

# *End-of-life decisions in pediatric intensive care. Recommendations of the Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care (SARNePI)*

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## **Summary**

End-of-life decisions represent one of the most complex and challenging issues in pediatric intensive care. These recommendations aim to offer Italian pediatric intensive care unit (PICU) teams a framework for the end-of-life decision-making process. The paper proposes a process based on the principle that the use of a diagnostic or therapeutic tool must comply with a 'criterion of proportionality'. Appropriately informed parents, as natural interpreters and advocates of the best interests of their child, can contribute in assessing the burdensomeness of the treatment and determining its proportionality. The decision to limit, withdraw or withhold life-sustaining treatments considered disproportionate represents a clinically and ethically correct choice. This decision should be made (a) collectively by PICU team and the other caregivers, (b) with the explicit involvement of parents, and (c) noting in the patient's clinical record the decisions taken and the reasons behind them. The withdrawing or withholding of life support can never entail the abandonment of the patient nor the withdrawal of any therapy aimed at treating any form of suffering. No action aimed at deliberately hastening the death of the patient is ever acceptable. These recommendations advocate a decision as far as possible shared by patient (whenever feasible), parents and caregivers. Ensuring that all involved are kept fully informed and that there is open and timely communication between them is the key to achieving this. It is the physician in charge of the patient's care and the head of the unit who bear the main responsibility for the final decision.

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## Introduction

Intensive care is the branch of medicine concerned with the diagnosis and treatment of patients with pathologies that put their lives in immediate danger, owing to acute disorders of vital organs or functions (1,2). The category of critically ill patients also includes those who, because of their primary pathologies or the treatment they have undergone, present a high risk of developing predictable serious complications (1,2). The above considerations apply equally in the case of pediatric patients.

By its very nature, intensive care medicine means that intensivists, including those in pediatric units, have to confront crucial life-and-death decisions concerning their patients. Even more than in other disciplines, the intensive care medicine comes up against the *therapeutic limit*: modern medicine, however sophisticated and 'aggressive', often is not able to restore patients to health, to save their lives or even merely to have a significant impact on the evolution of their illness. Society today frequently has little awareness of this limit, covers up and censors death (3), and sometimes entertains unrealistic expectations from medicine (4).

The fact that intensive care not infrequently proves ineffective in coping with the gravity of the patient's illness, and moreover that the care may itself increasingly give rise to conditions of limit, necessarily raises many questions, clinical and ethical, as to the advisability and the acceptability of maintaining life support. These issues have generated serious in-depth debate in Italy as elsewhere (3,5–10). In the pediatric field, the situation is further characterized by two specific aspects, namely the frequent impossibility of involving patients in the decision-making process (owing to their age, their limited awareness of self, and of what is happening, etc.) and, as a result, the particular role which parents take on in interpreting and advocating the good of their child.

Currently, the majority of child deaths in developed countries in the west take place in hospital (11), over 70% of them in intensive care units (ICUs) (11–14).

The end of life and the decision-making process, which may lead up to and accompany it, constitute a complex issue both clinically and ethically. This *complexity* needs to be confronted seriously, calmly, and with methodological rigor.

In Italy, to date, no scientific Society in the pediatric field has drawn up any specific recommendations on end-of-life issues relating to children. With this paper, the Bioethics Study Group of the Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care (Società Italiana di Anestesia e Rianimazione Neonatale e Pediatrica: SARNePI) aims, on behalf of SARNePI, to offer an initial contribution on the subject of end-of-life decisions in pediatric intensive care medicine.

## End-of-life decisions in pediatric ICU

### *Dignity of the patient*

Every patient, even with physical and/or mental disabilities, maintains his/her dignity during illness and on the approach of death. Every patient, whatever his/her clinical condition, remains fully a person in all circumstances, and as such deserves total attention and respect. In each stage of the illness, therefore, every reasonable effort must be made to ensure effective treatment and palliation of the symptoms according to the best possibilities and the most appropriate standards.

