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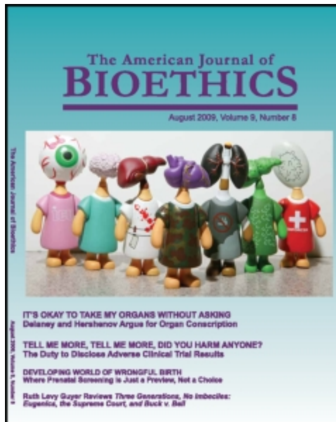

The American Journal of Bioethics
Publication details, including instructions for authors and subscription information:
http://www.informaworld.com/smpp/title~content=t713606739

A Case Against Justified Non-Voluntary Active Euthanasia (The Groningen Protocol)

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First Published on: 01 November 2008

To cite this Article Jotkowitz, Alan, Glick, S. and Gesundheit, B.(2008)'A Case Against Justified Non-Voluntary Active Euthanasia (The Groningen Protocol)',The American Journal of Bioethics,8:11,23 — 26

To link to this Article: DOI: 10.1080/15265160802513085

URL: http://dx.doi.org/10.1080/15265160802513085

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The American Journal of Bioethics, 8(11): 23–26, 2008
Copyright © Taylor & Francis Group, LLC
ISSN: 1526-5161 print / 1536-0075 online
DOI: 10.1080/15265160802513085

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Target Article

A Case Against Justified Non-Voluntary Active Euthanasia (The Groningen Protocol)

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The Groningen Protocol allows active euthanasia of severely ill newborns with unbearable suffering. Defenders of the protocol insist that the protocol refers to terminally ill infants and that quality of life should not be a factor in the decision to euthanize an infant. They also argue that there should be no ethical difference between active and passive euthanasia of these infants. However, nowhere in the protocol does it refer to terminally ill infants; on the contrary, the developers of the protocol take into account the future quality of life of the infant. We also note how the Nazi *Euthanasie Programm* started with the premise that there is some life not worthy of living. Therefore, in our opinion, the protocol violates the traditional ethical codes of physicians and the moral values of the overwhelming majority of the citizens of the world.

Keywords: autonomy, congenital abnormalities, euthanasia, disabilities, medical ethics

The Groningen Protocol for the active euthanasia (i.e., a deliberate act to end another person's life) of severely disabled suffering infants has recently been presented in a series of articles in the biomedical literature (Verhagen and Sauer 2005b; Verhagen 2006). While the protocol has attracted attention in the lay press, we are somewhat perplexed by the lack of response and debate in the bioethics community. The exception to this has been a recently published article by Manninen (2006a) justifying the protocol. As we have previously expressed our views on the protocol (Jotkowitz and Glick 2006), the purpose of this essay is to critique the arguments by Manninen (2006a) in support of the protocol and to hopefully to begin a serious discussion of the protocol in the bioethics community.

We welcome the article by Manninen (2006a) arguing the ethical case for the Groningen Protocol, which allows for non-voluntary active euthanasia of selected infants and echo her call to take a moment to remember the strength of all the families with terminally ill, impaired, or suffering infants. We feel that the protocol is certainly one of the most pressing ethical issues facing the medical community and recognize the importance of amicable and civilized debate on this issue before other countries follow the lead of the Netherlands. Notwithstanding our openness to debate on the protocol, we feel strongly that the protocol and any effort to actively euthanize infants is morally unacceptable and violates the traditional ethical codes of physicians and the moral values of the overwhelming majority of the citizens of the world. In the following discussion, we will address the points that Manninen (2006a) raised in supporting the protocol and note the reasons for our vigorous disagreement with her and the protocol.

In attacking the opponents of the protocol, Manninen (2006a) takes them to task for labeling the protocol as a "Hitleresque type of eugenics programme" (643). While some commentators in the popular press might have used similar language in condemning the protocol, respected bioethicists have addressed their serious moral concerns with the protocol without resorting to hysterical comments. It is to these ethicists that Manninen should have responded in her defense of the protocol.

Manninen (2006a) is certainly correct that, in order to morally assess the protocol, one has to study it seriously. She quotes the five criteria that make up the protocol, focusing on the first two, which state that suffering must be so severe that the infant has no prospects for a future and that there is no possibility that the infant can be cured or alleviated of the affliction with medication or surgery. She claims that this

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means that quality of life is not an issue in deciding which infants are eligible for the protocol, but that the crucial issue is that the infant is terminally ill. We have a number of problems with this interpretation. First, if that is what is meant, why not simply state that the protocol refers to terminally ill infants? One could even define what is considered terminally ill. The protocol does not refer to *terminally ill infants* but those that "have no prospects for a future" (Manninen 2006a, 644). To our mind, that terminology is very vague: What is meant by "no prospects for a future"? What kind of future? That is open to much interpretation and, perhaps, was purposefully left vague.

