

Bioethical Dilemmas In Neonatology

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“Doctors should be guided by the four fundamental virtues of Beauchamp and Childress: compassion, loyalty, discernment, and moral integrity.”¹

BIOETHICS: CONCEPTUAL ASPECTS

Put simply, bioethics, from the Greek *bios* (life) and *ethos* (ethics), is the ethics of life or practical ethics. But this concept goes beyond individual and collective needs in the face of changes and paradigms that emerged in the twentieth century, and consequently many concepts have also emerged. The various viewpoints from the humanities, health, and exact sciences, as well as medicine, law, and philosophy, allow us to place ourselves into the position of the other, to rethink moral values and discuss conflicts. One of the most complete concepts was presented by Kottow, in 1995²:

“Bioethics is a set of concepts, arguments and norms that value and ethically legitimate human acts [whose] effects deeply and irreversibly affect, in a real or potential sense, living systems.”

For Motta et al., bioethics extends to moral dilemmas regarding (1) the process of dying, (2) research involving living organisms and the development of *biotechnosciences*, (3) primary health care and questions related to the practice of family health strategy teams in reformulating the health care system, (4) the

allocation of resources in public health, (5) and ecological concerns related to the environment.³

Euthanasia: a Greek term suggested in 1623 by Francis Bacon as “APPROPRIATE TREATMENT FOR INCURABLE DISEASES”; can be translated as “good death” or “appropriate death.” Today the term means to bring about death without patient suffering, for merciful purposes.⁴

Orthothanasia: Proper actions taken to care for a dying patient. This may refer to appropriate palliative care provided to the patient.⁴

Dysthanasia: a way of artificially extending life that has no prospect of cure or improvement; this unnecessarily makes death more painful and costly.⁵

Besides the changes in the meaning of death through the ages, death has marked our cultures and is at the center of various religious beliefs. We are living in a time of the cult of youth, the medicalization of life, and concealment of death, which has come to be seen as a sign of failure. Hospitalization and intensive care units are characteristic of the technological revolution that has completely changed medicine, death, and dying.⁶

Intensive care units (ICUs) began to receive patients with incurable chronic diseases, or extremely premature infants, with a wide array of clinical complications; we provided them with the same care offered to acutely ill patients or those with a chance of making a full recovery. We have offered these patients a precarious type of survival, one that in some cases may not extend beyond a vegetative state. The sacredness of life, in other words, life as an intangible possession, may conflict with the quality of life. Currently the emphasis is on new knowledge and new technologies, to the

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detriment of teaching of the art of being a physician. The notion of the whole is lost, along with the bio-psychosocial and spiritual dimensions. "Heal sometimes, relieve often, comfort always."⁶

VULNERABILITY

The concept of vulnerability comes from the Latin *vulnus*, which means "wound," and we can also cite the verb *vulnerare*, meaning "to cause damage or injury". Thus, being vulnerable is being susceptible to injury, to mistreatment, to suffering. Vulnerability was first introduced into the vocabulary of bioethics in 1979, in the *Belmont Report: ethical principles and guidelines for the protection of human subjects of research*; this document provided guidance on fundamental ethical principles in human experimentation. This document addresses racial minorities, the economically disadvantaged, sick patients, and institutionalized individuals. Other documents indicate: a) especially children, pregnant or lactating women, the very elderly, and the homeless, whom literature and history have shown to be the most affected in disaster situations; b) people who have little opportunity for choice or who are subject to coercion in their decision-making.^{7,8}

BIOETHICS, THE BEGINNING OF LIFE AND ABORTION

Abortion is defined as the termination of pregnancy before the fetus can survive outside the uterus.

The bioethical dilemma should be reviewed from the perspective of the *principle of the sanctity of life* (PSL), which refers to life as something of divine or natural origin that cannot be interrupted, but also from the perspective of the *principle of respect for autonomy* (PRA), which considers the autonomy of the person and their free will, including in moral decisions. The autonomy of a woman or a couple, in the case of abortion, would be sufficient to justify their choice, as they are competent to decide what is important in their lives.²

In Brazil, abortion is illegal except when the pregnant woman's life is at risk or when the pregnancy is the result of rape; in these cases consent is required from the pregnant woman or her legal guardian.

Evidence-based medicine helps in ethical decision-making, qualifying it for appropriate clarification for the families, who should participate in the decisions.⁹

According to Suzanne Toce, "appropriate decisions about treatment and appropriate resuscitation of extremely low-weight newborns should never be the triumph of hope over reason, nor the victory of ego over uncertainty." And because this is a difficult decision, the parents of the child must participate and be well-informed about the situation.¹⁰

Technological advances in neonatology currently allow life to be maintained in situations described as incompatible with life, such as extremely premature neonates with multiple malformations or serious neurological injuries. Therefore, some authors have questioned whether these measures do nothing

more than indefinitely delay death, which can evolve into therapeutic obstinacy.⁹

Hill showed that the ethical discussion about dying with dignity was not often addressed in medical training at the end of the last century, and not much has changed since then. Only five of the 125 medical schools in the United States offered education on the end of life, and only 26 of the 7,048 medical residency programs in the US addressed this topic at scientific meetings.¹¹

The lack of adequate knowledge and instruction during medical training, such as learning how to communicate and knowing how to deliver "bad news," hampers the exchange of information between patients and the healthcare team. This could be one of the reasons for delays in recommending palliative care and the maintenance of therapeutic obstinacy. A physician should have sensitivity in knowing exactly the right time to deliver "bad news," as well as empathy, with the goal of maintaining the family's hopes without raising unrealistic expectations.

