

Lethal Defects in Foetuses and Neonates Palliative Care as an Alternative to Eugenic Abortion, Eugenic Infanticide, and Therapeutic Obstinacy

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*Fearing that death will wrench our child away from us,
we tear him away from life; wanting the child not to die,
we do not allow him to live.*

Janusz Korczak

*Without this realization and awareness about what is
happening in each person's feelings, it is impossible to try
to transform invasive action into an action of accompanying.*

Rubén Bild

Definition of terms

I propose that a lethal (*L. letalis*) defect in a foetus or newborn be understood as: (1) a developmental anomaly that leads to spontaneous abortion, immature delivery, or intrauterine death; (2) a developmental anomaly leading to the premature death of a live-born child, irrespective of any therapy that may be applied; and (3) a developmental anomaly classified as grounds for legal abortion.¹

Developmental anomalies belonging to the third category do not necessarily have to be lethal *per se*, but in all three cases, the anomaly leads to the death of the foetus, either directly or indirectly, and so, in effect, is lethal.

Epidemiology

The number of live births in Poland totalled 374 244 in 2006 and 387 873 in 2007.² The approximate number of all congenital malformations, deformations, and chromo-

somal abnormalities (CMDCA) in this population can be assumed to be about 3%, which means that the number of newborns with these disorders born in Poland in 2006 and 2007 was about 11 200 and 11 600, respectively. Table 1 presents these statistical data.

In 2006, CMDCA caused the deaths of 835 children between the ages of 0–17 years, which is 21% of all deaths in this age group (in 2006, a total of 3990 children aged 0–17 years died in Poland). Among children dying in the first year of life in 2006, 31% died of CMDCA (that year, 2238 children under the age of 1 died in Poland, including 694 from CMDCA). CMDCA were responsible for 28% of the deaths of neonates in 2006 (of the total number of 1623 neonatal deaths in Poland in 2006, 459 were from CMDCA).

Not all CMDCA are fatal. The statistical figures cited above show that only about 7% of all CMDCA in live-born children are lethal (as understood in point 2 above).

The total number of deaths due to CMDCA in the entire population in 2006 was 985. Notably, as many as 71% of deaths due to lethal defects occur in the first year of life; the remaining 14% occur in older children and 15% in adults.

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Table 1. Statistical data on the number of live births and frequency of congenital defects, deformities and chromosomal abnormalities (Q00-Q99) and mortality from them

Category	Number	Year	Source
Live births	374 244	2006	Central Statistical Office
	387 873	2007	
Congenital malformations, deformations, and chromosomal abnormalities (Q00–Q99)			
Frequency per 10 000 live births	267.8*	2002	Polish Registry of Congenital Malformations ³
Deaths (neonates, < 24 hours)	187	2006	Central Statistical Office
Deaths (neonates, 1–27 days)	272		
Deaths (infants, 28 days – 11 months)	235		
Deaths (children, 1–17 years)	141		
Deaths (adults, ≥ 18 years)	150		
Deaths (entire population)	985		

* Assuming that the registry figures are somewhat underestimated, the author has accepted a frequency of 3% for CMDCA in the population.

The CMDCA that most frequently lead to death in children are: congenital malformations of the circulatory system (38%, n = 316 in 2006), multiple congenital malformations, not elsewhere classified (16%, n = 130 in 2006), and congenital malformations of the nervous system (11%, n = 91 in 2006).

Eugenic abortion

In 2007, a total of 282 eugenic abortions were performed in Poland on the basis of a prenatal diagnosis (Fig. 1);⁵ this is probably the lowest rate in Europe and explains why the frequency of CMDCA (ca. 3%) in neonates in Poland is higher than in countries with higher eugenic abortion rates.

Eugenic infanticide

Verhagen and Sauer, Dutch physicians, advocates of compassion-motivated infanticide of neonates with CMDCA (erroneously termed euthanasia by them) define three categories in this population of patients.⁵ The first includes neonates who will die shortly despite the use of continued invasive medical technology, e.g. children born with severe lung hypoplasia. The second group comprises neonates that potentially may survive, whose expected

