Eur J Pediatr (2001) 160: 364–368

© Springer-Verlag 2001

ORIGINAL PAPER

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)

Received: 13 November 2000 and in revised form: 4 January 2001 / Accepted: 7 January 2001

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

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

* 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, Martti Siimes and Ma Zach

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.

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.

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 withold 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.

The infant cannot ask to have its treatment (or even its life) terminated. Does this imply that the infant always has to be treated, or can parents make the decision for their infant? Parents do have the obligation to care for their infants, but does this mean also the right of refusal of treatment?

Role of physicians

According to the Hippocratic Oath, physicians are obliged to try to keep their patients alive. The same oath, however, also sets some limits. The physician also has the obligation to prevent suffering as much as possible and to refrain from treatment when treatment cannot be regarded to be in the interest of the patient. Therefore, although the main guideline for the physician is to keep his patients alive, there can be circumstances where, looking at the best interest of the patient, he or she should refrain from treatment.

Should the projected outcome of the infant influence physicians?

A child is at the beginning of his or her life. When the projected outlook is one full of suffering or without means of communication with the environment, may or should this influence decisions? The severity of suffering and possibilities to communicate in either way are, in adults, considered to be important indicators in a decision whether or not to stop or initiate treatment. There seems to be no ethical reason why the outlook should not be taken into consideration in the case of a newborn, despite the fact that he or she cannot decide for themselves about what suffering it acceptable.

May doctors decide not to treat?

The question is whether doctors may decide not to treat an infant and let nature take its course, even when the ultimate effect will be death. As stated above, the Hippocratic Oath but also that of Maimonides, does not request treatment under all circumstances. If treatment is futile or clearly not in the interest of the patient, the job of the physician is to prevent suffering and not to prolong life.

May doctors decide to let an infant die?

Some infants are born with such extensive abnormalities that despite the most optimal treatment, the outlook will be one of severe and endless suffering. The same can be true in infants who survive due to intensive care but where a prediction as to the severity of the abnormalities can only be made when the intensive care period is over. In these patients, a life full of suffering, a suffering that cannot be ameliorated by any means, can be predicted. This is a life where the adult, given the option, might want his or her life terminated. As stated in the ethical principles, intentional killing should be rejected in infants. On the other hand, giving medication to relieve suffering which may, as a side-effect, accelerate death, can be justified.

Moral considerations

The following items can be taken into account in the prediction of the expected life of the infant

1. Projected suffering and burden.

If it can be foreseen that the life of the infant will be full of suffering and pain that cannot easily be relieved, one has to ask whether this is a life to be lived.

2. Communication with the environment.

A unique feature of a human being is its possibility to interact with its environment. If this will never be possible, an important quality of life is lost.

3. Dependence on medical care.

The option for the child to live his or her own life can be severely impaired when they are almost completely dependent on medical care for survival. This can limit the development of the infant to an inaccessible degree.

4. What is the life expectancy of the infant?

One has to balance the life expectancy against the burden of treatment. If the burden of treatment is intense and the life expectancy rather short, initiation or continuation can be questionable.

When the group of paediatricians, nurses and other caretakers treating the patient has serious doubts whether continuation of treatment is in the best interest of the patient, this should be discussed with the parents. The rights of parents regarding the decision about continuation or discontinuation are not clear. If under conditions as indicated above the parents ask the treatment to be continued, it will be done. On the other hand, if the healthcare team and parents are both convinced that continuation of treatment is not in the best interest of the infant, treatment will be discontinued; even when the ultimate result is the demise of the infant.

Role of parents

There is a difference in opinion between lawyers about the extent to which parents can make decisions. Some lawyers are of the opinion that parents have the obligation to care for their infants and that they have to care under all circumstances. Others feel that caring for can also implicate asking for discontinuation of treatment when the parents, after having been fully counselled, are of the opinion that the life of their child will be so full of

unrelieved suffering that their child's death is an act of mercy.

In the case where the parents are of the consistent opinion that treatment is not in the best interest of the child, a great responsibility lies with the physician. Under circumstances where he or she has also serious concerns about the outcome, the wish of the parents has to be acknowledged and followed. When on the other hand the paediatrician cannot agree with the request not to institute or to withhold treatment, he or she has the obligation to consult a colleague or refer the parents to a colleague. When both paediatricians are convinced that treatment should be done in the best interest of the infant, it should be done despite the wishes of the parents. In extreme cases, legal measures might have to be taken.

