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

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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

Part I of this article reviews notions of therapeutic futility, redirection of care criteria, patient and family rights, and concepts about the value of life. Part II defines, first of all, the situations that deserve considering the redirection of care and then delves into aspects of communication and the complex process of end-of-life decision-making.

CLINICAL CONDITIONS IN WHICH THE REDIRECTION OF CARE MAY BE CONSIDERED

The redirection of care option should be approached with great sensitivity. In pediatrics, it is morally correct to implement the redirection of care in the following circumstances:[1]

- Inevitable death in the short term.
- Intolerable disease for the patient (not applicable to neonates).
- The burden of treatment outweighs the benefits.
- No benefit from the treatment.

An aspect that hinders the decision-making process is that there is uncertainty most of the time. Actually, the problem is the degree of uncertainty. In neonatal practice, timing of the redirection of therapeutic goals depends mainly on the patient's condition and the clinical setting, the degree of uncertainty regarding the prognosis, and the emotional state of the parents. The assessment of prognosis is a key factor because it is the instrument we use to assess whether treatments are proportionate or disproportionate (in this case supporting the consideration of therapy discontinuation).

THE UNCERTAINTY OF THE "GRAY ZONE"

When faced with complex situations in which decisions must be made regarding the care to be provided, controversy may arise among the health care team, and the right path to follow may not be clear.

Pediatrician and bioethicist Mark Mercurio states that, in order to define situations of this nature, it helps to ask ourselves whether we consider that therapies: a) must be offered invariably, i.e. treatment is obligatory and should not be refused; b) should not be offered because doing so is considered inadmissible; and c) it is permissible to offer them, in view of a prognostic and moral uncertainty.[2,3] In other words, in the third scenario, in which the extent of prognostic uncertainty in relation to the patient's course is high, doubt also arises as to what is ethically optimal. This has been called the "gray zone" because of the difficulty to define it.

RESPONSIBILITY FOR THE DECISION-MAKING PROCESS IN THE GRAY ZONE

When decisions have to be made in this gray zone, it is important to define who should have the last word. In conscious adults, there is currently a consensus that patients themselves, exercising their autonomy, have the right to make the decision after having been informed of the options. In the case of newborn infants, who lack autonomy, options are their immediate family, i.e., their parents, or the health care team. This is a complex issue. Nowadays, there is consensus that parents have the right to decide for their children, since it is accepted that they are in the best position to define what is in the best interest of their children, as long as they do not incur in abandonment, neglect or abuse.[4,5]

As mentioned before, it is important to recognize, at the same time, that this right does not imply an obligation, given that many parents cannot assume a responsibility that causes them anguish and, eventually, guilt. In these situations, health care providers should empathize, make informed recommendations, seek agreement, and avoid placing the burden of the decision on the parents.

Either way, in this gray zone, we are faced with a situation in which any option seems wrong. In the case of patients with severe conditions that affect their quality of life or are life-threatening, those options are to continue life-sustaining therapies or to allow death. A decision needs to be made after reflection through informed discussion among the parties involved.

It is rightly said that the worst decision is the one not taken, to let things run their course without facing them, without considering how to improve the patient's care and living (or dying) conditions. In other words, the problem must be faced, since not making a decision is a decision in itself, which is arbitrary and potentially devastating.[6]

It is interesting that both sides (continuing therapy or withdrawing life-sustaining measures) are ethically defensible. Reasonable people may disagree as to which is the "right" path. At this point, it is relevant to mention two revealing and interesting concepts that help to analyze this problem.

The first concept is proposed by Spanish ethicist Diego Gracia and refers to speaking of problems rather than dilemmas, as these questions are so often posed.[7,8] Gracia states that turning a problem into a dilemma is to reduce it to two potential courses of action and, when this occurs, extreme positions emerge as the only possible alternatives. He advocates learning to identify all conflicting values and seeking the optimal course of action, pointing out that this is our moral duty. Gracia says: “It is not a matter of choosing the highest value at the expense of the others, but about doing our best to bridge all conflicting values. Ethics is not about the good, but about the best, the optimum.”[9] The proposal is to reach this point by exercising caution, through deliberation and reflection.