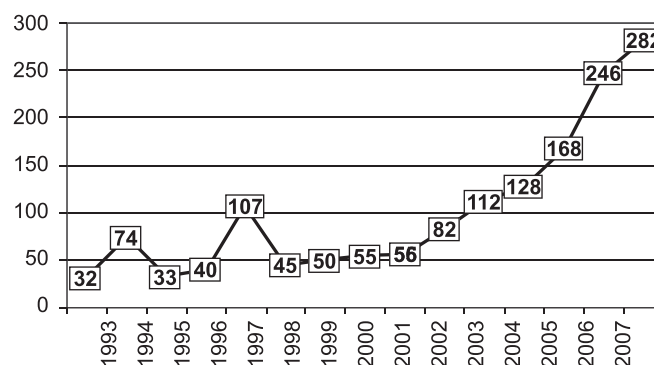


Fig. 1. Abortion on the basis of prenatal diagnosis in Poland in 1997–2007.

quality of life after the intensive care period is very grim, e.g. children with holoprosencephaly. The third group encompasses patients who do not depend on medical technology for physiological stability, but whose suffering is severe, sustained and cannot be alleviated, without any hope of improvement. An example are children with epidermolysis bullosa, Hallopeau-Siemens type.

The above classification shows that not all neonates with serious CMDCA die naturally during the perinatal period. Many of them will survive, despite a poor prognosis.

Verhagen and Sauer published the criteria used when qualifying neonates for so-called euthanasia (known as the Groningen protocol). These are: functional disability and severe pain with hopeless prognosis; lack of self-sufficiency; future inability to communicate; expected hospital dependency; and long life expectancy.⁶

The approach represented by Verhagen and Sauer precludes the possibility of providing palliative care for newborns with CMDCA. In this author's opinion, the classification and criteria proposed by them could be used to qualify children not for so-called euthanasia, but rather for palliative care and protection against therapeutic obstinacy.

In their criticism of the Groningen protocol, Chervenak, McCullough and Arabin⁷ revealed that among the 22 newborns killed by Dutch doctors, 21 were born with spina bifida. Among the points made by these authors is that a congenital defect like spina bifida does not cause either pain or suffering that could be considered unbearable.

Therapeutic obstinacy

In this paper, the terms therapeutic obstinacy, relentless medical intervention, and persistent therapy are used in the sense defined as follows: "Persistent therapy is the application of medical procedures with the goal of supporting vital functions in a terminally ill patient that

Table 2. Place of death from congenital malformations, deformities, and chromosomal abnormalities (Q00-Q99). Poland 2006. Data from the Central Statistical Office

Age group	Hospital deaths		Deaths at home		Deaths in other places	
	no.	%	no.	%	no.	%
Children (aged 0–17)	778	93	43	5	14	2
Entire population	870	88	87	9	28	3

results in prolonged dying, and is associated with excessive suffering and/or violation of the patient's dignity. Persistent therapy does not include basic nursing, control of pain and of other symptoms, or feeding and fluid administration, as long as these actions are beneficial to the dying person.⁸

Most deaths due to lethal defects in children (> 90%) occur in hospital (Table 2). This suggests that before death, children with lethal defects are subjected to intensive therapy, surgery, and resuscitation. This can be considered therapeutic obstinacy that is an assault on the child's human dignity.⁹

Goc et al. (from a centre in Katowice, Poland) published the results of intensive therapy used in 20 neonates who were born with the lethal Edwards syndrome (trisomy 18).¹⁰ The diagnosis was made prenatally in only 8 cases. In 16, the children were delivered by caesarean section. Fourteen were resuscitated upon delivery. Nine underwent surgery. Fourteen died in the intensive care unit before reaching one month of age (average survival, 20 days); the authors do not report if these were the same children who were resuscitated immediately after birth. Six children were discharged from the intensive care unit (on average after 66 days); they were not followed up. The authors draw the following conclusions: (1) lack of prenatal diagnosis results in unnecessary caesarean sections; (2) despite aggressive therapy, most of the newborns die; (3) prompt karyotype determination (by FISH) makes it possible to avoid many invasive procedures and surgeries.

Poland lacks legislation that safeguards children with lethal defects from obstinate therapy and allows parents to refuse the treatment that is proposed and to take the child home in situations in which doctors want to employ resuscitation, intensive therapy, and surgical intervention. Opting for home hospice care in lieu of hospital treatment is considered by some doctors as "euthanasia". There have been cases of physicians going to court to have parental rights suspended in order to be able to implement relentless medical intervention against the will of the parents, or of coercing the parents to give their consent

to treatment under the threat of suspension of parental rights.

