

Ethical Aspects in Neonatal Intensive Care. Ethical Issues in Neonatal Intensive Care

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Abstract

Recent progress in neonatal care have significantly improved the prognosis and chances of survival of critically ill or extremely preterm neonates and have modified the limits of viability. However, in some circumstances, when the child's death can only be briefly postponed at the price of severe suffering, or when survival is associated with severe disabilities and an intolerable life for the child and his/her parents, the application of the full armamentarium of modern neonatal intensive care may not be appropriate. In such circumstances the limitation of intensive treatments (withholding or withdrawing) and shift towards palliative care, can represent a more humane and reasonable alternative. This article examines and discusses the ethical principles underlying such difficult decisions, the most frequent situations in which these decisions may be considered, the role of parents in the decisional process, and the opinions and behaviours of neonatologists of several European neonatal intensive units as reported by the EURONIC study.

Keywords: *Neonatal Intensive Care; Neonatal Ethics; Limitation of Treatments; Newborn Infant*

The commented article addresses a current, frequent and often not adequately confronted topic, such as the ethical aspects to consider for decision making within Neonatal intensive care units (NICU).

The focus of the same is on those cases in which the uncritical application of all the technology available in THE NICU has as a result either to postpone death briefly with the cost of severe suffering, or to guarantee a Survival with severe disabilities and an intolerable quality of life for the child and their families. These two particular situations are being questioned by both physicians, nurses and family members, as well as from various disciplines including sociology, ethics, and jurisprudence.

In this way, the idea has begun to emerge that in certain circumstances, intensive treatment can be replaced by palliative care aimed at reducing pain and improving the well-being of the patient and his family, instead of maintaining or prolonging the life to any cost.

After making a brief historical review and point out how this new paradigm is looking for, for 30 years, settling in neonatology, concludes by pointing out that the proportion of deaths associated with limiting the therapeutic effort has been increasing over time. Towards the end of the last century, most of the neonatal deaths were preceded or accompanied by some form of limitation of the therapeutic effort [1].

In the study known as "EURONIC" (European Research Project) developed between 1996-1997, in 144 neonatology from 12 different countries, investigated the opinions and experiences of physicians related to ethical issues and Involvement of parents. The results were disparate among the different countries, especially with regard to the acceptability of limiting treatments under certain circumstances. There was a coincidence that limiting intensive care, including mechanical ventilation, is an acceptable and ethically justifiable possibility in certain circumstances, notwithstanding the differences between professionals of different Countries were related to the most concrete way of proceeding to achieve this objective and the cases in which they would be willing to include in that approach [2].

In the developed analysis, the two ethical positions traditionally posed as antagonistic are put in evidence: one is that which considers the "holiness" of Human life, considering it as a divine gift and its absolute value. According to this position, it is stated, any course of action that accelerates or facilitates the death of the patient is considered "anti-ethical", whereas, at the other extreme, putting in the center of the scene the "Quality of life" proposes that it would be sensible Change the approach to palliative care, if it is determined that survival would deprive the person of some minimal qualities that characterize human life.

It also addresses the issue of viability and situations typically considered as being included within the criterion of limiting therapeutic effort. Of the situations pointed out, I limit myself to indicate that of those children with bad prognosis in the long term and poor quality of life predictable, whose approach will be made in the commentary.

In the conclusions, emphasis is placed on the way in which aspects such as gender, religion, clinic experience, personal family situation, being or not in pairs, having or not children, have been identified in the aforementioned study As the reason that impacts on the variability of opinions among professionals, and how patterns seem to be given specifically in each country, which clearly explains the importance of historical, social, cultural and legal factors in the approach of these issues.

According to the authors, the expectation of a consensus on these sensitive subjects is unrealistic, especially considering the prognostic uncertainty in each case. Openness to deliberation and participation is proposed, as is also indicated by the inability to clearly identify a fully appropriate and satisfactory position when the four most important ethical parameters are included: Biological life, Parental authority, the best interest of the child and the dignity of the human being.

However, it clarifies, it is necessary to consider the possibility of making imperfect or fallible decisions, even if this can be disturbing considering the present era of "evidence-based medicine". There seems to be no alternative but to learn to deal with doubt and uncertainty, to value the merit of commitment, to admit the possibility of error at the same time of being able to use the error to improve.

Comment: "In most cases, ignorance is something superable. We don't know why we don't want to know "Aldous Huxley. English writer (1894-1963).

Bioethics has erupted into the reality of neonatal care services, since situations that require reflective analysis are very regularly presented. In his relative recent emergence, Potter (scientist who coined the term) referred to it as "wisdom of Science". Bioethics has been said "(...) It is not a discipline that puts limits, but is the prudence applied to the actions of man in the technological age" [3].

Reflective analysis is imposed because ethical uncertainty tends to be the rule, rather than the exception in the care of severely ill or extremely premature infants.

A good first step is to recognize that many of the proposed courses of action have uncertain results. That is, while there are statistical data that correlate the result in mortality and morbidity with gestational age and birthweight, no professional can guarantee that part of the statistical graph is going to be located that neonate.

This deduces the importance of individualizing care and making an integral approach, which implies banishing from our practices processes of work in which decisions are taken in the form of "algorithm".

