

## ORIGINAL ARTICLE

# THE GRONINGEN PROTOCOL FOR NEONATAL EUTHANASIA - OUR PERSPECTIVE

## PROTOCOLO DE GRONINGEN PARA EUTANÁSIA NEONATAL – A NOSSA VISÃO

Daniela Alves<sup>I,II</sup>, Eva Dias-Costa<sup>II,III</sup>

### ABSTRACT

**Introduction:** The Netherlands has pioneered the implementation of recommendations and laws regulating voluntary active euthanasia. Since 2002 it has allowed active euthanasia in children aged 12 and over. The Groningen Protocol, established in 2005, introduced the possibility of ending the life of newborns who fulfill certain specific criteria. It was drafted by Verhagen and Sauer at the University Medical Centre in Groningen and was granted authorization for national implementation from the Dutch Association of Pediatric Care.

**Methods:** A literature search was conducted to analyze the Groningen Protocol and arguments supporting and opposing it.

**Results:** Seemingly competing tenets of principlism – respect for autonomy, beneficence, nonmaleficence, and justice – are invoked as core arguments both for and against the protocol. The scale hangs in the sense of opposition to the protocol, essentially because of the weight of some of the arguments presented.

**Conclusion:** From our perspective, the Groningen Protocol seems to have been built primarily to allow deliberately ending the life of a newborn baby without fear of criminal prosecution. In addition, included criteria are prone to subjectivity and may lead to abuse. The protocol's proposal to regulate a very rare practice such as the anticipation of death in a seriously ill newborn promotes acceptance of active euthanasia for those who are most vulnerable and cannot express their own will.

**Keywords:** ethics; neonatal euthanasia; Groningen Protocol

### RESUMO

**Introdução:** A Holanda tem sido pioneira na implementação de recomendações e leis que regulamentam a eutanásia ativa voluntária. Desde 2002 que permite a eutanásia ativa em crianças com idade igual ou superior a 12 anos. O Protocolo de Groningen, criado em 2005, introduziu a possibilidade de terminar a vida de recém-nascidos que preenchem determinados critérios específicos. Foi criado por Verhagen e Sauer na University Medical Centre de Groningen e recebeu autorização para implementação nacional por parte da Dutch Association of Paediatric Care.

**Métodos:** Foi efetuada uma pesquisa de literatura e subsequente análise dos argumentos a favor e contra o Protocolo de Groningen.

**Resultados:** Os princípios da bioética – respeito pela autonomia, beneficência, não maleficência e justiça – são invocados como argumentos

- I. Centro Materno Pediátrico, Centro Hospitalar Universitário de São João. 4200-319 Porto, Portugal.  
up199703364@med.up.pt
- II. Faculdade de Medicina da Universidade do Porto. 4200-319 Porto, Portugal.  
up199703364@med.up.pt; eva@upt.pt
- III. Instituto Jurídico Portucalense, Universidade Portucalense. 4200-072 Porto, Portugal.  
eva@upt.pt

principais, tanto na defesa como na oposição ao protocolo. A balança pende no sentido da oposição ao protocolo, essencialmente pelo peso dos argumentos apresentados.

**Conclusão:** O Protocolo de Groningen parece ter sido essencialmente elaborado para permitir terminar de forma deliberada a vida de um recém-nascido sem receio de acusação criminal. Além disso, os critérios para a sua ativação incluem alguma subjetividade e podem levar a uso abusivo. A proposta do protocolo de regulamentar uma prática muito rara como é a antecipação da morte num recém-nascido gravemente doente promove a aceitação da eutanásia ativa naqueles que são mais vulneráveis e incapazes de manifestar a sua vontade.

