

Neonatal Euthanasia: The Groningen Protocol

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ABSTRACT: For the past 30 years, voluntary euthanasia and physician assisted suicide of adult patients have been common practice in the Netherlands. Neonatal euthanasia was recently legalized in the Netherlands and the Groningen Protocol (GP) was developed to regulate the practice. Supporters claim compliance with the GP criteria makes neonatal euthanasia ethically permissible. An examination of the criteria used by the Protocol to justify the euthanasia of seriously ill neonates reveals the criteria are not based on firm moral principles. The taking of the life of a seriously ill person is not the solution to the pain and suffering of the dying process. It is the role of the medical professional to care for the ailing patient with love and compassion, always preserving the person's dignity. Neonatal euthanasia is not ethically permissible.

Euthanasia is defined as the act of intentionally ending the life of a terminally ill and suffering person in a quick and painless manner for reasons of compassion and mercy. Euthanasia was practiced by the ancients. The term means “good death,” and the practice was to allow the patient to die in peace and with dignity. For the physician, it would mean caring for the patient and alleviating pain and suffering. However, the physician of ancient times could also cause the death of the patient. One physician would heal; another would provide the poison draught to cause the death of the patient. The Oath of Hippocrates (ca. 500 BC) was the first attempt from a group of concerned physicians to establish a set of ethical principles that defined the physician as healer, rejecting the role of executioner. The principle of “*primum non nocere*,” first do no harm, from where the modern concepts of beneficence and non-maleficence are derived, became one of the guidelines in the doctor-patient relationship.^{1,2}

The current concept of euthanasia is based on the utilitarian worldview; the main principle is individual autonomy. The value of the individual is defined in terms of quality of life and contribution to society. Voluntary euthanasia is euthanasia provided for a competent person with his informed consent. Involuntary euthanasia is euthanasia performed without the person's consent.

In the Netherlands, voluntary euthanasia and physician assisted suicide have been legal since 2002. However, the courts had failed to exercise judgment on both these practices since 1984. This unofficial permission by the courts led to their widespread use by the medical community and eventually acceptance by the public. In the Netherlands, euthanasia is defined as the intentional termination of the life of a patient by an individual other than the patient at the patient's request. This definition requires active termination of the life of the patient and voluntary request by the patient.³ Involuntary euthanasia is also practiced widely. Frequently it is the Dutch physician who decides who lives and who dies.⁴

In the 1990s, end of life issues for neonates and infants became a concern for the Dutch pediatric community. A nationwide survey⁵ in 1995 showed that of 1041 deaths of children within the first year after birth, 62% of deaths were preceded by an end of life decision; in the neonatal intensive care unit (NICU) the frequency was 87%. End of life decisions were: to forego life sustaining treatment in 57%; to administer potentially life shortening drugs to treat the pain and suffering in 23%; and to give a drug to hasten death in 8%. A drug was given to cause death in 1% (15-20 cases) of neonates who were not on life sustaining treatment. The motives for this act

were no chance of survival in 76% of cases, and poor prognosis if remained alive in 18%. A repeat survey⁶ that included the years 1995 to 2001 showed similar results, with 68% of deaths preceded by end of life decisions. Most of the decisions were to withdraw or withhold life sustaining treatment. Deliberate ending of life of babies remained at 1%, or 15-20 cases yearly. An average of only 3 cases/year of neonatal euthanasia had been reported to the authorities. Obviously, most were not being reported.

These surveys showed that euthanasia of neonates and infants was common practice in the Netherlands. In 2002, the Groningen Protocol (GP) for neonatal euthanasia was developed with the intent to regulate the practice of actively ending the life of newborns and to prevent uncontrolled and unjustified killing.⁷ The GP for neonatal euthanasia proposes five criteria: (1) diagnosis and prognosis must be certain, (2) hopeless and unbearable suffering must be present, (3) diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor, (4) both parents must give informed consent, (5) the procedure must be performed in accordance with the accepted medical standard. The authors of the protocol affirm that when these criteria are met, neonatal euthanasia is ethically permissible. The Dutch supporters of neonatal euthanasia state the legal and social climate in their country is receptive to the practice of euthanasia.⁷

Data from all 10 Dutch NICUs were collected for a 12 month period (Oct 2005 through Sep 2006) to evaluate the experience with neonatal euthanasia after the GP was introduced. The most common direct cause of death was withdrawal of life saving treatment (92%); of these 58% were unstable babies with inevitable death and 42% were stable with poor future quality of life. One case of deliberate ending of life was found. The authors concluded that the deliberate ending of life in severely ill newborns may occur less frequently than previously assumed. Supporters of the GP concluded that contrary to predictions by the critics, fewer babies were being euthanized.⁸ The supporters state improved prenatal screening had resulted in more second trimester abortions for congenital malformations.⁸ The babies were being euthanized in utero.

