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When is that moment? The criteria for withdrawing treatment from terminally ill children – in the context of the recurring problem of "passive euthanasia"

Kiedy jest ten moment? O kryteriach zaprzestania leczenia u terminalnie chorych dzieci – w kontekście powracającego problemu „eutanazji biernej"

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Abstract

Introduction and objective: The article aims to formulate criteria determining the right moment to discontinue life support to a terminally ill child at the end of life. The argument refers to two standards guiding critical decision-making: medical futility and the patient's best interests. When a child demonstrates discernment, account must also be taken of their reasoning. The deterioration of a child's health, which precedes the decision to stop further therapeutic efforts, is a clinical condition that immediately precedes torment that can only lead to death, or a situation of complete and definitive exclusion of positive perception and feeling. **Materials and methods:** The case review covers the specificity of birth in conditions of extreme prematurity, with lethal malformations and with neurodegenerative diseases. **Results:** This study shows that it is possible to draw a line between lawful consent to the death of a patient and unlawful passive euthanasia. **Conclusions:** The individual quality of life perceived by the child in question is crucial. In the final phase of terminal disease, there is no medical or moral reason for pain and suffering. Nor is there support for vital functions in a state of deep collapse caused by irreversible brain damage. The insistence of parents to continue such care is more a question of satisfying their own emotional needs and can be judged as a violation of the child's right to die in peace and dignity.

Keywords: child, terminal illness, passive euthanasia, best interests, futile treatment

Streszczenie

Wprowadzenie i cel: Artykuł ma na celu sformułowanie kryteriów ustalających właściwą chwilę, by zaprzestać czynności wspomagających życie dziecka nieuleczalnie chorego i u schyłku życia. Argumentacja odwołuje się do dwóch standardów kierujących podejmowaniem krytycznych decyzji – daremności terapeutycznej i najlepiej pojętego interesu pacjenta. Gdy dziecko wykazuje własne rozeznanie, uwzględnienia wymagają ponadto podawane przez nie własne racje. Pogorszenie zdrowia dziecka, które stawia przed decyzją o zaprzestaniu dalszych wysiłków leczniczych, to stan kliniczny, który bezpośrednio poprzedza męczarnie prowadzące już tylko do śmierci, albo sytuacja całkowitego i definitywnego wyłączenia pozytywnego postrzegania i odczuwania. **Materiał i metody:** Przegląd przypadków obejmuje specyfikę narodzin w warunkach skrajnego wcześniactwa, z wadami letalnymi i z chorobami neurodegeneracyjnymi. **Wyniki:** Opracowanie dowodzi, że możliwe jest wytyczenie granicy między zgodnym z prawem przyzwoleniem na śmierć pacjenta a niedozwoloną eutanazją bierną. **Wnioski:** Kluczowe znaczenie ma indywidualna jakość życia postrzegana przez dziecko, o które chodzi. Jedną z istotnych wskazówek powinien stanowić stosunek cierpień i dolegliwości do korzyści odnoszonych z życia w takim stanie. W schyłkowej fazie śmiertelnej choroby dla bólu i cierpienia nie ma żadnej medycznej ani moralnej racji. Nie ma jej

również podtrzymywanie czynności życiowych w stanie głębokiej zapaści wywołanej nieodwracalnym uszkodzeniem mózgu. Naleganie rodziców, by kontynuować taką opiekę, zaspokaja bardziej ich własną potrzebę emocjonalną oraz może być oceniane jako naruszenie prawa dziecka do umierania w spokoju i godności.

Słowa kluczowe: dziecko, choroba terminalna, eutanazja bierna, najlepiej pojęty interes, terapia daremna

PREFACE. THE LEGAL INTEREST OF A MEDICAL SUBJECT IN A CASE FOR THE DISCONTINUATION OF TREATMENT

Ethical and legal reflection on the comfort of dying children is one of the most painful experiences, and at the same time seems to violate a kind of social taboo. The death of a child is presented as an event contrary to nature, arousing violent emotional opposition, and often also a reflex of denial from society, leading to the desire to fight to extend the child's life, even for just one day. It is therefore all the more difficult to discuss the meaning of intensive life support for critically ill children. Parents are inevitably led by their own views when assessing the situation. In the context of their decisions, reference is made to the category of rights, autonomy, and respect for private life. A doctor is allowed to stop futile treatment, the continuation of which would contradict current medical knowledge. However, the indications may be ambiguous.

The discontinuation of futile treatment should be a medical decision, dictated by medical knowledge and the best interests of the patient, without the need for judicial involvement. Strictly speaking, the rationale for the withdrawal of futile treatment is the lack of medical indications for its continuation and, consequently, the absence of any obligation on the part of the medical practitioner to maintain unsuccessful treatment. However, the balance of health benefits and side effects or other ailments does not always present itself clearly. The child's parents, in particular, may find it difficult to come to terms with the fact that their child's life is inevitably coming to an end and medicine has no means of stopping this. The so-called "protocol for the cessation of futile treatment", which is drawn up collegially in such circumstances, is sometimes perceived by the patient's relatives as a death sentence, even though this "sentence" was in fact issued by the incurable disease. This, in turn, can often lead to desperate protests, which may take the form of reports to law enforcement authorities that doctors intend to kill the patient or have already done so by withholding resuscitation or disconnecting life support. In the event of a disagreement between doctors and the child's parents about further treatment, the guardianship court should have the casting vote. However, under Polish civil procedure, adjudication is filled with formal obstacles. While substantive legal grounds for adjudication exist in the relevant acts, there are no defined criteria for decision-making, no clear formal basis for granting the doctor or the hospital the status of a party to the proceedings (as an entity having a separate interest in a particular decision), and thus no procedural instruments for filing motions for evidence, receiving court documents, or the right to appeal against unfavourable decisions. Perhaps this accounts for the lack of spectacular rulings that would set precedents and provide directional guidance for other cases of this nature.

The substantive legal basis for seeking substitute authorisation from the guardianship court for the treatment of a decisionally incapable patient is Article 32(2) of the UZL (Ustawa o zawodach lekarza i lekarza destysty/Act on the Professions of Doctor and Dentist)[1], which applies equally to adults and children. Formally speaking, the court's competencies extend only to giving consent to the implementation of treatment, and not to its cessation. This argument was made by a family court chairwoman when the hospital's legal adviser alerted her to a problem with stopping futile treatment in a patient whose relatives, unable to accept it, occupied the patient's room in the intensive care unit. The problem is therefore not contrived. The literal wording of the law suggests the decision is up to the judge, but one has to resort to a functional interpretation of the provision. It is supposed to supersede the will of the patient, and that can, after all, be both positive and negative. Polish courts have already issued rulings showing that such a negative will of a patient who is incompetent at the time of adjudication, and documented by a previously made statement called an advance directive, needs to be respected[2]. The mechanism of the court's refusal to authorise treatment is not sufficient for this, as the subject of the request may well be the demand raised on behalf of the patient to stop the unwanted treatment. While it is true that rulings have been made in positive treatment authorisation proceedings (i.e. blood transfusions for Jehovah's Witnesses), formally preventing a ruling in the opposite direction through this route presents itself as a concept bearing marks of absurdity. This is because accepting it would lead to the conclusion that, in a guardianship case, the medical entity has no way to establish under the authority of the court that it is not bound

1. Ustawa z dnia 5 grudnia 1996 r. o zawodach lekarza i lekarza dentysty (t.j. Dz. U. z 2021 r., poz. 790, 1559).
2. See: Postanowienie SN z 27.10.2005 r., III CK 155/05. Orzecznictwo Sądu Najwyższego Izba Cywilna 2006; 7–8: 137; Postanowienie Sądu Okręgowego w Warszawie z 23.01.2008 r., sygn. VI Ca 582/07; Karcz R: Zgoda pacjenta na zastosowanie metody leczenia; status procesowy zakładu opieki zdrowotnej w postępowaniu sądowym z urzędu. Glosa do postanowienia z 23 stycznia 2008 r. Sądu Okręgowego w Warszawie, VI Ca 582/07. Państwo i Prawo 2008; 11: 143–146; Postanowienie Sądu Rejonowego z 12.12.2006 r., II RNs 580/06 – follow: Karcz R: Obrona pacjenta przed niechcianą transfuzją w praktyce sądowej. Prawo i Medycyna 2007; 4: 39.

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by a duty of care, or that, under equivocal circumstances, it does have such a duty.

With all this in mind, the question of the legal interest on the part of the medical practitioner or the hospital in obtaining an adverse decision needs to be assessed. In non-prejudicial guardianship proceedings for the authorisation of medical treatment, the medical subject usually acts in the role of notifying the court of the need to initiate proceedings *ex officio*. The scope for presenting one's own arguments is limited to the content of the notice[3]. Conversely, the status of a full participant in proceedings concerning a person's significant affairs provides much greater opportunities. In practice, however, the courts deny this to doctors, although there are times when they grant such attributes to a hospital[4]. A party to a civil lawsuit or a participant in a non-litigious proceeding is an entity that has a legal interest in obtaining a specific outcome in its favour. The source of misunderstandings and the denial of such status to medical entities seems to be the conviction that they do not have a substantive legal interest on their side. Only initially can the view be defended that a medical entity does not have its own interest in obtaining a ruling permitting the implementation of a specific treatment, because only the patient has such an interest[5]. This applies when the patient is legally independent and retains factual competence. The Warsaw Regional Court rightly ruled that courts are not authorised to rule on the treatment of a person with full legal capacity who has consciously opposed a particular method of treatment. In other words, the court cannot adjudicate a "dispute" between a doctor and such a patient. However, the evaluation changes when it comes to a patient who is legally dependent or actually incapable of making decisions, is in serious danger to life or health, and whose preferences remain unknown. The object of the judicial authorisation is then to undertake necessary treatment beyond the urgent case or to stop futile treatment – when the patient would otherwise lose their life as a result. As a rule, doctors have a duty to save their patients in the event of a life-threatening emergency, which arises from Article 30 of the UZL, while the treatment provider, on the basis of Article 15 of the UDL (Ustawa o działalności leczniczej/Act on Medical Activity)[6], may not refuse treatment to a patient who needs it because of a life-threatening emergency. Failure to fulfil these duties risks criminal and civil liability on the part of the direct perpetrators and, on the part of the hospital, entails the sanction of compensation. The medics therefore have a substantive legal interest and a statutory basis to establish that, under the circumstances, they were not under such obligations, i.e. the omission was lawful. They also have a substantive legal interest in confirming that it is their duty in the given circumstances to treat an incompetent patient, including a child, despite parental objections. Examples from foreign case law provided later in this article show that the hospital is not denied the status of a party to the proceedings, even though it is a guardianship procedure conducted *in re*. However, Polish procedural regulations on this matter are exceedingly laconic and practically confined to two provisions: Article 570 of the KPC (Kodeks postępowania cywilnego/Code of Civil Procedure): The guardianship court may initiate proceedings *ex officio* (i.e. also on request – MB) – and Article 572 of the KPC (§ 1. Anyone to whom an event justifying the initiation of proceedings *ex officio* is known is obliged to notify the guardianship court of it). The structure of the legislation thus implies that the medical entity may choose whether to limit its role to neutral notification of the court or to act as an applicant representing its own interest and claiming the attributes of a party in the proceedings.

Further complicating the adjudication of such cases is the fact that medical substantive law does not even provide decision-making criteria according to which adjudication should take place. This is bluntly described by practising judges as a "legal wilderness", consisting of unknown adjudication criteria, unclear status of the medical subject in the proceedings, the impossibility of appointing an *ex officio* representative for the patient, and even reasonable doubt as to whether service of a copy of the order is due to the medical subject, since the latter is not a participant in the proceedings[7]. *De lege ferenda*, it would seem useful to appoint either an *ex officio* representative[8], or a guardian *ad litem* for the patient. This applies in particular to situations where consent to treatment is refused by the legal representative of a legally dependent person, including the child's parent. Polish law does not even provide such an elementary solution as the application of the criterion of the child's welfare in all official decisions concerning the child. This principle

3. As Rylski points out, an application to initiate guardianship proceedings should be distinguished from a notice under Article 572 of the Code of Civil Procedure, which initiates proceedings *ex officio* (Rylski P: Uczestnik postępowania nieprocesowego – zagadnienia konstrukcyjne. Wolters Kluwer Polska, Warszawa 2017: 332).
4. An example is provided by a research report on the subject conducted and commented on by Jerzy Słyk. The author himself presents, in effect, a shaky and undecided position. At one time he is opposed to granting medical entities and physicians a legal interest in the adjudication, elsewhere he states that the physician's legal interest in the court's adjudication "appears to be capable of being grasped". He concludes, however, that the practice of treating the hospital as a participant in the proceedings "must be assessed critically in terms of its compliance with the procedural rules" (Słyk J: Zezwolenie [zgoda] sądu opiekuńczego na udzielenie świadczenia zdrowotnego dorosłemu pacjentowi. Prawo w Działaniu 2023; 54: 7–49).
5. Karcz R: Zgoda pacjenta na zastosowanie metody leczenia; status procesowy zakładu opieki zdrowotnej w postępowaniu sądowym z urzędu. Glosa do postanowienia z 23 stycznia 2008 r. Sądu Okręgowego w Warszawie, VI Ca 582/07. Państwo i Prawo 2008; 11: 143–146.
6. Ustawa z 15 kwietnia 2011 r. o działalności leczniczej (t.j. Dz. U. z 2022 r., poz. 633, 655, 974, 1079, 2280, 2705, 2770).
7. The doubt is resolved positively, but only for pragmatic and common-sense reasons. At most, the incompetent patient could be given a copy of the order on the duvet.
8. Such a demand was made by the judicial community. See: Blikowska J: Zabieg medyczny na nieświadomym pacjencie tylko za zgodą sądu. Rzeczpospolita 29.08.2016. Available from: https://www.rp.pl/prawo-dla-ciebie/art3257681-zabieg-medyczny-na-nieswiadomym-pacjencie-tylko-za-zgoda-sadu; Strus-Wołos M: Ochrona praw osób z zaburzeniami psychicznymi w postępowaniach z zakresu prawa osobowego dotyczących bezpośrednio stanu zdrowia psychicznego (Work in process of publication, provided as a courtesy).

