

Neonatal and Infantile Euthanasia: More Exceptional Situations

NEONATAL VE İNFANTİL ÖTANAZİ: İSTİSNAİ DURUMLAR

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Abstract

Physician assisted death is a practice carried out in very special circumstances which allow an exception to the universal prohibition of killing someone. This exception is justified because it is an answer to a patient's request and his right is recognized on the decision to end his life.

But there are some situations that are even *more* exceptional because, although there is not a request from the patient, it could be possible to justify to cause his death. This discussion, related to neonatal euthanasia, is analyzed in this paper.

Key Words: Neonatal euthanasia, groningen protocol, medical ethics

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Özet

Hekim yardımlı ölüm, birini öldürmenin evrensel yasağına istisna sağlayan, çok özel koşullarda yerine getirilen bir uygulamadır. Bu istisna, hasta talebine bir yanıt olması ve yaşam sonu kararını onaylama hakkı nedeniyle savunulur.

Ancak, daha da istisnai bazı durumlarda, hastanın talebi olmadığı halde ölümüne neden olma savunulabilmektedir. Bu makalede, bu tartışma, neonatal ötanazi ile bağdaştırılarak analiz edilir.

Anahtar Kelimeler: Neonatal ötanazi, groningen protokolü, tıp etiği

Physician Assisted Death When Requested by a Patient

Euthanasia is an option to end one's life legally allowed only in the Netherlands and Belgium. By its definition, a person that suffers from an incurable illness or medical condition, which in his particular point of view, causes him to lead an undignified life, can receive assistance from his physician aiding him to have a painless death. In the United States, the state of Oregon has also recognized and defended the patients' free will to make the decision to end their lives. But in Oregon, the physicians' help consists only of providing the patients with a prescription of lethal dosage that will be taken by the patients themselves without the physician's presence or aide.

In the Netherlands and Belgium, no distinction is made between euthanasia and physician assisted suicide, neither from the legal nor the ethical point of view. The patient can choose the method which he prefers. If it is an assisted suicide, unlike Oregon, the physician must be there in case it is necessary to help the patient if any complication occurs.

In these places in which physician assisted death is allowed, certain requirements must be fulfilled: 1) The patient must make a voluntary and well-considered request; 2) the request must be based on a comprehensive knowledge of his situation; 3) the patient has intolerable suffering, physically or mentally, with no prospect of improvement; 4) there are no reasonable alternatives to treat or relieve his suffering; 5) the physician has taken a second opinion from an independent colleague. In Oregon, there is also a requirement that the patient has a life expectancy of under six months.

In the Netherlands, the law recognizes the minors' requirement, between ages 16 and 18, when parents or guardians have taken part in the decision. The law also examines the minors' requirement, between ages twelve and sixteen, when parents or guardians agree with the decision to end their lives. In Belgium, there is a discussion on a bill to extend the rights of euthanasia for minors by not imposing age limits as long as these are considered

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arbitrary. Although parents or guardians' opinions will be considered as important, they won't be able to decide for their children. The central issue to honor a minor's request will be the child judgment capacity, which must be assessed by his physician.¹

To date, there are few countries that allow physician assisted death, although there are many that are discussing the convenience of allowing it, including Mexico. Legalizing this practice has not been a factor that has increased significantly the frequency in which people ask and receive this help. It is unknown how often it is practiced where it is forbidden, but it is very likely that there are critically ill persons who would rush at the first chance they see to finish their lives as they fear they may not have another opportunity.² This situation is very different for patients that know they have for certain the physician's help to end their lives once they decide that moment has arrived. This is a condition in which the end of their lives can and will come with great peace. In the end, many of them die without needing the aide.

More Extraordinary Situations

It is understood that the law has to define very clearly the boundaries in which a particular action is allowed. Euthanasia and physician assisted suicide are legally allowed because individual autonomy is considered a central value. For this reason, these practices are excluded for those patients that are not able to express their will.

The problem is that there are people that would benefit by receiving euthanasia but are not able to ask for it. That happens with neonates and infants with very severe illnesses or incapacities which have no treatment, neither for cure, or pain relief, but cause very serious limitations that affect severely the quality of their life. In many cases, when faced with this situation, parents and physicians agree that the best option for those children would be to die. Nevertheless, doctors feel very uncomfortable in causing their death because they would be acting against the law.

For this reason, in the Netherlands there has been an intense debate focused on extending euthanasia for neonates and babies. It is important to distinguish this medical decision from others that are taken with babies that are very ill and whose lives are on hold by artificial means. In these cases, the end of life can happen as a consequence of withdrawing those treatments because this decision is considered a proper medical practice. Intensive treatment is not an aim in itself, neither is the survival, as it is always important to consider that life goes together with an acceptable quality.³

Extreme Situations

It is obvious that there are extreme suffering situations those ones that lead parents and physicians to consider death as the best option for a baby. It is the case for children that are born with the most severe form of spina bifida, for children

that are born very prematurely or with very serious congenital malformations that cause significant respiratory, renal and neurological deficiencies, as well as for babies that suffer skin diseases that can cause terrible pain.

