

**BIOETHICAL TRAINING  
OF THE PEDIATRIC  
ONCOLOGY TEAM**

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*Erica Boldrini*

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**Abstract:** With the emergence of Bioethics, autonomy was raised to the status of an ethical/bioethical principle. Autonomy presupposes willingness and ability. The minor does not meet the conditions for autonomous decision-making. Parental authority gives parents the responsibility to decide the lives of their children, always for their benefit. However, faced with life-threatening situations, situations become more challenging: Why do parents insist on obstinate measures? Would the family's obstinacy be supported by medical intervention? What is the best interest of the terminally ill minor patient? Is it possible to end life with dignity, without prolongation or anticipation of death? Reflections like these arrive at a common question: does the team that cares for children with cancer have bioethical knowledge? Can she make decisions without violating principles? The environment and teaching techniques need to facilitate reflection and respectful debate on moral issues inherent to everyday life.

**Keywords:** Bioethics, cancer, child.

"I will apply the regimens for the good of the sick according to my power and understanding, never to harm or harm anyone."

*Hipócrates*

The Hippocratic Oath gives the physician the prerogative to know and determine what is best for his patient, centered on the principles of beneficence and non-maleficence. This (Hippocratic) model lasted for centuries and inspired the paternalistic model, which is no longer accepted in contemporary times.

With the emergence of Bioethics, autonomy was raised to the status of an ethical/bioethical principle, together with justice, operating an empowerment of the patient who, with clear and complete information about his health condition, can

participate in the decision-making process.

Autonomy presupposes willingness and ability, and is concretely manifested in the requirement of free and informed consent as a condition for carrying out morally accepted interventions. Autonomy prescribes freedom, that is, the dignity of being, insofar as what is considered worthy behaves individually.

Bioethics is based on respect for the dignity of the human person, considering this dignity as enunciated by Kant in the categorical imperative: "Act in such a way that you treat humanity, both in your own person and in the person of any other, always and simultaneously as a end and never simply as a means." 1

But what about the minor patient? It does not meet the conditions for autonomous decision-making, so alternative systems such as the surrogate judgment or the best interests model, carried out by surrogate decision-makers, are necessary.

Parental authority gives parents the responsibility to decide the lives of their children, guiding them while they are insufficient to make a decision, always for their benefit, that is, it gives them the task of taking care of their children. In the surrogate judgment, the preferences of adolescent patients can be reliably determined, allowing a broad assessment of values and interests. In children who have never been able to, or who have been previously and can no longer be reliably able, the best interests model is applied.

However, faced with life-threatening situations, such as cancer, are the most challenging situations. Pediatric Oncology is a specialty permeated by questions and this search for answers is a long journey of reflections. It is based on the logic of probability, which reduces the level of uncertainty as much as possible, but it is not possible to eliminate it.

During the course of the disease there is a cloudy period, when defining proportionality is confusing, and it is difficult to determine the exact boundary between reasonable and futile treatment. The advancement of medical technology increases treatment options and decision making becomes increasingly complex. It is important to keep in mind that there are no formal, clearly defined directions for employing either approach.

Rules for selecting, continuing, or discontinuing a cancer-targeted therapy must consider tumor biology, clinical status, symptom burden, prognosis, patient and family preferences, and “new therapies.” The technological imperative presupposes a non-existent certainty. The performance of all available treatment seems to correspond to the interests, however, we know that there is no legal obligation for futile measures (the idea that what you can do to fight against death), since there are treatments that are not justified, because they are not capable of promoting the maintenance of life or do it at the cost of intolerable suffering.

So why do we hear that as long as there is life there is a chance? Why do parents insist on stubborn measures? Have they not been properly communicated? Is the right to information being violated?

Some physicians, out of compassion, communicate unrealistic expectations that may inappropriately alter the choices patients make about treatment. Others, have difficulty accepting that death is sovereign to technology, and that this misperception encourages dysthanasia. Others still use therapeutic obstinacy as a moral defense that “everything has been done”, for fear of being accused of omission.

We can not forget that if this “doing everything” can hurt the *primum non nocere*, then be considered medical misconduct. The right to life is a subjective right, which

establishes prerogatives for the achievement of projects and values, and must not be seen as a duty, or an object of interest only in its permanence.

So would patient/family obstinacy be supported by medical intervention? There is substantial variability in how parents are informed, but also in how this information is absorbed. The impact of the bad news cannot be estimated, because there are particularities of each family nucleus in terms of culture, beliefs, values, way of expressing feelings and doubts. Understanding depends not only on clear communication, but also on the emotional stress and grief they find themselves in.

Another possibility is that the patient/family, even if helped by correct medical practices, will not understand it well enough not to enter the universe of obstinacy. Faced with the possibility of the death of their children, parents often decide for their own interests in maintaining life and not in the presumed interest of the minor.