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can only be derived from international documents, where it is commonly present.

Examples of foreign cases show that treatment entities there use litigation procedure to gain assurance that the patient treatment under review will be lawful. The designations of some cases highlight the litigation aspect by explicitly naming the treatment entity in the case title: *Airedale NHS Trust v. Bland* (1993); *Portsmouth NHS Trust v. Wyatt & Ors* (2004); *An NHS Trust v. MB* (2006); *Alder Hey Children's NHS Foundation Trust v. Evans* (2018). In the well-known *Anthony Bland* case, the hospital declared that its concern was precisely to ensure that doctors would act lawfully and that withholding aggressive life-sustaining treatment from the patient would not expose them to a charge of manslaughter. Such a determination is all the more important when objections to the manner of medical care are raised by the patient's relatives, who may seriously decide to notify law enforcement authorities of a suspected crime. Then the case for determining the obligation or lack thereof is the only way to obtain certainty about the law, and therefore the medical entity cannot be denied a legal interest in a ruling addressed to it, either permitting the cessation of treatment or ordering it to be maintained.

This article seeks to address the question of the criteria whereby medical due diligence and medical ethics would suggest terminating life support for a child with a fatal prognosis. In professional medical recommendations, bioethical literature, and judicial practice, two standards are usually used to guide critical decision-making: medical futility and the patient's best interests. Kazimierz Szewczyk, proposes interpreting "best interests" as "best understood interests", arguing that the term "best" erroneously implies the need to determine some ideal best interest of the patient in question, while it is only the interest best understood by the parties involved – the doctors and the parents representing the child[(1)]. The use of the plural in the original, on the other hand, captures what seems to be the key aspect of this criterion: the need to consider the balance of multiple factors[(2)]. When a child shows an understanding of their circumstances, the decision is additionally complicated, as their own reasoning must be acknowledged. The subject of consideration here are specific cases of birth in circumstances of extreme prematurity, with lethal defects, neurodegenerative illnesses, and other incurable diseases. Each of these groups has its own specificity in terms of identifying the right moment when further medical intervention would be pointless and merely interfere with a peaceful passing.

The analyses were carried out on the basis of case studies, most of which were settled by court rulings. Some of these have already been analysed in my earlier studies, so I take the liberty of citing extracts taken from them. I also return to the terminological issues considered earlier, because the blurring of the boundaries of certain concepts is sometimes used to create a "chilling effect": coercion to continue futile treatment out of fear of being charged with deliberately killing the patient. Before this happens, however, doctors, hospitals, and their lawyers may be advised at the outset to apply to the guardianship court for substitute authorisation to discontinue treatment in the event of disagreement between medical personnel and the child's parents regarding the issue of futile treatment, clearly emphasising and specifying in the application their own legal interest. That legal interest lies in establishing that the medical personnel are not obliged to maintain treatment deemed futile for the child in question, and that its discontinuation will therefore be lawful, in particular that it will not violate the obligations arising from Article 30 UZL and Article 15 UDL. The legal interest is thus to legalise the planned omissions. In the background of such cases, there is usually a fear on the part of doctors of being accused of failing to provide medical assistance in circumstances requiring it – i.e. failing to fulfil basic duties towards an incompetent patient. Such a clear formulation of the claim is likely to make the judiciary aware that not only the welfare of the child, in the broad sense of the term, but also the legal security of the doctors caring for him or her, needs to be taken into account in adjudication, and may contribute to the unification of practice in the application of civil procedures. In turn, the status of the applicant would enable the medical party to appeal decisions in which the courts attempt to evade taking a substantive position.

CESSATION OF FUTILE TREATMENT IS NOT EUTHANASIA

The conceptual distinction between the medically justified cessation of futile treatment and the offences of intentional homicide, euthanasia murder, or assisted suicide can be made mainly by referring to the therapeutic purpose of the treatment and to the indications of current medical knowledge. The same applies to demonstrating the fundamental difference between withholding futile treatment and euthanasia, which is reprehensible from the point of view of medical ethics. A thorough comparative analysis of these concepts was first conducted in 2019[(3)], except that it referred to the then-current wording of the Code of Medical Ethics (Kod Etyki Lekarskiej, KEL) and the anachronistic terms "extraordinary therapeutic measures"[9] and "persistent

9. A critical dissection of the criteria for dividing therapeutic measures into ordinary and extraordinary has long been carried out by the American bioethicists Tom L. Beauchamp and James F. Childress. Referring to the literature and the judgements of the courts, they proved the vagueness and utter unhelpful relativisation in this now ancient division. Ordinary measures were initially referred to as standard and generally recognised in the medical community, while extraordinary measures were referred to as experimental or novel. Thus, the evaluation was only concerned with the mode of treatment; the degree of prevalence and recognition of the method among medical practitioners were decisive, without taking into account the condition of the individual patient, including possible benefit. (In re Quinlan, The Supreme Court of New Jersey, 31.03. 1976, 70 N.J. 10 (1976), 355 A.2d 647, https://law.justia.com/cases/new-jersey/supreme-court/1976/70-n-j-10-0.html). The doctors claimed that the ventilator was a routine device, while the clergy considered it to be an extraordinary therapeutic measure, the use

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treatment" used therein. Consequently, the deliberations on this topic were characterised by strong criticism, dictated primarily by the KEL's use of inadequate and therefore inappropriate concepts, and by the acknowledged penetration of these flawed concepts into legal discourse. Further references to the problems considered took place in connection with the high-profile 2021 case involving a Polish patient with the initials RS, for whom life-sustaining measures were discontinued in a UK hospital[4]. Subsequently, the interdisciplinary team at the Patient Ombudsman produced a position paper in 2021, confusingly titled "Standards". However, instead of clarifying the issues, it introduced confusion between the concepts of futile and persistent treatment[5]. The terminology was reordered in the bioethics collective work "Konsultacje etyczne w praktyce klinicznej", aimed primarily at doctors, published in early 2024[6]. A detailed comparative analysis of the terms "futile treatment" and "persistent treatment" was carried out by Małgorzata Świderska[7], while Anna Alichniewicz analysed the very definition of futile treatment from a bioethical perspective, showing that it is not unambiguous[8]. Over the years, clinical practice guidelines have been developed by successive groups of medical specialists, where the term "futile treatment" has been used more and more widely in place of the rightly criticised term "persistent treatment". Three key documents were developed in paediatrics.

"Rekomendacje dotyczące postępowania z matką oraz noworodkiem urodzonym na granicy możliwości przeżycia z uwzględnieniem aspektów etycznych" is a document concerning perinatal care[9]. It mainly describes the medical criteria that provide the basis for clinical decision-making. Some of the basic criteria when deciding on resuscitation of the newborn in the delivery room are the gestational age and the strictly defined duration of the resuscitation – as prolonging resuscitation may cause significant and irreversible damage to many organs. On the other hand, it was pointed out that, although the doctor is not appointed to assess the quality of life of the child, they should not be indifferent to the child's suffering resulting from what is described as "persistent" treatment. It was emphasised there that doctors are not obliged to continue inexpedient treatment, while pushing for further treatment will require the approval of the guardianship court and overcoming the parents' lack of consent by this means. Parents, on the other hand, have the legitimacy to oppose a course of treatment, but they cannot bindingly insist on a particular treatment. Disputes arising between doctors and the child's parents should be resolved by the court. The medical balance sheet is only a starting point[10,11].

The guidelines "Wytyczne na temat terapii daremnej na oddziałach anestezjologii i intensywnej terapii dziecięcej"[12] (OAITD – paediatric departments of anaesthesiology and intensive therapy) state that it is the duty of the doctor treating a child with an advanced, incurable chronic disease to periodically assess the balance of benefits and losses that result for the patient from the treatment provided. It is very important that the treatment team is guided by the best interests of the child, taking into account current medical knowledge, therapeutic options and taking into account the opinion of other specialists. The legal representative, on the other hand, should be the representative of the interests of their child but often, being unable to come to terms with the separation, may more or less consciously seek to keep them alive at all costs, contributing to the child's suffering. Therefore, the doctor has the task of encouraging the patient's loved ones to try to understand the child's position and to adopt the child's point of view rather than their own. The guidelines include a list of procedures that need to be continued as palliative care. These include gastrointestinal feeding (also via gastric tube, PEG – if tolerated), hydration, and intravenous glucose supply. On the other hand, the list of therapeutic procedures that will not be undertaken or will be discontinued in the OAITD consists of cardiopulmonary resuscitation, mechanical respiratory support, pharmacological and electrical circulatory support, antibiotic treatment, parenteral nutrition, blood product transfusion, surgery and other invasive procedures (which does not apply to procedures that improve patient comfort), mechanical circulatory support, extracorporeal respiratory support such as ECMO, renal replacement treatment, and extracorporeal liver function support. ECMO, renal replacement treatment and extracorporeal support of liver function. The guidelines therefore prescribe palliative surgery to improve comfort in living (or dying), allow no artificial ventilation, but require continued feeding as long as the body is receiving it.

In comparison, the comprehensive 2011 paediatric guidelines[13], which were published a decade earlier, use the term "persistent treatment" and list the criteria for this: acting against the best interests of the patient, acting against the

of which was not obligatory and the patient's father had the moral right to decide to disconnect it. Thus, as can be seen, the ways of understanding the same concepts were clearly diverging. The court recognised this problem and, in its reasoning, drew attention to the "vagueness" of their understanding in the case at hand and the possible relativisation when the same procedure is considered ordinary for a patient with a chance of recovery (e.g. a ventilator for a child undergoing a critical phase of polio), but extraordinary in view of the enforced maintenance of vital processes in a terminal or vegetative state. The usefulness of this distinction for decisions on the continuation of life-sustaining procedures is therefore presented as highly questionable. In the 1983 report of the Presidential Commission for the Study of Ethical Problems in Medicine, Biology and the Behavioural Sciences, Deciding to Forego Life-Sustaining Treatment, it was stated that the distinction between ordinary and extraordinary therapeutic measures had already become so confusing that, for the sake of those involved in resolving difficult situations, these formulations should be avoided. From a moral point of view, it only makes sense if it is based on an analysis of the benefits and burdens experienced by the patient: ordinary measures produce more benefits than burdens, while extraordinary measures produce significantly more burdens than benefits. See: Beauchamp TL, Childress JF: Zasady etyki medycznej. 4th ed., Książka i Wiedza, Warszawa 1996: 212–214; Boratyńska M, Konieczniak P: Persistent treatment. In: Safjan M (ed.): Medical Law. Cases and Commentaries. Wolters Kluwer Polska, Warszawa 2011: 406–416; Boratyńska M, Malczewski J: Niewspółmierne środki terapeutyczne. In: Zielińska E (ed.): System prawa medycznego. Tom II. Regulacja prawna czynności medycznych. Część 2. Wolters Kluwer Polska, Warszawa 2019: 597–602.

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patient's beliefs, acting against the dignity of a human being, and acting against nature – the consequences of which are prolonged dying, undue suffering, and violation of dignity. While they aptly recognise the vagueness and ambiguity of the term "persistent treatment", they do not call for its amendment or clarification[8: at 11].

In 2010, Magdalena Rutkowska and Slawomir Szczepaniak reported that Poland lacks a real field for discussion of this issue. Concrete decisions are not made based on the criteria of the good – which characterise the attitude of an ethicist – but rather with reference to the principles shaped by one's worldview. As a result, they are presented as absolute – which corresponds to an ideological stance[14].