Manninen (2006a) herself demonstrates the inconsistencies of her argument by stating "the protocol does not make judgments on quality of life but it is rather clear that the infant in question must be terminally ill—that is, the infants must have no prospects, not an impaired prospect, for a valuable future life" (645). In the text of her claim that the protocol refers to terminally ill infants and does not address quality of life, she states that the defining characteristic of a child eligible for the protocol is not having a "valuable future life" (645). If the issue is solely life span, what does that have to do with having a valuable future life? It is obvious that there are many definitions and degrees of what constitutes a valuable life and certainly, quality of life is part of the equation. In addition, in discussing a case of a baby born with spina bifida where more than half of these infants would be expected to die, she classifies this case as being very close to terminal in nature. In our minds, "more than half" is not a definition of terminal illness, but it again appears that the overriding factor here is the poor future quality of the infant's life. No one would argue to euthanize infant car crash victims, even if more than half would be expected to die.

If the overriding factor in the Groningen Protocol is that these deformed babies are terminally ill and suffering, why not logically extend the protocol to infants or young children with other terminal illnesses, such as cancer, which, in many cases, is certainly an untreatable terminal illness. If not, is it because children with cancer somehow look more human? Finally, the developers of the protocol themselves state that the protocol is for:

> infants with a hopeless prognosis who experience what parents and medical experts 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 (Verhagen and Sauer 2005b, 960).

Therefore, their conclusion is:

> 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 helps us to clarify the decision-making process (Verhagen and Sauer 2005b, 962).

Manninen (2006a) claims that future quality of life should not play a role in infant euthanasia, but the developers of the Groningen Protocol clearly think it should. She must then disagree with the protocol she is trying to defend.

In Verhagen's (2006) detailed summary article in which he elaborates, defends and explains his protocol, the term "terminal" does not appear even a single time. In fact, he makes it unequivocally clear that the protocol refers to infants who are not terminal. He discusses three categories of infants:

1) Those who will die in spite of the most advanced technology;
2) Those who can survive only with intensive therapy and who will die when this therapy is withdrawn;
3) Those who are not dependent on intensive medical treatment and whose suffering is sustained and severe and cannot be alleviated.

The Groningen Protocol is intended specifically for the third group—the non-terminal, severely suffering infants without hope for improvement (Verhagen and Sauer 2005a).

Manninen (2006a) refers to the case of a Baby Doe born in Indiana with Down syndrome and a tracheoesophageal fistula, which could have been repaired with an operation that the parents refused. The Indiana Supreme Court let the parents' decision stand, and the infant subsequently died. Manninen criticizes the decision of the Supreme Court by stating "in passively euthanising Baby Doe, the medical staff violated his most basic welfare interest and one of the primary moral tenants of modern medicine: to do no harm" (645). We could not agree more; thus the Groningen Protocol violates on this note the moral charge: to do no harm. Manninen argues that the Groningen Protocol is ethically superior to the court decision to allow Baby Doe to die, because Baby Doe was not terminally ill; and Manninen does not see a substantive ethical difference between active and passive euthanasia. If Manninen herself condemns euthanasia in infants who are not terminally ill, why should not she also censure the protocol, which, according to its originators, was intended for non-terminal, severely suffering infants? Does not the principle of "do no harm" also apply to these infants as well?

We find it hard to defend the ethical justification for the active euthanasia of infants. As we have argued previously (Jotkowitz and Glick 2006), euthanasia in adults is based largely on the concept of human autonomy, and this principle is obviously missing when dealing with infants. Manninen (2006a) and others justify infant euthanasia by claiming that it is in the best interest of the infant. With modern methods of pain control and palliative care, it is difficult to see how this interest should override the almost universal ethical imperative prohibiting the active taking of another's life. If we begin to invoke killing individuals 'for their own good' it should not be difficult to find other instances in which one might invoke such a principle.

In addition, physicians tend to overestimate the importance of quality of life on a patient's desire to live. For

example, a survey of quadriplegic patients who were artificially ventilated indicated that most would opt for resuscitation again in the event of a cardiac arrest (Gardner et al. 1985)—a finding that is surprising to many physicians. Obviously there are substantial differences between quadriplegic patients and children with spina bifida, but nevertheless we should hesitate before dismissing the powerful will to live in many patients. Kon (2007) has argued against the protocol because of the inability of physicians and parents to assess the extent of the infant's suffering.

Manninen (2006a) recognizes this possibility and states "rather the concern is that people will be killed 'for their own good' when they are too incompetent to express their wishes: wishes that would have revealed their desire not to be euthanized. This is a very important concern, but one that I do not think the Groningen Protocol is in danger of causing, given that the subjects of euthanasia—in this case infants—possess no will to be defied (this concern would be an issue, however, if the protocol were ever expanded to include people who do have wills and preferences on the matter; for example, older children, adults, and elderly people)" (650). Such a possibility is indeed frightening and might lead to a situation in which individuals, while still competent, might have to express their desire not to be euthanized because of the danger that the protocol might be extended to patients at the other end of the age spectrum with "no will"; for example, the elderly bedridden patient with bed sores suffering from severe Alzheimer's disease, which many view as a terminal disease. At least, these patients can potentially declare their desire not to be euthanized before the dementia becomes severe.

