

Guidelines regarding ineffective maintenance of organ functions (futile therapy) in paediatric intensive care units

Alicja Bartkowska-Śniatkowska¹, Elżbieta Byrska-Maciejasz², Maciej Cettler³, Maria Damps⁴, Konrad Jarosz⁵, Magdalena Mierzewska-Schmidt⁶, Marek Migdał⁷, Irena Ożóg-Zabolska⁸, Andrzej Piotrowski⁹, Marcin Rawicz¹⁰, Magdalena Świder¹¹, Mariola Tałałaj¹², Marzena Zielińska¹³

¹Department of Paediatric Anaesthesiology and Intensive Therapy, Poznan University of Medical Sciences, Poznań, Poland

²Department of Anaesthesiology and Intensive Therapy, University Children's Hospital of Cracow, Poland

³Department of Anaesthesiology and Intensive Therapy for Kids, Provincial Polyclinical Hospital in Toruń, Poland

⁴Department of Anaesthesiology and Intensive Care, Upper Silesian Child Health Centre, Faculty of Medical Sciences in Katowice, Medical University of Silesia, Poland

⁵Department of Clinical Nursing, Pomeranian Medical University, Szczecin, Poland

⁶Department of Paediatric Anaesthesiology and Intensive Therapy, Medical University of Warsaw, Poland

⁷Children's Memorial Health Institute, Warsaw, Poland

⁸Department of Paediatric Anaesthesiology and Intensive Therapy, COPERNICUS PL, Gdańsk, Poland

⁹Department of Neonatology, Medical University of Warsaw, Poland

¹⁰The Warsaw Hospital for Sick Children, Warsaw, Poland

¹¹Department of Anaesthesiology and Critical Care Medicine, Clinical Provincial Hospital No. 2 in Rzeszów, Poland

¹²Department of Anaesthesiology and Intensive Care of Children and Adolescents with the Postoperative and Pain Management Department, Białystok Medical University, Białystok, Poland

¹³Department of Paediatric Anaesthesiology and Intensive Care, Wrocław Medical University, Wrocław, Poland

Abstract

In Poland, guidelines for the management of ineffective treatment of children in neonatal and paediatric departments developed by the Polish Neonatal Society and the Polish Paediatric Society, have been published. The specific problems of futile therapy in paediatric anaesthesiology and intensive care units should be defined and solved separately. For this purpose, the guidelines presented below were prepared. They present the principles for managing children for whom therapeutic options available in paediatric anaesthesiology and intensive care units have been exhausted and ineffectiveness of maintaining organ functions, i.e. futile therapy, has been suspected. The decision to withdraw futile therapy of a child is undoubtedly one of the most difficult for both doctors and parents, and for this reason, it should be made collectively, respecting the dignity of the child and his/her parents or legal representatives, and continuing the management aimed at relieving the child's pain and suffering, as well as minimising anxiety and fear. Due to the small amount of reliable evidence-based data, the guidelines constitute the consensus of the Group of Experts and are dedicated to minor patients treated in paediatric anaesthesiology and intensive care units.

Keywords: futile therapy, palliative care, paediatric intensive care unit.

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CORRESPONDING AUTHOR:

Prof. Alicja Bartkowska-Śniatkowska, Department of Paediatric Anaesthesiology and Intensive Therapy, Karol Marcinkowski University of Medical Sciences in Poznań, Poland, e-mail: asniatko@ump.edu.pl

BACKGROUND AND RATIONALE

The death of a child is different from the death of an adult. It concerns a person on the threshold of life, on whom the attention of the whole family is focused. The death of a child violates the foundations of its existence and becomes a particularly difficult and sometimes even unacceptable experience for parents [1, 2]. This situation is complemented by the lack of our own experiences with the death of

relatives, acquired in the past in multigenerational families with many children, in which passing away of successive generations made it possible to become familiar with death and, in a way, prepare for it [3]. The death of a child is always shocking and devastating [4]. In many cases, parents are unable to come to terms with the death of their child and some of them unknowingly make the dying child suffer by exerting various pressure on the medical

team, being convinced that they are doing it for the child's sake [5, 6].