The 2011 guidelines certainly aimed to change mindsets, as evidenced by the passage in the introduction: "In paediatrics, in particular, the recognition of a child's right to die with dignity and to stop treatment is extremely difficult. The currently formulated statement that a doctor in a no-chance situation should withdraw from a treatment that prolongs the life and suffering of the child – is often not fully understood and applied. Therapeutic persistence, which makes it impossible according to ethical principles to 'accept death' and affects its natural course, is a moral and legal transgression"[13: at 9]. Nevertheless, the abandonment of artificial nutrition in children with dysphagia due to neurological diseases is considered unethical there – as leading to "cachexia and death by starvation"[13: at 117]. As Kazimierz Szewczyk rightly pointed out, the guidelines do not address situations where treatment is futile or those that carry an unbearable burden. According to him, the "all-round good idea of the document" has been largely destroyed by the confusion of concepts of different provenance: the terms "futile treatment", "extraordinary measures", and "disproportionate" are used in the document as *de facto* synonyms for "persistent treatment". The guidelines thus reproduce the narrowly defined and only locally used concept of therapeutic persistence, and the omission of artificial nutrition in children with neurological swallowing loss is therein principally regarded as unethical[1]. It is not a new argument that more progressive jurists raise the need for statutory regulation of these issues and accentuate the *de lege lata* inconsistencies at a systemic level[15,16]. Regarding the case of the Polish RS patient in the UK, where futile treatment was withheld, I argued that the law should in no way replace medical knowledge, which is paramount, but could establish procedural safeguards, mandate collegial decision-making, and formulate a list of factors to be taken into account[3: at 222]. This would increase doctors' sense of security and give them the confidence to decide; however, as foreign cases show, it will not resolve violent conflicts with some of the patient's relatives[10]. In the absence of specific statutory solutions, professional guidelines and recommendations serve as decision-making criteria in accordance with the principles of medical knowledge. However, they lack consistency and uniformity. While the 2021 guidelines present a state-of-the-art approach, their scope of application remains limited.

The reduction of therapeutic futility to terminal procedures is also reflected in the "Raport zespołu ekspertów przy Rzeczniku Praw Pacjenta": "This paper adopts the term futile treatment to describe end-of-life medical therapies that offer no benefit to the patient. [...] It seems that the term futile treatment more clearly captures the essence of the problem: to do something that is pointless, that is futile, is a waste of energy and time, and ultimately remains harmful because it increases suffering, prolongs agony"[5: at 16]. Attempts to narrow the concept of futile treatment to end-of-life care only perpetuate conceptual confusion and, in doing so, represent a regression in relation to the findings of modern medical knowledge. The same confusion and misrepresentation have long prevailed in various legal studies which still refer to the concepts of "persistent treatment" and "extraordinary measures". This refers to works that either date back to or were rediscovered[11] at a time when, for at least two years (i.e. as of 2014), the "Guidelines for dealing with the ineffectiveness of sustaining organ function (futile treatment) in patients deprived of the ability to make conscious declarations of will in intensive care units" had already been in circulation, using the appropriate terminology of "futile treatment" and referring comparatively to the term "persistent treatment", highlighting differences and pointing out inaccuracies[17]. The inconsistency between the terminology adopted in medical science and non-substantive legal studies urgently needs to be rectified to ensure legal security for doctors.

The guidelines in question immediately address these terminological discrepancies in the introduction by recognising that the phrase "futile treatment" more accurately describes management that does not achieve the intended therapeutic benefit than the term "persistent treatment". The phrase "futile treatment" more accurately describes the decision regarding the maintenance of organ function in patients treated in intensive care units. The term "futile treatment" was used to describe the maintenance of organ function without benefit to the patient and without the possibility of achieving the intended therapeutic goals.

10. One example in particular is the case of Vincent Lambert, recognised on several occasions by numerous national authorities and by the ECtHR, which examined respect for human rights in the French Law on the Rights of the Sick and the End of Life in its 2005 version, known as Loi Leonetti.

11. Posted on the Medycyna Praktyczna portal in 2018, the sweeping study by W. Wróbel from 2009: Rezygnacja z uporczywej terapii w świetle polskiego prawa. Available from: https://www.mp.pl/etyka/kres_zycia/46416,rezygnacja-z-uporczywej-terapii-w-swietle-polskiego-prawa. The term "persistent treatment" is also used by Sroka T: Article 38, In: Safjan M, Bosek L (eds.): Konstytucja RP. Tom. 1. Komentarz do art. 1–86. C.H.Beck, Warszawa 2016: thesis 115. Both authors refer to the definition of persistent treatment still taken from the draft law on the protection of the human genome and the human embryo and the Polish Bioethics Council (known as Gowin's draft) – 6th Sejm, Druk No. 3467, 2009, modelled on the consensus of the illegitimate Working Group on Ethical Problems of the End of Life.

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Its continuation was considered a "medical malpractice", with the understanding that decisions to limit futile treatment should be made collegially.

The concept of "persistent treatment" has taken deep roots and its eradication requires intensive persuasive efforts within the medical community as well. Experience shows that in Poland the legislature cannot be relied upon, so the new Code of Medical Ethics must play a substitute role, supporting the existing laconic legal provisions. Contrary to appearances and the declared impossibility by some lawyers[12], these provisions offer a reasonably consistent legal framework for medical conduct in conditions of therapeutic futility, but they require thoughtful interpretation, and the new solution adopted in the KEL is likely to greatly facilitate it.

Under Polish law, a doctor is obliged to provide medical assistance in any case where delay could cause danger of loss of life, grievous bodily harm, or serious disorder of health (Article 30 of the UZL), but also – to perform the profession in accordance with the indications of current medical knowledge, methods and means available to them, in accordance with the principles of professional ethics, and with due diligence (Article 4 of the UZL). Criminal law, on the other hand, criminalises both intentional and unintentional exposure to direct danger of loss of life or serious disorder of health, as well as intentional failure to render assistance in danger. From this, it follows that, under Polish law, the obligation to take and continue therapeutic measures is determined by the indications of medical knowledge. There is no such obligation without positive indications, so in a particular case, a sufficient justification for refusal or cessation of treatment is the lack of indications for its maintenance. On the other hand, there is an obligation to provide medical assistance in any case of imminent danger to life. In medical law, however, what is fundamental to the evaluation of medical actions and omissions is the therapeutic purpose of the intervention. The norms of medical law function as special provisions that take precedence over the norms of criminal law. If circumstances justifying lawful injury to a human being – up to and including a fatal outcome – are regulated by medical law, then these norms determine the abrogation of unlawfulness of such an act or omission. Thus, in the legal relationship between the doctor and the patient, criminal law and the Criminal Code do not apply directly, but only in an auxiliary manner[13]. The science of criminal law has developed the construct of the countertype of a therapeutic act, which consists of a set of four prerequisites that legalise medical intervention in a patient's body. Without their fulfilment, such an act would constitute a violation of numerous personal rights and, under criminal law, would amount to intentional bodily harm with the use of a dangerous instrument. These justifying circumstances are: a therapeutic purpose, conformity of the action with current medical knowledge, proper consent provided by the patient (or, alternatively, by a person or body appointed to represent his interests), and the doctor's possession of the appropriate, formally confirmed qualifications[14]. In the same way, the countertype theory applies equally to the cessation of treatment: there is no obligation to continue it, so the omission is legal, as long as at least one of the premises legalising the prior action is no longer valid. This means: the absence of the therapeutic purpose of the interference, failure to observe the laws of medical knowledge, referred to simplistically as medical malpractice, or the patient's autonomic discord. In other words, the failure to provide medical assistance in circumstances involving the risk of at least grave bodily harm can be qualified, for example, as the crime of failure to render aid in distress or exposure to imminent danger of at least grave bodily harm. However, only if there are no special circumstances justifying the failure to act – namely, the lack of indications for treatment, the futility of further treatment, or the lack of patient consent. Therefore, due to the auxiliary nature of criminal law in this legal sphere, the typification of crimes against life should not be a premise for clinical decisions in medicine. Medical law determines the scope of permissibility of such actions independently – albeit with the necessary reference to the body of medical knowledge, practice, and ethics. It is therefore crucial to define professional rules for initiating or withholding treatment in cases commonly referred to as hopeless. These rules make up the objective criterion of medical due diligence. Thus, the rules of medical knowledge are a subset of the rules of professional due diligence, which are referred to in general in Article 355 of the Civil Code, and, with regard to medical professionals, in Article 4 of the UZL and other medical professional laws[(18)].

The new Code of Medical Ethics has officially introduced the concept of futile treatment into the rules of medical ethics, finally abandoning the term "persistent treatment". The change in nomenclature is not insignificant in its implications. Therapeutic futility also defines the limits of medical care for patients who are clinically stabilised, but with permanent cognitive incontinence as a result of irreversible loss of most brain functions, and whose lives depend (quite literally) on numerous tubes supplying water, food, and oxygen. Limiting the assessment of either persistence or futility solely to terminal conditions would not resolve the most important and, at the same time, most difficult questions. Meanwhile, it is crucial to determine the advisability of further treatment in light of the chances of improving or maintaining health. With regard

12. For example Tymiński R: In: Walewski P: Daremny ból. Polityka 2025: 10: 41.
13. See also Boratyńska M: Tak zwana eutanazja bierna w świetle nowych technologii. Gubernaculum et Administratio (in work).
14. Buchała K: Prawo karne materialne. Państwowe Wydawnictwo Naukowe, Warszawa 1980: 314; Andrejew I: Polskie prawo karne w zarysie. 5th ed., Państwowe Wydawnictwo Naukowe, Warszawa 1978: 222.

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to terminal conditions, it is pointless, because all that matters is the alleviation of pain and other distressing symptoms accompanying dying. The limits of duty are initially defined by the indications of current medical knowledge. Beyond the indications, there is no duty. What is futile lies beyond those indications and is not only non-obligatory, but rightly considered medical malpractice and, according to the current wording of the KEL, constitutes an ethical prohibition. And finally – via Article 4 of the UZL – it falls under the criteria of professional propriety. The introduction of the notion of futility, which is widely accepted in the medical community, into the KEL sends back into oblivion the previous ideas of defining "persistent treatment", and with them – the revolving implications echoed by legal scholars in commentaries on the Criminal Code or the Constitution.

The World Medical Association defines futile treatment as treatment that "offers no reasonable hope of recovery or improvement" or from which "the patient is permanently unable to experience any benefit"[19]. Within such defined boundaries, the maintenance of a patient's vital functions using specialised apparatus may be considered futile. At this point, a terminological problem arises. Many people refer to the abandonment of life-sustaining treatment as "passive euthanasia", either approvingly or in a decidedly pejorative context.

Medical ethics generally do not permit euthanasia. The World Medical Association Code of Medical Ethics defines euthanasia as "a physician deliberately administering a lethal substance or carrying out an intervention to cause the death of a patient with decision-making capacity at the patient's own voluntary request"[20]. Such a restrictive understanding of euthanasia – as an active intervention – may resolve the issue at the level of medical ethics, but the problem remains when the interpretation of criminal law does not follow the same direction. The message from Catholic circles is that all euthanasia is evil. The term "passive euthanasia" as a prohibition is frequently used by principled proponents of the idea of the sanctity of life. The word "euthanasia" is thus becoming a tool of oppression and a means of exerting pressure on physicians. This conceptual confusion, on the other hand, is conducive to arguing that when a case is "one of euthanasia"[21], it refers to any cessation of keeping a patient alive and can be used as a charge of intentional homicide. The "use of euthanasia", regardless of how the term is defined, is considered incompatible with the medical ethos, and the same problem may arise in legal assessment.

Sometimes the omission of life-sustaining treatment is called "passive euthanasia" in good faith by some bioethicists as well. An attempt at ethical evaluation of such cases was made as far back as 1984 by Zbigniew Szawarski with regard to children suffering from incurable conditions[22]. The cases cited by Szawarski also remain relevant in light of current medical developments. One of Szawarski's staunchest critics, Rev. Tadeusz Biesaga, has portrayed his views as "brutal" and as an "emotive persuasion" in favour of, among other things, euthanasia, to which Szawarski is said to be urging suffering humanity"[15]. This criticism lacks merit and is based on winning emotions, and the vocabulary used reflects the heated nature of the polemic. I have posted a discussion and update of Szawarski's case studies in another paper[23]. Jacek Hołówka, on the other hand, argues that passive euthanasia is practiced in any hospital when it abandons another attempt to restore a heartbeat using electrodes, and it is clear from the context that the author sees nothing wrong with this[24], as did Szawarski or James Rachels earlier[22,25]. Such generalisations, however, can prove dangerous when the term "passive euthanasia" is used in a commentary to the Criminal Code concerning the crime of murder[16]. While this is accompanied by the caveat that it is not a crime to discontinue treatment in end-stage conditions, there is no explicit reference to the criterion of therapeutic futility, despite the fact that the 2014 medical guidelines should have long since normalised this concept[17]. It is free to argue that this will only result in a change in the Code of Medical Ethics as more noticeable.

Using the term "passive euthanasia" in the context of crime multiplies doubts instead of removing them. This is illustrated by the following case study. A patient with amyotrophic lateral sclerosis (SLA) had entered the advanced stage of the disease, at which point he was offered mechanical ventilation. The patient refused. When he lost consciousness, doctors soon intubated him, ignoring his earlier refusal. After waking up, the patient continued to protest, but his wishes were ignored. Using this example, the doctors explained to the students that turning off artificial ventilation would constitute "euthanasia".

