

Neonatal ethics in ELBW

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The last ten years, the next ten years in Neonatology

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Abstract

The delivery of extremely low gestational age newborns and extremely low birth weight infants presents challenging ethical issues for caregivers and parents. Major concerns regard the high mortality and morbidity resulting in long term sequelae, the limit of viability as well as the conflict and difficulty in judgement involving “quality of life” and “sanctity of life” issues. Other paramount ethical concepts include the newborn’s best interest, the decision to initiate or withhold treatment at birth and the decision to withdraw treatment with the consequence that the infant will die.

On the basis of the ethical principles of beneficence, autonomy, justice and nonmaleficence we will discuss the best interest standards, the standard for the decision making process and treatment decisions, which should always be governed by the prospect for the individual infant.

In this paper we propose that ethical questions should not be regulated by law and the legal system should not interfere in the patient-physician relationship.

Continuous improvement in medicine over the last decades led to increased treatment possibilities, which on the other hand also resulted in more ethical dilemmas. Therefore, today more than ever, it is essential that the neonatologist becomes familiar with basic ethical concepts and their application to clinical reality.

Keywords

ELGAN, ELBW, best interest, decision making, withholding and withdrawing treatment standards, ethics.

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Introduction

The delivery of an extremely low gestational age newborn (ELGAN) involves difficult ethical issues for caregivers and parents. Decisions with respect to antenatal treatment are often complex since they affect both mother and fetus and the risks and benefits may differ strongly between each of them. Therefore, such challenging decisions should be made in collaboration with the parents and the team of perinatology after a thorough discussion including all available information [1].

According to literature it is still not clear which infant born at the threshold of viability should be resuscitated and provided neonatal intensive care. There is a considerable debate among clinicians about the limit of viability. Whereas some infants are too immature and initiating resuscitation in such cases might be futile because the risk of death or severe morbidity would be unacceptably high, other preterm infants are sufficiently mature and not initiating resuscitation would be unacceptable [2]. Since this uncertainty surrounds the decision whether to resuscitate extremely low birth weight (ELBW) infants, accurate planning and consensus between members of the perinatal team are essential. Planning enough time for consultation with the family is paramount in order to clarify all aspects.

In developed countries the survival of ELGAN and ELBW infants has considerably improved over the last three decades. The limit of “viability”, defined as birth at 24 weeks gestation, continuously shifted towards earlier gestational ages, determining also an increased risk of long term sequelae such as developmental delay and physical handicaps among survivors.

Elevated mortality and morbidity raised ethical concerns in the management of ELBW at the limit of viability in clinical practice and decision making is complex and remains challenging.

There are still many unanswered questions: which survival rate should be regarded as

sufficiently hopeful to legitimate initiation of resuscitation? Which survival rate should be regarded too poor to justify withholding of resuscitation? What kind of morbidity would be deemed as acceptable? Where is the limit between good standard of care and excessively aggressive treatment? What is the “best interest standard” for the newborn? Who should decide whether withholding or withdrawing treatment?

Ethical principles

The ethical principles proposed by Beauchamps and Childress apply also to ELBW infants [3].

The first principle, termed “beneficence”, admonishes the physician to provide a clinical management which, in evidence-based clinical judgement is reliably expected to result in a clinical condition where benefit prevails over harm for the patient.

The second principle of “autonomy” holds that individuals have the right to make decisions regarding their own medical care. Exhaustive information provided by the clinician is a prerequisite for such decisions: if the patient is a neonate the parents must become surrogates for medical decision making.

The third principle of “justice” requires care providers to make treatment decisions based on the best interest for the infant regardless of race, ethnicity or social-economic background, taking into account “proportionality” of treatment.

The fourth principle of “nonmaleficence”, without ambiguity the most important ethical principle, advises health care providers to do no harm.

Neonatologists as well as all other caregivers should solve bioethical issues and conflicts guided by these principles.

The best interest standard

The principle of “best interest” is central to medical practice. All decisions concerning medical care should reflect the best interests of the infant. Since critically ill infants are unable to articulate or advocate for their own interests, it is fundamental that societal safeguards guarantee their protection [4].

Although there is often conflict and difficulty in judgement involving “quality of life” and “sanctity of life” issues, the surrogates have to outweigh the maximum benefits and minimum harms to newborn infants as objectively as possible. This

brings some degree of objectivity into the process of determining “the best interest”. Impartiality is paramount since parents, doctors and medical staff involved in the decision making process may have different opinions and ideas about what is in the best interest of the baby. In fact, the perceptions of doctors, nurses and parents are influenced by personal values and experiences, making it difficult to define which are the right choices and processes in individual cases [5].

