

Considering ethical dilemmas related to brain death in newborns

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Abstract

Brain death (BD), as the irreversible and permanent loss of cerebral and brainstem function, is relatively uncommon among newborns who need life support. It is considered the result of an acute and irreversible central nervous system insult. Asphyxia, severe intracranial hemorrhage and infection are the most common causes of BD in children. BD diagnosis is usually based on clinical criteria.

Dilemmas about life prolonging treatment for severely compromised infants – as brain dead infants are – has become challenging since neonatal intensive care unit (NICU) care has developed, quality of life and resource issues are nowadays continuously underlined. Caring for premature babies is expensive and costs have risen especially since an increased number of infants with handicaps survives. Intensivists' main duty is first to save lives and then to interrupt treatment in certain conditions like detrimental brain damage.

The objective of this article is to present ethical decisions regarding brain dead newborns in order to balance between organ donation necessities and withholding/withdrawing treatment, with respect to the important role of infants' parents in the process.

Keywords

Ethics, brain death, newborn.

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Introduction

Brain death (BD) is the permanent and irreversible loss of brainstem and cortical function [1]. Terms like brainstem, neocortical and whole brain death are not identical [2].

Loss of brain function arises medical, ethical and philosophical issues [3]. Loss of brain function is also loss of human life, even though heart and spinal cord may still operate [4-5]. Development of cardio respiratory support in neonatal intensive care units (NICU's) rises the need to define BD criteria in newborns [6]. BD criteria in adults can be implemented for children, infants, full-term newborns (except for premature newborns < 37 weeks gestational age [GA] because of insufficient data) despite differences in brain function assessment, resistance to hypoxia and aetiology of BD [7-9]. Guidelines from task forces emphasized the importance of medical history/clinical examination in determining the aetiology and irreversibility of coma, specifying age-related observational periods and ancillary neurodiagnostic testing. Determination of BD in newborns is based mainly on clinically accepted neurological criteria [10]. Age-related observational periods and neurodiagnostic tests are still needed to be evaluated for BD diagnosis in children under 1 year of age [8]. 1987's BD guidelines for children younger than 1 year of age in United States, were recently revised in 2011 by Nakagawa et al. [7]. These guidelines are based on the definition of coma cause, irreversible cessation of higher brain function in addition to brainstem, exclusion of reversible causes, clinical neurological examination criteria, neurodiagnostic tests and suggestion of specific observational periods according to age. BD diagnosis in newborns > 37 wks GA to 30 days of age is mainly established on neurological examination and ancillary testing. Combination of neurological examination (unresponsive infant in coma with loss of brainstem function), electro cerebral silence (ECS) and/or no flow on cerebral blood flow (CBF) study for a 24 hours observational period is confirmatory of BD [7].

Lack of knowledge, consistency to BD diagnosis guidelines, inability to adequately assess brainstem function and level of consciousness in premature infants of gestational age < 37 wks make BD diagnosis in newborns invaluable [11, 12].

Definition of BD is necessary for two main reasons:

1. to permit withholding/withdrawing treatment; interruption of curative treatment;

2. to provide vital organs for the purposes of transplantation; from cadaveric or live related donors. In UK organ donation is not implemented for children under 2 yrs of age, whereas in other western commonwealth countries donation and transplantation procedures in this age group are customary [13].

In the following paper, we present a moral and medical framework within which guidelines should be followed regarding quality for end of life care for detrimental CNS damage in newborns as in BD. Organ donation decisions are out of the scope of this article.

Moral duty in the NICU environment

Despite the fact that neonatal intensive medicine has considerably evolved over the last three decades, neonatologists are confronted with some important and complex ethical dilemmas/questions. During this period, treatment has significantly progressed and nowadays it is possible for many more infants to be safely discharged home. Decisions for prolonging life or interrupting treatment in severely compromised newborns reflect the opposite sites of intensivists' medical and ethical duty, in this highly controversial and debatable issue [14].

Doctors' moral duty is fulfilled by a number of principals: First, the doctor must always take under consideration the newborn's perceived/best interests. Second, every newborn, regardless of his birth weight, gestational age or clinical situation has the right to his preservation for survival and on the other hand the right to die with dignity. Third, patient's right to control his own destiny should be respected. Regarding newborns, their parents decide on behalf of their child [15, 16].

Ethical dilemmas decisions are a really difficult task, while medical paternalism, doctor's character (compassion, humbleness, courage) or beliefs, parent's character, relations and ignorance of the NICU environment are all mixed together under a very painful and stressful feeling due to their beloved child's seriously deteriorated health status [17]. However, it is worth pointing that doctors and nurses should not act as technical managers and, when it is required to use end-of-life treatments for severely compromised newborns, consequences for the newborn itself and its family should always be considered. Additionally, medical staff should always have in mind that available human and financial resources are limited while demands are not.

