

Decisions concerning resuscitation and end-of-life care in neonates. Bioethical aspects (Part I)

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ABSTRACT

Coping with the death of a newborn infant requires training and reflection regarding the end-of-life decision-making process, communication with the family, and the care to be provided. The objective of this article is to analyze in depth the salient aspects of neonatal bioethics applied to end-of-life situations in newborn infants. Part I describes notions of therapeutic futility, redirection of care criteria, patient and family rights, and concepts about the value of life. Part II analyzes situations that deserve considering the redirection of care and delves into aspects of communication and the complex process of end-of-life decision-making in newborn infants.

Key words: newborn infant, bioethics, decision-making, end-of-life care.

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INTRODUCTION

The development of the 3rd edition of the Manual for Neonatal Resuscitation by the *Sociedad Argentina de Pediatría*, based on the evidence gathered by the International Liaison Committee on Resuscitation (ILCOR), led the members of the Task Force for Neonatal Resuscitation of the Committee on Fetal and Neonatal Studies (Comité de Estudios Fetoneonatales, CEFEN) to discuss bioethical reflections in depth.¹ In the corresponding chapter of the Manual, concepts were briefly expanded compared to the previous version, given the characteristics of that publication.

The objective of this special article is to analyze in depth the salient aspects of neonatal bioethics applied to situations of resuscitation and the end-of-life decision-making process in newborn infants.

THERAPEUTIC FUTILITY

The death of a newborn infant seems a contradiction in itself, a mistake of nature. However, neonatal mortality is a reality and a problem that concerns various disciplines, such as public health and bioethics. The latter is because the manner of death of patients is fundamental. In this regard, the “how” has at least two aspects: the first one is related to the decision-making process surrounding the end of life of a neonate; the second one focuses on the care provided to the patient in these final moments. This article will address the first aspect.

Studies that have assessed how patients die in the neonatal intensive care unit (NICU) have shown that, in industrialized countries, the proportion of newborn infants in whom death follows a decision to limit life-sustaining therapies has been increasing.² In this article, the term “redirection of care” has been chosen instead of the classic term “limitation” because there is consensus that it better defines the meaning of a strategy that consists of redirecting therapeutic goals from healing or improving health to avoiding suffering and pain and providing comfort.³ It is emphasized that care is not limited, but adjusted to each patient according to these goals. A recent study carried out in Argentina shows that only 28% of newborn infants who die in the NICU do so after a process of redirection of care.⁴ The question that arises is when should redirection of care be implemented? As an important part of finding an answer to this question, the concept of therapeutic futility must be explored.

The definition of futility in the context of health has been controversial. A recent survey among 146 neonatal health care providers that asked about how they defined the term *therapeutic futility* showed varied definitions; the most common were:⁵

- 1) treatments that do not lead to a meaningful life (in terms of a compromise in quality of life);
- 2) treatments that do not prevent death;
- 3) treatments that do not change the patient’s outcome;
- 4) treatments that lead to pain and suffering.

The American Medical Association’s Council on Ethical and Judicial Affairs has indicated that “a completely objective and specific definition of futility is unattainable.”⁶ Thus, alternative terms have been proposed: potentially inappropriate therapies, medically inadvisable therapies, clinically inadequate therapies, among others. One strategy that helps to find appropriate terminology is to consider whether we are referring to a medical diagnosis or a moral assessment. In this sense, Wilkinson and Savulescu have stated that “the concept of futility reflects a perceived need by doctors to limit patient or family autonomy and a way to justify a decision not to provide life-sustaining treatment.”⁷ These authors, considering that the term refers to a therapy of such low efficacy that doctors believe it should not be provided, have proposed to discuss “medically inappropriate” instead of “futile” therapies. This is for two reasons: firstly, they argue that “medically inappropriate” makes it clear that these are value judgments made by medical professionals; secondly, because the inappropriateness of treatment highlights the importance of being clear about what treatment is appropriate for. It could be said that the term “futility” is directed towards the professionals’ perspective, it focuses on the physicians’ understanding of the situation, while speaking of “medically inappropriate therapy” does not put an end to the problem, but gives room to consider the opinions of the patients and their families, even if they disagree with those of the physicians. This concept moves away from medical paternalism and contributes to a shared decision-making process.