The ethical and legal assumption is that parents will make decisions that are in the best interest of their child. On the other hand, parental authority is not absolute and can and should be challenged when conflicting assessments of the infant’s best interest arise [6]. Therefore, if the patient cannot make informed choices, physicians have a greater obligation to assess the best interest for the patient and to advocate for this interest regardless from parental wishes [4].

The most appropriate decision should be made based on effective and transparent communication between all the participants in the decision making process. Mutual trust and tight cooperation of the team and the parents is fundamental, as well as placing the infant as much as possible in the centre of the considerations.

Decision on which standard

The *Critical care decision in fetal and neonatal medicine* report of the Nuffield Council on Bioethics [7] and the policy statement of the American Academy of Pediatrics (AAP) on *Noninitiation or withdrawal of intensive care for high risk newborns* [8] emphasize the ethical challenges clinicians face when trying to achieve the main purposes: “to save the lives of infants with treatable conditions, to minimise suffering and indignity, and to maximise the quality of life in survivors”.

In different western countries treatment decisions are based on different strategies: 1) the “statistical prognostic strategy” implies that treatment may be withheld directly at birth in newborns with very unfavourable prognosis according to a statistical estimate; 2) the “wait until certainty strategy” implies a near universal initiation of resuscitation and intensive care treatment. According to that policy, all preterm infants are treated rather aggressively until there is almost certainty of either death or irreversible coma; 3) the “individualized prognostic treatment strategy” with initiation of resuscitation in almost every infant immediately

after birth to maximum efficiency and capacity followed by regular re-evaluation of the clinical condition, response to treatment and individual prognosis with the option of withdrawing treatment in case of medical futility or a very poor prognosis [9]. Regardless of the treatment strategies the parents’ response and inputs remain an essential component in decision making within the Neonatal Intensive Care Unit [10].

Treatment decisions

On the basis of estimated prognosis there are three categories of treatment decisions for ELBW infants:

- if early death is very likely and survival would involve a high risk of unacceptably severe morbidity, intensive care is not recommended;
- if chances of survival are high and the risk of severe morbidity is low, intensive care is advised;
- in the “gray zone”, where prognosis is uncertain but likely to be very poor and survival associated with a diminished quality of life, parental desires should determine the treatment approach [7, 8].

Once the treatment option has been chosen there is no place for half-hearted care. Uncertainty may still remain after a decision is made, but with time going by treatment may be difficult to stop. Sometimes there may be an early window for withdrawal of life support, but if decisions are delayed, the risk that the patient will survive with severe impairment may increase [11]. Intensive care is only justified in the intent to save the infant’s life and to avoid subsequent damage. If treatment merely prolongs the dying process, there is no need to continue or pursue it.

Withholding versus withdrawing treatment

Whereas it is widely accepted that there is no moral, ethical or legal distinction between withholding and withdrawing treatment, in practice physicians are more reluctant to discontinue a treatment once it has begun [8, 12]. To withdraw treatment after having initiated it may be felt as more justified by physicians, since it suggests the idea that the infant was at least given a chance. Withholding or withdrawing of life sustaining treatment might reasonably be considered in the newborn period in the brain death child, in the permanent vegetative state, in the no change

situation, in the no purpose situation and in the unbearable situation [13].

Once medical support is discontinued or death is inevitable, human and compassionate care should be provided to the nonviable or dying neonate and its family, the specifics of palliative care must be individualized [4].

The role of legislation

To our opinion – we are not allowed to practice outside the law – ethical questions of this kind should not be regulated by law and the legal system should not interfere in the patient-physician relationship, otherwise the conflict between the physician's conscience and the law will often become inevitable [14]. Decisions regarding the treatment or the non-treatment of ELBW infants should not be influenced by fear of punishment, but based on the patient's best interest. Once responsible doctors and parents act upon a carefully made decision, there should be no conflict with the law. In such situations, man-made judgements are of little value.

Conclusion

Today, more than ever, the neonatologist needs to become familiar with basic ethical concepts and their application to clinical reality. We have to face increased knowledge, modern technology and some aspects of contemporary society by acting in the best interest of the patient providing ethically responsible care to ELBW infants. Keeping in mind that ethics is a term to describe “doing good”, as neonatologists we should always strive to do our best to improve our “professional skills” together with our “human skills” such as humanity, understanding, empathy, compassion, generosity and respect for the values of others [14].

Declaration of interest

The Authors declare that there is no conflict of interest.

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