Manninen (2006a) has great difficulty understanding an ethical distinction between passive and active euthanasia, and we recognize this difficulty from a Western secular perspective. However, many of the world's citizens have a markedly different ethical framework, which ethicists should take into account in our multicultural world. The theocentric Judeo-Christian tradition defines murder as the active taking of another person's life except in self-defense. Passive euthanasia, in contrast, is not defined as murder, and, although it is discouraged, there might be exceptions, such as in terminally ill suffering patients. In Muslim tradition, euthanasia for any reason is prohibited, and there is a warning from Mohammed against escaping hardship by taking life (Hathout 1992). Buddhism prohibits the taking of life because it is an obstacle to the attainment of Nirvana, the highest ideal (Osuntokun 1992). From these ethical perspectives, it might justified in withholding or even withdrawing care in suffering infants but active euthanasia can never be sanctioned.

The Groningen Protocol has the potential to validate the slippery-slope argument against allowing euthanasia in selected populations. Manninen (2006a) admits that this possibility worries her, but she downplays the concern because the protocol does not address quality of life issues but only terminally ill infants. As we discussed previously, this does not seem to be the position of the developers of the protocol. In addition, at present only a small number of cases of newborn euthanasia are reported to the authorities in the Netherlands (Verhagen and Sauer 2005a). One wonders if the unreported cases in the Netherlands meet the strict criteria of the protocol and if less severely ill infants have been euthanized.

To her credit, Manninen (2006b), in a follow up communication, concedes that the protocol is now being applied to infants who are not terminally ill and that she herself has difficulty justifying this application. This admission by one of the strongest defenders of the protocol only strengthens our slippery slope argument.

Furthermore, the whole notion of a protocol is disturbing to us. A detailed protocol with internal and external checks and balances tends to minimize the impact of what we feel is an ethically problematic act. We also have great difficulty with physicians alone determining the morality of their actions, in this case justifying infant euthanasia. There are too many examples throughout history of physicians and scientists who distorted morality for what they felt were the betterment of the individual or society. Given the moral complexity nature of the issue it is disturbing to note the lack of input into the protocol by nurses, social workers, psychologists, clergy, ethicists, and the lay public all of whom could give highly valued input and differing perspectives.

Finally, regarding the accusation of the Groningen Protocol as a "Hitleresque type of eugenics programme," (Manninen 2006a, 643) we agree that this comparison is out of proportion. The so-called *Euthanasie Programm* intended to 'get rid of' handicapped individuals for economic considerations and to kill people from other races for ideological reasons, whereas the proponents of the Groningen Protocol act out of mercy and compassion, acting—in their opinion—only in the best interest of their patients. Furthermore, during the *Euthanasie Programm,* people were killed without—or mostly against—the patient's or the family's consent, whereas the Groningen Protocol clearly asks for the parents' consent. Therefore, we concur that this comparison does not contribute to the understanding of the complexity of this ethical debate; and this tactless accusation is unjustified.

However, the basic concepts of the Groningen Protocol, which defines individuals with physical limitations as having "no prospects for a future" (Manninen 2006, 644) and consequently ending their life actively does reminds us of the distinction of worthy versus unworthy life (*lebenswertes und lebensunwertes Leben*). These concepts are well known in the early stages of the Nazi ideology and led ultimately within a short time to the uncontrolled killing of unworthy life. Based on this historical experience, we may be oversensitive and cannot accept the concept of individuals having "no prospects for a future," to justify active killing of suffering infants. On the slippery slope, these ethical principles might get out of control and led to the active killing of other individuals. In this context, the reference to the ideological development of German physicians during World War II should help us to identify the dangerous early change in medical attitudes, as summarized perceptively by Leo

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Alexander (1949), medical expert at the Doctors' Trials in the Nuremberg War Trial (December 9, 1946,–August 20, 1947):

> Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually, the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitable sick (Alexander 1949, 44).

This historical experience provides physicians with an absolute and infinite moral obligation to care for severely, chronically and non-rehabilitable sick individuals. Therefore, the Groningen Protocol justifying active killing presents an ethically unacceptable and dangerous attitude. We would like to encourage our colleagues in Netherlands to rethink carefully the applicability of the Groningen Protocol and also call on the international bioethical community to resist in accepting this seemingly innocent first step.

In the spirit of academic discourse, we have presented our disagreements with the Groningen Protocol and its defenders, but we are also motivated by a sense of moral outrage at what we are witnessing. In a world which seems to have lost the value of the ultimate worth of every human life and is awash with wanton killing, medicine should be at the forefront in fighting this epidemic, thereby fulfilling its traditional role of preserving not ending life. We truly sympathize with the children and their families and modern medicine should do everything in its power to lessen their suffering without resorting to euthanasia.

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