The second concept is proposed by English medical bioethicist Dominic Wilkinson and refers that dissent is not a bad thing, an idea that in this context of end-of-life care is novel, intelligent, and overcoming.[5,10] A few years ago, when considering the discontinuation of life-sustaining therapies, the prevailing idea was that, before presenting it to the family as an alternative, the health care team should come to a unanimous agreement about it. It was argued that, if there was at least one person who disagreed with such measure, it should not be considered, since the outcome (the patient’s death) was irreversible and, in the face of a difference of opinion, the continuation of life should be prioritized.

Wilkinson and Julian Savulescu, Australian philosopher and ethicist, have proposed accepting dissent, rejecting the utopian idea of reaching unanimous consensus. These authors speak of a “reasonable disagreement.” In this path or decision-making process, reasonable disagreement does not refer to considering whimsical opinions, but to establishing a serious discussion, being willing to listen to other people, considering different positions as long as they are well-founded and argumentative, and adding that those who propose them must be willing to carry out those actions and be responsible for their consequences.[5] It must also be understood that we have to be ready to be tolerant and support the decision that is made, even if we do not share it.

COMMUNICATION AND DECISION MAKING

In the decision-making process, it is important to recognize how we approach this path. Pediatrician and ethicist John Lantos calls for a new approach in which physicians help parents discern their own values and ethical commitments when faced with an unexpected situation involving decisions about life.[11] The shift in the focus from outcome to process is subtle but relevant; rather than an ethic of conflict resolution, this approach calls for an ethic of value clarification. Lantos says that, too often, physicians think that data are not only necessary, but also sufficient to guide parental decisions. He believes this is a serious mistake because, while important, knowing the data is only one aspect of the problem. He invites physicians to help parents use data, starting with understanding and clarifying their goals, values, and priorities. Only in this way will health care providers be able to put the data into context so that they can be used.

Moreover, parents often do not see the usefulness of statistical data.[12] Firstly, people do not really understand statistics, and even less so in stressful situations. Secondly, this approach inevitably incorporates the well-known phenomenon of the “framing effect.” The same factual information can be presented in ways that lead to very different decisions. Thirdly, percentages describe results from infant groups. Parents want to know what the outcome will be for their baby, which is much more difficult to define. Finally, many life and death decisions are not made by rationally considering statistical data only; instead, emotions play an important role in decision-making. It is important to consider them in these conversations. In addition to data information, parents value religion, spirituality, compassion, and hope when making this type of decisions. As a result of their reliance on these values, they generally want physicians to demonstrate compassion and provide emotional support rather than advise on the basis of a protocol.[13]

Accompanying the decision-making process requires an honest and committed communication among all members of the health care team. Many times, the views of family interaction and their emotions are very different depending on the observer. In general, the dialog created between the nurses caring for patients and their families is very close and allows them to gather more details about their knowledge. The physicians may also have a closer view, although they generally do not have a close contact, and this allows them to have a more distant perspective, which is also necessary to find the best way to make decisions. Therefore, both the closeness and smallest details and the distance and its perspective are two sides of the same coin, both necessary to provide the best opportunity for that family.

At this point, we return to a basic question: who is responsible for making decisions? In the field of neonatology, Lynn Gillam highlights the importance of recognizing the gray zone and prioritizing the opinions of parents.[14] Gillam proposes the term "zone of parental discretion" but, as the literal translation to Spanish may lead to misunderstandings, we have chosen to refer to it as "zone of parental informed decision" (*zona de decision informada parental*) because it refers to a situation in which parents will have to face difficult decisions and will need all the information to be able to make them. This zone implies a protected space in which parents can legitimately make decisions regarding their children even if those decisions seem suboptimal to some health care providers (*Figure 1*).

Parents' views and wishes are ethically relevant to decisions about the medical treatment of their children. They are the ones who know their children because they live together (with the exception of newborns admitted to the NICU after birth), are most interested in their well-being (in general), and define the values around which to raise them. Therefore, positions will vary from one family to the other. According to current academic bibliography, the idea of working on agreeing on behaviors to be taken with parents as an integral part of the decision-making process for children is largely uncontroversial. At the same time, while there is recognition that parents' opinions are important and that their wishes should be heeded and respected, there must also be a limit, beyond which parents' wishes may be disregarded.

