of flooding, along with many injured or dead people. The main coastal road is a variable distance from the sea, and some areas had been spared. People who had been on higher ground when the tsunami hit were instrumental in bringing injured persons to the hospital.

As events rapidly unfolded, the staff implemented the hospital's Major Incident Policy — a protocol that had been practiced two weeks earlier, when a disaster was simulated involving 80 people injured

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