The term "persistent therapy" means repetitive activities that last for a long time but it does not refer to the consequences of such procedures. "Futile therapy", on the other hand, refers to the goal of these activities, which cannot be achieved. In the Polish medical nomenclature, both terms are used synonymously/interchangeably, which is not correct. The concept of persistent therapy appears in the document issued in 2011 by the Polish Paediatric Society, entitled "Withholding and withdrawing life-sustaining medical treatment in children. Guidelines for doctors" [7]. In the document entitled "Guidelines regarding the ineffective maintenance of organ functions (futile therapy) in ICU patients incapable of giving informed statements of will", issued in 2014 by the Polish Society of Anaesthesiology and Intensive Therapy, the concept of futile therapy was used as a more precise and appropriate [8].

So far, guidelines have been developed by the Polish Paediatric Society [7] and the Polish Neonatal Society [19]. However, they do not apply to patients admitted to paediatric intensive care units, where we face the inevitable end of life and the question of whether we act in the best interest of the dying child or we succumb to family pressure and our own mental and moral limitations [10, 11]. The specific problems of futile therapy in paediatric anaesthesiology and intensive care units should be defined and solved separately. For this purpose, the guidelines presented below were prepared. They present the principles for managing children for whom therapeutic options available in paediatric intensive care units have been exhausted and ineffectiveness of maintaining organ functions, i.e. futile therapy, has been suspected, taking into account respecting child's dignity and relieving pain or suffering.

We should strive for a situation in which legal representatives, most often parents, accept the fact that their child's therapy is futile, or at least understand the reasons why the treatment team decided so.

Their consent should not be required. The decision to withdraw futile therapy, undoubtedly one of the most difficult, according to Article 37 of the Act on the Professions of Physician and Dentist [14], should be made collectively. Since the decision concerns withholding or withdrawing certain forms of treatment because of their futility, its basis should be sought in Article 38 of the aforementioned Act, which refers to the right to decide to withdraw or withhold treatment. Such a decision must be made collectively and documented in writing in the medical records.

The legal representatives should represent the interests of their children; however, they are often

unable to accept death and may more or less consciously try to keep the child alive at all costs, contributing to his/her suffering [12, 13]. That is why the doctor's task is to encourage the relatives to understand the child's situation and accept his/her point of view, not their own. An additional difficulty may sometimes be caused by the parents' lack of agreement in their assessment of the situation. The doctor is not obliged and should not fulfil the parents' demands regarding the initiation or continuation of futile therapy. In such situations, acting in accordance with the parents' wishes would be inconsistent with the constitutional principle of respecting human dignity, as well as with Art. 4 of the Act on the Professions of Physician and Dentist, and would violate the patient's right to die with dignity and peace (Art. 20 paragraph 2 of the Act on the Patients' Rights and Patients' Rights Ombudsman) [14, 15].

It is worth emphasising that sometimes legal representatives are the first to address the issue of medical futility in their child. Such situations are especially likely when the child is treated in various medical institutions and there is no permanent attending doctor. The parents' wish to end the therapy, which in their opinion is futile, as well as the lack of their consent to stop it, is not binding on the doctor. In such a situation, when the doctor considers it justified to continue the treatment, according to Article 34 (6) on the Professions of Physician and Dentist [14], he/she may undertake medical activities against the will of the legal representative only after obtaining the consent of the court. Therefore, to continue treatment against the will of the legal representatives, it is necessary to obtain the consent of the court, and thus the doctor is obliged to apply for it.

GUIDELINES METHODOLOGY

The guidelines were developed by the Group of Experts consisting of specialists in anaesthesiology and intensive care who work in the paediatric anaesthesiology and intensive care units, established by the Paediatric Anaesthesiology and Intensive Care Section of the Polish Society of Anaesthesiology and Intensive Therapy. Due to the limited access to reliable evidence-based data, the guidelines constitute the consensus of the Group of Experts and are designed for minor patients treated in paediatric intensive care units.

GUIDELINES REGARDING INEFFECTIVE MAINTENANCE OF ORGAN FUNCTIONS (FUTILE THERAPY) IN PAEDIATRIC INTENSIVE CARE UNITS

It is not always easy to determine at what point intensive therapy becomes futile [16, 17]. Some examples of clinical situations in which medical futility should be considered are presented in Table 1.