**Palavras-chave:** ética; eutanásia neonatal; Protocolo de Groningen

## INTRODUCTION

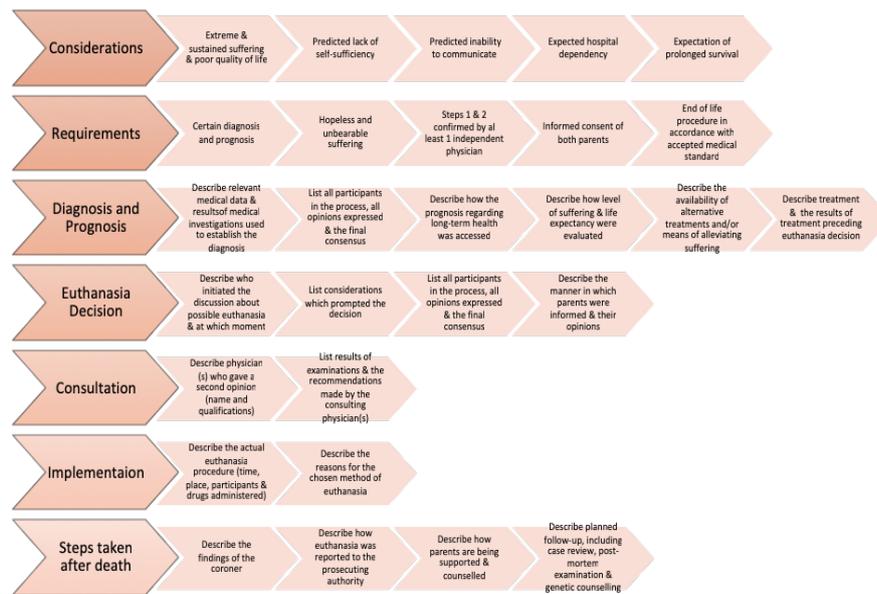
Voluntary active euthanasia is legally accepted in The Netherlands in competent adults and children over 12 years of age. In 2005, the Groningen Protocol (GP) was introduced specifying criteria to allow ending the life of newborns who were thought to endure unbearable suffering. It was created by two doctors – Verhagen and Sauer – from the University Medical Centre in Groningen in collaboration with the local prosecutor. Since then, it has been revised and supported by the Dutch Association of Pediatric Care. According to the authors, newborns for whom end-of-life decisions are considered can be divided into three groups. Group 1 encompasses infants who will die shortly despite the use of continued invasive medical technology. These are infants with an underlying disease for whom death is inevitable, although in some cases they can be kept alive for a short period of time. Children born with severe lung hypoplasia may serve as an example. In most cases, when treatment futility is apparent, ventilatory support is removed so that the child can die in the parents' arms. Group 2 consists of patients who can potentially survive, but for whom the expected quality of life after intensive care is very grim. Different groups of patients may fall into this category, such as infants with severe congenital intracranial abnormalities (e.g., holoprosencephaly) or severe acquired neurological injury (e.g., asphyxia or severe intracranial hemorrhage). Children in this category are expected to die when intensive treatment is withdrawn. Group 3 encompasses patients with a poor prognosis, who do not depend on technology for physiological stability and for whom suffering is severe, sustained, and cannot be alleviated. Such an example is children who survived thanks to advanced technology but for whom, after completion of intensive treatment, it becomes clear that life will be full of suffering and with no hope of improvement.

Retrospectively, treatment start might have been reconsidered for these children if the outcome had been previously known. Another example is children with serious congenital malformations or diseases that cannot be treated, and as a result of this condition, the child will experience sustained suffering that cannot be alleviated throughout life (e.g., epidermolysis bullosa, type Hallopeau-Siemens). Also in this group are children from group 2 who were expected to die after stopping intensive care treatment but remained alive with severe suffering.<sup>1,2</sup> Five types of consideration support the decision to end the lives of these children. The first is extreme and sustained suffering and poor quality of life regarding functional disability, pain, discomfort, poor prognosis, and hopelessness. The second is a predicted lack of self-sufficiency. The third is a predicted inability to communicate and the fourth is expected hospital dependency. The final consideration is the expectation of prolonged survival. In addition to the above-mentioned considerations, five requirements must be fulfilled in order to carry on the decision to end the patient's life.<sup>2</sup> Firstly, diagnosis and prognosis must be certain. Secondly, evidence of hopeless and unbearable suffering must exist. Thirdly, the first and second requirements must be confirmed by at least one physician not involved in the patient's care. Additionally, both parents must provide informed consent for the act. Lastly, the procedure ending the patient's life must be performed in accordance with accepted medical standards. Ultimately, the GP applies to a small and selected group of infants with a 'hopeless prognosis' who 'parents and medical experts deem to be in unbearable suffering'.

The Netherlands remains the only country to provide a legal mechanism protecting physicians who engage in deliberately ending the life of a newborn.<sup>3,6</sup>

## METHODS

An online search was performed on PubMed, Scopus, and Web of Science using the mesh terms/keywords "Groningen Protocol" AND "euthanasia" AND "ethics". After abstract reading, 33 articles were selected. The authors subsequently discussed results and elaborated a protocol diagram (**Figure 1**) and a table with arguments for and against it (**Table 1**).



