

Paediatric palliative care – a personal perspective

Tomasz Dangel considers the difficult questions which arise in the treatment of terminally ill children, and the decisions that have to be made about palliative care and the cessation of active interventions

Life is not an absolute good and death is not an absolute evil¹

Medical treatment decisions for children with incurable diseases are very difficult. Healthcare professionals face the following questions:

- Have all possibilities of curative treatment been exhausted?
- Are life-prolonging methods appropriate?
- Is the child to be informed about the poor prognosis?
- Is further treatment agreeable to the child?
- Who is to care for the child in the terminal phase?
- Where is the child to die?

Current knowledge and technology allow physicians to predict fairly accurately the probability of anticancer treatments being successful, yet all children cannot be cured. The cessation of treatment, which occurs when the negative effects on the child exceed the positive ones, is not an easy decision for the physician. The family generally regards this as a 'death sentence'. Attributing to the physician a role of the judge, who 'brings in the verdict' or 'condemns to death', is a misconception. It is not the physician but the disease which causes death.

Key points

- Decisions about the treatment of children with incurable diseases are difficult but inevitable.
- Cessation of curative treatment represents a change of philosophy where prolonging life is no longer the objective; instead, the goal is to improve the quality of the remaining life.
- Withholding life support is appropriate for children dying of life-threatening or life-limiting conditions.
- Parents' and children's decisions should be supported.

Definitions

- **Curative treatment** should be understood as applying anticancer treatment for patients whose prognosis for cure is likely.
- **Palliative treatment** should be understood as applying anticancer treatment for patients whose prognosis for cure is unlikely. This treatment is implemented for two reasons:
 - to control symptoms
 - reluctance to cease anticancer treatment.
- **Palliative care** should be understood as a holistic approach to the patient and family, which consists mainly of symptom control. Anticancer treatment is generally associated with side-effects, which in turn require further treatment. This treatment may be considered as a fourth category. It should be recognised that some patients die as a result of toxicity from anticancer treatment.

Cessation of curative treatment

The main goals of curative treatment are to cure disease and to prolong life. Cessation of curative treatment should be understood as a change of philosophy: prolonging life is no longer the objective; instead the goal is to improve the quality of the remaining life.

The processes of making decisions to stop curative treatment may differ. In practice, a distinction should be made between the following:

- The decision is made by the physician, the parents and the child.
- The decision is made by the physician and parents, without the child's involvement.
- The decision is made by the physician against the parents' wishes.
- The decision is made by the parents against the physician's wishes.

Decision made by physician, parents and child

This is the optimum situation for all. It facilitates cooperation between the physician and the family.

Decision made by physician and parents alone

This is understandable and appropriate in the case of a small child who cannot understand the situation. However, it is dishonest to withhold information from an older child. In the latter case, the family may expect hospice staff to keep 'a conspiracy of silence' about poor prognosis. This dysfunctional communication results in the child becoming isolated and hospice care may be compromised.

Decision made by physician alone

This occurs when parents are unable to accept the death of their child and remain convinced that the curative treatment should proceed. Some may continue to seek out curative therapies elsewhere and the child often dies during this process. Initiating hospice care is not appropriate at this time, because superficial approval by the parents does not mean cooperation with hospice philosophy. The parents will expect hospice workers to 'save their child' and to pursue aggressive therapies.

Decision made by parents alone

When continuation of anticancer treatment is proposed, parents may wish to spare their child unpleasant side-effects and refuse treatment. This decision is made against the physician's advice. The physician may have difficulties cooperating with the hospice and try to encourage parents to reverse their decision. Hospice care should be undertaken in response to the parents' and child's wish. This may require careful negotiation with the hospital staff.

Sometimes a child requests cessation of curative treatment. By law, a minor does not have the right to consent to or to reject treatment but the views of the child must be considered. When parents and the physician are disputing a treatment decision, the courts may intervene based on the child's welfare. 'Child's welfare' in family law should be a universal panacea. Its precise denotation has not been properly defined legally or ethically. In judicial practice, it is open to different interpretations and it is prone to the subjective opinion of a judge.²

Pace³ describes two cases of parental refusal to treat their child, investigated by Canadian courts between 1985-1986. In the first case, a mother refused chemotherapy for her three-year-old child who was suffering from cancer. The hospital took the mother to court. The first judge granted the hospital's petition but this decision was reversed on appeal since there was only a small chance of recovery and the side-effects from the chemotherapy would be severe.

In another similar case where a 12-year-old Jehovah's Witness was suffering from leukaemia, the judge found that it was not

necessary for the child to undergo chemotherapy and blood transfusion, because the child had objected to the treatment. The court stated that chemotherapy addressed the disease only in a physical sense and failed to address emotional needs and religious beliefs. In other words, the treatment failed to consider the whole person.