In addition to a diagnosis "beyond the possibility of therapy," the doctor and healthcare team should direct care toward physical, affective, and emotional comfort for the family as well as the newborn, as stated in the principle of beneficence, where doing good is acting in favor of the patient's best interests. Beneficence does not necessarily imply using scientific knowledge to preserve life at any cost. "Doing everything" for a terminal patient could mean offering palliative care and avoiding dysthanasia.¹²

There are no fixed rules of conduct with regard to ortho-thanasia, but there are ethical principles for guiding actions. Each case must be considered individually, seeking to strike a balance in decisions, and avoiding therapeutic obstinacy in end-of-life situations. Clinical bioethics commissions can assist in decision-making and future guidelines.⁵

The decision on whether to withdraw life support, not offer life support, or not resuscitate cannot be put into practice without agreement from a representative. One particular problem appears when parents request removal or non-provision of life support without the doctor's conviction that this is acceptable from a medical point of view, for the best interests of the patient. In this case, the principle of beneficence should prevail over the patient's autonomy and should be investigated in depth, preferably by a multidisciplinary team including a psychologist, psychiatrist, social worker, a clergy member, and a bioethicist, in addition to the parents. In this situation, a factual and unbiased opinion from a bioethics committee can be extremely useful.^{13,14}

Quality of life is the main reason neonatologists cite in decision-making. In an article on medical decisions involving life and proposals for our reality, the Brazilian Federal Council on Medicine points out that we doctors, especially intensive care physicians:¹³

"question ourselves about our decisions related to the end of life, because we have the clear perception that we still make excessive and inappropriate use of technology, unnecessarily prolonging human suffering, making poor use of finite health resources and poorly occupying the insufficient number of beds in ICUs and emergency wards;

b) we see ourselves as powerless, from a legal point of view, to make any decision to withhold or withdraw life support;
c) We feel there is a lack of standards and guidelines about how to treat these patients.”

BIOETHICAL CONSIDERATIONS ABOUT THE THERAPEUTIC DECISIONS AND THE LIMIT OF VIABILITY

The best predictors of survival in extremely premature newborns (NB) are birth weight and gestational age (GA). The survival rate with respect to birth weight between 400 and 499g is 10–20%, and for gestational age less than or equal to 23 weeks the survival rate is 10–30%. The predictors are prognostic estimates of the chance of survival.^{15,16}

Bioethics does not distinguish “do not start” and “interrupt.” Ethically, it is more acceptable to withdraw therapy than to not start it, because it offers the patient the benefit of the doubt. But the question remains: when to start or stop neonatal intensive care? Determining factors in the physician’s need to resuscitate are:¹⁵

- Doctor: trained to save lives, and does this automatically;
- Responds to the family’s request to “do everything possible;”
- Legal restraints. The therapeutic obstinacy adopted by many medical professionals stems from inadequate training and a preventive attitude against lawsuits;
- Conflicts with parents, colleagues, the administration, or the physician himself or herself.

The following situations are considered higher-risk: a) extreme prematurity as established by feasibility analysis; b) multiple congenital malformations as established by analyzing compatibility with life, and c) chronically ill patients without possibility of treatment.

“The doctor should try to cure those who can be cured, reduce disease morbidity when possible, and ensure patient comfort. Finally, when the disease progresses and the patient is about to die, the doctor is must acknowledge this and ease the process of death.”

Hippocrates, 430 BC

One of the biggest dilemmas occurs in the delivery room, where vigorous measures are often taken to resuscitate extremely premature neonates that may have a prognosis of vegetative state. But the delivery room is the most inappropriate place to make this decision. “Not starting or stopping” may lead to the same consequences as “not interrupting,” since both will lead to serious consequences in the child.^{13,14,15}

The World Health Organization considers palliative care as the active and total care of the child’s body, mind and spirit, involving family support, starting at diagnosis and extending throughout treatment.¹⁷

Hospital commissions on clinical bioethics, though few in Brazil, assist healthcare teams, patients, and families about decisions, principles of beneficence and non-maleficence and palliative care, as seen in the table below.¹⁸

Neonatal palliative care makes sense for births that occur at the limits of extrauterine viability, those arising from neonatal

Table: Ethical principles and end-of-life care

ILLNESS		
LIFE		DEATH
Savable	Reversal of Expectations	Inevitable death
Preservation of life		Relief of suffering
Relief of suffering		Preservation of life
Beneficence		Non-maleficence
Non-maleficence		Beneficence

resuscitation with irreversible complications, and in unexpected situations such as severe perinatal asphyxia or severe malformations in the newborn that were not diagnosed during the prenatal visits. For many newborns with survival limited by extreme prematurity or congenital malformations, and for those who develop complications during the neonatal period, there comes a time when limiting aggressive care measures aimed at extending life is considered the most ethically and medically appropriate course of action. In this sense, in the words of Daniel Serrão, “not everything that is technically possible is ethically acceptable.”¹⁹ Therefore, recognizing the need to change the direction of care away from the curative model and enhancing palliative measures must be accompanied by actions that incorporate an interdisciplinary approach and are aimed at supporting the dying baby and the family during this very difficult period.

“If there is a legal problem, it seems to me that the challenge is to bring the laws in line with the requirements of ethics.”

Délio Kipper, 2000

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