PAPER

The Groningen Protocol for newborn euthanasia; which way did the slippery slope tilt?

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ABSTRACT

In The Netherlands, neonatal euthanasia has become a legal option and the Groningen Protocol contains an approach to identify situations in which neonatal euthanasia might be appropriate. In the 5 years following the publication of the protocol, neither the prediction that this would be the first step on a slippery slope, nor the prediction of complete transparency and legal control became true. Instead, we experienced a transformation of the healthcare system after antenatal screening policy became a part of antenatal care. This resulted in increased terminations of pregnancy and less euthanasia.

INTRODUCTION

It is widely known that The Netherlands was the first country in the world to legalise euthanasia in adults. Justification is based on the patient's voluntary request (autonomy) and on the doctor's assessment of the patient's hopeless prognosis and unbearable suffering. Less well known, even among the Dutch, is the fact that in The Netherlands neonatal euthanasia for severely defective newborn babies is also legal under very narrowly defined circumstances. Although formal legal change has not yet taken place, the legal development has developed far enough to be reasonably confident about what Dutch law is on the subject.[1] One of the reasons that legal developments have come about was the strong confidence of the Dutch that legal control could and should serve as a measure of control of medical practice. Medical practice, in turn, has been partly shaped by the consistent and deeply rooted belief among Dutch doctors and the public that in sick newborns and infants not all options for treatment must always be used.[2–4] In other words, some children might be allowed to die, for example, if their prospects in life turn out very grim. Even newborn euthanasia might be permissible in such situations.

In this paper, the gradual evolvement of that concept over the last decade is described with an emphasis on the developments regarding newborn euthanasia. This description may be of particular relevance, given the recent international discussions and uproar in the media in response to a publication about post-birth abortion.[5] The authors of that paper argued that if abortion, at the parents' request, is thought to be permissible under certain circumstances, then infanticide should also be permissible under relevantly similar circumstances. As no other society has legalised abortion and newborn euthanasia under certain (strict) circumstances, the experiences of the Dutch may be of value to others and contribute to the discussion.

Basic words or descriptions such as withholding or withdrawing life-sustaining treatment, terminal care, life-ending measures, active ending of life, termination of life, neonaticide or infanticide, post-birth abortion and neonatal euthanasia are often used interchangeably, yet they convey very different meanings to clinicians, patients, families and others. Those different meanings can lead to unintentioned confusion at the bedside, among healthcare providers, in the media and in the international debate, and may result in potentially harmful consequences. Clinicians rely on words, and so consistent use of predefined terminology in highly precarious matters such as medical end-of-life decisions about severely ill newborns is very important.

In this paper, end-of-life (EoL) decisions are medical decisions with the effect or the probable effect that death is caused or hastened. They include the decision to withhold or withdraw life-sustaining treatment, the decision to administer medication with potentially life-shortening effect to alleviate pain and suffering and the decision to deliberately end the life of physiologically stable newborns with lethal drugs that otherwise would not have died. The term 'neonatal euthanasia' is used for the latter decision.

END-OF-LIFE DECISIONS IN NEWBORNS, THE SITUATION BEFORE 2005

Neonatal EoL decision-making in The Netherlands has been studied quite intensely over the last 10–15 years. Two nationwide surveys in 1995 and 2001 showed that the majority (65%) of infants younger than 12 months of age died because life-sustaining treatment was withheld or withdrawn.[6 7] The decision to do so was made for babies with an incurable disease and inevitable death in 60% of cases. In the remaining group of patients, the decision was made for quality of life reasons and concerned patients who might otherwise have lived if this treatment had not been withheld or withdrawn. Those studies also showed that in 1% of all cases, medication was administered with the explicit intention to hasten death. Based on these data, it was estimated that at least 15–20 cases of deliberate termination of life take place annually. At that time, not many details about those babies were available, except that they did not have any life-sustaining treatment(s) (LST) that could be withheld or withdrawn. Despite a legal obligation for doctors to report those cases, and the acknowledgment in two court cases that giving drugs to hasten death was sometimes the most humane

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thing to do, only three cases of neonatal euthanasia per year were actually reported and reviewed between 1997–2005.[8] We analysed those cases retrospectively and found that they all concerned babies with complex inoperable congenital malformations (mainly spina bifida) combined with other complications and/or chromosomal abnormalities.