What is the best interest of the terminally ill minor patient? Not having the possibility of self-determination, is it still possible to end life with dignity, without prolonging or anticipating death?

To make decisions is a routine and it is important that, in addition to technical knowledge, one has bioethical knowledge, because a merely technical decision cannot be the best and, consequently, violates the principle of non-maleficence, injuring the dignity of the human person.

From the above, the question is: does the team that cares for children with cancer have bioethical knowledge? Can she make decisions without violating principles? In highly complex clinical situations, there are many uncertainties regarding the best conduct, the one that will provide the greatest benefit to the patient. The principlist theory

is an indisputable resource, but sometimes insufficient for adequate deliberation and a pertinent decision. What the team understands about a particular intervention is not always what the family accepts or what the patient wants, and in this scenario conflicts arise, making it difficult to solve the problem. 3

Regarding the team itself, a mechanistic, fragmented and reductionist practice is still observed, which establishes superficial bonds, and pays attention to the disease and not to the patient. Technological medicine uses artifacts of all kinds, and it is sometimes difficult to define where the human ends and the machine begins. The characters of the supposed knowledge and the supposed suffering are, above all, people. From actions and reactions, conflicts with biological and psychosocial representations result.4.

Health-related professions have a high demand for morally competent professionals, but when students are trained only to deal with the technical aspects of their profession, not the moral ones. Thus, it is difficult to recognize a moral problem in itself. They are reluctant to accept the idea that decisions are no longer just in their hands, in their conceptions of what is right or wrong, good or bad, fair or unfair.

But... What makes someone have different conceptions about what is right or wrong, fair or unfair? The hypothesis that morality is innate, or capable of being formed through communication or indoctrination, is refuted. Both knowledge and values and morality are the result of an internal process, which emerges as a result of their interaction with the social environment. Social interaction and critical thinking are essential for the development of this (moral) competence.5

The patient sometimes needs a paternalistic relationship and expects from professionals a figure of tutor, as he is unable to fully manifest

his autonomy. At another time, he will demand an informative relationship from the same professional, he will want him to be a specialist who informs. At other times let him be a counselor, and even a friend with whom to discuss difficult decisions. The complexity of management involves putting the patient and their family at the center and adapting to how they change over time. It's not about negotiating, it's about mediating. Mediation stems from communication, understanding and agreements. The mediator tries to generate possibilities and resources. It must comply with the precepts of good clinical practice and one of them is to provide all clarifications about the available forms of treatment, their benefits and possible risks, taking into account the patient's level of education, ensuring that there was the necessary understanding of the information presented. 6

The perspective that has the biopsychosocial model as a reference provides an integral view of being and falling ill that comprises the physical, psychological and social dimensions, which considers the uniqueness of each individual. Intuition and common sense are not enough to reduce the uncertainties characteristic of conflicts present in the clinic. Excellence requires technical accuracy and responsibility in decision making. A relationship of trust, a good communication channel and a systematized process are fundamental elements to articulate the technical and ethical dimensions of the medical act.

But... How does the individual acquire or develop the ability to evaluate moral issues and make decisions? It would be naive to believe that the mere educational action is capable of transforming society, given the complexity of social, economic and political relations. But it is equally naive to imagine that education or educational processes may have no role to play in transformative processes.

Common sense knowledge is not enough for formal discussion. Let us not minimize the importance of theoretical content, of the so-called “toolbox”, but for bioethics it is essential to include practical wisdom that enables the solution of concrete problems in everyday care. There must be specific training, to prevent serious distortions from happening in the understanding of theories that can reinforce prejudices, stereotypes and even pure and simple misinformation. The environment and teaching techniques need to facilitate reflection and respectful debate on moral issues inherent to everyday life. 7

It takes critical-thinking individuals who are able to present and defend their positions with valid arguments rather than force or intimidation. It is the so-called practical ethics: a connecting discipline, which seeks to establish a bridge between theory and practice, which is recognized as one of the greatest challenges of bioethics.

The patient expects, in addition to being treated by a good technician who advises him on the disease in question, that he welcomes

him, embraces him in his entirety. The relationship between health professionals and patients is very sensitive, due to the complexity of feelings involved, due to the uniqueness of values that each one presents, due to the asymmetry between people in unequal conditions. 8

The other cannot be seen as someone to be convinced, but someone with whom to dialogue, stimulating appropriate arguments, provoking cognitive conflicts. We also need to welcome the suffering of the family and for that we need to allow them to express themselves.

Thus, from bedside bioethics (which reconciles prudence, expertise and zeal with beneficence, non-maleficence, autonomy and justice) the patient will no longer be seen from a reductionist perspective of a disease to be understood as a whole.

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