Recognizing that national, cultural and religious differences do exist, for end of life decisions significant questions must be answered. In what clinical situations are such decisions appropriate? How is 'quality of life' being determined for the neonatologist? Who should be responsible for such decisions? When should the prolonging life question be erased? What are the appropriate measures for BD newborns?

Clinical situations for end of life treatment

Infants with severe congenital malformations (i.e. anencephaly), extreme prematurity with major CNS complications, serious CNS damage (i.e. by infection, hemorrhage, hypoxic-ischemic encephalopathy) and BD are considered candidates for end of life decision making process [18].

'Quality of life' judgments

Severe abnormalities or catastrophic brain damage may have disastrous effects on newborn's quality of life, which is of great importance for any treatment decision to withhold/withdraw treatment [12].

Quality of life means capacity for future health, development and well-being, potential ability to communicate (to act and interact, to have meaningful relationships with others) and at least substantial intellectual function. It does not have to do with probable physical handicap and generally the conception of considering the infant as a burden (as a human being or on financial terms) for the society is misleading.

Responsibility for decision making

Ethics committees' role for end of life decisions remains advisory in most European countries as is often the common practice in USA. End of life treatment decisions and support to the family becomes a responsibility of the intensive care team. Doctors and parents must be viewed as partners in the decision-making process with a measure of prudence considering that legislation for BD diagnosis and handling these infants in most countries remains unclear. It is important to remember that in situations like BD there is no moral difference between a decision not to commence/continue treatment and to withhold/withdraw treatment when the outcome will be death any way.

When should the prolonging life question be erased?

The key question here is at what point, if the prognosis is so poor, prolonging life should be morally justified? Additionally if an infant has a detrimental CNS damage for whom possessing/achieving self awareness is impossible, should this impair the doctors' decision of non-treatment?

Doctor's clinical wisdom is proved when he balances infant's benefits/interests with burdens/costs of treatment. Since there are no benefits for the infant with BD and death is beyond doubt, interpreting BD diagnosis with extreme accuracy is vital for parents and medical staff to help them decide if a newborn should be supported further or not. In this case of a brain dead newborn the prospect of a 'demonstrably awful life' is sufficient for selective nontreatment to be appropriate. It seems morally justified to withdraw treatment in circumstances where diagnosis and prognosis of recovery without detrimental consequences is not possible beyond doubt, and where doctors and family agree that continued survival cannot be in the patient's best interests [19]. Clearly, when it is determined that prognosis is so poor and the burden of treatment appears to outweigh the benefits, like in brain dead newborns, it is considered ethically appropriate to discontinue aggressive life support and employ comfort measures.

Non-treatment and comfort measures for brain death infants

Once decision of non prolonging infants' life has been taken, the medical team's main obligation is to 'treat for dying' by providing comfort measures. There is a need to be consistent in relation to selective non-treatment. Thus the infant must be made comfortable with sufficient analgesia, appropriate hydration and nursing care. Once the decision is that sustaining life is against the neonate's best interests, all life prolonging treatments should be withheld. Consequently administration antibiotics, resuscitation and even, on occasion, artificial nutrition should be withheld [20].

Gradually, in countries where there is a tendency to wait for a virtually certain prognosis of impending death, it is becoming evident that, with the ongoing discussion of the ethical issues relating not to prolong life, there has been a swing towards a more deliberated approach to decision-making in intensive care units. We should also remind that

date and time of decisions to withhold/withdraw life sustaining treatment, along with the clinical documentation and parental confirmation must always be entered into newborn's medical notes.

Conclusions

BD criteria for newborns and adults have a common basis despite different central nervous system pathology (immaturity of reflexes, open sutures/fontanelles and intracranial pressure changes). BD should be based mainly on neurological clinical examination and ancillary testing. Combination of neurologic examination, ECS and no flow on CBF study in a preterm or term newborn for 24 hours observational period is confirmatory of BD. Physicians are not familiar with the diagnosis of BD, although is extremely crucial for parents and medical staff to realize this 'end of life' condition.

Judgments about non-treatment (to withhold or to withdraw treatment) of BD newborns, should only be taken by clinical in charge consultant neonatologists.

It is essential for physicians to develop a greater understanding for BD certification in newborns and also to be familiar with end-of-life care methods.

Neonatologists acting in the BD newborns' perceived/best interests and taking under consideration 'quality of life' judgments should use and not misuse their moral right to withdraw supportive measures. Parental support and decision-making progress should be handled sensibly and scientifically based, respectively.

The goal should always be to provide a broad implementation of the ethical and medical principles for end of life decision making, achieving the desired balance between benefits in favor of patients' best interests and burdens of treatment.

Declaration of interest

The Authors declare that there is no conflict of interest.

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