Withdrawal of life-sustaining treatment thus needs to be confronted with the category of euthanasia and the penal law.

The concept of "passive euthanasia" cannot, therefore, be abandoned altogether, but for legal evaluation, it is worth narrowing down the boundaries of unlawful omission according to the criterion of actual breaches of medical duty. For the sake of legal certainty, which generally prohibits euthanasia, the adoption of reasonably clear criteria for passive euthanasia is therefore dictated by a legal rather than a moral necessity. Doctors need guidelines which, at the same time, define the boundaries of legal security. In other words, they need to know what behaviours – with particular reference to omissions – cannot expose them to criminal charges. Let us, therefore, try to clarify what unauthorised passive euthanasia is in medical terms. Passivity means

15. Biesaga T: Bioetyka utylitarystyczna Zbigniewa Szawarskiego. In: Biesaga T (ed.): Bioetyka polska. Wydawnictwo Naukowe PAT, Kraków 2004: 146.
16. See: Kokot R: Art. 150 III/2. In: Stefański R (ed.): Kodeks karny. Komentarz. C.H.Beck, Warszawa 2020.
17. The concept of "persistent treatment" and "passive euthanasia" is used nomen omen persistently and inadequately and in bad faith, because using arbitrary assumptions by Roszkiewicz in an article with a biased title: Czy można uśmiercić pacjenta z powodu niskiej jakości życia? Uwagi na tle orzecznictwa Europejskiego Trybunału Praw Człowieka. Forum Prawnicze 2023: 1: 16–36.

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the omission of certain acts. A person can be charged with omission when they remained passive despite having a duty to act. The primary duty of a physician is to save the life of a threatened patient using medical means but following current medical knowledge. However, interpretations of such general formulations diverge. Acting or neglecting to act outside of these indications is not obligatory. Because of this, the consent to the patient's death through the omission of medical actions can be regarded as reprehensible only if there is an obligation on the part of the doctor to act, which was omitted with the merciful intention of hastening the patient's death[26].

Passive euthanasia, on the part of the doctor, would therefore have to be an omission dictated by compassion for the patient's suffering and hastening their death, which breaches medical duties: failure to resuscitate, administer medicine, or perform life-saving surgery – but only when it violates the obligations. However, when the obligations cease, there are no grounds for alleging infringement. Therefore, a decision is made to classify the activities as either mandatory or optional (based on the balance of positive and negative consequences of treatment)[27]. A legally unacceptable, punishable omission that meets the criteria for passive euthanasia will therefore be an infringement of medical duty – that is to say, a medically unjustified abandonment of treatment that would have been of benefit to the patient, motivated by compassion for the suffering person and intended to hasten their death. Situations meeting these criteria are extremely rare, but the point is precisely to show, by way of contrast, that a failure to provide medical care in accordance with medical knowledge cannot be considered unlawful.

A completely separate issue is the suspension of life-sustaining treatment when, due to the patient's condition, it does not benefit them. Withdrawal of life-sustaining treatment, when it does not bring benefits to the patient in a particular condition, as a rule, is considered medically and morally justified and legally permissible. Futile treatment is not a subject of obligation. Refraining from continuing it does not constitute misconduct, and continuing it would be an error of medical procedure. It is crucial to determine the desirability of further treatment in terms of the chances of improving or maintaining health, or at least keeping the patient in a relatively stable state with a satisfactory quality of life. Discontinuing treatment in circumstances of therapeutic futility is legally grounded. If it spares further suffering, it is a humanitarian act.

Practising the profession in accordance with current medical knowledge is one of the obvious criteria for the appropriateness of medical activities. However, it requires clarification of which activities count as mandatory. The answer is provided by the state of medical knowledge translated into the clearest possible professional guidelines and an assessment of the clinical condition of the patient in question. Clinical practice guidelines supported by the authority of medical societies are important. They are conducive to good practice, and their additional function is considered to provide doctors with a sense of legal security. Compliance with the criteria formulated therein makes it possible to avoid the allegation of infringement of the rules and liability. They contain many valuable directives and valuable findings[see e.g. in Britain: 28], but they cannot be regarded as a universal recipe for every circumstance. Critical moments in the dynamics of the disease and symptoms, entailing the need for decisive decisions, are easier to grasp in specific situations.

The literature provides evidence of parents insisting on aggressive and invasive life-prolonging treatment for critically ill newborns. There is a growing tendency to honour such wishes, even for children born with Edwards syndrome, heart disease, or prematurity under 26 weeks of pregnancy. There is talk of the "ethics of abdicating" doctors from difficult decisions in favour of the parents' preferences. This is thought to be a by-product of respect for patient autonomy, which extends to "parental autonomy" in decision-making[29]. Parents, due to their exceptional closeness to the child, are usually best positioned to determine the child's best interests, assess the quality of life, and predict the ability to cope with treatment[30,31]. They are also held accountable for their care and thus bear the main consequences of the decisions taken[32]. In the well-known *Charlie Gard* case, his parents argued that state intrusion into such a private area of life as child upbringing means an erosion of fundamental constitutional values and renders their parental rights ineffective[18]. In *Williamson,* Lady Hale J ruled that, in a free society, parents should have a high degree of autonomy in the way they perform their duties[19]. Privacy also includes the right to autonomy, and parental autonomy requires the freedom and independent decision-making of children. Any restrictions may be seen as undermining this right, causing some parents to feel disempowered in their "parental rights". However, parental rights are not absolute and have never been treated as such[33]. Emotional involvement can lead parents to evaluate a child's best interests from their own perspective rather than empathising with the child's situation. *Alfie Evans*' parents understood the importance of their son's brain scan but avoided confronting its implications[20]. The "necessary balance is ensured by the best interests test", but it is sometimes assessed as minimally protecting the right of parents to respect for privacy and family life. Opponents argue that this task is better met by the competitive concept of "serious harm" proposed in relation to critically ill children[34]. It requires the state to refrain from interfering until a defined risk arises on the part of the child. According to some, it is supposed to safeguard the most vital goods and interests of the child – physical health, vitality, integrity and normal functioning

18. *UKSC, In the matter of Charlie Gard (Permission to Appeal Hearing)* (2017).
19. *R. (on the application of Williamson) v. Secretary of State for Education and Employment* [2005] UKHL 15, at 72.
20. *Alder Hey Children's NHS Foundation Trust v. Evans* [2018] EWHC 308 (Fam) at 38.

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of the body, lack of pain, suffering or grotesque disfigurement, intellectual efficiency, and emotional stability[35]. Others justify external intervention only by the need for immediate action[36] or when children do not have their basic needs met[37].

This problem seems to be somewhat misplaced. Parents, understandably, would like to make decisions according to their own conviction and without the intervention of state authorities. However, they often have in mind their own privacy rather than the privacy of a child who is not their own, but a vulnerable person requiring proper care, in the context of which the word "power" is completely out of place. Parental rights are not independent but serve the proper fulfilment of parental responsibilities and are subordinated in individual legislations to either the "welfare of the child" or the "best interests of the child". Third-party interference can be felt privately by parents as a perception of agency. However, allowing "autonomous" decision-making about the child in the context of respect for privacy respects the personal beliefs and values of the parents (or the convictions of those around them who submit out of fear of social condemnation) more than the best interests of the child. Meanwhile, the best interests test is about what a child patient needs as a person, i.e. to care only about their feelings. The quality of life perceived by that child is crucial, when it proves to be "unbearable". One important consideration should be whether suffering is commensurate with the expected benefits of treatment. Parents would like to keep their child with them for as long as possible and cherish their presence and life. If they hear about a parenteral probe or mechanical ventilation, they will probably give their consent without thinking. However, the question is what benefits it brings in the terminal phase of the disease and whether those benefits outweigh the ailments associated with surgical tracheostomy. It is therefore necessary to define what constitutes the privacy of that child, considering in the first place the symptoms of their critical illness. This requires empathy with the child and their position only: what else is the child able to feel and how is the child affected by the current condition? With serious damage and a lack of successful forecasts, intensive life support actually prevents a peaceful passing.

Representation of a child's rights by parents is sometimes erroneously equated with the rights and freedoms of the parents themselves, and restricting decisions on the child's case is treated as an attack on civil liberties. However, rights and freedoms are legislated to protect self-interest. The Polish Constitution guarantees parents "the right to provide their children with moral and religious upbringing and instruction in accordance with their beliefs" (Article 53(3)). The misunderstanding stems from the erroneous treatment of medical care in terms of upbringing. Deciding on medical care is included in the satisfaction of health needs, and these fall into the strictly custodial category and are listed in the KRO (Kodeks rodzinny i opiekuńczy/Family and Guardianship Code)[21] separately from upbringing – as custody of the person: "Parental authority includes, in particular, the duty and right of parents to exercise custody over the person and property of the child and to raise the child, with respect for the child's dignity and rights" (Article 95 § 1 KRO). Deciding on health matters is not part of upbringing activities and is not covered by constitutional freedom. Therefore, it is not possible to decide autonomously on these matters and be guided by personal beliefs. Parental authority here does not give room for free choice: it should be exercised as the child's welfare and the public interest require (Article 95 § 3 of the KRO)[38]. According to Article 17 of the UPP (Ustawa o prawach pacjenta i Rzeczniku Praw Pacjenta/Act on Patient Rights and the Patient Rights Ombudsman)[22], consent to a health care service "has the right" of both the patient and the legal representative of a legally dependent patient, and the identity of the wording of the two provisions creates the risk of interpreting self-consent and surrogate consent in the same way. However, there is no symmetry between the two. Self-consent is a sovereign right of the patient, while surrogate consent is a competence whose executor is strictly bound by the criterion of the ward's welfare[39,40].

The decision on the child's health care is not a manifestation of the parent's own freedom. The parent is only granted the authority to represent the interests of the ward. This requires consideration of many factors, but not one's own point of view. The right to give surrogate consent to medical treatment and to perform other medical activities on the child cannot be treated as independent and autonomous. Therefore, operating in this context with the concept of "parental autonomy" is a misunderstanding.

The only genuine parental right is the right to personal contact with the child, because it also satisfies the self-interest of the entitled person. Other prerogatives are reduced to duties of due care and are exercised in the interest of the child. Their side effect can be the satisfaction of the personal need to care and a sense of moral and emotional satisfaction from the duty fulfilled. There is undoubtedly an element of the right to privacy in the sense of enjoying undisturbed family life, but only within the limits set by the child's welfare. The disruption of harmony can be more distressing when there is interference with surrogate critical health decisions, such as continuing or discontinuing futile treatment. It is then possible for family life to be ruined or paralysed, convoluted and disintegrated, caused by the loss of a beloved child, the despair of watching their prolonged torment or the sacrifice of everyone, including siblings, to care for severe disabilities[38: 52–53].

Determining what medical care will be appropriate for a child, taking into account their clinical condition, the prognosis of improvement, and various therapeutic options,

21. Ustawa z dnia 25 lutego 1964 r. Kodeks rodzinny i opiekuńczy (t.j. Dz. U. z 2023 r. poz. 2809).
22. Ustawa z 6 listopada 2008 r. o prawach pacjenta i Rzeczniku Praw Pacjenta (t.j. Dz. U. z 2024 r. poz. 581).

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is not the domain of one decision-making group – neither parents nor doctors – and has been repeatedly reviewed by guardianship courts in different countries over the years. This is a typical way of protecting the rights of dependents in care, and there is nothing unusual about it. Decisions on critical issues are the most difficult, the most prone to error, and have irreversible consequences for another person; therefore, they cannot be of a quasi-discretionary nature. Parents' opinions are listened to with attention and empathy, but their decision is not predominant. The review powers of the court represent the state supervision of the proper exercise of parental care. Physicians do not, of course, have the right to positively decide on the treatment of children as a substitute or against the views of their parents, unless it is a medically dictated urgent action necessary to save life or seriously endangered health. However, medical duty does not include futile treatment. This creates a triangle of decision-making interdependencies, where parents have the power to oppose specific treatments, but cannot legally insist on specific treatments. However, medical indications can be vague and uncertain due to many uncertainties about the prognosis. Therefore, the views of doctors and parents may differ, and there is nothing unusual in this, because finding the right answer requires a balancing of many factors. If doctors, contrary to the parents' wishes, insist on continuing treatment, they must seek the approval of the court and thus overcome the parents' lack of consent to medical activities perceived as *bona fides* in accordance with the best interests of the child.

The final straw in the process of gradual deterioration that precedes the decision to cease further efforts is the clinical state that immediately precedes unbearable suffering that can only lead to death, or a situation of complete and definitive exclusion of positive perception and feeling. Physicians can be expected to take a rational and pragmatic approach, representing the current state of medical knowledge, but their judgment can only be trusted if they are not influenced by their own philosophical beliefs or use moral evasions so as not to endanger anyone.