According to Szeroczyńska,¹¹ "There is no doubt that the lack of detailed legislation regulating what is acceptable and what is not acceptable for the terminally ill does not serve either respecting the will of the patient or the security of medical practice. It seems inhumane to agree with the provision of the criminal code stating that all behaviours shortening life are forbidden." According to Poland's Criminal Code, a prohibited act (e.g. the crime of mercy killing, art. 150 § 1 kk)¹² can be committed both actively and passively, that is, by refraining from an action that in a given situation was mandated by law. An example of such a mandated action can be art. 30 of the Act on the Profession of Physician, which states that "a doctor is obligated to provide medical help in every case in which a delay in providing it could lead to the risk of loss of life, serious bodily harm, or serious loss of health." In the opinion of Szeroczyńska this also applies to the case of not undertaking medical intervention in a terminally ill patient. In this way, 150 § 1 kk stands in conflict with art. 31 of the Medical Ethics Code, which states that "in terminal conditions, a physician is not obliged to initiate and conduct resuscitation, relentless medical intervention, or to use extraordinary medical means".¹³ In light of the above, it seems justified to call for a revision of Polish law to make it conform with this principle of medical ethics.

The on the Profession of Physician in principle allows doctors to conduct therapeutic experiments on children against the will of their parents: "Art. 25 par. 1-6: In the event that the legal guardian refuses permission for the participation of the patient in a therapeutic experiment, a request for permission may be filed with the competent Court of Guardianship with jurisdiction over the location of the entity conducting the experiment. Art. 25 par. 1-8: In cases of urgency and immediate life-threatening emergencies, it is not necessary to obtain the consent referred to in par. 1-6. Art. 34: A doctor may perform an operation or use a method of treatment or diagnosis that carries increased risk for the patient (...) without the consent of the patient's legal guardian or competent court if the delay caused by the need to obtain such consent places the patient at risk of loss of life, serious bodily harm, or serious loss of health."¹⁴

Wichrowski¹⁵ analyzed the attitudes towards patient autonomy prevalent in modern medicine and delineated two orientations: paternalism (based on respect for the objective good of the patient) and libertarianism, otherwise known as antipaternalism (based on respect for the subjective will of the patient). Medical paternalism maintains that it is the doctor who knows what is best for the

patient. The therapist may conceal and distort information when this serves the objective good of the patient. The “therapeutic prerogative” as understood in this approach constitutes the essential mode of action and should be exercised in every doubtful situation. The opposite approach, libertarianism, i.e. antipaternalism, is based on absolute respect for the informed expression of a patient’s will. A person’s autonomy may be restricted only when it poses a threat to others.

Catholic ethics, founded on natural law, give the patient the right to undertake informed decisions that the physician should accept with respect. The *Charter for Health Care Workers* states that: “The patient is not the anonymous object on which medicine is practiced, but a responsible person who should be called upon to participate in the improvement of his health and to attain a cure. The patient should be guaranteed the right to make personal choices and not to be dependent on the decisions and choices of others. (...) The patient should be informed about experimentation, its purpose and possible dangers in such a way that he will be able to express his consent or refusal in a fully informed and free manner. The physician has only such true authority and rights over the patient as the patient himself gives him. (...) When there is danger of death, which cannot in any way be avoided by using available means, in clear conscience it may be decided not to take advantage of treatment that may bring only uncertain and painful prolongation of life, without desisting from providing such ordinary care that, under similar circumstances, the patient is entitled to. Making such a decision should not cause the physician to feel qualms that he refused help to someone in danger. (...) In respect to the physician and his co-workers, this is not a question of deciding whether a patient will live or die. This is about being a physician, that is, about looking for and deciding about, in good conscience and according to his best knowledge, measures respecting the life and death of the patient entrusted into his care. This responsibility does not always entail the obligation to use every available means in every case. It may also mandate refraining from using these means stemming from the serene and peaceful acceptance of death as being integrally connected with life. This may also mean respect for the decision of the patient to refuse such means”.¹⁶

The Council of Europe Recommendation 1418 on the protection of human rights and the dignity of the terminally ill dated June 25, 1999 contains the following recommendations:

1. Absolute prohibition of intentionally taking the life of terminally ill or dying persons, active euthanasia, whether or not the person has expressed the wish

to die, recognising that a terminally ill or dying person’s wish to die never constitutes a legal justification to carry out actions intended to bring about death (art. 9c).