With only 15% to 20% of the estimated number of cases being reported, the conclusion seems reasonable that the practice of neonatal euthanasia clearly existed before 2005 but it was not at all transparent.

THE GRONINGEN PROTOCOL FOR NEONATAL EUTHANASIA

Our group developed an approach to identify situations in which neonatal euthanasia might be appropriate and published the protocol for this in the *New England Journal of Medicine* in 2005.[9] This protocol, known as 'the Groningen Protocol for neonatal euthanasia' (GP), has five major criteria that make euthanasia permissible: (1) diagnosis and prognosis must be certain, (2) hopeless and unbearable suffering must be present, (3) a confirming second opinion by an independent doctor, (4) both parents give informed consent and (5) the procedure must be performed carefully, in accordance with medical standards.

The trigger for us to make the protocol, at the time, was a huge dilemma about what the best intervention would be for a baby girl with the severest type of a lethal skin disease named epidermolysis bullosa.[10 11] The disease caused excruciating pain and suffering. The parents requested euthanasia and the doctors agreed that the suffering was intolerable and hence the request understandable. The legal threat of potentially being prosecuted for murder or homicide, however, made us refuse the parents request. We transferred the patient back to the referring paediatrician. When we were notified how the baby had died 3 months later, we decided to make a protocol that would help us to choose euthanasia if that might be appropriate in future cases. In addition, we wanted the protocol to help regulate the practice of neonatal euthanasia and make it more transparent. Its publication immediately generated an international controversy[12–16] and forced doctors to analyse the differences between the existing approaches in palliative care that are common in many countries, such as withholding and withdrawing life-sustaining treatment or the administration of high doses of narcotics to relieve suffering, and the Dutch approach of actually giving lethal medication to end life.

One of the main arguments raised against the GP was the 'slippery slope' argument: the GP is a first step down a slippery slope and would lead to widely increased use of neonatal euthanasia (erosion of norms). In addition, it was argued that ending the life of a newborn is a violation of a doctor's obligation to preserve life and permitting doctors to do so will have a negative impact on how the medical profession is perceived.[17 18] Those in favour of the GP argued that the protocol allowed doctors to be openly accountable for their decisions to all members of society. The transparency of the process of reflection and action required by the GP serves as a mechanism to strengthen the patient's trust in their doctor.[12] Legalisation is an effective way to regulate end-of-life practice and make it more transparent.[1]

Most people would probably recognise that evidence for most of the 'pro' and 'con' arguments is very difficult to obtain. An important question, however, and one that we thought might be relatively easy to answer is: has either of the predictions come true? Has euthanasia for neonates increased or decreased after the implementation of the GP? Are cases reported? To answer that question we analysed the data of the two studies that reported how babies died in Dutch neonatal intensive care units (NICUs) following publication of the GP, and reviewed all reported euthanasia cases between 2001–2010.

THE SITUATION AFTER 2005: WHICH WAY DID THE SLIPPERY SLOPE TILT?

Withholding and/or withdrawing life-sustaining treatment was the mode of death in 95% of the patients dying in the NICUs.[19 20] In 60% of cases, this concerned unstable babies with an inevitable death while the remaining 40% was in stable newborns for quality of life reasons. One newborn with type II osteogenesis imperfecta was classified as neonatal euthanasia.[19] The attending doctor intentionally increased the morphine medication until death occurred after it became evident that the patient's intolerable suffering could not be relieved otherwise. They issued a certificate declaring the child's natural death. The medical team reviewed the case several weeks after the infant's death and concluded that in retrospect, their practice could best be described as deliberate ending of life. The case was not reported to the legal authorities.