TABLE 1. Examples of clinical situations in which medical futility should be considered

Clinical situation	Examples
Diseases and conditions which can be treated but treatment may be ineffective and futile	Neoplasms Chronic failure of the heart, liver, kidneys Children after subsequent unsuccessful transplantations Advanced spinal muscular atrophy (SMA) Chronically ventilated children (e.g. spinal muscular atrophy) Some metabolic diseases
Diseases and conditions in which premature death is inevitable, although, with the use of advanced medical measures, the child's health may be relatively satisfactory for a long time	Cystic fibrosis disqualified from transplantation Advanced neuromuscular diseases (e.g. muscular dystrophies) Complex heart defects that cannot be fully corrected, e.g. HLHS
Progressive diseases and conditions in which there is no causal treatment, although survival can be long-term	Advanced metabolic and neurodegenerative diseases
Irreversible diseases and conditions, but not progressive, leading to severe disability; increased risk of premature death results from the tendency to complications, e.g. frequent infections, pneumonia, aspiration	Severe cerebral palsy; congenital, post-traumatic, post-inflammatory and hypoxic damage to the central nervous system
Lethal diseases or conditions in which intensive care should not be undertaken and palliative care is always indicated	Edwards' syndrome Patau's syndrome
Congenital anomalies in newborns and/or preterm newborns who due to the nature of the defects, extreme prematurity and/or its complications have no chance to live in an acceptable condition	Potter's syndrome An extreme form of diaphragmatic hernia with severe, bilateral pulmonary hypoplasia Concomitant severe defects, e.g. of the central nervous system and heart, diaphragmatic hernia, or myelomeningocele Massive central nervous system haemorrhage
Undiagnosed children, despite the use of available diagnostic methods, in whom long-term (for at least several months) observation indicates severe, irreversible functional damage causing suffering to the child	A child with no or minimal contact with the environment, showing no developmental progress, suffering from recurrent seizures and/or spasms
Patients treated in ICUs, in whom therapeutic options have been exhausted and/or a vicious circle of further complications has developed, recovery is most unlikely, and continuation of treatment is associated with suffering of children and their families	A patient treated with ECMO, who had extensive central nervous system haemorrhage A premature infant with grade IV central nervous system haemorrhage and secondary hydrocephalus, with bronchopulmonary dysplasia, persistently ventilated, with a ventriculoperitoneal shunt, developing NEC and shunt infection, followed by sepsis and renal failure

Decision-making process in chronic diseases

In the case of chronically ill patients with a poor or doubtful prognosis, the first talks with parents should be carried out by a paediatrician or neonatologist, a palliative medicine doctor (if the child is under the care of a hospice) and an anaesthesiologist taking care of the child receiving mechanical ventilatory support at home [14–18]. The doctor's task is to prepare the parents for treatment failure, even if the child's condition is initially stable. In some situations it is best to refer the child to a hospice at an early stage. The hospice will provide the patient with full, professional palliative care at home, thus saving unnecessary and distressing hospitalisations [17]. In the event of an unsuccessful prenatal diagnosis, a plan for such management may be established and approved by parents before the child is born. It often happens that the initial condition of the patient justifies the full treatment, while the duty of the doctor treating a child with advanced incurable chronic disease is to

periodically assess the balance of benefits and losses resulting from the treatment. Talking to parents at an early stage of the disease allows them to prepare for treatment failure and to accept decisions, which also include the lack of indications for unjustified admission to the paediatric intensive care unit [19–21].

Emergency decision-making process

In the case of emergencies, when the child was previously healthy, parents are usually under enormous stress related to an unexpected and extremely difficult situation. Information about an unfavourable prognosis and irreversibility of a child's condition may evoke very different reactions – from doubt and denial to aggression.

Conversations with parents require a lot of tact, patience and, at the same time, openness. It may be helpful to involve appropriate specialists from outside intensive care, especially providing psychological support to parents in this difficult situation [22].