Let us imagine how these situations can be observed by taking a closer look at them with two examples taken from infants in the Netherlands. In one of them, the physician took the decision of actively provoking the end of the child's life. This action caused him to be charged with murder. He was acquitted of all charges because in the trial it was considered that he had acted ethically after facing a conflict of duties and deciding to relieve the unbearable suffering instead of prolonging life. In the other, the physician involved abstained from provoking the death to the baby to avoid prosecution.

The first case took place in 1993 and Dr. Henk Prins participated in it. This gynecologist applied a lethal injection to a baby that had been born with a very severe form of spina bifida and hydrocephaly. These were two of the decisions related with baby Rianne's end of life. On the first day of her life, a decision was made not to operate and on the fourth day, the parents requested their child's death to the physician. In the first decision, there were five participants, including Dr. Prins: a neurologist, a neurosurgeon, a pediatrician and a pastor. They decided that the operation would have only prolonged her life without treating the symptoms and consequences of the birth defect and would have created the necessity for subsequent operations. The team took into account the extent of the brain damage that would have limited significantly the child ability to communicate, to walk, to sit by herself, to control all bodily functions and to feel any sensation in her lower extremities.⁴

The next decision was about how the baby should die. It would have been possible to give her narcotic analgesics (morphine-like drugs) to diminish the pain and that would have caused her death. But that would have prolonged her suffering and would have introduced new complications that would have created specific needs for medical decisions to treat or to not treat the new problems.

Dr. Prins applied the lethal injection once the parents requested him to do that as they didn't want to extend an ambiguous situation that implied so much suffering for their daughter.⁴

The second case was treated in Dr. Eduard Verhagen's clinic. It was about a child that was born with an unusual skin disease, *epidermolysis bullosa*, that causes blisters by simple contact, which can become infected and lead to sepsis and death. Each time a blister bursted, the baby's body remained in torment, which caused an uninterrupted crying. The parents couldn't hold their child without breaking the skin. The baby had to be bandaged and had to have his bandages changed daily, which caused the skin to

be removed so the heartbreaking crying began again. The parents decided that ending his son's life was the best for him and so they told to the doctors, who agreed that it was the only way to end the baby's suffering but they felt unable to help because they would be acting against the law. Fortunately, some days later an infection caused the child's death. After this experience, Dr Verhagen was convinced that it was necessary to face the issue related to euthanasia in babies in order to find solutions that would allow its application in an open way but with strict controls.⁵ This decision led to the Groningen protocol.

The Groningen Protocol

According to the present law in the Netherlands, a physician that accelerates a baby's death has to inform the local coroner, who determines in each case if the physician acted in accordance to appropriate ethical and medical judgment. If not, he is to be prosecuted. The Dutch Pediatric Society has called for a new approach to report a child's hastening death. It proposes that physicians could inform initially to a multidisciplinary committee (integrated by a lawyer, a physician and ethicist), just as it is done when an euthanasia is reported. This new approach would eliminate the crime lab to an action that is performed by pediatricians obeying their professional duty. It would be less threatening to follow the notification requirement, which would achieve greater transparency and supervision of what currently remains a largely secretive practice. It would also eliminate the fear that nowadays prevent some doctors from responding to a parents' request of hastening their severely ill child's death. Regrettably, in some cases, parents have felt obliged to cause their baby's death by themselves.³

Of the 200,000 children born in the Netherlands every year, about 1,000 die in the first year of life and in some 600 of these cases pediatricians take decisions to end their lives as they are babies with very severe illness or incapacities.⁸ Most of these decisions involve withholding medical treatment or instituting palliative care only, but in about 20 of these cases the physicians will actively end the child's life, at which just two or three of these cases are reported to a local coroner.⁶

In 2002, Dr. Verhagen signed a research protocol between the Groningen University Hospital clinic and the judicial authorities. The aim was to obtain information on the situations in which neonates and babies lives are actively ended, which would help to decide changes in the current law.

This protocol allows pediatricians to cause a child's death when both parents, together with the medical team, consider that the child is suffering greatly with no hope of treatment or relief and will have a very poor quality of life in the future. This research includes collecting data about diagnosis, prognosis from each baby, how the decision of ending his life was taken, the second opinion from another

colleague, the euthanasia procedure and the steps followed after the death. However, following the protocol does not guarantee that the physician will not be prosecuted.³

Since implementing the protocol, the physicians at Dr. Verhagen's clinic have reported four cases in which a deliberate ending procedure in newborns was performed. None have resulted in prosecution against the clinic or the pediatricians. Based on this experience, the Dutch Pediatric Society has agreed to adopt the protocol's guidelines and has proposed that they could also be followed by other physicians to end a child's life when they consider that is the best option for him. According to Dr Verhagen, the confirmation of the acceptability of this practice by the professional society has been an important step. "The ball is now with the politicians". They have to give the next step to extend the legal procedure that allows euthanasia in adults to be applied also with babies.⁷ It seems that the Government has taken the first steps to make the necessary law changes.⁸

Some Reflections

There are many questions to face when reflecting on active termination of life on neonates and babies.