These two examples illustrate the necessity of including the needs of both the parents and the child in deciding whether to continue or cease treatment. The Western legal system is attempting to increase the rights of children in specific medical situations. A mature/emancipated minor is perhaps capable of making decisions about their medical treatment.³ The 1995 guidelines give children of seven years and older the right to assent to, or refuse, participation in drug testing.⁴ Society has a moral responsibility to consider extending this right to accept or refuse treatment to other groups of children, such as the terminally ill, receiving aggressive experimental treatment.

Terminology

At present, it is possible to distinguish three kinds of agreement to drug testing on people:

- **Consent** of an adult. This is where consent is expressed by adults or in some cases by persons qualified as a 'mature/emancipated minor' (near the age of majority with sufficient understanding of medical procedures and perhaps medically emancipated in the treatment of certain conditions, including venereal disease, pregnancy or drug abuse).
- **Permission** of parent(s). This occurs when parents allow treatment or research to be carried out, when the subject is a child.
- **Assent** of a child. This involves an active agreement by the research subject, usually obtained from any child with an intellectual age of seven years or more. This protection provides the opportunity for a child of seven years or older to refuse participation in studies or procedures done for research purposes.⁴

Choice of the place of death**Remaining in hospital**

When curative treatments clearly fail, the dying child often remains in hospital, as a result of:

- The unanimous decision of the physician, parents and the child.
- The decision of the physician, without the conscious agreement of the parents or child.
- The decision of the physician and parents, without the conscious assent of the child.
- The decision of the parents where the physician is neutral, without considering the child's wishes.
- The decision of child where the parents and physician are neutral.

The optimum situation, when deciding about future treatment, is where parents, child and physician come to a mutual agreement

Decision of physician, parents and child

This decision should be respected. The hospice should offer its help in providing care of the child dying in the ward and support the family.

Decision of physician, without the conscious agreement of parents and child

This results from the physician providing ambivalent and inadequate information, creating an illusion that further treatment is indicated. The family may be unaware of the child's approaching death and may not have time to consider whether the child should stay in the hospital or return home. This also means that the child is unaware of the situation and cannot be involved in decisions. When children express an awareness of approaching death, there may be no acknowledgement of their feelings. Hospital philosophy is cure-oriented and does not support the concept of palliative care. Therefore, inadequately informed children and their families may expect life-supporting interventions. These patients are not referred to the hospice and die in hospital.

Decision of physician and parents, without the conscious assent of the child

This is appropriate in the case of a small or unconscious child. If the child is able to understand the situation, it is dishonest to exclude them from the decision. The exclusion of children usually occurs because the adults cannot communicate openly and/or cannot accept their child's death. The likelihood of changing the attitudes of the physician and parents is not probable, so hospice staff should remain available for consultation but should not intervene without invitation.

Decision of the parents where the physician is neutral, without considering the child's wishes

Parents may feel unable to care for the dying child at home for psychological, housing, organisational or financial reasons. Parents' greatest fears about care at home relate to:

- Difficulties in controlling symptoms.
- A lack of cooperation by medical and nursing staff.
- Anxieties about dealing with the events at the time of death and immediately afterwards.⁵

If these fears can be anticipated and allayed, most parents will select home care for their child, if the option is offered.⁵ All these matters should be discussed with the parents, who are encouraged to talk frankly with the child and to make a collective decision. If they decide that their child should remain in hospital, the decision must be respected and supported.



Children, in the terminal stages of disease, should have the right to accept or refuse treatment



Children may feel lonely and isolated, unable to talk about their feelings of death and dying

Decision of child where the parents and the physician are neutral

The child may choose the hospital as the place of death, often due to the attachment and trust the child has for the physician and nurses. It may also be due to feelings of a lack of safety at home and a wish to protect the parents from distress. This decision should be respected since it is often too late to change the home situation.

Home care

For most families, care of the dying child at home is the preferred option. There are certain preliminary conditions, outlined by Martinson and Enos,⁶ which should be fulfilled:

- Cure-oriented treatment should have been discontinued, so that the emphasis can be on palliative care and adding quality to life.
- The child must want to be at home.
- The parents must want to have the child at home.

- The parents, other children in the family and/or significant others must recognise their own ability to care for the ill child.
- There should be a nurse available and willing to be on call 24-hours-a-day for professional consultation and support.
- The physician must agree with the plan and be willing to be on call as consultant to the nurse and to the family.⁶

The success of palliative home care depends upon the acceptance and acknowledgement of these criteria by all parties – the referring doctor, hospice staff, the child and the family.