2. Respect for the terminally ill or dying person’s right to self-determination, including taking into account the person’s expressed wishes with regard to undergoing, ceasing, or refusing particular forms of treatment, also if they had been expressed earlier in an advance directive or living will, or the terminally ill or dying person is represented by a proxy for health matters nominated by that person (art. 9b).
3. In situations in which an advance directive or living will does not exist, the patient’s right to life is not infringed on (art. 9b-vi).
4. Every patient should be ensured access to high-quality palliative care, in particular, to adequate pain relief, even if this treatment as a side-effect may contribute to the shortening of the individual’s life (art. 9a).

The psychology of paternalism

The problem of paternalism and the iatrogenic consequences of this approach in Polish paediatrics unquestionably exists. Understanding the behaviour of physicians and parents representing this orientation is not possible without psychological analysis.

Bild has conducted such an analysis. He described the emotional reactions of physicians and parents facing the inevitable death of a child, which he calls a catastrophic situation. They experience fear, pain, disillusionment, regret, and guilt. Lack of awareness about these feelings leads to continuation of measures to which the child is subjected that become cruel, invasive, and harmful. They are in essence a defence mechanism that serves to reduce one’s own suffering at all costs. Bild concludes: “Without this realization and awareness about what is happening in each person’s feelings, it is impossible to try to transform invasive action into an action of accompanying”.¹⁸

Gómez García expands on Bild’s concept, stressing the need to develop self-awareness. “With awareness, at one point we connect with the patient through an understanding of ourselves that involves a spiritual dimension. Knowing our own core, our inner life or our True Self gives us the security to understand the limits between the patient and us. We perfectly know where our beliefs and ideas end and where the ideas or beliefs of the patient and his family start. We do not need to talk about spirituality; we need to be ready to share spiritual moments with our patients. The efficiency of any member of a paediatric palliative care team will be determined by awareness, scientific knowledge, technical skills, and sense of responsibility towards the

patient and family. None of these aspects should be neglected.

I strongly believe that to improve the quality of our care to dying children and their families we need to work continuously on awareness. Any form of training should regard awareness as an important part of it.”¹⁹

The right to life and the right to death

Janusz Korczak (Henryk Goldszmit) formulated the concept of children’s rights. He was a paediatrician and the author of an antiauthoritarian educational system that respected the needs and aspirations of the child.²⁰

Korczak proposes four basic children’s rights:

1. A child’s right to death (“The ardent, rational, and balanced love of a mother must grant the child the right to premature death.”);
2. A child’s right to the present (“Fearing that death will wrench our child away from us, we tear him away from life; wanting the child not to die, we do not allow him to live.”);
3. A child’s right to be himself (“You say: ‘My child’. No, not even during the months of pregnancy or in the hours of labour, is the child yours.”);
4. A child’s right to speak his mind, to actively participate in our deliberations and decisions about him.

The right to life can not be considered in abstraction from the right to death. This apparent paradox is, for an experienced paediatrician, a fully consistent and obvious fact, resulting from the decisions he has to make in cases of terminal illnesses in children. Acknowledging the right to life and death should stem from the acceptance of nature—its laws, and its mistakes (e.g. genetic ones). The occurrence of incurable diseases in the pre- and postnatal period is considered to be a natural phenomenon, as is the fact that about half of childhood deaths occur in the first year of life. It is the questioning of the natural aspect of the occurrence of incurable disease in foetuses and newborns, more specifically, the refusal to accept their natural course, that leads, on the one hand, to eugenic abortion or eugenic infanticide (the Groningen protocol) and, on the other, to therapeutic obstinacy.

Acknowledging only the right to life and concomitantly opposing death restricts the practice of medicine to only measures aimed at prolonging life. This one-sided approach, by questioning the right to die, may lead to paternalism, iatrogenic interventions, medical experiments, and therapeutic obstinacy. In perinatology, this is expressed in such contradictions as the refusal of the right to refrain from undertaking measures prolonging the life of those children, who earlier could have been subjected to legal eugenic abortion, if “prenatal examinations or other medical

evidence point to a high probability of serious, irreversible damage to the foetus or incurable, life-threatening disease”.