Against this individualized care they conspire several factors that we frequently find within our services, and that clearly Grafica Arnaez, *et al.* in a graph published in 2017*: Insufficient resources, Distrust of the capacities of the rest of the team, the aggressiveness of the treatments without evaluating benefits, the prognostic uncertainty, among other aspects, impact on the person (moral and emotional anesthesia, physical and psychological imbalances), in the Team (intolerance to discrepancy, less cohesion of the group) the family (low assertive communication) and the patient, determining a worsening quality of care and negatively affecting decision making.

When the fragmentation of our gaze operates, the integral approach is truncated. In this way, the decisions begin to take a more difficult course each day to rectify. It is there when in a deeper, often belated and retrospective analysis, that “ethical dilemmas” do not usually settle in a sudden or unexpected way in our services.

An extreme premature RN atraviesa the difficulties associated with the challenges of its prematurity in the first stage. But it fails, however, to improve its respiratory status and fails in attempts to extubate. That is, instead of responding as traditionally responded The premature, that neonate does so in a particular way, which keeps him dependent on the respirator. How long? What’s the limit? Because this is not an isolated fact: Meanwhile, his brain is damaged, its growth stops and its quality of life deteriorates to that point of difficult return towards which the health team went without warning? Decision after decision.

The days pass, the events occur and the response algorithmic proposes an intervention for each complication that is presented. In this exercise uncritical, thoughtless and fundamentally fragmented, the sum of the days are translated, inexorably in weeks, and that of weeks, in months. And there it appears, installed in all its splendor, the ethical dilemma. A child, who is already five months old, dependent on the respirator, suffering, at the same time the embarrassment and pain of his family, who waits for him outside the neonatology, each of our algorithmic interventions. There we have that little boy, dependent on a respirator, with a brain that does not grow, within a neonatal intensive care unit, inserted into a health system? Whose derivation is difficult (when not impossible) because that same system cannot cure it. Is that the ethical dilemma? What happened to all the decisions that preceded it?

The answer that arises when this question is raised, usually brings together the following common notes that characterized pre-decision making: Unilateral medical hegemony - medical paternalism is still in effect in our practices although Banished from the academy-a poor or poor communication with the family and fragmentation in the boarding.

In the face of this panorama, I think that the nursing should renews the role it occupies. The permanence in the unit puts us in the privileged but also compromised situation of being those who share more closely the experiences of the families. However, our involvement in decisions is underestimated. “Unfortunately, few neonatal nurses are actively involved in the decision-making of their patients, regardless of whether they feel interested and trained to do so. The participation of the nurse in the decision making process is fundamental. The relationship of empathy and continuous presence that establishes the nurse with the family, allows him to have a better knowledge of the reality of the parents (values, socio-familial circumstances and emotional adjustment). Its exclusion in the decision making power the disinformation, can cause tension, frustration and misalignments in its professional role” [5].

What are our tools in these circumstances?

In the first place, and as always, knowledge. In the same way that we form in the knowledge of techniques and emphasize in keeping up to date to provide the best available care as the best scientific evidence present, we have to commit ourselves to know and respect the rights of our and ensure that the decisions taken are ethically correct. Unlike biological or technical aspects, we do not have scientific evidence to help us in ethical matters. Therefore, the permanent, indispensable, sustained and demanded exercise of the refethical lexicon for each RN, in each case, in each family and in each circumstance, all, necessarily, different, must be incorporated as an individual habit, which Spread and generate group reflection, involving our colleagues and other health team professionals.

Today we know that there are no magic formulas that give specific answers for each case raised but that the most wise proposal is the use of deliberative processes [4]. These processes, whose systematic use requires practice and radical changes in some aspects of working processes within neonatal intensive care units, do not seek as much“(…) To achieve certainty, which does not exist, but to reasonably manage uncertainty and to make a prudent decision” [4]. To install this method, it is necessary to exercise the deliberative method as a habit in

decision making, to involve permanently the parents in the decision making, to adopt at any moment a holistic look (not by organs or systems), to identify the Ethical problems, making decisions and proceeding to register the deliberative process as such in the medical history.

The neonatal palliative care Ivo for those born premature to the limit of viability, or who do not respond to intensive treatment is an option that will gradually loom in the reality of our services. As nurses, we must commit ourselves to the early identification of those infants who meet the criteria for admission to a palliative care program, always flexible, dynamic and individualized. Ideally there should be consensus (the Protocol of Action of the Spanish Society of Neonatology is cited as an example) [6] that address the situations of initiation of treatment or its suppression in conflict situations during the period Neonatal, based on the reality of each service so that the prognosis is realistic, that is to say, the possibility of survival and future quality of life is related to the care and results in the center in which that baby is going to be treated.

Conclusions

Accepting the limits on neonatal care, uncertainty and irreversibility of some situations is a great first step that all professionals should take on. Early detection of situations in which it is not possible to cure and should opt for the palliative approach can prevent the ethical dilemma from being installed as such. There are other courses of action, in which "dignity", this concept often abstract or ambiguous, gains dynamism to translate into a real and concrete situation whose benefits impact on the newborn, family and professionals.

The search for interventions that optimize communication, encourage decision-making through deliberative processes, the writing and implementation within our units of action protocols that guide the health team, are actions that are They present us as a huge challenge but also as an opportunity to accompany the families that go through these complex situations, positively impacting the reality of the protagonists of these stories as they travel the hard challenge and Providing tools to achieve an effective coping when, sometime later they try to rebuild the meaning of the lived.

If our challenge as committed professionals are to care, with more reason it will be, when it is not possible to cure.

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