The Dutch model for regulating paediatric euthanasia

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INTRODUCTION

As of 1 February 1st, 2024, Dutch regulation allows euthanasia for children. The Netherlands was the first country to permit euthanasia. It was first permitted for adults, then for neonates in situations when a dying patient is suffering, and palliative treatments are ineffective, and now also for children. PediatricPaediatric euthanasia remains technically illegal but can be performed with minimal risk of prosecution under accepted criteria. The Dutch approach is different from other countries. In this viewpoint, we describe and analyse the Dutch model and suggests lessons that others can learn from the Dutch experience.

In the Netherlands, euthanasia is defined as 'the active ending of the life on request'. Euthanasia was first permitted in adults and children with a capacity of 12 years and older, then in infants and now is legal for children of 1–12 years. That initial approval reflected the beliefs of the Royal Dutch Medical Association (KNMG) that a doctor's duty to preserve life sometimes conflicts with their duty to relieve suffering. In such cases, the doctor is free to choose which duty to honour. The KNMG recognised that euthanasia should always be a last resort to be used only after other approaches to the relief of suffering had failed.

The Dutch approach to legalisation has been complex. It included public discussion, litigation, legislation, regulation and ongoing revaluation. Through this process, the Dutch ended up with a regulatory approach that is different than in other countries. Euthanasia remains technically illegal. Each case of euthanasia must be reported to regional oversight committees. Those committees then report their evaluations to a public prosecutor who has the discretion to decide whether to bring criminal charges against the doctor if his/her actions were judged by the committee as not showing due care for the patient.

This unique approach reflects the ethically controversial nature of euthanasia. It is an attempt to balance a desire to make the practice available to patients who might seek it and, at the same time, a recognition of the need for careful oversight to prevent misuse.

NEONATAL EUTHANASIA IN THE NETHERLANDS

Euthanasia was initially approved only for competent adults and children >12 years. Then, around 1995, two cases galvanised a national debate in The Netherlands about whether to legalise neonatal euthanasia. One baby had trisomy 13, the other had a severe myelomeningocele. In both cases, doctors and parents decided to give the babies lethal injections. The physicians were prosecuted and then acquitted on the grounds that they had acted 'according to scientifically and medically reasonable judgements, and in line with ethical norms'. This led to other cases of neonatal euthanasia.

Between 1997 and 2004, there were 22 reported cases of neonatal euthanasia. A review of these cases showed misunderstandings about the types of interventions that ought to be labelled 'euthanasia'. To address these misunderstandings and practice variations, Dutch doctors developed the 'Groningen Protocol', which clarified and codified criteria for euthanasia in newborns (table 1).[1]

The goal of the protocol was to standardise practice and allow both transparency and accountability. The protocol was controversial. Many doctors worldwide criticised it for vagueness, permissiveness and ableism.

Despite the criticism, the protocol was incorporated into a legal regulation in 2007. It also put in place a mechanism for formal oversight by a national review committee composed of a legal expert, an ethicist and three physicians. The committee reviewed whether each case met the protocol criteria and reported the results of their review to the public prosecutor, who could decide whether to prosecute.

To the surprise of many critics, especially those who predicted a slippery slope towards widespread euthanasia of disabled babies, the enactment of the protocol was followed by a dramatic drop in the number of neonatal euthanasia cases. Prior to the protocol, there were three to five cases per year. In the 18 years after the protocol, there were only three cases.[2]

There are different hypotheses about why cases became so rare. First, many neonatal euthanasia cases were for myelomeningocele. More widespread use of antenatal folic acid supplementation has led to a decrease in the number of babies with neural tube defects. Additionally, the Dutch healthcare system changed its protocols for antenatal screening, so more cases of myelomeningocele were diagnosed prenatally. In more severe cases, parents chose to terminate pregnancies, so there were fewer babies born with severe neural tube defects.

A second possible explanation is the rapid growth in paediatric palliative care (PPC) programmes. At the time the protocol was developed, there were no PPC programmes in the Netherlands. In 2013, the Dutch Paediatric Association (DPA) issued extensive professional guidelines for PPC services.[3] The Dutch government funded eight PPC centres and a National Centre of Expertise in Children's Palliative Care. The growth of PPC likely led to decreases in the number of cases in which babies experienced intractable suffering.

Today, neonatal euthanasia remains technically illegal, while there are accepted criteria for performing it with minimal risk of prosecution. Its use is extremely rare.[2]

Table 1 Criteria for neonatal euthanasia in the Groningen Protocol (age group 0–12 months)

1.	The suffering of the child has to be unbearable and without any prospect of improvement
2.	The physician must inform the parents about the infant's diagnosis and prognosis
3.	The parents had to agree with the decision
4.	An independent physician had to be consulted and agree with the decision
5.	Physician assistance in dying had to be provided with due care

Source: Verhagen and Sauer.[1]

CONSIDERING PAEDIATRIC EUTHANASIA

Once euthanasia was approved for adults and children >12 years and newborns, parents and physicians began to publicly question why severely ill children

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between 1 and 12 years old and their parents were denied access to similar options.