The British Royal College of Paediatrics and Child Health lists the “no chance” situation among those situations in which it is acceptable to withdraw life-support therapy or abstain from it. In those cases, treatment only delays death, does not improve the patient’s quality of life, and does not increase his potential. Unnecessary extension of treatment under such circumstances is futile and contrary to the best interest of the patient. This is why the physician is not legally obligated to provide it. Moreover, if such futile therapy is knowingly continued, it may constitute a violation of the European Convention on Human Rights and Fundamental Freedoms or be perceived as inhumane and degrading treatment as defined by in this Convention (Article 3: “No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”).²¹

In Catholic ethics, we find an important statement: “Life on earth is a fundamental gift but is not absolute. Therefore, the limits of our obligation to maintain life should be defined. Distinguishing between ‘proportional’ measures, which may never be rejected so as not to anticipate and cause death, and ‘extraordinary’ measures, which may and should be rejected, so as not to fall into therapeutic obstinacy, is the decisive ethical criterion in delineating these limits.”²² Therapeutic obstinacy is, according to Pope John Paul II, the use of measures particularly exhausting and burdensome for the patient, dooming him to artificially prolonged agony. It is a violation of a dying person’s dignity and the moral obligation to accept death and to allow it to take its natural course.

The WHO Expert Committee similarly views this problem, formulating what is called the relativity principle: “...life is not an absolute good and that death not an absolute evil. A moment arrives, at different times for different patients, when technologically aided efforts to extend life may interfere with higher personal values. In this circumstance, life-prolonging efforts should give way to other forms of care.”

The relativity principle of relativity is supplemented by the principle of proportionality, which states that “...life-prolonging treatments are contraindicated when they are the source of more suffering than benefit. Dogmatic adherence to a “life is sacred” principle may result from failure to recognize the limits of medicine and particularly of a patient’s physical and moral resources. Medicine reaches a limit when all it can offer is an extension of function, which is perceived by the patient to be a prolongation of dying rather than an enhancement of living. It is therefore ethically justifiable to discontinue the use of life-prolonging techniques when their ap-

plication imposes strain or suffering on the patient out of proportion to the benefits that may be gained from them.”²³

One of the signs of therapeutic obstinacy that violates the patient’s dignity is employing resuscitation that interferes with the natural process of dying. Protection of a child from this type of intervention (which unfortunately is routine in hospitals) is possible by advance entry of a DNR (*do not resuscitate*) order in the child’s medical documentation. “The decision on resuscitation is made by the doctor and depends on his assessment of therapeutic prospects.”²⁴

Poland’s Civil Rights Ombudsman postulates that terminally ill children be protected from pain, suffering, and unnecessary medical and diagnostic procedures; they are entitled to the active and comprehensive care of a home hospice that ensures adequate palliative care aimed at improving the quality of life.²⁵

Palliative care

Paediatric palliative home care is based on ensuring active and complex in-home care for incurably ill children at high risk of premature death. Its intention is to protect the dignity of the child, improve his quality of life, and safeguard him from obstinate therapy and iatrogenic treatment. It includes symptom control, psychological, social, and spiritual support.²⁶

Referring to the above definition, I propose the following definition of perinatal palliative care (PPC). PPC is ensuring comprehensive support for the parents of foetuses and newborns with lethal defects and care for newborns with these defects, aimed at ensuring comfort and protection from therapeutic obstinacy. It encompasses symptom control in the child and psychological, social and spiritual support for the parents, including support during bereavement. The child can be cared for in a neonatal ward or at home by the parents and hospice if the child survives delivery and is discharged from the hospital.

Poland is unique among European countries not only because it has the highest percentage of CMDCA in newborns and the lowest number of eugenic abortions, but also because it has the best developed network of home hospices for children, which covered 92% of the population in 2008. This author’s study conducted among Polish hospices providing palliative home care for children has shown that about 20% of the patients they treat are children with CMDCA (Table 3). For example, the Warsaw Hospice for Children (WHC), which provides palliative home care, treated 365 patients between 1994–2007; among them were 74 children with CMDCA, who accounted for 20% of this group.

The number of children with CMDCA currently referred by neonatologists and paediatricians to home hospices is relatively small. It can be expected to rise gradually as cooperation develops between prenatal diagnosis and neonatology units with home hospices for children.²⁸

Prenatal diagnosis should provide parents with the right to make decisions pertaining to giving birth to the child or undergoing eugenic abortion based on access to a wide range of consultants, especially paediatric surgeons. For this reason, the official statistics relating to the outcome of surgical treatment of life-threatening congenital defects (e.g. diaphragmatic hernia, complex heart defects) at particular centres should be made public, e.g. on the Internet. Unfortunately, these results are not generally available.