### *Proportionality of treatment*

The availability of a diagnostic or therapeutic tool does not in itself impose the obligation to use it. The use of a diagnostic or therapeutic tool must comply with a *criterion of proportionality*, even in intensive care. This criterion results from comparing and weighing up the *appropriateness* of the means under consideration (including factors such as suitability, efficacy, chances of success, durability of the result, practical feasibility, complications and negative effects, economic cost, etc), as against its *burdensomeness* (i.e. the cost in terms of suffering caused to the patient in relation to the

expected benefits). The proportionality of the treatment is defined by both the physician and the patient, on the basis of their specific competences and capacities (15). It is the specific competence of the physician, on the grounds of his/her professional skills, to precisely define the appropriateness of the means. Proportionality cannot therefore be assessed in an abstract or generic fashion for a particular diagnostic or therapeutic tool, but has to be evaluated for each individual patient, considering his/her particular clinical history, objective state of health, needs, psychological resources, and personal values (ascertained through careful listening, open dialogue, and with sufficient time). Neither the physician nor the patient (or his/her parents) may impose or demand treatment not judged to be proportionate.

In the pediatric field, where adequate involvement of the patient in the decision-making process is only rarely possible, the parents constitute the natural interpreters and advocates of the best interests of their child. Appropriately informed parents can therefore contribute to understanding the degree of burdensomeness of the treatment and to determining its proportionality.

Both parents and caregivers should exercise great prudence in considering the child's clinical condition and/or disability as 'intolerable'. People with disabilities can also live fulfilled lives and caregivers should be aware that what they themselves find intolerable might not be intolerable to the patient (and/or the parents) (10).

Every effort should be made to ensure that decisions regarding the proportionality of treatment are correctly reached on the basis of sound and rigorous *clinical criteria* (diagnosis, possible therapies, effectiveness of treatments carried out, prognosis). In some circumstances, however, our current knowledge does not permit precise definition of the diagnosis and prognosis (such as in certain congenital syndromes which, to date, lack a precise etiology). Thus, the physician may be faced with the objective and devastating consequences of an illness without being in a position to 'put a name to it', and may therefore be called upon to take decisions in situations of particular *uncertainty*. This aspect, intrinsic to medicine, needs to be openly acknowledged and should lead on one hand to great prudence when taking decisions,

and on the other to deploying and involving all possible competences to improve accurate diagnosis and prognosis.

The intensivist should refrain from pursuing with unreasonable obstinacy 'partial' results or objectives (i.e. those having no significant impact on the patient's clinical condition and/or the evolution of the disease), which in fact could be immaterial or harmful to the overall good of the patient.

### *End-of-life decision-making process*

The decision to *limit, withdraw, or withhold life-sustaining treatments* considered disproportionate (according to the criteria outlined above in the paragraph '*Proportionality of treatment*'), thus allowing the evolution of the illness to take its natural course towards death – without forgoing any assistance and treatments considered appropriate – represents a clinically and ethically correct choice (6–8,10,16). Apart from the exceptional cases, such decisions are not made in a single step but via a specific *decision-making process*.

Under normal circumstances, therefore, the decisions to limit, withdraw, or withhold life-support treatments should be made:

1 *collectively* by ICU staff, together with all the caregivers who can contribute to defining as precisely as possible the diagnosis, prognosis, and appropriateness of the treatment:

- intensivist;
- attending physician (pediatrician, surgeon, etc);
- family pediatrician;
- nurses;
- consultants for specific problems (such as palliative care specialist);

2 *with the explicit involvement of parents*, as the natural interpreters of the best interests of the patient and with a particular role in defining the proportionality of the treatment;

3 *noting in the patient's clinical record* the stages of the decision-making process, the decisions taken and the reasons behind them.

From the ethical standpoint, there is no difference between withdrawing and withholding treatments (whether pharmacological or non-pharmacological, such as mechanical ventilation and dialysis) despite the different emotive impact (5,6,8,10).

The decision-making process which precedes and accompanies the end of life needs to be carefully aimed to:

- 1 precisely describe the patient's clinical history;
- 2 identify the possible options for diagnosis, treatment, and assistance;
- 3 identify the persons involved and their specific responsibilities;
- 4 define the values involved and the ethical aspects of the various possible options;
- 5 assess the legal aspects (particularly in view of the absence in Italy of any specific laws regarding end-of-life decisions).