Ethical dilemmas for children's hospice staff

Parental request for blood tests for their dying child

Parents often address such a request to the hospice nurse. The reasons for the request may be:

- To establish the diagnosis of anaemia and/or blood disorders, so that their child can be treated with transfusions.
- Temporary improvement creates a need for objectively assessing their child's condition.
- A wish to monitor the effect of any alternative unconventional therapies.
- A suggestion from the doctor previously treating the child.

The nurse will need to explore the reasons for such a request with the family. The fundamental question is: 'What purpose does this invasive procedure serve?' Families may need to be reminded and reassured that this procedure will only cause the child additional discomfort and will not change the final outcome. For children with a longer life expectancy, the rationale for performing this procedure must be to improve, not prolong, the patient's life. In some home-care settings, particularly in Poland, a hospice nurse is frequently asked to take blood unnecessarily from a child. In these situations, the nurse must be confident in refusing such requests and should be supported by the hospice physician.

Parental request for transfusion of blood and blood products

The request for a transfusion generally indicates denial of the impending death of the child. Transfusions should never be performed in a home setting. In some rare situations, they could be considered for symptomatic improvement but never for the prolongation of life.

Article 31 of the Polish Code of Medical Ethics⁷ says that: 'At terminal stages, the physician is not obliged to undertake and continue resuscitation or persistent therapy or apply extraordinary means.'

According to the Catholic church, 'when death is imminent and cannot be avoided by

the use of available resources, one is allowed, in good conscience, not to make use of treatment which may result in uncertain and painful prolongation of life. At the same time, there should be no cessation to routine care which is normally given in similar cases. It should not be a cause for concern on the part of the physician, as if they had refused help to someone in danger.'⁸

A World Health Organisation (WHO) expert committee considers mechanical ventilation, chemotherapy, surgery and intravenous nutrition therapies as aggressive in the care of terminally ill patients.¹ This list is not exhaustive and could include catecholamines (intravenous drugs supporting the circulation), intravenous antibiotics, blood and blood products. Transfusion of blood and its products is considered as extraordinary means, applied according to strict medical indications. Blood and blood products may not be available and can be expensive.

According to the Polish Code of Medical Ethics, a physician is not obliged to apply extraordinary means in terminal cases. The question is whether a physician has the right to apply extraordinary means. If so, by which authority do they possess this right? And should they be morally and legally responsible when the agony of the dying child is prolonged?

Using intensive care technologies

The goal of intensive care is to maintain the life functions of critically ill patients who have life-threatening problems. Employing this technology is justified when the intervention creates a possibility of recovery but it is not consistent with hospice care. Inappropriate and excessive interventions to prevent the act of dying must be avoided.⁹ Slipko suggests that: 'Not only is a physician not obliged to apply life support measures but in justifiable circumstances he is obliged not to apply them.'¹⁰

A distinction must be made between a dying patient for whom the prolongation of life with intensive interventions is not appropriate and the incurable child, treated with intensive care technologies, who wishes to return home. If the conditions previously stated by Martinson and Enos are fulfilled⁶ and the hospice has well-trained staff and suitable equipment (respirator, infusion pumps, oxygen concentrator), home care can be considered and is often more appropriate than keeping the child in hospital. As the patient's quality of life improves, the child and the parents' desire to spend the last period of life together at home can be fulfilled.

Unfortunately, some terminally ill children are admitted to intensive care. The consequence is that the child's life is maintained by life support therapies. The withdrawal of intensive

therapy will result in the child's death. However, it is crucial to understand that the death is caused by the disease, not by the withdrawal of life support measures.

There is no ethical difference between withholding and withdrawing life support measures.⁹ Such behaviour, although ethically acceptable, is undertaken reluctantly in Poland, especially in the case of conscious patients.

Hospice home care may be an alternative to:

- Leaving the incurable child in an intensive care unit.
- The withdrawal of life support from the child with an incurable disease.

Withholding and withdrawing life support is appropriate for children dying of life-threatening conditions, such as cancer, and patients with life-limiting conditions, such as cystic fibrosis. In the latter group it is more difficult to define the terminal phase (when the application of life-prolonging methods is no longer appropriate) (Table 1).

Feeding difficulties

For parents, the thought that their child is dying of hunger is difficult.^{1,3} If the child refuses to eat or drink, nutrition should not be applied or forced. This also includes the use of intravenous infusions. The parents need to understand that a child's lack of thirst and hunger are normal symptoms in the terminal phase of disease. The use of intravenous drips will not prevent death. If a child experiences swallowing difficulties, the possibility of gastric feeding should be seriously considered. If this option is selected the following should be considered:

- The standpoint of the patient and the family.
- The child's anticipated length of life.
- The degree of discomfort caused by hunger.
- The child's state of consciousness.
- The child's general condition (gastrostomy usually demands general anaesthesia).