These are situations in which patients receive no benefit from the therapy they are receiving (their condition has become irreversible and there is no reason to believe that the treatment will be effective). Continuing to provide treatment in this manner has been called therapeutic

obstinacy (or therapeutic cruelty). In her doctoral dissertation, María Martha Cúneo calls to reflect on this issue, saying: "If we recognize newborn infants as human persons, with an intrinsic value in themselves, that value has to be protected both from the abuses of therapeutic neglect and from the exaggerated and disproportionate use of the means, providing them a guarantee of protection against both opposite ends."⁸

CRITERIA FOR THE REDIRECTION OF CARE

Therefore, we are faced with a situation in which the withdrawal of certain therapeutic measures is considered ethically adequate. In attempting to define the situations in which the redirection of care can be considered, two groups of conditions emerge: 1) those in which life is limited in "quantity", including brain stem death, imminent death, and inevitable death; and 2) those in which life is severely limited in "quality".⁹ The latter group includes conditions of severe and irreversible neurological compromise, and others in which the burden of either the disease or the treatment (understood as the manifestation of pain or suffering) is so high that it does not justify continuing, since there are no benefits of prolonging life.

Basically, two criteria have been put forward to consider the redirection of care. The first (and most widespread) criterion is based on whether continuing treatment is against the patient's "best interests" and may harm the patient (either by leading to a prolongation of death or by severely and irreversibly compromising the present and future quality of life). The second criterion is related to the concept of distributive justice and refers mainly to the consideration of whether continuing treatment could be harmful to other patients.

To define the "best interest", it is proposed to perform a balance of burdens and benefits.¹⁰ If talking about finding a balance, on the one side we have the positive aspects (life chances, well-being/quality of life) and on the other side, the negative aspects (pain/suffering, either from the disease or from the treatment). Whether the positive aspect is remote or the negative aspect is prevalent, the patient may benefit less from continuing therapy (it would not be in their best interest).

In any case, the concept of best interest makes us believe that there is only one best response, when we actually know that complex cases require consideration of multiple options,

multiple interests, and multiple values. In addition, that is not how decisions are made on a daily basis; our decisions are not always oriented to the best interest of our children (e.g., the food we provide, the place where we live, the school we send them to, etc.). Many years ago, Donald Winnicott established the concept of "good enough" parenting, underlining the impossibility of being perfect and freeing us from the guilt of not being able to be perfect for our children.¹¹ Being good enough does not mean being mediocre, but doing the best possible given the circumstances, taking into account the real world and accepting that benefits are always accompanied by problems.¹² The paradigm is about improving while doing, learning from failure, coping with complexity, and adapting to human weakness. This conceptual idea may also help us when we have to make end-of-life decisions for our children.

Something that makes this approach more intricate is that, in such balance, what is usually weighed is the biomedical interest rather than the general well-being (emotional, social, spiritual factors), which is as important in the development and life of human beings. Furthermore, the interests of the family members involved (mother, father, siblings), who may also suffer from the situation, are overlooked. It is important to consider these interests in the decision-making process. Although the patients' interests must be prioritized, it is necessary to assess the consequences of the decisions on their families, especially when talking about newborn infants with many years ahead of them. Just as it is said that there are no diseases but sick people, it can be said that there are no sick newborn infants in isolation, but in the bosom of a family. The momentous decisions being discussed have deep effects on the parents and other family members. If the decision leads to the survival of a child, very often this will result in a substantial burden of care for many family members. If, on the other hand, the decision leads to the death of the child, it is the parents who will bear the greatest emotional burden of the situation. In addition, it is quite unnatural to separate the interests of parents from those of their children. There are overlapping and interdependent interests, and neonatal health care providers must understand the difference between what is thought that parents should do and what they should be allowed to do.¹³

Finally, it is also reasonable to consider the social environment in which the family lives when

making decisions. First of all, the presence of inequalities and social injustice could influence decisions about continuing or discontinuing a specific therapy. If social inequalities are allowed to influence decisions about which therapies to offer, somehow we become participants in that injustice. Considering them would enable different ethics depending on the availability of resources. On the other hand, health care providers feel that they have no responsibility for them and cannot modify them, so they often do not take them into account. However, social inequalities are a reality and not taking them into account may lead families into predictably disastrous situations. Reality cannot be ignored. The impact that decisions will have on the interests of close relatives, their projection over time, and all the actions that can be implemented to modify that reality should be identified as best as possible.

An alternative approach to the best interest criterion is that of the “harm principle”, in reference to the ancestral *primum non nocere* principle, classically attributed to Hippocrates. Applied to end-of-life decisions, this approach proposes not to institute therapies if the child is likely to suffer significant harm from the decision. Relying on the harm principle allows for “good enough” decisions and does not require a single best response to maximize the child’s well-being.¹⁴ This approach involves focusing on the absence or minimization of harm in establishing a particular therapy. It can also be used in reverse, i.e., if the treatment does not result in significant harm to the child, its administration may be acceptable. While, as with the best interest concept, determining meaningful harm depends on the values at stake, asking yourself whether “is this harmful?” is less rigorous than whether “is this best?”