DISCONTINUATION OF NUTRITION AND HYDRATION

The cessation of futile therapeutic measures, however, leaves open the question of how to proceed with feeding and hydration using specialised techniques. Artificial nutrition for an "otherwise healthy" and independently breathing patient in a vegetative state is a procedure on which their life directly depends. As a result, the crucial decision is not to stop futile treatment in the strict sense – understood as fighting the disease – but to remove the feeding tube. The recognition of nutrition as futile renders it non-obligatory, but it is difficult to establish criteria for the futility of nutrition. Dissent prevails even in the highest adjudicatory bodies, as shown by the minority opinion of the European Court of Human Rights (ECHR) in the famous *Vincent Lambert* case (2015). Although the court ruled that the cessation of a patient's life support in a Persistent Vegetative State (PVS) was lawful and did not violate human rights, the dissenting opinion included the words: "a severely disabled person who is unable to communicate his wishes about his present condition may, based on a number of questionable assumptions, be deprived of two basic life-sustaining necessities, namely food and water […] The case before this court is one of euthanasia, even if under a different name"[23]. Despite repeatedly using all the collegial procedures required by French law to adjudicate and decide on treatment, appeal proceedings continued for four more years. After Lambert's death in 2019, Dr Vincent Sanchez, the physician who led the medical team, was accused by the patient's mother of failing to help him in danger. Both court instances handed down acquittals, but the mere fact of a criminal case does not encourage doctors to make firm decisions about incompetent patients without the support of their relatives. Vincent Lambert was the patient whose life essentially hung on a feeding tube at a crucial moment. Treatment for the root cause of the VS had been completed, and independent breathing regained, but consciousness and decision-making competence had not returned, nor could he swallow food. The patient could not decide for himself, and the withholding of CANH (clinically assisted nutrition and hydration) by third parties is equated with a sentence of death by starvation. In this reasoning, key issues of law and medical ethics converge: when it is legal and ethical to stop treating a patient, and whether assisted feeding is a form of treatment and thus subject to its rules, or whether it belongs to the unshakeable principles of primary care. Decisions of this kind are sometimes referred to as euthanasia.

The well-known and oft-cited clash between two perspectives: the concept of feeding and hydration as either part of compulsory primary care or as a specialised medical procedure justified within the limits of therapeutic expediency seems to have brought the discussion to a dead end. The main arguments can be summarised as follows. The classification of artificial nutrition as a therapeutic activity implies, in principle, an obligation to continue, but allows for its discontinuation when it proves futile. The classification of CANH as a non-medicinal activity, on the other hand, makes it an obligation falling within the scope of so-called primary care.

It is considered that artificial nutrition is too different from other medical measures to allow the establishment of a moral standard that could provide a common basis for evaluation. Accordingly, certain medical measures may be dispensed with, but the administration of food and liquids may not be disregarded. Feeding the hungry is one of the "simplest gestures that show care" and "an excellent symbol of the fact that human life is always inscribed in the life of the whole society and community"[27: 217,41,42]. Withholding

23. *Lambert and Others v. France*, judgement ECHR, June 5, 2015, 46043/14; http://hudoc.echr.coe.int/fre?i=002-10758.

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CANH is therefore considered tantamount to killing. The cause of death is then not the fatal disease, at some stage depriving the patient of the ability to feed themselves, but the omission of physicians who fail to provide food and fluids. Such statements appear as an issue in the discussion on the lack of difference between killing and letting die[24](See polemically: 27: 160–162,43,44).

These claims have been extensively analysed over the years, but the unshakeable principles are, one might say, evergreen. They do not change or evolve. They just bloom in the same shape from time to time: Beauchamp and Childress cited the view of C. Everett Koop (U.S. Surgeon General) who, in 1982, declared that the death of children born with severe defects by the withdrawal of nutrition was a kind of infanticide by starvation to death[25]. In Poland, Zbigniew Szawarski argued against such a view(22). Nevertheless, a Koop-like thesis is present in the paediatric guidelines of 2011. "Discontinuation and withdrawal of persistent life-sustaining treatment in children. The abandonment of artificial nutrition in children with dysphagia in the course of neurological diseases is considered unethical there as leading to 'cachexia and death by starvation'"(13). The 2015 minority opinion in the *Vincent Lambert* case strikes the same tone.

However, one could just as well argue the opposite: a patient who is no longer fed and hydrated artificially dies as a result of the progression of the disease or an injury resulting in an inability to eat and drink normally(see for example: 45, see polemically: 43: 122).

Patients in a VS, however, are not "ill" in the common sense of the word, yet they can be kept alive for many years without feeling anything. It may be argued that the symbolism of nutrition loses its meaning when a person permanently ceases to feel such needs, for this means – as Daniel Callahan puts it – that the body gradually shuts down its functions. Artificial nutrition and hydration are supposed to meet the individual needs of patients, not just maintain normal physiological parameters(46). The symbolism of care is not an argument in itself: it can only be considered valid if the care benefits the patient. When the clinical condition is not promising to improve, such external supply only sustains a purely biological continuance, and, for this reason, its futility can legitimately be considered(4: 178–185).

As rightly noted in the famous House of Lords' judgment of 4 February 1993, in the *Anthony Bland* case[26], medical treatment and care are provided for the benefit of the patient. If a patient has suffered irreversible brain damage, is permanently unconscious, and, in the unanimous opinion of the experts, has no prospect of recovery, then continued life support must be considered pointless. Continuing the invasive treatment would be justified only if it brought any benefit. However, neither continued vegetation thanks to artificial nutrition nor death caused by its discontinuation are associated with any feelings on the part of the patient. Artificial preservation of biological life is a futile and useless activity that serves only itself, but not the person of the patient. However, the judges stipulated, among other things, that if the patient showed even the slightest glimmer of consciousness, this would create a "non-zero" interest in continuing the treatment. The guardian *at litem* of Anthony Bland submitted that artificial feeding was an ordinary caring action, such as the duty to feed a baby or an incapable person, that is an elementary duty which existed independently of all questions of treatment and which the person in charge could not omit to perform. Judges did not accept this argument. In their opinion, feeding a person in a vegetative state is not the same as feeding a baby, for such a person is not capable of obtaining food and swallowing, that is of eating and drinking in the literal meaning of these words. Tube feeding is a highly invasive procedure and is inevitably associated with the continuous use of catheters and enemas, and as a consequence, constant fighting with urinary tract infections. In this context, ordinary humanitarian care is not an issue. In the Court's opinion, there is an analogy to the ventilator, which artificially breathes air in and out of the lungs of a patient incapable of breathing normally. Judges did not accept analogies submitted by the guardian *at litem* that discontinuance of artificial feeding in the present case was equivalent to cutting a mountaineer's rope or severing the air pipe of a deep sea diver. Discontinuance of life support should properly be categorised as an omission. The use of the word "omission" may seem inadequate where discontinuance of life support requires some active step to press the button. However, in the context of life sustenance, discontinuing the procedure is not different from failure to initiate it(See more: 47).

The dispute is irresolvable because the position regarding all nutrition as compulsory primary care has been influenced by the Catholic doctrine and is the result of a top-down assumption, so it does not lend itself to rational persuasion. The adoption of one of the two views depends essentially on social convention: whether such invasive nutrition should be treated on par with medical treatment and judged according to therapeutic expediency or treated as an unshakeable principle of care.

Assessing the appropriateness of maintaining CANH requires an answer to the question whether it provides a real and perceived benefit to the patient at a given stage of treatment. If, on the other hand, nutrition and hydration are only implementing a top-down rule, it is unnecessary from the point of view of the patient's well-being, and this is the main argument in favour of lawful discontinuation. When the continuation of care is of no benefit to the recipient, its value becomes purely abstract. Caring for a person who

24. See also: Beauchamp TL, Childress JF: Principles of Biomedical Ethics. 6th ed., Oxford University Press, Oxford 2009.
25. Koop CE: Ethical and surgical considerations in the care of the newborn with congenital abnormalities. In: Horan DJ, Delahoyde M (eds.): Infanticide and the Handicapped Newborn. Brigham Young University Press, Provo: 89–106, esp. 105; follow: Beauchamp TL, Childress JF: Zasady etyki medycznej. 4th ed., Książka i Wiedza, Warszawa 1996: 216.
26. *Airedale NHS Trust v. Bland* [1993] IM ER 821 Hls.

does not need to be fed is detached from the interests of the person being fed, ceases to serve them, and becomes an empty phrase. It serves the benefit of third parties only: it provides the caregiver with positive reinforcement and the moral satisfaction that they are "doing their bit". In this, I think, one must look for the reasons for the absolute insistence on maintaining CANH even for decades in patients in a state of permanent loss or initial lack of consciousness. This balance does not consider the individual interest of the patient, but the emotional needs of those close to them who take comfort from their continued life. It could be argued, perversely, that if the patient does not care anymore, then at least others should be allowed to enjoy it. In this case, however, the unconscious patient becomes a 'toy' in the hands of others, serving others' needs and interests, which is clearly unacceptable.

The implicit assumption that people always need food and water does not stand up to the fact that such needs are not felt by patients in an irreversible VS and, consequently, there is no perceived benefit in satisfying them and no positive effect on the quality of life in this state. Although withdrawal of CANH leads to death from starvation and thirst, this effect is a normal consequence of illness or injury. Assisted feeding does stop it, but only temporarily, as it offers no hope of lasting improvement and is therefore pointless from this point of view. The inability to eat independently due to the loss of the swallowing reflex abrogates the duty to feed on the part of caregivers who are not qualified to use methods requiring medical knowledge. However, the possession of adequate knowledge, skills, and means does not always automatically prejudge the existence of such a duty on the part of physicians. The decisive factor should be the considerations of purposefulness understood in two ways: as therapeutic – that is, for the improvement or preservation of health, or as the satisfaction of individual needs with the benefit felt by the patient. The fact of staying alive but in a VS does not in itself constitute a subjective advantage. The futility of applying CANH to such patients should be understood as sustaining a purely biological duration without any perceived benefit. Feeding is not purposeful in itself. It is not unusual to see the desirability of feeding in terms of individual benefit, just as the desirability of treatment. Unnecessary nutrition must be considered futile regardless of whether it is assigned the status of a medical procedure or a symbol of caring and humanity in a particular case. Withdrawal of CANH which brings no perceptible benefit to the patient, should, therefore, be considered morally and legally permissible. It cannot be included in the category of "passive euthanasia" because, in such circumstances, the continuation cannot be a duty.

CASES

In the previous part of the article, the theoretical aspects of the cessation of futile treatment were analysed in the context of a possible breach of medical duties, a violation of professional ethics, the criteria for qualifying certain behaviours as passive euthanasia, and the potential commission of a crime. This section of the article will cite several well-known and representative medical cases, decided abroad by court rulings, as a source of arguments for withholding or continuing a treatment with highly questionable chances of success, or treatment deemed futile at some stage. I will juxtapose these with domestic cases, reported by parents and commented on mainly by bioethicists. Although these cases are few in number due to limited access to such knowledge for non-physicians, some of the constatations made in the course of foreign litigation may nevertheless prove useful for applying to such cases. It is desirable that there are as few such disputes as possible, but on the other hand, resolving them under the solemnity of the court allows the public to become familiar with the reasoning, thereby promoting a mature and substantive discussion of such problems. It is unfortunate that, so far, this discussion has not developed in Poland, and individual cases of children, usually known second-hand, only trigger emotions that drown out rational thought.

Newborns born in extreme prematurity

The difficulty in assessing cases of premature birth arises from the fact that if the infants are born "beyond" healthy, i.e. unaffected by birth defects, their condition cannot be described as end-of-life. The hope that they will be able to survive and improve their health is, in principle, justified. However, the lack of clear boundaries between the concepts of "prolongation of life" and "prolongation of death" creates problems with the unequivocal qualification of corresponding clinical situations. The most intense discussion in the global literature concerns the limit from which one may speak of the medically assisted possibility of premature newborn survival: determining the parameters of gestational age and/or body weight at which, after applying the latest achievements of medicine, it is possible to keep the newborn alive. This threshold was set by World Health Organization (WHO) for birth statistics at 22 weeks of gestation or 500 g body weight. However, epidemiological studies show that survival at such low neonatal maturity is negligible[48]. Currently, WHO assumes that viability can be considered when a child has a 50% chance of survival with or without intensive neonatal care intervention[49]. Despite enormous technological progress, that threshold remains at 24 weeks' gestation. Moreover, WHO itself recognises that, at present, in most high-income countries, premature babies born around 24 weeks of gestation have a 50% chance of survival[49]. The use of baseline data for statistical purposes should not be confused with actual survival, which is assessed mainly on the basis of the degree of development of internal organs, for which the arithmetic of pregnancy is only indicative. Many countries have introduced the concept of a "border zone" in their recommendations, referring to a period of gestational maturity during which there

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is great uncertainty about the survival and assessment of the development of the newborn. This zone is defined differently in various countries and ranges between the 22nd and 25th weeks of pregnancy. Below this interval, only palliative care is proposed to protect the newborn from suffering during the transition to natural death. In addition, it is now pointed out that the criteria of gestational age and body weight are insufficient. Decisions are further complicated by the fact that the organs of extremely immature newborns continue to develop, which may result in remedial processes[49]. When this fails, death occurs due to multi-organ failure, most often circulatory and respiratory failure[50]. A separate issue is, therefore, rescuing the neonate immediately after birth in order to correctly diagnose and determine the chances of survival and potential treatment options. Another problem is maintaining life in the event of a sharp deterioration of the condition after some time. The so-called "waiting resuscitation" gives time to observe, gather information, obtain test results, and discuss possible reductions in procedures in the event of a very poor prognosis[50]. No medical decision is ever certain, so in the case of newborn babies, it is only possible to make a prognosis. This is as normal as any statistical risk of complications, although in this category of cases it is characterised by the greatest uncertainty, because the gradual progression of development is moving in the opposite direction of organ failure. Withdrawal of treatment with slim chances of success does not amount to euthanasia in any adequate sense of the word, but acquiescence to death by ceasing futile and vicious treatment. The balance of benefits and discomforts also needs to take into account the suffering inflicted on a pain-stricken being by sustaining vital functions with the use of a ventilator, feeding probes, and intravenous infusions. Invasive surgeries, although feasible, are sometimes disproportionate to the possibility of survival and the anticipated quality of the existence preserved at such cost. Some decisions can be painful, and if the problem overwhelms the parents, the guardianship court must step in to make them[see more: 51].