TABLE 2. List of procedures that will be continued as palliative care

Palliative care plan	
1	Basic nursing procedures (bedsore prevention, maintenance of proper body temperature, etc.)
2	Administration of drugs and use of procedures alleviating pain, fear, anxiety, and other symptoms of suffering
3	Enteral feeding (including a gastric tube, PEG – if tolerated)
4	Hydration, intravenous glucose
5	Relieving dyspnoea
6	Psychosocial support

TABLE 3. List of therapeutic procedures that will be withheld or withdrawn in ICUs

	Type of procedure	Withholding	Withdrawing
1	Cardiopulmonary resuscitation		
2	Mechanical respiratory support		
3	Pharmacological and electrical support of the cardiovascular system		
3	Antibiotic therapy		
5	Parenteral nutrition		
6	Transfusion of blood products		
7	Surgery and other invasive procedures*		
8	Mechanical circulatory support		
9	Extracorporeal respiratory support, e.g. ECMO		
10	Renal replacement therapy		
11	Extracorporeal liver support		

*Does not concern the procedures improving patients' comfort

Decision-making process in paediatric intensive care units

In both cases, i.e. chronic diseases and emergencies, the decision to initiate palliative procedures must be based on the full conviction and evidence of poor prognosis, confirmed by diagnostic tests and opinion of competent specialists [23, 24]. Such a decision should be made collectively; it often takes time to make it, but it should not be excessively delayed. Before making the decision, it is important to obtain the opinion of people involved in the treatment and care of the child. It is very important that the therapeutic team act in accordance with the best interests of the child, taking into account the current medical knowledge, the opinion of other specialists, and therapeutic options [25, 26]. In the case of doubt, additional opinions should be obtained, and a wider group of specialists should be involved in the decision-making process, for example by creating formalised interdisciplinary commissions in hospitals to support and/or participate in the decision-making process. If the child is able to express his/her opinion and participate in making decisions about the scope

and methods of treatment, this opinion must also be taken into account.

The decision to withdraw futile therapy should be made by at least two anaesthesiology and intensive care specialists, in consultation with a doctor and/or a team of other specialists involved in the therapeutic process, in consultation with the head of the ward or a person authorised, and consistently followed by the entire medical team. The decision should not be left to the doctor on duty.

Any decision to withhold or withdraw futile therapy has to be recorded in the patient's medical history. The parents must be informed of it, and the doctor should record this fact in the medical records. It is also advisable to note the parents' opinions in this regard. The documentation should specify in detail the limitation of the therapy, i.e. which procedures will be performed/continued, if necessary, and which will be withheld or withdrawn. The presented form can be used to document a further management plan. The first part contains palliative management, which will be continued for each patient (Table 2). The list of procedures is intended to show parents that the decision to initiate palliative care does not mean the end of caring for their child. The second part of the form contains procedures that can be undertaken or not and will be continued or withdrawn if they have already been initiated, but their continuation is medically futile. Withdrawing particular procedures must not be associated with additional suffering for the patient (Table 3).

It is worth noting that in the case of intensive care procedures, such as mechanical ventilation, it is easier to withhold than to withdraw them, although, from the ethical point of view, both measures are considered to be equivalent.

Palliative care

The decision to withdraw futile therapy means discontinuing therapeutic activities that do not lead to the patient's recovery but only prolong the process of dying. The moment of making such a decision is the transition from therapeutic measures to palliative care [27, 28]. The medical procedures that are not able to cure the patient are withdrawn, and those aimed at ensuring comfort in the last stage of life will be implemented and/or continued. When further support of organ functions is no longer beneficial for the child, cannot change the unfavourable prognosis, and is considered futile, palliative care begins to play a dominant role in managing patients in intensive care units. Palliative care is a holistic approach aimed at preserving the dignity of the child and his/her family and meeting the physical, mental, and spiritual needs of the patient in the termi-

PROTOCOL

PROTOCOL OF MANAGEMENT REGARDING INEFFECTIVE MAINTENANCE OF ORGAN FUNCTIONS (FUTILE THERAPY) IN PATIENTS OF PAEDIATRIC INTENSIVE CARE UNITS

Patient's name:

Personal Identity Number (PESEL):

According to the current state of medical knowledge, it should be stated that the patient's organ failure is irreversible and permanent. In this situation, undertaking and continuing specific methods of maintaining the functions of organs becomes a futile therapy, thus harmful to the patient.