Review of the reported euthanasia cases revealed that, following the GP, euthanasia had decreased from 15 to 2 cases over 5 years.[21–23] The two cases were babies with lethal epidermolysis bullosa. In spina bifida, euthanasia decreased from 15 to 0 cases. We tried to find out why this was. Starting in 2007, structural ultrasound examination at 20 weeks was offered to all pregnant women at no extra cost. Before that time, access to ultrasound screening was only available for women above 35 years of age and/or on strict medical indication. The reports published by the registry of congenital malformation and by the national registry for termination of pregnancy (TOP) showed a significant increase of TOP before the 24th week of foetuses with spina bifida after 2007 in comparison to the preceding 5 years.[24] These findings yield the conclusion that a transformation of the healthcare system (antenatal screening policy became a part of antenatal care) resulted in increased abortions and fewer incidences of euthanasia. In addition, it seems fair to conclude that the effects of the GP were totally different from those predicted by either supporters or critics.

ARE ALL CASES REPORTED?

The apparently very low reporting rate may be totally explainable by the developments in prenatal screening as stated above. However, one cannot exclude the possibility that doctors might still be hesitant to report their case after their patient died from euthanasia. Certainly, the reporting has become easier because the requirements for due practice and the legal position of the doctor have been made much clearer by the GP. In addition, the government has helped to lower the doctors' barrier to reporting by adjusting the reporting procedure in that the initial reporting would be made to a multidisciplinary committee of experts (consisting of ethicists, doctors and legal people) instead of the prosecuting office. This committee has been in place since 2007.

One of the possible reasons for the low reporting rate could be that different healthcare providers still define newborn euthanasia differently. The use of paralysing medication at the end of a newborn's life in the NICU, as described in two recent studies,[25 26] may serve as an example. Some Dutch doctors administer this medication, which is similar to the medication used for euthanasia, on parental request to stop the gasping efforts of the dying baby. They do not consider their action as euthanasia but as symptom management and part of palliative care. Those cases are never brought to the committee. Consensus among the medical profession has not yet been reached on this delicate issue, but it probably will be after the

publication of a report by the Dutch Medical Association on this subject in 2013. The report is expected to contribute to even more transparency of medical practice and more efficient legal control.

CAN EUTHANASIA EVER BE PREFERRED OVER OTHER LIFE-ENDING INTERVENTIONS?

The finding of increased abortions and less euthanasia following the introduction of prenatal screening raises the interesting question about the moral difference between euthanasia and abortion. It can be argued that for some patients, neonatal euthanasia might be preferable to second trimester termination. The level of certainty available to establish the diagnosis and prognosis, for example in babies with congenital malformations, is often much lower at 20 weeks in comparison to the situation after birth. After birth, the medical team and the parents will have much more time to plan the diagnostic procedures needed to increase the quality of the diagnosis and prognosis. More time (and more expertise) might be available to discuss with the parents about all the treatment options including the option of palliative care. If all stakeholders conclude that the prognosis is very grim, the babies condition is judged as one with sustained and intolerable suffering, and the parents request for euthanasia, why should that not be permissible as an alternative to second trimester termination? In addition, the question can be raised what the moral difference is between euthanasia and withholding feeding and hydration? This question has gained importance after the publication by Diekema *et al*[27] and the American Academy of Pediatrics (AAP) Committee on Bioethics.[27] After reviewing the medical, ethical and legal issues relevant to the withholding or withdrawing of medically provided fluids and nutrition in children, they conclude that withdrawal thereof is ethically acceptable in limited situations. The practice of withholding feeding and hydration is another example of an approach in palliative care that might need rethinking. I'd like to argue that for some patients and/or parents, neonatal euthanasia might be preferable to withholding feeding and hydration. Especially in the situation, although rare, that every hour every day of life imposes an intolerable burden on the baby and the parents. The outcome in such a situation is clear: the baby will die soon; If the parents wish to shorten that course, and organise their child's death more in the way they have envisioned it, shouldn't euthanasia be available for them?

CONCLUSIONS

In The Netherlands, neonatal euthanasia has become a legal option and the Groningen Protocol contains an approach to identify situations in which neonatal euthanasia might be appropriate. In the 5 years following the publication of the protocol, neither the prediction that this would be the first step on a slippery slope, nor the prediction of complete transparency and legal control became true. Instead, we experienced a transformation of the healthcare system after antenatal screening policy became a part of antenatal care. This resulted in increased terminations of pregnancy and fewer instances of euthanasia.

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