However, without reference to a specific case, these criteria are presented as a set of dry generalities. A vivid example of decision-making doubts is provided by the British case of Charlotte Wyatt, illustrating the dynamic development of the clinical situation of a premature baby.

Charlotte Wyatt was born prematurely (2003) at 26 weeks' gestation and weighed 458 grams – as a newborn on the verge of viability. She was brain damaged and had severe problems with her organs – pulmonary hypertension resulting from damage to her lungs with recurrent urinary tract infections and worsening kidney function. In the first year of her life, Charlotte had to be resuscitated three times. She had severe respiratory failure requiring ventilation and needed to have her head constantly enclosed in a transparent plastic box and receive almost the maximum oxygenation possible. Doctors established that Charlotte had no sense of sight or hearing and would remain effectively without volition. Their prognosis was that she would not develop neurologically or respond to stimuli – except distress and pain – including future treatment, and were unanimous in describing her quality of life as terrible and the endurance of further aggressive treatment as intolerable. The hospital that provided her care asked the court for a declaration that it would be lawful to withhold artificial ventilation should Charlotte suffer a fourth crisis. The parents were hoping for "a miracle born of divine intervention" and contested the application. While it was not illegal to use a ventilator, the doctors believed that with such a dire prognosis, it was not in the best interests of the child. They were particularly reluctant to perform surgical tracheostomy. This sparked a year-and-a-half dispute, during which six rulings were issued. In the first[27], Mark Hedley J, privately chair of The Lawyers' Christian Fellowship[28], repeatedly stressed the adoption of a strong presumption in favour of the preservation of life. He stated that, to respect Charlotte's sanctity of life and her right to dignity, recourse should be made to the principle of best interests. As one of the important factors to be taken into account, he highlighted the concept of "intolerable to that child", according to which the court may consider the cessation of maintenance of life to be lawful if it determines that the continuation of treatment so reduces the quality of life of the child that it becomes intolerable. The phrase "to that child" emphasises that the test refers to the child and not to the party making the decision. Hedley J emphasised that "the issue in all probability is not whether this baby should live or die but how and when she should die". In his view, any consideration of best interests for a person at risk of imminent death should involve securing a "good" death – not under anaesthetic or during painful and futile treatment, but peacefully, in the arms of those who love her most. As a result, the judge authorised the doctors, in the event of disagreement with the parents, not to submit the child to artificial ventilation or similar aggressive treatment. This relief was "only permissive, not mandatory declaration". The key was to assess Charlotte's actual condition at the time of making the decision. The girl's condition was slowly improving. The need for administered oxygen decreased, and her responses to the environment and stimuli became better and better. At the third sitting in April 2005, the judge concluded that Charlotte's improved state of health no longer allowed her life to be described as intolerable. The child began to respond to loud noises, looked behind large coloured objects, and usually no longer needed sedatives. However, experts continued to argue that Charlotte would not be able to withstand the invasive efforts to manage another respiratory crisis, given her severe chronic lung disease and

27. *Portsmouth NHS Trust v. Wyatt & Ors* [2004] EWHC 2247 (Fam) 7 Oct. 2004 (called Wyatt No 1).
28. http://www.lawcf.org/index.asp?page=Mr+Justice+Mark+Hedley, follow Szewczyk K: Kazus Charlotte Wyatt – opis; Interdyscyplinarne Centrum Bioetyki UJ, http://bazy.incet.uj.edu.pl/dzialy.php?l=pl&p=31&i=3&m=27&n=1&z=&kk=126&k=187.

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malnutrition resulting from food intolerance. The prognosis that such "futile aggressive treatment" would restore her to her current condition seemed slim and would most likely either threaten her chance of a peaceful death or return her to an "intolerable" existence[29]. The judge again ruled ahead of time not to implement ventilation, although he stipulated that his verdict needed ongoing review, and the Court of Appeal upheld this ruling[30]. The hospital asked for a ruling that, in the event of a further dispute with the Wyatts, the final decision would rest with the doctors. However, Hedley J considered that a "novel" declaration of this sort was not required[31]. A doctor is obliged to act in the best interests of the patient, working "in partnership with the parents". However, clinical judgment can comprise an intellectual dimension and a "professional conscience, intuition or hunch and the clinician cannot be compelled to act contrary to his or her conscience"[32]. This, according to the judge, provided the doctors with sufficient protection. Further improvements in Charlotte's health justified the prognosis of leaving the hospital, but after trial visits at home, she developed a cough and a viral infection. In the event of deterioration, only the use of a ventilator would be viable, but doctors still considered this to be futile and contrary to her best interests, given Charlotte's lung condition. At the end of the dispute, the judge again issued a "permissive, not mandatory" order leaving the decision to the doctors[33]. Charlotte's body self-controlled the infection. She remained dependent on oxygen, required increased round-the-clock care and feeding by tube, with the mental development of a 12-week-old child. At the end of 2006, she was permanently discharged from hospital(based on: 52).

Charlotte Wyatt's case is a model example of a detailed and conscientious consideration by the court of the slowly changing pros and cons of the girl's situation, taking into account the extreme suffering involved. Media coverage also reached Poland, my homeland: an article was published with the sensational headline "Parents fight the hospital for the life of their child"[34], as if the doctors wanted the patient dead. On the other hand, the axis of judgements was a life without pleasure and the amount of suffering paid for by a treatment that had not worked in the first place.

One day in the hospital, Charlotte was found to have a fractured femur. This had nothing to do with abuse or mishandling but was due to her extremely brittle bones. The doctors decided to administer diamorphine, although the parents refused, fearing that it would affect her breathing[35]. The fact that Charlotte recovered enough not to spend her life in the hospital is not thanks to her parents or the public, but to the doctors. Clearly, allowing them to stop invasive medical techniques in the event of another acute crisis and granting the freedom to make decisions based on clinical chances did not result in hasty consent to death. The doctors only wanted to preserve their professional freedom to decide not to take disproportionate medical measures(2: 140–145, see also: 53). Judge Hedley said that parents' wishes should be taken into account to the extent that a doctor's professional judgment and conscience allows, but no further.

Children affected by lethal malformations

Children with lethal malformations usually do not live long after birth, but each case is different, and therefore both the length and quality of life may vary. The lethal nature of some defects may be determined by their severity – examples include Down syndrome or spina bifida. It is understood that improvement is, in principle, excluded; however, in some cases, it is possible to live a tolerable quality of life for a certain period of time. Surgical corrections will not remove the cause of the disease, but they can improve functioning. Still, the invasiveness of the intervention, its likelihood of success, and its potential to improve overall health are not insignificant considerations.

Numerous cases of ruling on the withdrawal of over-invasive and futile treatment with reference to the best interests of the child, understood as protecting it from excessive suffering, are referred to in Richard Huxtable's extensive study(based on: 52: 40–44). According to him, the British standard of resolution in all similar cases is essentially the same: the decision depends on the best interests of the patient(based on: 52: 37), starting with the *Re B* case of 1981[36]. B, named Alexandra, was a newborn with Down syndrome and bowel obstruction. Corrective surgery could relatively easily remove the obstruction and prevent death. However, doctors disagreed on whether the child's health situation was "worthy" of surgery, and Alexandra's parents were strongly opposed to the procedure. The decision of the court of first instance, which was made in favour of the parents, was subsequently overturned by the Court of Appeal, with the critical remark that the judge had been too concerned about the wishes of the parents, while his duty was to consider the best interests of the child. Alexandra may have been severely physically and mentally disabled, but not to the point where the operation made no sense. In authorising the procedure, Lord Templeman J pointed out that the outcome might have been different if "severe proven damage" had been demonstrated, which would have condemned the child to a life full of pain and suffering, and "awful that in effect the child

29. *Re Wyatt (a child) (medical treatment: continuation of order)* [2005] EWHC 693 (Wyatt No 3). Based on: Huxtable R: Law at the limits of life: children, welfare and best interests. In: Huxtable R (ed.): Law, Ethics and Compromise at the Limits of Life: To Treat or not to Treat? Routlege, London 2013: 34–36.
30. *Wyatt & Anor v. Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181 (*Wyatt No 4*).
31. *Portsmouth NHS Trust v. W* [2005] EWHC 2293 (*Wyatt No 5*).
32. Ibidem § 40.
33. *Re Wyatt* [2006] EWHC 319 (*Wyatt No 6*).
34. Pszczółkowska D: Rodzice walczą ze szpitalem o życie dziecka. Gazeta Wyborcza 22.04.2005. Available from: http://wiadomosci.gazeta.pl/wiadomosci/1,60085,2667836.html.
35. *Re Wyatt (a child) (medical treatment: continuation of order)* [2005] EWHC 693 (*Wyatt No 3*).
36. *Re B (a minor) (wardship: medical treatment)* (1981) 1 WLR: 1421.

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must be condemned to die". However, in the event of an unknown prognosis, it would have been inappropriate to refrain from the operation[37]. In connection with this ruling, the well-known criminal law scholar Glanville Williams put forward the argument that failure to perform a life-saving operation on a severely defective newborn could always expose the parties to a murder charge unless the facts of the case meet the criteria for a "Templeman exception"[38].

A different assessment was made by a US court in an earlier case known as the *Baby Houle Case* (1974). Robert Houle was born with many injuries. His entire left side was malformed; he had no left eye, was practically without a left ear, had a deformed left hand; some of his vertebrae were not fused(54) (the spine image may correspond to open meningomyelocele symptoms). Suffering from a tracheoesophageal fistula, he could not be fed orally. Inhaled air entered the stomach, and stomach contents entered the lungs. The condition of the child deteriorated significantly after the first day of life. Circulatory failure caused hypoxia, and extensive brain damage was suspected (later it turned out that the child had a hidden heart defect and lung hypoplasia). Reflexes deteriorated, and pneumonia developed. However, the tracheoesophageal fistula, the main and immediate threat to life, could be operated on relatively easily. The parents refused to give their consent due to the accompanying complications and profound deformities. The case was brought to court because several doctors from the hospital had a different opinion. After passing the case through successive instances, the Supreme Court ruled that, from the moment of birth, a human being is entitled to full legal protection, and the most fundamental right of every human being is the right to life. He ordered an urgent operation[39], as a result of which the child died in hospital. The doctors and the court focused, as can be seen, on the immediate cause of the threat to life, and not on the presumed defect of the neural tube and the generally unsuccessful prognosis. However, in the overall assessment of the case, it would be necessary to take into account the sum of all damage and subsequent complications, which, *prima facie,* could indicate a condition so severe that even a successful operation would merely prolong the agony.

Carrying out an invasive procedure with poor prognosis or its abandonment and limitation to palliative care can pose a serious dilemma. In Poland, a case of this type occurred in 2012. Madzia Słabiak was born with hypoplastic left heart syndrome (HLHS), a lethal defect caused by aortic stenosis. With this defect, palliative surgery immediately after birth and three or four highly invasive cardiac surgeries in the first years of life do not eliminate the cause of the disease but, if successful, may prolong life. The procedures are associated with a significant risk of death or serious complications, and the heart remains abnormal, with an active single ventricle, resulting in severe disability and major limitations. Madzia's poor prognosis was further aggravated by a narrowing of the foramen ovale. The girl's parents decided to refuse treatment. They declared that they wanted their daughter to be able to pass away in peace, surrounded by their love, without condemning her to pain and suffering. They also declined resuscitation. Among the doctors in the maternity ward, disapproval prevailed, but unexpected support came from the ethics committee of the paediatric hospital, where Madzia was planned to be transported. The committee issued an opinion stating that doctors are not obliged to apply for a court permit that opposes the will of the parents because, with such a prognosis, the parents "have the right" to refuse treatment. The statistical mortality in such cases is about 50%, and Madzia would have faced an even greater risk. The committee found no reason to believe that the parents acted to the detriment of the child, driven by excessive fear or misguided pity. Finally, the parents were able to take the child home and give her palliative care. Madzia survived for 38 days. She passed away peacefully and without suffering, with her parents and under the care of a home hospice(55).