Taking into account the current clinical condition of the patient, after careful reading the medical documentation and presenting the current health situation to the patient/parents/legal representatives, a decision is made to stop the futile therapy and start palliative treatment of the patient.

Clinical, ethical, and environmental considerations were taken into account when making this decision, and a list of procedures that will be continued as palliative care and a list of therapeutic procedures that will be withheld or withdrawn was established.

CLINICAL ASPECTS

Primary diagnosis:

Current clinical condition and therapeutic problems:

Consultants' opinions (if necessary):

ETHICAL AND ENVIRONMENTAL ASPECTS

Since the therapy is futile and the patient's organ function is ineffective, palliative procedures will be carried out to ensure the best possible comfort for the patient. Specialist nursing care will be continued, as well as relieving symptoms such as pain, anxiety, dyspnoea, convulsions, or fever.

The patient will be hydrated and fed as needed. Constant contact with parents, close relatives, and those supporting the patient will be ensured, depending on the needs and organisational possibilities.

To determine the best interests of the patient in his/her current condition, the following people were talked to:

Patient (if possible):

Family members/close relatives or friends (name, kinship/relations):

1)

2)

3)

The following issues have been discussed:

- 1) Possible past declarations of the patient's will to continue life-sustaining procedures in a situation comparable to the current one.
- 2) Possible previously expressed wishes of the patient regarding management in the life-threatening /end-of-life situations that his/her family or close friends are aware of.
- 3) Moral and ethical beliefs accepted by the patient.
- 4) Patient's current state of awareness and prognosis concerning survival, clinical improvement, recovery, and rehabilitation after discharge from the ICU.
- 5) Currently used treatment methods, including their effectiveness and invasiveness, a plan for further management.

STATEMENT

Withholding or withdrawing of the above-mentioned procedures (Table 2) is fully justified. Their initiation or continuation will be medically futile and harmful to the patient.

1) Specialist in Anaesthesiology and Intensive Care

Name

Signature

Date

2) Specialist in Anaesthesiology and Intensive Care

Name

Signature

Date

3) Head of Department

Name

Signature

Date

4) Medical Specialist

Name

Signature

Date

nal phase of the disease. The procedures protecting physical functions include pain relief as well as prevention of dyspnoea, cold, and hunger.

Meeting the mental and spiritual needs of the child requires proper preparation of the environment and constant cooperation of the medical team with parents and, if possible, with the child. These activities include:

- preparation of the room, taking into account the comfort of the child and his/her family:
 - an isolated room (if possible),
 - a dedicated nurse (if possible),
 - avoiding noise and excessive lighting,
 - liberalisation of the visit scheme (constant presence of parents, possible visits of those who do not belong to the family); it may be necessary to equip the room with additional elements.
- patient preparation:
 - comfortable position,
 - avoiding unnecessary monitoring, reducing lights of screens,
 - avoiding blood sampling,
 - removal of unnecessary drains, catheters, vascular accesses, etc.
- staff preparation:
 - a plan for the management of a terminally ill child should be discussed with the medical team,
 - attention should be paid to the fact that all staff should be focused on preserving the dignity of the child and his/her family in the final stage of the disease; in particular, potential conflicts with parents should be avoided,
 - after the child's death, the family should be provided with a "time of silence"; the family should be allowed to stay and say goodbye in privacy, without the presence of staff members or time pressure [29–31].

The ABCDs of dignity-conserving care (attitude, behaviour, compassion and dialogue), which is a set of principles defined in Anglo-Saxon literature, may be useful [30].

- Attitude: we should make sure that our life experiences do not affect the nature of the care provided.
- Behaviour: it is necessary to make it clear to the family that the patient is important to us; do not avoid eye contact during the conversation, look in the eyes, and do not use specialised language.
- Compassion: sensitivity to suffering and desire to bring relief.
- Dialogue: expanding the level of dialogue: respect the child's personality traits, encourage the family to recall memories, strive for the presence of people who could help the family survive difficult moments.

In situations that cause conflicts between the attitudes of medical staff and the child's family, it may be helpful to seek the help of other specialists, for example in the field of palliative medicine or clinical psychology.

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