A consortium of Dutch researchers studied the ways that children died in a nationwide qualitative study. They interviewed 64 parents of 44 children with life-limiting conditions aged 1–12 years on care and decision-making. The study revealed that there were cases of intractable suffering but that such cases were rare.[4 5] In most cases, effective palliative care could relieve pain. In some cases, however, despite all that PPC had to offer, children were still suffering.

Based on such studies, and supported by the DPA, the Dutch Minister of Health started the process of developing regulations for paediatric euthanasia among children aged 1–12 years.[6] These were similar to the regulations for neonatal euthanasia, with the important exception that the regulations do not explicitly articulate criteria to determine which children will be eligible. The regulation is conceptualised from the start as a work in progress. At the outset, euthanasia will only be used as a last resort to stop intractable suffering; the consent or assent of the child will be sought whenever feasible, and doctors will be held to the standard of due care.

The Dutch approach is unique. The only other jurisdiction that permits euthanasia in children is Belgium, but only in minors with capacity (table 2).

GENERALISABLE LESSONS FROM THE DUTCH EXPERIENCE

Doctors around the world struggle with the conflict of duties that arises when a patient is dying, they are suffering and palliative treatments are ineffective. There is an inevitable moral ambiguity surrounding such cases. Philosopher John Arras summed this up, 'Ethical ambiguity pervades the issue. Most seriously impaired children should be treated, some should be allowed to die. Substantive principles are available, but their application is fraught with difficulty and danger. Although this pervasive ambiguity is difficult to live with, we can be sure that attempts to ignore it, to reduce the problem to a simple formula, will lead to an illusory and counterproductive quest for moral certainty'.[7] The Dutch take this understanding one step further and believe that some babies should be helped to die.

The unique Dutch approach has three important features. First, euthanasia remains illegal. Doctors who practice it must know and follow the guidelines. Second, by requiring reporting, it makes it easy to monitor practices and study trends. Finally, this approach did not require a change in criminal statutes, only a modified way of interpreting them. This approach balances autonomy, oversight, privacy and transparency.

Although the developments after legalising newborn euthanasia have not resulted in undesired changes in practice or widespread use, we must acknowledge the potential risks of this approach. There is the fundamental consideration that accepting paediatric euthanasia may result in accepting that the lives of disabled or severely ill children are worth less than others. There is also potential concern about the slippery slope phenomenon and that guidelines will not be strictly followed. The due care criteria that seem strict and firm at first may be changing over time and norms become eroded. This may result in an undesired practice of 'quick and easy' euthanasia instead of a well-considered palliative approach. Parents might consider euthanasia to avoid the burden of caring for a severely impaired child. Current policy provides free healthcare for children but abolishing it could create financial strain. Or, policymakers may cut funding for palliative care knowing that euthanasia is available and healthcare providers and society as a whole may become less motivated to provide good palliative care. We also acknowledge that one of the system's challenges is the post hoc review, which could cause clinicians to refrain from offering euthanasia out of fear of publicity or legal sanctions.

These potential harms are serious. Dutch society must be constantly alert for the occurrence of these harms and be ready to revise protocols if needed.

Table 2 Comparing of the regulatory approach in two countries allowing paediatric euthanasia

	Age group	Conditions	Review process
Netherlands	Adults and children with capacity >12 years	► Hopeless and unbearable suffering with no prospect of improvement and no reasonable alternative ► Patient's own request	Post hoc review of all cases by committee
	Children, 1–12 years	► Hopeless and unbearable suffering with no prospect of improvement and no reasonable alternative to treat the suffering ► Additional due care criteria being developed by medical profession (expected in 2024) ► Parental consent	Post hoc review of all cases by committee
	Newborns, 0–12 months	► Hopeless and unbearable suffering without prospects of improvement, treatments are futile and no reasonable alternative to treat the suffering ► Parental consent	Post hoc review of all cases by committee
Belgium	Adults >18 years	► Constant, unbearable physical/mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident ► Patients own request	Post hoc review of all cases by committee
	Children with capacity of discernment (no age limit)	► Medically futile condition of constant and unbearable physical suffering that cannot be alleviated and will result in death within the foreseeable future, resulting from a serious and incurable condition caused by illness or accident ► Patients own request. The child must be counselled by doctors and a psychiatrist or psychologist, and the child's decision must be approved by the parents	Post hoc review of all cases by committee

Judicial review and 15 years of safe neonatal euthanasia practice in the Netherlands are reassuring. However, new issues may arise with children aged 1–12 years. We believe the Dutch system will be able to monitor euthanasia in this age group and make adjustments as needed.

While we recognise that every culture is different, we think that the Dutch experience offers some insights into the process of regulating ethically controversial medical practices that might be useful for other countries.

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