Kazimierz Szewczyk observed that an important factor inducing many doctors to undertake aggressive treatment is an attitude that is seemingly ethically principled, or serves as a kind of moral refuge. Repeated declarations such as "it is my duty to save lives in all circumstance", intended to put an end to any discussion, stem both from a misunderstanding of the aims of medicine and from a reluctance to engage in deeper moral reflection(1).

From other sources, it is known that in the US, some medical units offer palliative care for such cases, referred to as "comfort care", which consists of not introducing Prostin (a drug that allows the child to survive until surgery) and focusing on relieving unpleasant symptoms. This path is described by the mother of a boy with HLHS diagnosed in the 20th week of pregnancy – Amy Kuebelbeck – in the book titled "Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life". The path that Amy took in deciding not to treat her son is similar to that of Madzia's parents. However, Amy failed to obtain permission to take Gabriel home(55).

Some lethal defects are diagnosed only at a certain stage of life, when the child begins to show more and more disturbing symptoms that herald imminent death. It may also happen that a progressive disease, before it develops its terminal form, leaves some time for a good life. Then it is important to be able to recognise the moment when medical intervention should cease, since death is certain.

In 2006, a British court ruled on the case of 18-month-old M, who had been diagnosed with the most severe form of spinal muscular atrophy (SMA), a genetic condition that gradually removes the ability to move muscles voluntarily. The condition is degenerative and progressive, meaning it can only deteriorate towards an inevitable death. By the time of the hearing, M could only move his eyebrows to indicate

37. *Re B (a minor):* 1424.
38. Williams G: Letter: Life of a Child. The Times, 13.08.1981: 9; follow: Huxtable R: Law, Ethics and Compromise, at 38.
39. *Maine Medical Center v. Houle*, Maine Supreme Judicial Court No. 74–145 (Super Ct, Cumberland City, ME February 14, 1974).

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pleasure or pain. However, it was accepted that he may have normal cognitive function and that he could hear and occasionally see. M could survive for a few more years or might die suddenly and soon. He required positive-pressure ventilation via an invasive endotracheal tube. He could not swallow and was fed through a gastrostomy tube. The treating doctors considered that M's quality of life was so poor and that the burdens of living were so great that it was unethical (the word "cruel" was used) to continue keeping him alive artificially, and that his endotracheal tube should be withdrawn[40]. The hospital sought permission to withdraw M's life-sustaining ventilation, but the parents objected. M was conscious. It was probable that he continued to see, hear and feel, and have a close relationship with his family. He may well have been aware of his surroundings, and of his family and the people close to him, and have the normal thoughts and mental processes of an 18-month-old child. There was no objective evidence to suggest that his cognition was normal – but none to indicate that it was abnormal, either. M also seemed to gain pleasure from TV and DVDs as well as music played to him on CDs. However, it was not possible to give an opinion about his cognitive function, as it was impossible to assess. It was also very difficult to determine how much discomfort or distress M experienced. In Holman J's opinion, the positives felt by M, although not subject to "mathematical" quantification, outweighed the discomfort, anxiety, and pain described by the doctors. This proportion would certainly change as M approached the inevitable end of his life. Therefore, the judge refused to allow the withdrawal of pressure ventilation but agreed not to implement other life-saving measures (like cardiopulmonary resuscitation – CPR). "There are, however, procedures which go beyond maintaining ventilation, which require the positive infliction of pain and which, if required, will mean that M has moved naturally towards his death despite the ventilation. If that point is reached, it would be in his best interests then to withhold those procedures even though he would then probably die"[41].

The court ruled differently in the case of K – a five-and-a-half-month-old girl[42]. She was born prematurely with congenital myotonic dystrophy (CMD), a neuromuscular disorder causing chronic muscle weakness. K was a severe case. She had major issues with gut motility, leaving her unable to tolerate milk feeds. She required mechanical ventilation by CPAP (oxygen delivered under pressure through small tubes into the nostrils) and was dependent on artificial nutrition given intravenously via the central line (total parenteral nutrition – TPN). Progressive muscle dystrophy was accompanied by numerous complications. Infections led to septicaemia. This caused thrombocytopaenia (low platelets), which in turn led to a large right-sided intraventricular haemorrhage (bleeding into the fluid cavity on the right side of her brain). Following her second episode of septicaemia, K was afflicted by a left-sided focal seizure involving rhythmic twitching of her left arm and left leg. The consultant neonatologist situated her clinical state somewhere between "no chance" and "no purpose", with a prognosis that she was unlikely to survive one year. Treatment could be considered futile and burdensome, as the dysfunctions had deteriorated irreversibly and she was experiencing increasing discomfort. In this state, it was considered unreasonable to expect K to endure such a degree of irreversible impairment. The ruling allowed for the removal of the central line and the initiation of palliative care. Potter J concluded "that it would not only be a mercy, but it is in her best interests, to cease to provide TPN while she is still clinically stable, so that she may die in peace and over a comparatively short space of time"[43]. Nobody opposed.

On the other hand, the Polish case known as "Chazan's newborn" provides a negative example of an approach to caring for a suffering child. After the prenatal diagnosis of numerous and severe foetal defects, the future parents asked for a termination of the pregnancy on embryopathological reasons. They were prevented from exercising this right by the then director of the Holy Family Hospital in Warsaw, Bogdan Chazan[44]. The boy was born in June 2014 and lived for nine days. He had a cerebral hernia accompanied by anencephalia. The bone loss of the skull cover was so significant that the right hemisphere of the brain was covered only by membranous tissues and fused with them, forming the wall of a vast fluid reservoir, with parts of the brain preserved only fragmentarily. The examination showed, among others, massive hydrocephalus with reduced brain mantle, left ventricular distortion, a left frontal cyst, and dramatic craniofacial deformities[45]. The size of the defects and the extremely poor prognosis meant transition to palliative care in a hospital setting, including analgesic administration of morphine. In addition to the incubator and intravenous irrigation, enteral feeding was provided through a probe, and the site of bone loss was secured with a sterile dressing. Initially, the child's condition was stable. On the sixth day of life, progressive respiratory and circulatory failure occurred, while by the ninth day, the child intolerance to nutrition, cardiac arrest, and death. The cause was extensive purulent leptomeningitis, softening of the neuroglial tissue, and features of cortical and white matter atrophy. The child died in agony, which, according to the parents' accounts, was not suppressed by morphine. The pain was prolonged by artificial nutrition. Without it, the patient would have died faster

40. An *NHS Trust v. MB* [2006] EWHC 507 § 10.
41. Ibidem par. 91.
42. *Re K (a child) (withdrawal of treatment)* [2006] EWHC 1007, Follow: Huxtable R: Law at the limits of life: at 48.
43. Ibidem par. 57.
44. See: MAW: Śledztwo w sprawie odmowy aborcji przez prof. Chazana umorzone. Newsweek Polska 4.05.2015. Available from: https://www.newsweek.pl/polska/sledztwo-w-sprawie-odmowy-aborcji-przez-prof-chazana-umorzone/mx589bh.
45. Case description according to the autopsy report made available with the permission of the prosecutor's office. Parents' report: https://serwisy.gazetaprawna.pl/zdrowie/artykuly/878315,rodzice-dziecka-ktorym-prof-chazan-odmowil-aborcji-po-urodzeniu-lekarze-bali-nam-sie-je-pokazac.html.

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and would not have lived to experience the moment when the suppuration and putrefaction process caused unbearable pain. The parents were probably too devastated by the situation to question the doctors' decisions.

Polish legal practice also involves the case of a child with Krabbe disease who was born in 2008. The case emerged during a compensation claim for negligent prenatal testing (the parents' claim was dismissed due to the non-fault nature of the diagnostic error)[46]. A boy named D was born with a cleft upper lip, maxillary alveolar process, and hard and soft palate. He was also soon diagnosed with bilateral hearing loss. After six months, the boy was hospitalised for loss of appetite, increased muscle tone, contracture of his upper extremities and spasticity in his lower extremities. During another hospital stay, at the age of seven months, he was diagnosed with Krabbe disease, spastic quadriparesis, regression of psychomotor development, symptomatic epilepsy, bilateral otitis media, and gastroesophageal reflux. Probe feeding and hospice care, and consultation with the Metabolic Disorders Clinic were recommended. Two and a half months later, D was hospitalised again and treated surgically for reflux. Krabbe disease is associated with great suffering, which is relieved with strong medications. The child died four months after surgery. Until his death, he required constant care and feeding through an enteral probe. Both parents lived with the knowledge that, after a few months of suffering, their son would die, as the same thing had happened to their first child. They seem to have relied on doctors' decisions on how to provide care. The case is particularly difficult to evaluate, as the symptoms of the disease did not occur immediately. However, it had been known for some time that D was dying, and the reflux prevented him from taking food by the usual route. Yet the patient was operated on and fed by probe until the end. The question remains: why, when he had no chance of survival anyway and required painkillers. Pain relief is, of course, justified, but feeding only prolonged dying[(23)].

By way of an addendum, another recent case of a child with Krabbe disease must be cited here. It illustrates, at the same time, the possible attitude of parents to a properly drawn up protocol for discontinuing the child's futile treatment. Noah was the son of a well-known travel reporter and photographer. He was diagnosed with the disease at the age of six months and died before he was two years old[47]. Symptomatic treatment with bone marrow transplantation is now possible, and this fact changes the perspective somewhat. Experimental gene therapies are also underway. Noah's diagnosis, however, came too late for him to be eligible for treatment. His mother perceived the late diagnosis and the omission of treatment as an injustice and has called for the introduction of newborn screening for Krabbe disease (which is very rare and mainly affects individuals of Scandinavian origin). In desperation, she even subjected her baby to intravenous stem cell injections in Slovakia and spinal cord injections in Thailand. "We wanted so much to save him that we did too much" – she admitted. In the end, the parents were allowed to take Noah home from the hospital in Krakow to die there, after the futile treatment protocol was drawn up and entered into the system. The mother described the procedure as a "verdict" and regretted that the decision was made by a medical consortium without even asking the parents for their opinion. The dying boy's parents tried to prolong his life using an artificial respiration mask they had received in Thailand. This brief description shows that medical communication with the parents of a child suffering from a fatal and rare disease was failing, leading them to misunderstand the critical situation and make desperate attempts to save what cannot be saved. Such parents become easy targets for charlatans. For the comfort of the child's short life, it would have been worthwhile to put more effort into properly informing the parents. According to the mother's report, they could not accept the painful truth until the very end. This carries the risk of medically unwarranted subjecting the child abroad to experimental therapies of dubious and unproven efficacy, as well as forcible and undermining already fragile health travel around the world in search of the impossible.

Difficult diagnoses

More decision-making problems arise with diagnoses of poorly understood diseases, even when the child enters the end-stage state and doctors plan to withdraw intensive care. The last line of resistance for desperate parents is to request experimental treatment. Here, arguments are put forward about the duty of doctors to seek all possible methods of treatment, even those of unproven effectiveness, or about their duty to maintain the vital functions of the patient until effective treatment is invented. This phenomenon is illustrated by the recent high-profile cases of Charlie Gard and Alfie Evans and, more recently, Indi Gregory. The first two have already been discussed in other studies[(33,56)], so they will be cited here only briefly. The court rulings have been widely commented on, but only specialists have the patience to analyse them legally and medically. Other recipients are generally content with press reports, which inevitably take shortcuts. Hence, it is easy to fall into a schematic superficiality that gives an incomplete picture and opens the door to interpretation abuse[48]. A verdict does not create reality, but rather documents important legal events and medical evidence. The epilogues can be read about in the press. Charlie Gard was diagnosed at the age of 8 months with mitochondrial DNA depletion syndrome (MDDS), which soon caused severe and permanent damage. Charlie

46. Sąd Apelacyjny w Białymstoku, wyrok z 24.04.2013 r. I ACa 787/12 (Portal Orzeczeń Sądów Powszechnych).
47. Demianowicz A: Trzeciego cudu nie było. Wysokie Obcasy 1.03.2025: 6–9.
48. E.g. Roszkiewicz J: Czy można uśmiercić pacjenta z powodu niskiej jakości życia? Uwagi na tle orzecznictwa Europejskiego Trybunału Praw Człowieka. Forum Prawnicze 2023; 1.