The other criterion proposed in end-of-life decisions relates to considering the possibility of harm to others as a consequence of providing (or continuing to provide) certain treatment to a patient. This is an indirect harm, based on the principle of distributive justice. The decisions based on this criterion have to do with the scarcity of resources. It is a matter of ranking patients according to prognosis.¹⁵ It is very difficult to determine when the life of a human being is worse than their death. The analysis based on distributive justice proposes the approach of deciding when one life is better than another and when a given life is worth saving based on the

availability of resources. Such approach is little addressed in perinatal medicine. In this regard, Savulescu asks to keep it in mind as it is “an elephant in the room,” something that no one wants to see, that people prefer not to discuss, but that is present and must be faced at some point (the tragic reality of the current SARS-CoV-2 pandemic has revived this discussion, although not in the field of neonatal medicine and bioethics).

THE RIGHTS OF PATIENTS AND THEIR PARENTS

It is worth mentioning some considerations that must be taken into account in the decision-making process. First of all, newborn infants have a right to medical treatment, and this right is independent of their parents’ wishes or physicians’ values. Newborn infants also have the right to be free from disproportionate, inhuman or degrading treatment and to be spared from suffering. These two sets of rights should be understood as complementary and interrelated.

On the other hand, parents have the right to receive the information they need to assist in the decision-making process on behalf of their child. In addition, they have the right to decide on the measures to be taken, as they are best positioned to ensure the best interests of their children (unless they engage in neglect, abuse or abandonment). This does not mean that they have an obligation to decide, because, at the same time, health care providers have a medical responsibility to suggest or recommend actions based on their knowledge and experience. The burden of these momentous decisions should not fall on the parents. Health care team members should be aware that taking measures related to the redirection of therapeutic goals is far from the concept of “there is nothing more to do.” On the contrary, it is the responsibility of the nursing and medical team to arrange a health care and assistance plan with specific actions based on the patients’ and their families’ needs and, with this same conviction, to convey it to the parents. The pain referred by parents when faced with the phrase “there is nothing more to do” is enormous and, in reality, health care through the perspective of the redirection of therapeutic goals is a position that implies a lot to do and, first of all, to take actions that reduce both the physical suffering of patients and the emotional suffering of patients and their families.

THE VALUE OF LIFE

The initial concept is that life, in its merely biological dimension, is not an absolute value. Francisco Elizari Basterra, theologian, states: "To respect physical life in itself, dispensing absolutely with what gives it meaning, its condition of human support, would be tantamount to falling into vitalism as a form of idolatry."¹⁶ Then, vitalism implies the position of ascribing an absolute value to physical life. According to this perspective, we should always treat our obligation would cease only with death. This is an extreme position, considered uncommon today in our setting. Balanced positions propose that physical life is not a good that must be preserved at all costs, but relative and subordinate to the good of the whole person.¹⁷ Therefore, it can be said that not any treatment is mandatory or necessarily good for any patient. Extreme views are not helpful. Just as vitalism would condition us to fall into therapeutic obstinacy, the other extreme, which we may call pessimism,¹⁸ would lead us to end life when it appears frustrating, burdensome, useless, or when there is a risk for sequelae. In other words, if the quality of life is not taken into consideration, there is a risk for excessive therapy; but if we only offer treatment when a high quality of life is foreseen, we fall into discrimination against the disabled.

There is an intermediate position, proposed by Richard McCormick, among others, who considers that life is both a basic and precious good, but a good to be preserved precisely on condition of other values, to the extent that those values remain attainable. McCormick states that these other values and possibilities are the ones that underlie the duty to preserve physical life and that dictate the limitations of that duty. Therefore, life is a relative good and the duty to preserve it is limited.¹⁹ Those values mentioned by McCormick take root in human relationships. Life can be said to be a value to be preserved to the extent that it contains some potential for human relationships.⁸ If, from a human opinion, "the potential for relationships is simply non-existent or the mere struggle for survival only entails for a completely submerged and stunted condition, this life has exhausted its potential."²⁰ That is to say, such existence does not require us to be kept alive.

Part II of this article will review the clinical conditions for considering the redirection of care and the complexity in the communication and decision-making process in the so-called "gray zone". ■

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