Pieter J. J. Sauer and the members of the Working Group*

Ethical dilemmas in neonatology: recommendations of the Ethics Working Group of the CESP (Confederation of European Specialists in Paediatrics)

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Abstract Neonatal intensive care has greatly improved the survival chances of a very sick infant. At the same time, it has also given rise to serious ethical problems. In all circumstances, however, parents and paediatricians and other healthcare team workers should continuously evaluate together what is in the best interest of the infant and react accordingly. It is also clear that the principle “the best interests of the infant” can be interpreted in different ways; therefore no simple guideline is possible.

Introduction

Recently a hospital in the United States was charged and ultimately had to pay a large sum of money to a family in order to cover the costs of looking after an infant who survived the neonatal period with a serious handicap. The infant was born after a pregnancy of 23 weeks. The parents were informed before the delivery about the potentials and risk of a newborn surviving a pregnancy of 23 weeks. Based on the risks of dying and the chances of a serious severe handicap later in life when surviving, the parents indicated that they did not wish their child to be resuscitated at birth. Despite this, the doctors resuscitated the infant and put her on the ventilator. Treatment was continued despite indications obtained after birth for a very severe handicap in later life and despite the wishes of the parents to discontinue treatment. The parents took the hospital and the doctors to court because they had not given consent to treatment. They found the hospital and the doctors liable for the costs of the treatment of their child. The hospital administration as well as the physician claimed that the infant was alive at birth and therefore had the right to be treated, regardless of parental wishes. This case clearly raises a number of questions regarding neonatal intensive care:

1. Should every newborn infant be treated, regardless of its situation (gestational age, illness etc.)?
2. Have the parents the right to make the decision for the infant; what is the role of other caregivers?
3. Once a treatment is initiated, should it be continued despite indications that the infant might survive with a very severe handicap?
4. When people other than the parents are given the right to decide whether to start or continue treatment, can they be held liable for the costs of treatment and care of a severely handicapped child?

Ethical principles that pertain to each newborn infant

1. Every human individual is unique and has the right to live its own life.
2. Every human individual has its own integrity which must be acknowledged and protected.
3. Every human individual has the right to optimal treatment and care.
4. Every human individual has the right to take part in society and what society has to offer.
5. The optimal purpose of all measures and decisions should focus on the “best interests” of the patients. It is acknowledged that the definition of “best

* Working Group members are: Timothy L. Chambers, Francis P. Crawley, Denis Gill, Ronald Kurz, Maria de Lourdes Levy, Andreas Constantopoulos, Nini Smedegard Olesen, Armido Rubino, Mariti Stuines and Ma Zach

P. J. J. Sauer (✉)
Department of Paediatrics,
Beatrix Children’s Hospital,
University Hospital,
PO Box 30.001,
9700 RB Groningen,
The Netherlands

Tel.: +31-50-3612470; Fax: +31-50-3611704
e-mail: p.j.j.sauer@bkk.azg.nl

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interests” can be more difficult to establish in the newborn infant.

6. Decisions should not be influenced by personal or social views on the value of life or absence thereof by the caregivers.

7. Retardation or disability alone is not a sufficient reason to stop treatment.

8. Withholding or discontinuation of life support measures are ethically equivalent.

9. Decisions to withhold or withdraw treatment should always be accompanied by optimal palliative therapy and dignified and comforting care.

10. The opinion of parents or the responsible representatives should be included in all medical decisions. Doctors treating the sick infant first should come to the conclusion on the basis of comprehensive facts. This should then be discussed with parents in thoughtful dialogue.

11. In the case of unclear situations and controversial opinions between members of the healthcare team or between the healthcare team and parents, a second expert opinion can be helpful.

12. Every form of intentional killing should be rejected in paediatrics. However, giving medication to relieve suffering in hopeless situations which may, as a side-effect, accelerate death, can be justified.

13. Decisions must never be rushed and must always be made by the healthcare team taking into account all the available evidence.

14. All decisions have to be based on evidence as solid as possible.

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**Categories of newborns**

In order to structure this article, various groups of patients will be discussed. Each division into groups is somewhat arbitrary; however, for a clear discussion the following groups are defined here:

1. Infants who will die shortly despite optimal treatment under the present and local treatment modalities.

   *Comment:* There are newborn infants for whom death is inevitable, although they can sometimes be kept alive for a short period of time. An example of this are those born with lung hypoplasia.

2. Patients who potentially can survive with intensive care, but for whom the expectations for the way they survive are very severe.

   *Comment:* Infants in this group are extremely preterm infants or those born prematurely who after a few days show severe brain abnormalities, for instance large intraventricular bleedings with seizures.

3. Patients who can survive for some period of time with non-intensive medical treatment, but with a life in which suffering will be severe and sustained.

   *Comment:* At least two subgroups can be distinguished in this category: (a) infants born with extensive abnormalities which will prevent them from living any form of independent life and where suffering will be extensive and cannot be relieved by any means. Examples are infants with very extensive forms of spina bifida. (b) A second group consists of those infants who survived due to intensive care, but at the moment are no longer dependent on intensive care; a very severe prognosis can be made as to the way they survive. In these infants one might not have wanted to start treatment if the outcome had been known. Examples are infants surviving after extensive hypoxic ischaemic encephalopathy.

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**Moral dilemmas**

In infants a number of moral dilemmas has to be faced.

Has every human being the right to be treated?

According to the principles stated above, every human individual has the right to be treated, regardless of potential handicaps and malformations. The question, however, is whether this rule is absolute and what is meant by treatment. In general, one can state that the right to be treated is not equal to the obligation of a physician to treat all patients. When there is a right to be treated, then there is also the right to withhold treatment based on the “best interests” of the patient. Treatment can also consist merely of symptom relief. When withholding treatment, however, one should never leave a patient in a suffering, unbearable situation.

The right to refuse or withhold treatment

The conscious individual has the right to refuse or withhold treatment based on the principle of integrity of the human body. Nobody can be forced to be treated against his or her will. The question is how to apply this principle to the patient who cannot express his or her will. Should all patients be treated because their will is not known, or can parents or other caretakers make the decision for the child that (further) treatment is not in the best interest of the infant and should be stopped?

Role of parents

It is generally accepted within the European Community that the patient who can express his or her will can refuse further treatment. In some countries within the European Community, patients who endure severe suffering that cannot be relieved by other means and where death is imminent, can ask to have their life terminated.