CLINICAL ETHICS

The Groningen protocol: another perspective

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The Groningen protocol allows for the euthanasia of severely ill newborns with a hopeless prognosis and unbearable suffering. We understand the impetus for such a protocol but have moral and ethical concerns with it. Advocates for euthanasia in adults have relied on the concept of human autonomy, which is lacking in the case of infants. In addition, biases can potentially influence the decision making of both parents and physicians. It is also very difficult to weigh the element of quality of life on the will to live. We feel an important line has been crossed if the international medical community consents to the active euthanasia of severely ill infants and are concerned about the extension of the policy to other at risk groups.

As practising physicians with an interest in bioethics we were disturbed after reading the article by Verhagen and Sauer on the Groningen protocol for euthanasia in severely ill newborns with a hopeless prognosis and unbearable suffering.¹ In the Netherlands all reported cases of infant euthanasia have involved patients with a severe form of spina bifida. We understand the impetus for the protocol and have no reason to doubt that the originators believe that they are acting in the best interests of the infant. We certainly empathise with the parents of these children and recognise the personal tragedy of each child born with this disease but take issue with the Groningen protocol for a number of reasons.

The primary ethical justification for active euthanasia in an adult patient with a terminal disease is the concept of human autonomy, which is the central principle of modern bioethics. A competent adult patient in the Netherlands with a terminal illness manifested by a poor quality of life has the right to end their life. In the original Dutch proposals there was an absolute insistence on initiation of the request by a competent adult. This justification by autonomy is obviously absent in the case of infant euthanasia and the procedure clearly violates the infant's autonomy. No protection or recognition is given to the human essence of the child born with severe spina bifida. The informed consent of the parents should not be adequate in the case of euthanasia. We do not allow surrogates to give informed consent for euthanasia in an adult and there are certainly cases where one must overrule the parents if they are clearly acting against the best interests of the child. In addition, there is a serious question about the quality of the informed consent of parents. The parents who agree to the decision are relying on experts to predict the future for them without having experienced it. Following a detailed checklist and documenting the discussion does not mean the parents have a true understanding of the situation. There is also the clear potential for bias in the parents' decision making because of the emotional, physical, and financial hardships they face in the long term care of a severely disabled child. This bias also extends to the state, which in addition to being charged with protecting the weak in society, is also in most instances financially responsible for

the infant's care. It is also impossible to separate the attending physician's personal ethical perspective and burden in caring for a chronically ill infant from the decision to actively terminate the child's life.

There also exists the issue of determining suffering and a poor quality of life in relation to individual patients. Physicians tend to overestimate the importance of quality of life on a patient's desire to live. A survey of quadriplegic patients who were artificially ventilated indicated—for example—that the vast majority would opt for resuscitation again in the event of a cardiac arrest²; a finding which 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.

Besides our above mentioned difficulties with the protocol, the whole idea of a protocol is distressing to us. We recognise the need for a protocol *if* euthanasia of severely ill infants is accepted, but a detailed protocol with internal and external checks and balances tends to minimise the impact of what we feel is a morally unacceptable act. We also have great difficulty with doctors alone determining the morality of their actions, in this case justifying infant euthanasia. There are too many unfortunate examples throughout history of physicians and scientists who distorted morality for what they felt was the benefit of the individual or society. Given the highly sensitive nature of the issue it is disturbing to note the lack of input into the protocol of nurses, social workers, psychologists, clergy, and ethicists, all of whom could offer highly valued input and differing perspectives. There is also no mention of public opinion and feedback from parents of children suffering with the disease.

Our main issue with the protocol is, however, a moral one. We agree that in certain situations it is reasonable and desirable to limit the level of care in these severely disabled and suffering infants: but the direct taking of human life crosses a major boundary line. Almost all civilised societies distinguish between an active act of taking another life and merely standing by and watching someone die. This distinction is recognised by most religions but is particularly felt by physicians and nurses, who have to perform the act, and who for centuries resisted the deliberate taking of human life.

When the various protocols for euthanasia in adults were first described, one of the major criticisms of them was the slippery slope argument. It was feared that any permission of active euthanasia, even under strict controls, would sooner or later lead to euthanasia of people who did not meet the rigorous criteria. The Netherlands experience bears this out fully, as exemplified by the present protocol. The history of euthanasia in the Netherlands shows that a major portion of acts of euthanasia both in adults and children are in direct violation of the guidelines promulgated at the onset of the euthanasia programme. These included: patient initiation of request; absolute voluntarism; severe suffering; consultation with another physician, and honest and full reporting to authorities. Today active consent is often not obtained and a high percentage of the cases are not reported to the

authorities. Indeed, in the article by Verhagen and Sauer,¹ they report that only a small number of cases of newborn euthanasia are reported to the authorities, indicating the extent to which Dutch physicians violate their own criteria. The report also states that forgoing or not initiating life sustaining treatment in children is acceptable to most European neonatologists. Yet a recent survey of neonatologists in European countries revealed that almost two thirds did not feel that withdrawal and withholding were identical.³ Clearly active euthanasia would be even more problematic for the overwhelming majority of European neonatologists.

Alternatives to euthanasia in the care of these infants certainly exist. Paediatric palliative care emphasises an interdisciplinary team approach to the physical, social, and psychological needs of the patient and their families, with expert management of pain and associated symptoms.⁴ This holistic philosophy of pain control, symptom management, and psychosocial support should be the standard of care for children with life threatening illnesses and resources should be provided for its implementation.

The sole criterion for ending the life of these infants is their poor quality of life. Who gave physicians the right to determine quality of life and to practise euthanasia on that basis? Infants need to be protected by society irrespective of their medical condition and not condemned to die. In many countries physicians have already abandoned the longstanding honourable medical tradition of not deliberately

terminating human life, by accepting a policy of active euthanasia in terminally ill competent adults; there is no justification for extending that policy to suffering children. In our minds the Groningen protocol is morally and ethically unacceptable and should be shunned by the international medical community.

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