Application of moral principles to patient categories

In situations where infants and children will die shortly despite optimal treatment under present and local treatment modalities: (a) the paediatrician should stop further medical treatment and use all possible resources to prevent suffering and pain of the infant and of the parents; (b) the decision to stop treatment is a medical decision. The decision has to be communicated to the parents. The parents, however, cannot force the paediatrician to institute or continue a treatment when this treatment will only increase the suffering of the patient without any chance of survival.

In a situation where there is a chance that the infant or child can be kept alive using intensive care treatment, however, the outlook regarding the predicted life of the infant is one full of suffering which cannot be relieved by any measure: (a) all possible investigations have to be instigated to predict the outcome of the infant as accurately as possible; (b) when both the treatment team and the parents are convinced that, in the very best interest of the child, treatment should not be started or continued, treatment can be withheld. If, however, the parents maintain that treatment should be started or continued, it has to be done. In case the treatment is not started or discontinued, all possible methods are used to prevent unnecessary suffering of the infant.

In a situation where a patient depends on non-intensive medical treatment in order to survive but the predicted life will be one full of suffering which cannot be relieved by any means: (a) all possible investigations have to be done to predict the outcome of the infant as accurately as possible; (b) the prognosis regarding the predicted life of the infant has to be discussed by the complete team looking after the patient. The prognosis also has to be discussed with the parents; (c) parents have to be informed completely about the chances of surviving and the expected life of the infant; (c) when all agree that the infant is suffering, all possible interventions have to be used to alleviate the suffering. When suffering can only be alleviated by measures which could, as a side-effect, shorten the life of the infant. these interventions are acceptable. If the parents do not agree, a decision will have to be taken by the medical team including a second opinion, whether to override parental views. If time allows, this may be done through legal procedures. In an emergency, the team which treats the patient according to his or her perceived best interests, documents the decision making and accepts later responsibility. Relief of suffering is the paramount responsibility of doctors.

Conclusions

Despite potential differences in opinion, the following general statements can be made:

- In the event of futile treatment, the primary obligation of the paediatrician is to counsel the parents and let the patient die with minimal suffering. The decision lies primarily with the physician.
- Where a patient might survive with the help of neonatal intensive care but the outlook as to how the patient might survive is very severe, the paediatrician and parents should discuss the best interests of the infant. If both parents and physicians believe that it is in the best interests of the infant to withhold further treatment, this should be done. If the parents ask for continuation of treatment, this should be done. Paediatricians should never stop treatment against parental wishes.
- In a situation where a patient is dependent on medical treatment but the predicted life will be one full of suffering which cannot be relieved by any means. all possible interventions have to be used to alleviate the suffering. When suffering can only be alleviated by means which could, as a side-effect, shorten the life of the infant, these interventions are indicated.

Further reading

1. Berseth CL (1987) Ethical dilemmas in the neonatal intensive care unit. Mayo Clin Proc 62: 67–72
2. Brody H, Campbell ML, Faber K, Ogle KS (1997) Withdrawing intensive life-sustaining treatment. Recommendations for compassionate clinical management. N Engl J Med 336: 652–657
3. Campbell AGM (1986) Ethical problems in neonatal care. In: Roberton NRC (ed.) Textbook of neonatology, Churchill Livingstone, Edinburgh, pp 35–41
4. Cuttini M, Nadai M, Kaminski M, Handen G, De Leeuw R, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. Lancet 355: 2112–2118
5. De Leeuw R, Beaufort AJ de, Kleine MJK de, Harrewijn K van, Kollee LAA (1996) Foregoing intensive care treatment in newborn infants with extremely poor prognoses. J Pediatr 129: 661–666
6. Doyal L, Larcher VF (2000) Drafting guidelines for the withholding or withdrawing of life-sustaining treatment in critically ill children and neonates. Arch Dis Child Fetal Neonatal Ed 83: F60–F63

7. Hatherill M, Tibby SM, Sykes K, Murdoch IA (1998) Dilemmas exist in withdrawing ventilation from dying children. BMJ 317: 80
8. Jonsen AR (1977) Introduction: ethics and neonatal intensive care. Monograph Apr 15: 1–8
9. Meadow WL, Lantos J (1999) Epidemiology and ethics in the neonatal intensive care unit. Qual Manag Health Care 7: 21–31
10. Nelson RM, Shapiro RS (1995) The role of an ethics committee in resolving conflict in the neonatal intensive care unit. J Law Med Ethics 23: 27–32
11. Sauer PJJ (1992) Ethical decisions in neonatal intensive care units: the Dutch experience. Pediatrics 90: 729–732
12. Singer P (1985) Neonatal intensive care. How much, and who decides? Med J Aust 142: 335–336
13. Versluys C (1993) Ethics of neonatal care. Lancet 341: 794–795