### *Sharing decisions*

Decisions should be made with the parents on the basis of knowledge and trust (10). It is crucial that end-of-life decisions be reached by means of decision-making paths that are *ethically considered, supported by appropriate arguments, explicit*, and as far as possible *shared* by those in the 'relational triangle' constituted by patient, parents, and caregivers.

The role of parents as natural interpreters and advocates of the best interests of their child combines with the ethical and professional obligation of the physician towards the patient to initiate and maintain only such treatment as is proportionate (see above paragraph '*Proportionality of treatment*').

Although parents' participation in the end-of-life decision-making process is therefore very important and should be supported in every way, it cannot be imposed on them. Parents should be encouraged to express their opinions and participate in meetings, but they should be allowed the freedom to choose their own level of involvement in the end-of-life decisions regarding their child (information only, participation in meetings, sharing the decision-making, etc.). In the course of the decision-making process and in reaching the final decisions, consideration must be given to the particular situation of stress (accompanied by fragility, guilt, feelings of inadequacy, anxiety, and depression, etc.), which parents often have to deal with on account of the serious condition of their child.

When the issue to withhold or withdraw life support is raised (by clinical team members, patient, or parents), the physician in charge of the patient's care and the head of the unit should lead the

decision making process (10) and should make every effort to achieve the objective of a shared decision (3), doing everything possible to ensure that health care team, parents, and patient are fully informed and that communication between them is open and timely. The physician in charge of the patient's care and the head of the unit bear the main responsibility for the final decision (3,10,17). This – even if hopefully made with the consent of the parents – cannot ultimately be left to them, with the risk of thus giving rise to or fuelling an intolerable sense of guilt. A shared decision is not automatically an ethically appropriate decision (the ethical acceptability of choices and actions is mostly determined by intentions and means employed). The sharing of decisions, no matter how widely, must always be subordinated to the goal of serving the best interests of the child.

If the circumstances permit it, every effort must be made to ascertain and to assess, in line with the capabilities and condition of the patient, the perception that the child has of the illness and of its evolution, the burdensomeness of the treatments, and his/her wishes regarding their continuation.

The decision-making process should also be carried out through specifically dedicated formal meetings, to be communicated in good time to everyone involved (caregivers, parents, etc.), to permit the widest and best informed participation possible (18).

Whenever reasonable doubts persist as to the possible efficacy of the treatment, life support must be maintained, and a precise clinical objective and/or a definite time limit may be established (19), specifically to assess the actual efficacy of the means adopted (*provisional intensive care*).

Similarly, whenever substantial doubts persist in defining the best interests of the child and the proportionality of the treatment, life support must be maintained.

The decision to limit, withdraw, or withhold life support can never entail the abandonment of the patient nor the withdrawal of any of the forms of therapy (pharmacological or non-pharmacological) aimed at treating any form of suffering and ensuring as far as possible the patient's physical, psychological, and spiritual wellbeing, according to his/her needs and convictions. However, no action aimed at deliberately hastening the death of the patient is ever acceptable (3,6,7,10,20).

If circumstances permit and if it is the wish of the patient and/or the parents, withdrawal of life support may be followed by transfer of the patient to another hospital ward or by discharge to his/her home. However, adequate levels of care and assistance must be maintained, especially as regards pain relief.

### *Managing conflict*

In confronting the gravity of the patient's clinical condition and the end-of-life decision-making process, conflicts may arise among physicians, between physicians and nurses, between the clinical team and parents, or between the parents themselves. Such conflicts are a natural expression of the complexity of the events and of the values involved and should be acknowledged, faced calmly, and with reciprocal respect. Timing and methods should be established to achieve truly effective communication among clinical team, patient, and parents (9,21). Every effort should be made to ensure that information is communicated clearly and is fully understood; that parents are encouraged to ask questions and are given adequate replies; that doubts are addressed and reassurance provided as to the determination not to 'abandon' the patient even in the case of limitation or withdrawal of treatment.