The pro-life decision of parents in cases of lethal foetal defects should not be interpreted by physicians as their automatic consent to resuscitation, intensive therapy, and surgical treatment of the newborn. After making the prenatal diagnosis of a lethal defect, consultation with a specialist in paediatric palliative care is called for. Contact of the parents with another family having a child with a similar condition who is under the care of a hospice should be facilitated. If the parents chose palliative care, performing a caesarean section and resuscitation of the

Table 3. Children (0–17 yrs of age) treated by home hospices in Poland from 2005 to 2007 according to major diagnostic categories²⁷

Diagnosis	ICD-10	2005	2006	2007
Neoplasms	C11-D34	100 (22%)	134 (23%)	122 (20%)
Metabolic diseases	E71-E88	38 (8%)	62 (11%)	60 (10%)
Nervous system diseases	G05-G98	185 (42%)	217 (38%)	239 (39%)
Conditions with perinatal onset	P21-P91	16 (4%)	15 (3%)	25 (4%)
Congenital malformations, deformations, and chromosomal abnormalities	Q00-Q99	83 (19%)	110 (20%)	116 (19%)
Other		20 (5%)	30 (5%)	49 (8%)
Total		442	568	611

newborn should be avoided. For this to be possible, it is necessary to make an appropriate advance order in the medical documentation. If the child survives the perinatal period, it can be discharged home under the care of a hospice. This procedure can be of benefit to many families who, because of their convictions, reject both abortion and therapeutic obstinacy.

The model described above has been successfully operating over the last few years in Warsaw (Poland), where we have the first centre in Europe that integrates prenatal diagnostics with palliative care.²⁹ In the group of 95 fetuses who were diagnosed with lethal defects, the pregnancy outcomes were: intrauterine death, 20 (21%), eugenic abortion, 33 (35%), live births, 42 (44%). Among the 42 live-born children, 30 died in hospital after birth (only one was subjected to persistent therapy at the demand of the parents), and 12 were referred to the WCH.³⁰

A movement for perinatal hospice programs exists in the USA.³¹ It was initiated by Amy Kuebelbeck, who published a book describing the history of her child with a prenatally diagnosed congenital heart defect and who died after birth without undergoing medical intervention.³²

Summary

Poland should develop and implement a new approach to diagnosing and treating children with lethal defects who survive beyond the perinatal period, and for those with other defects that, despite surgical treatment, cause serious disability (the size of the latter group is difficult to assess). Palliative home care should be taken into consideration as an alternative that is effective and less expensive than hospital treatment.

For the sake of ethical considerations, clinical and legal decision-making, and informing patient, it is important to clearly distinguish between:

1. life-prolonging treatment when there is a real chance for cure or remission;
2. life-prolonging treatment, when the chance for cure or remission is minimal (therapeutic obstinacy, therapeutic experiments);
3. withholding or withdrawing life-prolonging treatment and introduction of palliative care when the chance for cure or remission is minimal (refraining from the use of extraordinary means, ensuring ordinary means, alleviation of suffering, improving the quality of life);
4. euthanasia (acting with the intention of taking a life for reasons of compassion, withholding ordinary means).

Polish law needs to be amended to provide protection of the incurably ill from therapeutic obstinacy imposed by

physicians. The Polish legal system should allow the parents of incurably ill children to choose freely between options 2 and 3 when the chance of cure or remission is negligible. Physicians should limit themselves to determining these chances and to honestly presenting this information to the parents. They should not pressure the parents or court in order to obtain consent for therapeutic obstinacy or therapeutic experiments. Paediatric hospitals should have clinical ethics committees that assist parents and physicians in making difficult ethical decisions by formulating, at the parent's request, an independent opinion on a given case. Such a committee has been established at this author's initiative at the "Children's Memorial Health Institute".³³

The most important goal is, however, to delineate the limits of therapy in Polish paediatrics by defining extraordinary (disproportionate) means and ordinary (proportionate) means, and the precise difference between them. Paediatric palliative medicine should be officially recognized by the minister of health as a medical subspecialty and, as such, be acknowledged by the relevant scientific bodies as a legitimate part of paediatrics and perinatology. Only then will terminally ill children be able to exert the rights postulated by Poland's Civil Rights Ombudsman.²⁵

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