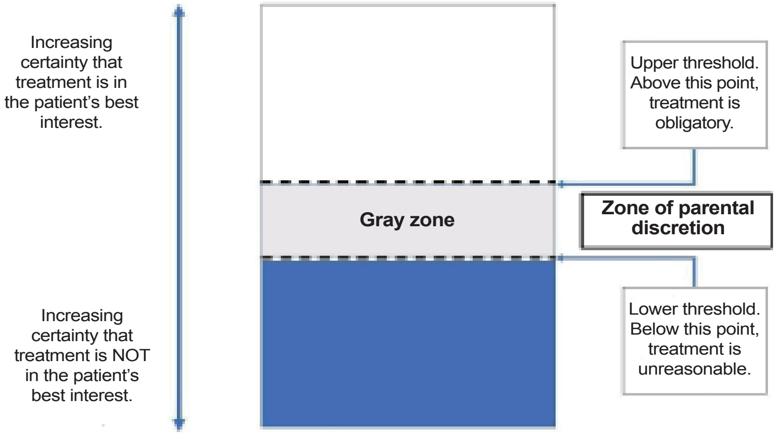
While there is agreement about respecting the zone of parental discretion, there is less agreement on how wide such zone is or what its boundaries are. Gillam proposes that the boundary should be guided by the harm principle: parents should not be able to make a decision "if the child is likely to suffer significant harm from the decision."[14] Wilkinson adds that the boundaries of the zone of parental discretion must also be marked by the possibility of harm to others, i.e., through a violation of the principle of distributive justice.[5]

The model of the physician-patient relationship (physician-parents in this case) considered with this approach has a deliberative (or consensual) nature. On the one hand, parents are considered to be best positioned to understand what behavior is in the best interest of their children (unless they engage in abandonment, neglect or abuse) and, at the same time, it is proposed that such momentous decision-making should be accompanied by the medical responsibility to suggest or recommend actions based on knowledge and experience. Parents should be supported so that they do not feel the full weight of responsibility on their shoulders.

Allowing parents to make choices on behalf of their newborn infants is more respectful of them as individuals than acting as if they had no interest. The active inclusion of parents in decisions about their children should be considered a *prima facie* obligation, i.e., unless there is some specific situation that justifies not including them.

It is very important to understand each individual and their differences, and to respect them. Catalan philosopher Torralba Roselló

Figure 1. In the zone of parental discretion (*zona de decisión informada parental*), treatment may be administered or withheld at the parents' discretion



invites us to reflect on the importance of this, pointing out that pain, losses, failures, and anxieties are perceived by each person from their personal perspective.[15] It is important to understand that the internalization of experiences differs based on the nature of each human being. The Recommendations for managing pregnancy and newborn infants in the limits of viability, developed by a group of professionals in Argentina, emphasize that assistance must focus on receptivity and uniqueness, and underscore that being receptive means being willing to respond to the needs of the person according to their vital rhythm, without accelerating or slowing down their usual processes, and that uniqueness refers to the fact that each person is a unique and unrepeatable being.[13] Annie Janvier is clear about this: “When we truly individualize and personalize our approach, we will contribute to the long-term well-being of the family. It is our obligation and privilege to serve our patients and their families in this way.”[12]

Finally, these issues require a context of maturity that allows the different opinions of the health care team members, that is based on respect and promotes communication among all members, otherwise inconveniences may arise that contribute to what has been called *moral distress*, defined as the painful feelings experienced when a person has clear moral criteria about what she thinks should be done but cannot do so due to external constraints, whether institutional, social or contextual.[16–18] The end result is a negative impact on personal integrity, physical and emotional well-being, job satisfaction, and patient care.

To sum up, there are several challenges that arise in these circumstances:

1. To define whether one is in the gray zone, or zone of parental discretion.
2. To accept that it is likely that not all parties involved agree on the path that seems optimal to follow. It is important to underpin one’s positions, be willing to listen to other opinions and, eventually, to change one’s mind.
3. To understand that, in this zone, parents’ opinions must prevail, even if some members of the team consider it is against the newborn’s best interest.
4. To define the limits of parental authority, i.e., reject decisions that represent abandonment, neglect or abuse by the parents.
5. To involve the entire team in the decision-making process and communicate the decision appropriately.
6. To know that the health care team may also be experiencing moments of uncertainty and, sometimes, lack of clarity, because each situation that calls for an ethical decision also challenges the emotions of each member and leads to their own individual reflection on the values exposed. It is important to consider the concept of moral distress.
7. To provide adequate care in an appropriate way. ■

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