In the event that disagreements persist, it is advisable to ask the opinion of someone from outside the team with recognized professional competence. In addition, the advice of the Unit for Bioethics may be sought, if there is one, or the opinion – if time and circumstances allow it – of the Ethics Committee. Authoritative as the Unit for Bioethics or the Ethics Committee is, their opinions on ethical matters cannot be considered definitive – the responsibility for decisions and actions belongs to those who carry them out – but they can give invaluable assistance in understanding the values involved and the ethical aspects of the various possible alternatives. Finally, in extreme cases, where the conflict proves irresolvable, a proposal to transfer the patient to another hospital or recourse to the courts may be considered.

As the basic criterion is in the best interests of the child, it follows that the wishes expressed by the parents, even when they have been properly informed, can have no binding value should they be manifestly in conflict with that interest (5,10).

### *Time and context*

The most appropriate *time* and *context* for listening to patient and parents, informing them, and determining with them, which treatments may be considered suitable and proportionate, is not when the acute event is faced in an emergency by the intensivist. When the evolution of the illness allows it, it is crucial for patient and parents to explicitly confront these delicate issues with the attending physician, determining in advance – that is, before the need for intensive care may arise – both an agreed diagnostic–therapeutic path and the limit up to which the treatment may be considered acceptable and proportionate. In this decision-making process, also the intensivist, if requested, may expediently offer his/her professional opinion.

### *Allocation of resources*

There is an ethical responsibility regarding the fair use of medical resources, especially if they are limited. This responsibility lies both with the intensivist, who has to assess the suitability of admission of a patient to the ICU, and with the physician, who requests such admission.

The approach of inevitable death is not an appropriate criterion for admission of a child to ICU (1,2). The ICU is not a 'place for dying', but rather the 'place for the fight for life'. It is the duty and responsibility of every pediatric physician to look after his/her patient throughout the advanced stages of illness and on the approach of death. This responsibility cannot be delegated to the intensivist, who may however offer his/her competence, together with other consultants, to provide the best treatment for the symptoms.

### **Additional issues and future prospects**

Certain additional issues may usefully be taken into consideration and various prospects may be suggested:

#### *Training*

Issues such as end-of-life ethics, end-of-life care, and communication should be formally recognized as specific areas of competence for the intensivist

(3,10,22,23). As such, it is to be hoped that they will be included in the training curriculum of the specialization schools of anesthesia and intensive care and will represent a normal objective of updating procedures (24). The same considerations may be made for the training (university and post-university) of nurses.

### 'Open' ICUs

Although Italian ICUs currently have restrictive visiting policies (25), there is no solid scientific basis for limiting visitors' access to ICUs and keeping them 'closed' (26–28). An 'open' ICU may be defined as a unit in which one of the objectives of the staff is a rational reduction or abolition of all unjustifiable temporal, physical, and relational limitations (28). It is particularly important that restrictions to the constant presence of parents and to visits from loved ones be lifted. An 'open' ICU offers the possibility of ensuring care and attention even when the *therapeutic limit* has been reached and death is imminent. 'Opening' intensive care is not only a useful and effective strategy for patient and family but also an expression of respect and greater care towards a person living through the difficult time of illness.

### Home care, palliative care, and hospices

It is to be hoped – if circumstances permit – that children can face the final period of their life and their death in their own home, in the company of their parents, and the most important figures in their affective sphere. Children, their parents, and families should be given proper assistance with the necessary support from physicians and nurses (*palliative care*), and with psychological help. This requires the provision of a suitable home care network with specific competence in pediatrics. In the final stages of life, a further, valuable contribution may also be offered by hospices, whose competences should – at least in Italy – be widened to include caring for children.

### Social awareness

It is ever more apparent that the *media* should contribute responsibly to fostering in Italian society,

an image of medicine which is more accurate and in line with reality. Certain forms of media sensationalism on the subject of science or health lead to the creation of a view of medicine in the collective imagination which is omnipotent, with illnesses brought firmly under control and death conquered. This frequently gives rise to the demand that treatments be continued at all costs, or that every possible diagnostic and therapeutic tool be deployed, without any serious reflection as to the proportionality of the treatments in question. It is a responsibility of everyone to increase awareness of the limits of human action, particularly in the field of health, even outside the restricted context of medicine and hospitals.

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