**Figure 1 - The Groningen Protocol**

**Table 1 - Arguments supporting and opposing the Groningen Protocol**

Against	For
Autonomy	We make choices on behalf of children all the time
Suffering is inherently subjective	There are means to accurately assess pain and discomfort in the newborn
The right to an open future	
The international law concept of the best interest of the child does not allow for euthanasia	The ‘best interest of the child’ argument
Discrimination	The distributive justice argument
The GP violates the first, <i>do no harm</i> command	Medical specialists who do not terminate hopeless, unnecessary, and unbearable suffering of the newborn do harm
The slippery slope argument	The “slippery-slope” argument is speculative
Pediatric palliative care is preferable and better aligned with the traditional healing goals of medicine	Pediatric euthanasia and palliative care are not mutually exclusive
The Protocol allows parents and society in general to commit infanticide as a means of escaping an unwanted burden of care	Parents typically love their children
The Protocol specifically applies to infants who are not terminally ill	The Protocol is misunderstood
The Protocol’s answer to the problem of measuring “quality of life” is purely procedural	
The Protocol is a substitute for accurate preimplantation or prenatal diagnosis	The Dutch state improved prenatal screening which resulted in more second trimester abortions for congenital malformations
There is a moral distinction between withdrawing treatment and deliberately ending life	There is no relevant moral difference between abortion, withdrawing treatment, and euthanasia
	A newborn is not a person (the postnatal abortion argument)
Harm to doctors themselves and to public perception of the medical profession	The cultural, moral, and legal background argument
The sanctity of life argument	Active termination of life of newborn babies is a reality despite explicit legal prohibition

## RESULTS

Authors supporting the Groningen Protocol mainly defend that ending the life of a newborn is an act of beneficence since in their perspective a life full of suffering and lack of independence is worse than death.<sup>1</sup> In the same line of thought, authors claim that, as there is no curative therapy in these cases, maintaining life violates the principle of nonmaleficence and those who do not end the newborn's life do harm.<sup>3</sup> It is additionally stated that withdrawing or withholding life-sustaining treatment is also a form of intentionally ending life, only slower and more painful since the process of dying is prolonged.<sup>7</sup> If a critically ill newborn is predicted to have severe and irreversible impairment, it is acceptable for parents and doctors to allow one to die; according to these authors, in such cases active euthanasia brings a beneficial state of affairs sooner than passive euthanasia.<sup>8-11</sup>

Even though a newborn has no autonomy to decide for oneself, these authors claim that parents and physicians are the best child advocates and already make decisions on one's behalf in all the remaining situations.<sup>1,12</sup> In fact, parents in The Netherlands may currently request life termination for severely impaired babies, although their request does not automatically prevail. However, if doctors believe that the child's life should be ended but parents do not agree, then parents' wishes prevail.<sup>8</sup> Overall, protocol advocates believe that it adequately and subtly balances medical responsibility and parental autonomy.<sup>13</sup>

According to protocol advocates, active termination of a newborn's life is a reality despite the legal prohibition, and this should be reason enough to regulate its application since it would impose societal accountability for end-of-life decisions.<sup>13,14</sup> This way, the protocol guides physicians' deliberations by itemizing what needs to be thought about done, and at the same time allows doctors to be openly accountable for their decisions in the eyes of society.<sup>8</sup>

Authors who studied the protocol after its implementation argue that causes of death in the Neonatal Intensive Care Unit in The Netherlands remained the same before and after protocol implementation and that euthanasia for spina bifida with comorbidities actually decreased from an estimated fifteen annual cases to zero. However, this was mostly due to an increase in the use of structural ultrasound examination at 20 weeks and to an increase in pregnancy termination in cases of fetuses with spina bifida.<sup>6,15-17</sup>

The principle of equitable resource distribution requires a fair and balanced comparative assessment of all possible options.<sup>18</sup> When resources are limited, provision of lifesaving treatment to infants with limited lifespan may entail that other children or adults are denied surgical or medical treatment, or that other children with impairment are denied educational and supportive care.<sup>19</sup> The

protocol is closely related only to the Dutch legal and bioethical culture, and its approach suits the legal and social culture.<sup>5,8,20-23</sup> There is a socially shared understanding that death is not the worst event that can befall a human being and medical practice has been partly shaped by this belief.<sup>8-15</sup> The Netherlands is not a particularly litigious society, nor are its physicians as troubled by big pharma pressure, entrepreneurial conflicts of interest, and inequities in the health care delivery system that eroded the doctor-patient relationship as physicians in other countries. Trust between Dutch people and their physicians is deliberately cultivated as a socially valuable good, and transparency of the reflection and action process required by the protocol serves as a mechanism for strengthening this trust.<sup>8-15</sup>

