

1. An introduction to the paper 'Deliberate termination of life of newborns with spina bifida, a critical reappraisal'

When discussing the possible treatment-options of newborns with congenital malformations such as spina bifida (myelomeningocele (mmc)), lots of scientific and ethical questions arise. Is starting active treatment of a newborn with spina bifida appropriate or proportional? When it is decided not to treat, what approach should then be followed? Is, in these circumstances, modern palliative treatment sufficient in dealing with possible discomfort, or should life-termination be considered as proportional in untreated cases?

Considering these questions, one has to be aware of the fact that newborns with spina bifida are not necessarily ill, let alone incurably ill, and that spina bifida is not a lethal malformation in itself, especially not so when treated actively.

By some however, it is felt that the future life of a newborn with (severe) spina bifida is incompatible with a dignified human life and that the prospects of these newborns are a life of unbearable and hopeless suffering. It is also claimed by some that the actual life of these newborns, right after birth, is already completely dominated by this unbearable suffering and that no other medical possibilities other than active life-termination will be sufficient in relieving this actual suffering.

It is only in the Netherlands that active life-termination of newborns is discussed openly, especially so since the article of Verhagen et.al. in 2005 in the leading Dutch medical journal where 22 cases of active life-termination in newborns were reported. All these 22 newborns appeared to have one single congenital malformation: spina bifida with hydrocephalus.

As a paediatric neurosurgeon however, I have treated newborns with spina bifida for more than 15 years, but I could neither recognize the claims made by Verhagen et.al. nor agree with their arguments given for life-termination.

In order to address this subject in a more scientific way, in 2005 in the Sophia's Children Hospital in Rotterdam the 'Rotterdam Prospective Study on Discomfort in Newborns with MMC' was started. I also began to study the literature and the history of treatment of newborns with spina bifida. When discussing this subject during the meeting of the International Society of Paediatric Neurosurgeons in Taipei in 2006 I was asked by the editor of *Child's Nervous System* to write an invited paper about this subject. It took me some time, but finally it appeared on the internet in October 2007 and it will be published in *Child's Nervous System* in due time. In this paper I discuss several aspects of this subject and I would like to present this text for the proceedings of the Congress in 2008.

Considering the topic of this meeting of the PAV, the needs of a (untreated) newborn with spina bifida are just the same as of all newborns, whether they are healthy or not, whether they are incurably ill or not, whether they are dying or not. Because these newborns do not 'suffer' refractory, life-termination is neither necessary nor can it be justified. I would like to conclude that in all circumstances doctors should be at the side of these newborns, not end their lives.

Rotterdam, november 2007

2. Abstract of the paper ‘Deliberate termination of life of newborns with spina bifida, a critical reappraisal’

Objects:

Deliberate termination of life of newborns (involuntary euthanasia) with meningocele (MMC) is practiced openly only in the Netherlands. ‘Unbearable and hopeless suffering’ is the single most cited criterion for this termination, together with the notion that ‘there are no other proper medical means to alleviate this suffering’. In this paper, both (and other) statements are questioned, also by putting them in a broader perspective.

Methods:

First, a historical overview of the treatment of newborns with MMC is presented, concentrating on the question of selection for treatment. Second, a thorough analysis is made of the criteria used for life termination. Third, a case of a newborn with a very severe MMC is presented as a ‘reference case’.

Conclusion:

‘Unbearable and hopeless suffering’ cannot be applied to newborns with MMC. They are not ‘terminally ill’ and do have ‘prospects of a future’. In these end-of-life decisions, ‘quality of life judgments’ should not be applied. When such a newborn is not treated, modern palliative care always will suffice in eliminating possible discomfort. There is no reason whatsoever for active life-termination of these newborns.

3. Biography of doctor de Jong (NOT a professor)

After completing his neurosurgical training in 1995 doctor de Jong was appointed as a consultant neurosurgeon in the Sophia Children's Hospital in Rotterdam, the Netherlands. During his work as a paediatric neurosurgeon he became especially interested in the treatment of newborns with spina bifida, not only in the medical aspects of this congenital malformation, but also in the moral and ethical ones.

About 5 years ago, he started to join in the national debate of active life-termination of these newborns in the Netherlands. He published several articles about this delicate and controversial subject, not only in newspapers, but also in national medical journals. In 2006 he was asked by the editor of Child's Nervous System (the official journal of the International Society of Paediatric Neurosurgeons) to write an invited article about active life-termination of newborns with spina bifida, which was published on the internet in October 2007 and will be published in Child's Nervous System in due time. This invited article is already received quite well by colleagues from all over the world and it will be used as a guideline for his presentation for the Congress.