A much simpler solution would be to feed the patient by nasogastric tube, although this is not well tolerated by patients and is, therefore, not recommended in palliative care.



Intensive intervention, in incurable children, should not be used to prolong life

Parental request to lie to the child

Often parents do not want to talk to their child about their disease and forthcoming death. Avoidance of this subject creates a dysfunctional home environment. Children's trust towards their parents, their closest source of support, will be compromised. Children may feel lonely and isolated and unable to talk about their feelings of death and dying. Hospice workers should encourage the family to talk openly to the child. Avoiding answers or lying will be condemning the child to loneliness in the face of death. This abandonment breaks one of the basic tenets of palliative care.

Unconventional medicine

Parents of a child with an incurable disease may often, in desperation, employ unconventional medicine. They are seeking a miraculous recovery, regardless of the opinion of the physician. These methods may be considered acceptable as long as they cause no discomfort (eg, arduous diets) and do not exclude therapy administered by the hospice. Hospice workers should not voice opinions about unconventional medicine. However, hospice nurses should inform the hospice physician about the patient's use of these medicines. Parents should be warned against giving large sums of money to people who say they can cure the child. This is particularly important when the hospice is financially supporting the family.

Summary

Decisions about the treatment of children with incurable diseases are difficult but inevitable. Those concerning cessation of curative treatment, commencing palliative care and choosing the place of death may only be taken when the physician expresses clearly the child's prognosis, the effectiveness of treatment and the possibilities of hospice home care.

All decisions should be made by both the parents and the child, if able. The role of the

Table 1. Differences between terminal cancer and a congenital life-limiting condition (eg, cystic fibrosis)

Cause of death	Cancer	Cystic fibrosis
Condition	Life-threatening, acquired	Life-limiting, congenital
Curative treatment	Exists	Does not exist
Life-prolonging methods	Applied during curative treatment	Applied since birth
Terminal phase	Begins at the cessation of curative treatment	Difficult to define

physician is to provide frank and objective medical information so that the family can make an informed choice about the care and treatment of their child. The hospice worker should inform the family of the principles of palliative home care. The parents' and child's decisions should be supported. This refers to delivery of care in both hospital and home settings.

Difficulties in providing palliative care may arise for the following reasons:

- Non-acceptance of the child's death by both the parents and/or the physician.
- Not including the child in decision-making.
- Non-acceptance of the philosophy of palliative care, which is improvement in the quality of life and a dignified death, rather than prolonging life.
- Not observing the six conditions for effective hospice home care.⁶

This article represents the opinions of the author and it is an attempt to encourage debate and dialogue concerning this difficult clinical area. It is hoped that the questions raised will

improve the quality of life of children with incurable conditions.

Acknowledgements

I am grateful to Professor Susan Fowler-Kerry and Professor Ilora Finlay for their advice and comments. This article was supported through grants from Astra Poland and Professional Partnership Program (Canadian Government).

References

1. WHO Expert Committee Report. *Cancer Pain Relief and Palliative Care*. Technical Report Series No. 804. Geneva: WHO, 1990.
2. Balcerek M. *Prawa dziecka*. Warsaw: PWN, 1986.
3. Pace NA. Legal and ethical considerations of consent in children: implications for anaesthetists. *Paediatr Anaesth* 1991; **1**: 21-24.
4. Committee on Drugs. Guidelines for the ethical conduct of studies to evaluate drugs in paediatric populations. *Paediatrics* 1995; **95**: 286-294.
5. Ward P, Oakhill A. Terminal Care. In: Oakhill A (ed). *The Supportive Care of the Child with Cancer*. Bristol: Wright, 1988: 238-259.
6. Martinson IM, Enos M. The dying child: at home. In: Corr CA, Corr DM (eds). *Hospice Approaches to Pediatric Care*. New York: Springer, 1985: 31-42.
7. Third National Congress of Physicians. *Kodeks Etyki Lekarskiej*. Warsaw: 1993.
8. Papal Council for Health Care. *Karta Pracowników Służby Zdrowia*. Vatican City: Michalineum, 1995.
9. Declaration of the Council of the World Federation of Societies of Intensive and Critical Care Medicine. Ethical guidelines. *Int Crit Care Dig* 1992; **11**(3): 40-41.
10. Slipko T. *Granice Życia*. Cracow: Wydawnictwo WAM, 1994.

Tomasz Dangel, Warsaw Hospice for Children, Department of Palliative Care, National Research Institute of Mother and Child, Warsaw, Poland

The physician must provide frank medical information so that the family can make an informed choice about the child's care