1) Thanks to the impressive development in medical attention, nowadays children that have been born with very serious illness or incapacities, as well as those who are born very prematurely, can survive. Nevertheless, this new capacity also raises new ethical problems because surviving is not always beneficial for the child. The lives that are prolonged are often very limited and suffering ones. How can one decide in which situations this new capacity is to be applied and in which not?

Physicians (and parents informed by them) face a great uncertainty in view of the unpredictable that are those children lives. There will be some children with very severe incapacities (all those present on baby Rianne) who will live a satisfactory life, from their point of view as well as from their families. There will also be some healthy children which lives will be very distressing due to different reasons. It happens this way because there are so many factors determining the quality of life in different persons. The problem is that the convenience of prolonging one child's life will only be certain *a posteriori* and decisions have to be made *a priori*.

2) Taking decisions concerning neonates and babies is especially difficult as their situation is very different from those who are able to express their will for ending their lives (or have expressed it in the past). How can one justify ending their lives?

It is understood that it is the parents' responsibility to decide on behalf of their children and that the physician must evaluate their request, just as any physician evaluates an adult's request for euthanasia.

Poor quality of life, together with an unbearable suffering, are part of the requirements followed by physicians and parents to decide ending one child's life. In addition to the uncertainty involved in predicting about them, one must take into account that they are subjective issues. That is why Dr. Prins recommends to analyze each situation by a team, take the decision between parents and physicians, and find objective criterions. The Dutch Pediatric Society states that it is not advisable to give treatment to extend a child's life who has been born with a severe disability if: a) he will be unable to communicate, b) he will be unable to hold by himself, c) he will need permanent medical attention, d) he experiences pain.

3) Is there an ethical difference between withholding medical treatment, which consequently causes death, and actively provoking it?

I return to Dr. Prins' experience. He thinks there is not such an inherent difference and that is why he accelerated baby Riannes's death. Nor does he find a difference between giving analgesics to reduce pain (indirectly causing death) and applying a lethal injection. In each case, the most appropriate action must be decided according to the particular circumstances. This physician would consider unethical if he had acted influenced by the legal consequences instead of injecting the lethal dose to the baby if he thought this was the best for her.

As for Tristram Engelhardt concerns, he refers to "unworthy life" as a concept, according to which, in some given circumstances, to live is worse than not existing at all. Therefore, there is a responsibility to prevent the continuation of that life as there exists the human capacity to do it. This concept is applied to the life of children with illnesses or disabilities that condemn them to a painful and marginal existence. From it, it is derived the duty to not extend that kind of life if the individual can not request that help by himself. In addition, if hastening death allows to avoid suffering, active euthanasia must be allowed.⁹

4) Finally, all these decisions, should they be taken by parents and physicians behind closed doors, or must they be publicly controlled by the legal system?

This question is being analyzed in the Netherlands. Criticisms have appeared immediately. For those who are opposed to euthanasia legalization, any step taken to extend the legal requirements of this practice is considered as a proof that allowing euthanasia in specific situations leads inevitable to apply it in an abusive and indiscriminated way later.¹⁰

One has to ask if the supposed risk called "slippery slope", is not bigger when a prohibition prevents to openly discuss the medical decisions that are made to end a life. Considering the extension of the law regarding euthanasia in the Netherlands, it is not the same as allowing it to be applied indiscriminately, but to offer this help to those who would be benefited by it and are not able to request it.

A very important event contributing to approve the Groningen protocol was the visit of a local magistrate to a neonatal intensive care ward, on a normal day, in Dr. Verhagen's clinic. This judge was confronted with the difficult decisions that pediatricians are forced to take.⁵ It is important that other persons, unfamiliar to these situations, have also this kind of comprehension. People should understand that the present debate it is not just about ending life trivially, but about allowing physicians to apply euthanasia when they consider it is the best option for a child and letting them be confident when reporting that action. It may be the most important decision a pediatric team will ever make.

Recently I reflected on these questions with a friend of mine. She made me see that there was a great difference between deciding to interrupt pregnancy when a genetic diagnosis makes the parents realize that the child they expect, if to live, would have a very poor quality of life, and deciding to end one child's life once he has been born. I totally agree with her. There is a great difference: the decision is even more difficult, but that doesn't mean that it is not valid.

What motivates parents to make any of those decisions, before or after birth? We said to each other that for most of them it must be the love to their children. It is possible that some parents are moved by pure convenience, but in most cases, parents must be influenced by a large combination of reasons and feelings. Who is to judge parents' motivations? In part, it is the physician responsibility because, if to act, he must agree with parents that they have taken the best decision. On the other hand, it is a fact that in the name of love some parents decide to extend their baby's life, even if this is not in his best interests.

There are more questions than answers because as far as we analyze in depth this subject, we find more and more dilemmas. I leave them on the table hoping we could forward in this important debate.

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