Violation of the principle of autonomy was the main argument used by authors opposing the protocol. Autonomy is the base for allowing euthanasia in adults. However, the newborn is unable to decide for oneself. Parents and doctors, who decide in the newborn's presumed best interest, are not immune to bias.<sup>24,25</sup> Thus, the protocol may allow parents and society in general to commit infanticide as a means of escaping an unwanted burden of care.<sup>4,18,26</sup> According to authors opposing the Groningen Protocol, beneficence resides in providing standard of care and withholding or discontinuing life-sustaining treatment and engaging in palliative care in newborns with critical conditions from which they cannot recover.<sup>27,28</sup> Particularly when referring to the foundations of protocol development, cases of newborns with spina bifida are not necessarily terminally ill situations; in such cases, the protocol could even apply to babies with no risk of dying and who could live well into adulthood.<sup>8</sup> Therefore, opposing authors defend that the protocol violates the universal first, do no harm command: when medical intervention is only burdensome to the life treated, then it is contrary to the child's best interest and even harmful to the child. In such cases, medicine has reached its limits on the basis of its own reason for existing and thus should not intervene except to palliate and comfort the severely ill newborn.<sup>18,29</sup> Other authors have also pointed out that the protocol is a substitute for accurate preimplantation or prenatal diagnosis.<sup>4,24</sup> Pregnancy termination before viability when a fetal anomaly as spina bifida is present is legally permitted in most developed countries, including The Netherlands, and has strong ethical support. Making modern ultrasound screening available for all pregnant women in the Netherlands – put into effect since January 2007 – had the unsurprising effect of eliminating cases in which the protocol was applied.<sup>28,30</sup>

The criteria for including patients in the Groningen Protocol include concepts as "hopelessness", "unbearable suffering", and "quality of life". As pointed out by some authors, there is no clear scientific evaluation for these parameters.<sup>4,20,28</sup> Suffering is inherently subjective, and the extent of the child's future suffering cannot be

accurately predicted.<sup>3,8,26,27,29,31,32</sup> The child has the right to an open future and some authors do not accept that life can be maintained or terminated according to the physician's understanding of what is a life with quality.<sup>6,18,20,23,24,26,33</sup> Also, there should be no cultural exceptions regarding life taking, as the core concept of professional medical ethics, the fiduciary responsibility of physicians, is transcultural, transnational, and transreligious.<sup>28</sup>

The argument of life sanctity was also summoned up, holding that life is intrinsically valuable and thus there is no need for children to prove through experience that they deserve to live.<sup>26</sup>

## CONCLUSION

Through the analysis of arguments presented by different authors regarding the Groningen Protocol, one must conclude that the scale hangs in the sense of opposing the protocol, essentially due to the weight of some of the arguments presented. Although protocol authors claim that it serves the child's best interest, the fact that it was mostly developed based on the particular case of newborns with spina bifida makes the protocol questionable. The attempt to regulate the extremely rare practice of anticipating the death of a seriously ill newborn promotes the acceptance of active euthanasia for those who are most vulnerable and cannot express their own will. Instead, efforts should be put into increasing and improving human and technical resources in prenatal and palliative settings. Although in particular cases a moral distinction between withdrawing life-saving interventions and active euthanasia may be non-existent, the risks of having such a protocol are too high. Best intentions greatly differ with time, as do economic and social circumstances and, ultimately, killing should not be trivialized. The distributive justice argument is particularly dangerous and can never be used to justify voluntary euthanasia: relatives and the state must never be permitted to influence end-of-life decisions in order to escape the burden of care. The post-natal abortion argument, on the other hand, has caused legitimate outrage, but it has the merit of showing that distinction between abortion and neonatal euthanasia is not as clear as one could assume. This must be taken into account when revisiting the ethical grounds for abortion, which is naturally the opposite of the proponents' intentions. Finally, tenants of bioethics must be regarded as universal, and therefore The Netherlands cannot claim exceptionality.

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**CORRESPONDENCE TO**

Eva Dias-Costa  
Instituto Jurídico Portucalense  
Universidade Portucalense  
Rua Dr. António Bernardino de Almeida, 541/619  
4200-072 Porto  
Email: eva@upt.pt

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