The claim that neonatal euthanasia is ethically permissible is based on the GP criteria. Requirements one and three affirm correct diagnosis and prognosis with confirmation by an uninvolved consultant. The second requirement addresses pain and suffering. The supporters admit that suffering is not measurable, even in adults, less so in the pre-verbal child. The fourth requirement calls for both parents to give informed consent. Parents can give permission, not informed consent. Parents are expected to act in the best interest of the child. The fifth requirement states ending the child's life must occur according to the accepted medical standard. Killing babies is not within the scope of medical practice for pediatricians. The American College of Pediatricians and others believe that these criteria are not based on firm moral grounds; there is much room for parental, physician, personal, social, and economic bias.^{9,10,11}

Most of the medically stable children euthanized for presumed poor future quality of life were diagnosed with spina bifida. This condition may present a wide variety of clinical manifestations, most of which are treatable. The competent practice of medicine aspires to improve the quality of life of patients by improving health and wellbeing. It is untenable for the physician to predict poor future quality of life and practice euthanasia on the basis of this prognosis.

Supporters of neonatal euthanasia claim there is no difference between withdrawing or withholding treatment and giving lethal medication to end life.¹² If death is imminent, starting or

continuing life sustaining treatment would only prolong the death process and result in more pain and suffering for the child and his parents. In this case, it is ethically permissible to withhold or withdraw disproportionate life support technology and allow death to result as the natural consequence of the patient's illness. Withdrawing or withholding life sustaining treatment in this clinical situation is not morally equivalent to active euthanasia.

In the United States, the issue of infant euthanasia surfaced in 1982. The primary case was "Baby Doe," a newborn infant with Down Syndrome and tracheo-esophageal fistula and esophageal atresia. The parents declined surgery and the provision of nutrition and fluids and the child died as a result. In 1983, a second case "Baby Jane Doe" born with spina bifida was not treated surgically but simply with antibiotics and dressings. These cases led to the Baby Doe Amendment to the Child Abuse Law which extended the definition of child abuse/neglect to include the withholding of medically indicated treatment to children with disabilities. The law, known as the Baby Doe Rules, went into effect in 1985. The Rules stated decisions made on the basis of future quality of life of the infants were not valid and advocated mechanisms for the reporting of such practices. The Baby Doe Rules have been rarely enforced in the years since 1985. At the same time, the practice of newborn medicine has evolved dramatically. Many more neonates of increasing prematurity and complex conditions are treated successfully. Infants born with chromosomal malformations receive surgical treatment routinely in most centers.¹³

In the article, *How Infants Die in the Neonatal Intensive Care Unit*, several neonatologists and a bioethicist describe the practice in a regional referral NICU in the United States. Infants who died from 1 Jan 1999 to 31 Dec 2008 were included. The level of clinical service provided at the end of life was categorized: care withheld, withdrawn or full resuscitation. More than 80% had care withheld or withdrawn as the primary mode of death. The authors claimed the large number of withholding of care "suggests improved recognition of medical futility and the desire to provide a peaceful death."¹⁴

The ideology that places the value of the individual in terms of quality of life and contribution to society will position the neonate, especially the child with a congenital defect, in a seriously dangerous situation. Not only have these children not contributed to society but they also present a large financial liability and their quality of life is unknown. Euthanasia of newborn infants with congenital defects could be justified if one follows this ideology. This belief system underlies the proposal for the allocation of resources which is a component of the Affordable Care Act (ACA). Dr. Ezekiel Emanuel, healthcare advisor and contributor to the ACA, promotes the Complete Lives System¹⁵ for allocation of scarce medical interventions. In this proposal, he submits that resources ought to be focused on adolescents and younger adults; whereas the youngest and oldest people were to receive attenuated interventions. Newborn infants would be the least worthy to receive medical resources.

The physician is a healer. The ends of medicine are health, cure and care. When a cure is not attainable and health cannot be restored, the physician must care for his patient. It is the physician's moral obligation. Modern medicine has the tools to relieve the pain and suffering at the end of life. There are many centers in our country that offer perinatal hospice services which provide assistance and resources at the home or at the hospice center. These centers offer resources to the parent and the caregiver.¹⁶ The medical professional ought to use his or her skills to care for the ill patient with love and compassion, treating physical and emotional pain

always with respect, preserving the person's dignity. Taking the suffering person's life is not the solution to the pain and suffering that are part of the dying process.

The taking of innocent life is never a moral act. Neonatal euthanasia is not ethically permissible.

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The American College of Pediatricians is a national association of licensed physicians and healthcare professionals who specialize in the care of infants, children, and adolescents. The mission of the College is to enable all children to reach their optimal physical and emotional health and well-being.

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