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suffered from the *RRM2B* mutation of MDDS. He could not move his limbs or breathe on his own, had frequent epileptic seizures, and remained without cognitive or sensual contact with his surroundings, except for his supposed ability to feel pain. His life expectancy was estimated at 6–9 months. Parents insisted on the use of "pioneering" nucleoside treatment. In fact, this type of treatment had not even reached the experimental stage in mice, let alone been tried on humans with this strain of MDDS. Despite this, a doctor in the U.S. initially agreed to carry out the treatment (for adequate remuneration), although there was no evidence that nucleoside treatment could cross the blood–brain barrier, which it must do to treat *RRM2B*. The doctor also confirmed during this telephone conversation that he had never treated with nucleoside treatment anyone who had encephalopathy. Therefore, he was unable to indicate on any scientific basis whether a patient with encephalopathy would respond positively[49]. Domestic and foreign specialists agreed that at such an advanced stage of the disease, treatment would be futile – it would not reverse brain damage or significantly improve health or quality of life, and it would expose the patient to additional suffering. Domestic courts considered that there was therefore a risk of significant harm and, based on the criterion of the best interests of the child, refused to allow Charlie to leave the country and decided to lawfully withdraw all treatment, save for palliative care, to permit Charlie to die with dignity. The court put its role in deciding the family's private case as follows: "Some people may ask why the court has any function in this process, why can the parents not just make the decision for themselves? The answer is that, although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child's best interests"[50]. The parents lodged a complaint with the ECHR. The court found no infringement and declared the application inadmissible, giving priority to the best interests of the child, including in particular his physical integrity[51]. It accepted as a starting point that when the fair balance that must exist between the competing interests and means of protecting the child, the parents and public order is upset, within the margin of discretion of national law, priority can and should be given to the best interests of the child (par. 107), taking into account the child's well-being in terms of bodily integrity. Such a solution is also supported by a broad international consensus based on the best interests criterion. The Court went on to note that the domestic courts found that there was a risk of significant harm to Charlie if the treatment requested by his parents was implemented in his case, because, according to experts, experimental treatment with no chance of success would not benefit the patient, but would only prolong his suffering. The findings of the national courts were considered by the Court to be thorough and meticulous, and in conclusion, the Court found no violation of the Convention and declared the complaint inadmissible. Finally, the doctors managed to convince the parents and the maintenance of the child's life was withdrawn with their approval. Charlie died on 28 July 2017[(57)].

American law provides for the possibility of using experimental treatment under compassionate use. However, its hypothetical efficacy in the case of Charlie Gard was questioned by experts and therefore the parents' insistence was not considered[(58)]. As has rightly been commented, even the granting of such consent by a domestic court would not guarantee access to treatment in the USA. It is under the strict control of the Food and Drug Administration, and pharmaceutical companies are not allowed to make untested products available to doctors[(59)], especially when the method is at such an early stage of development that it is doubtful that it will bring the benefits that the patient expects[(60)]. On the other hand, pioneers of novel therapies often face resistance from the medical community, and there would be no progress in medicine if they did not break the rules by means that are not always legal. Individual patients can benefit from this. However, formalised authorisation procedures aim to provide a civilised framework for experimentation and to protect dependent and vulnerable patients.

These remarks also apply, but only in theory, to Alfie Evans, who suffered from a progressive neurodegenerative disorder of unknown origin that had already destroyed almost his entire brain. Eventually, Alfie found himself in a deep coma, unable to receive stimuli. He lost the ability to swallow and required CANH and ventilator support, with no hope of any improvement. Doctors decided that treatment options had been exhausted and further intensive care would be futile and inhumane, so they recommended withdrawing it. His parents objected and wanted to transport Alfie by air to Italy, where the Vatican's Bambino Gesu clinic in Rome volunteered to keep him alive indefinitely (it had also previously made a similar promise to Charlie Gard). After hearing numerous opinions from specialists, Hayden J ruled that mechanical ventilation was no longer in the child's best interests and would not be legal at this stage, so he decided to gradually disconnect Alfie from the ventilator[52]. To justify his position, he cited, among other things, the Royal College of Paediatrics and Child Health's March 2015 recommendations, Making Decisions to Limit in Life-limiting and Life-threatening Conditions in Children: Framework for Practice. In its second order, dated 11/04/2018, it approved Alfie's inclusion in palliative care. The appeal of the parents was unanimously dismissed[53]. The Court of Appeal found that Alfie's best interests were served by neither the

49. *Great Ormond Street Hospital v. Yates and others* [2017], 11.04.2017 EWHC 972 (Fam) No. FD17P00103.
50. *Great Ormond Street Hospital v. Yates and others*: 11.
51. ECHR 27.06.2017. *Charles Gard and Others v. The United Kingdom*, No 39793/17.
52. *Alder Hey Hospital v. Evans* [2018] EWHC 308 (Fam), 20.02.2018.
53. Court of Appeal, Civil Division, 2018/PL/10809 [2018] EWCA 984 (Civ).

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continuation of on-site treatment nor the arduous travel for the same purpose to Italy, as it gave no hope of improvement and could cause additional suffering during transit[54]. The parents' complaint to the ECHR was rejected without examination, and their application for a life-sustaining security order was denied[55]. Mechanical ventilation was disconnected. Three days later, Alfie's father announced that the child was breathing on his own[56], and two days later, on 28 April 2018, Alfie died.

Both cases concerned treatment that was considered futile by national medical consultants. In the case of Charlie Gard, it was a denial of experimental treatment, completely untested on humans, offering very doubtful chances of alleviating symptoms, and only slightly delaying the moment of death, but at the expense of additional suffering, and the cessation of mechanical ventilation(61). Alfie Evans's case concerned artificial life support.

In the Alfie case, the position of the Expert Team of the Polish Bishops' Conference on Bioethics was issued. It claimed that the disconnection from the ventilator was an act of murder, and not a withdrawal of "persistent" treatment, because hydration, nutrition and ventilation fall within the scope of minimal care, as long as the body is capable of living, that is, as long as the processes proper to it "are not exclusively the result of forcing through medical procedures": in the event of brain death or when the organism reaches its "natural" end (terminal states as a result of old age, illness, the effects of an accident). Concern for the boy's welfare requires a search for the causes of his illness and methods of treatment, including alternative therapeutic solutions, even experimental ones. Abandoning persistent treatment when it is technically possible to sustain organ function that does not benefit the patient by improving his health is legally permissible only if it involves excessive or disproportionate discomfort or if it could not be evaluated as a life-saving activity in view of the fact that it merely prolongs the agonal state. "The legality of deciding whether it is in a particular patient's best interest to continue his or her treatment because of his or her ability to experience the world in a particular way is highly morally questionable and stems from a strictly arbitrary ruling on the norms governing social life. Deprivation of life under such circumstances should properly be understood as euthanasia or homicide" (par. 10). "A legal system that genuinely takes into account the principle of protecting the dignity of the human person requires life-saving measures to be taken until clearly opposed by the properly understood good of the human person, that is, only when the measures are glaringly disproportionate to their effects, prolong the patient's suffering and when they are not the cause of his death" (par. 11).

What we have here is a proliferation of fallacies and the imposition of impossible obligations on medical personnel, in particular the requirement to continue seeking treatment even after it has been ruled that the possibilities of medicine have been exhausted and the patient's health has steadily deteriorated. In doing so, the KEP proclaims that the criterion of quality of life is arbitrary. In doing so, it disavows the strenuous efforts of weighing multiple goods and factors in determining the best interests of a particular patient through numerous court rulings, which in light of the court decisions cited earlier amounts to mere principled lip service. Instead, the KEP operates on the notion of "properly understood good of the human person", and this only serves as a stark example of arbitrariness. This good supposedly allows the withdrawal of only such measures that both prolong suffering, are glaringly disproportionate to the effects and when they are not (?) the cause of death. It constructs the judgment that only in the circumstances it has specified is withdrawal of a patient's treatment "legally permissible". Meanwhile, nothing of the sort emerges from the common law. Therefore, it is all the more worth emphasising the usefulness of the concept of futile treatment, recognised by medical professionals, when resolving critical issues in medical care(2: 148–149).

Charlie's parents, along Alfie's, have called for a reform of the law that would shift the boundary of judicial interference in medical decisions regarding critically ill children from a best interest test to a concern of significant or serious harm. According to Allison Howells, there is another reason why allowing parents the freedom to make final decisions in cases involving a critically ill child is not appropriate. Their judgment is often impaired, and what they do in an effort to protect their children "makes them vulnerable to the factors of time, emotional energy and money spent", which should be taken into account in the course of litigation(62). It is done by the Best Interests Test, giving weight to the parents' views, but not overriding power(33).

An American case cited by Anna Alchniewicz can be offered in support of this argument. It involved a 13-year-old girl, Jahi McMath, diagnosed with brain death after complications from tonsil and soft palate surgery. According to California's version of the Uniform Determination of Death Act, death was pronounced, but the patient was not immediately disconnected from the ventilator, as state regulations mandate that the family be given a short time to say goodbye. This family, however, not only objected to disconnecting the ventilator, but demanded the implementation of artificial nutrition. The hospital refused, considering it unethical and incompatible with medical professionalism to perform treatment on a corpse. The case went to court, where a peculiar settlement was reached. The hospital agreed to release Jahi McMath's body to the coroner, who issued a death certificate on 3 January 2014, and listed the cause of death as "under investigation". Two days later, the girl was and transported to New Jersey, one of the two states, alongside New York, where it is possible to express

54. *In the matter of Alfie Evans No 2*, 20.04.2018 [2018] EWHC 308 (Fam): 13.
55. *Evans v. the United Kingdom*, ECHR 23.04.2018, No 18770/18.
56. Who was Alfie Evans and what was the row over his treatment? BBC News 28.04.2018. Available from: https://www.bbc.com/news/uk-england-merseyside-43754949.

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disagreement with the diagnosis of death according to neurological criteria. Jahi McMath was admitted to the Catholic University Hospital in New Brunswick. One of the surgeons performed a tracheotomy, and a feeding tube was connected. Much of the hospital staff was opposed to carrying out these measures on a corpse, but nevertheless Jahi spent the next eight months in the hospital's intensive care unit[63].

Similar to Alfie Evans was the clinical condition of less than eight-month-old Indi Gregory. Soon after birth, she developed symptoms of numerous ailments and went on to develop seizures. In summary, Indi had profound and devastating cardiological, neurological, and metabolic disorders, which caused progressive damage to the brain, characterised by epileptic encephalopathy, respiratory insufficiency, abnormalities in the brain, developmental arrest, and early death. She was also diagnosed with intestinal malrotation where the gut is not positioned correctly, for which she underwent a corrective surgical procedure. Indi was on full life support for about a month, intubated, ventilated, with multi-organ support, and sedated. She was receiving the highest level of intensive care support but showed no sign of recovery. Her conditions were untreatable. The hospital asked the court for permission to withdraw treatment in the event that she deteriorated to a point where such treatment would be required to sustain life. Because there was no prospect of recovery, Indi's life expectancy was very short. The multiple treatments she was receiving were causing her tremendous pain and suffering. Indi's parents opposed the application.

A consultant stated that currently Indi showed minimal awareness of the world around her and she had very poor neurological functioning. She was one of the most severely ill children Dr E had ever dealt with. A second opinion by Dr S, from a different hospital, concluded: "Very sadly, further ventilation, painful procedures, or resuscitation is not appropriate. This is on the basis that physiological deterioration is occurring regardless of treatment, and that the severity of her progressive neurological condition is such that she can no longer benefit from continued life". A High Court judge, Peel J, took the view that the parents did not recognise the pain Indi was suffering, perhaps because they saw her through their own lens, which was "completely understandable. They were hoping against hope for something positive to emerge"[57]. However, the evidence clearly established that Indi was experiencing significant pain and distress several times a day, each episode lasting up to ten minutes. This pain was caused by her multiple treatment interventions. With a heavy heart, Peel J came to the conclusion that the burdens of invasive treatment outweighed the benefits. The significant pain was not justified when set against the incurable set of conditions, very short life expectancy, no prospect of recovery and, at best, minimal engagement with the world around her. Having weighed up all the competing considerations, the girl's best interests would be served by permitting the hospital to withdraw invasive treatment in accordance with the care plan presented – weaning Indi off intubation within one week and facilitating the use of a bag mask for up to a week after extubation, providing her with treatment to alleviate pain, and making her as comfortable as possible. That might take place at home or in a hospice, according to the parents' choice. At a later sitting, Peel J ruled that he could not consent to Indi being taken home because of the medical requirement to always keep her in a state of sedation – a 24/7 care package (with two nurses in attendance) – which would be very problematic to arrange. He also denied the parents permission to take Indi to a hospital in Italy for treatment there[58]. In Britain, as in Poland, it is possible to provide care through a home hospice, but there are many indications that the court did not trust Indi's parents and decided to prevent them from taking the child abroad. All the more so, since in the meantime Indi was granted emergency Italian citizenship by the country's prime minister, Giorgia Meloni, as part of an extraordinary last-minute attempt to have her flown to the Bambino Gesu clinic in Rome for treatment. However, the judges referred to the intervention by Italian consular officials as "wholly misconceived". Indi died in a hospice on 13 November 2023, four days after three appeal court judges ruled that life support treatment could be withdrawn only in a hospital or hospice, and not at the family home[59].

The point is that at some stage of medical care for a patient with irreversible brain damage, after the withdrawal of other forms of treatment, it is possible to maintain vital functions using invasive techniques. As long as mechanical ventilation and parenteral nutrition are in place, the patient is considered "alive". The child receives only pain stimuli from the environment, but the pain can be relieved by sedation. This is the case, for example, in Poland. Individuals might spend years in a vegetative state in nursing homes[60]. Among them are children admitted shortly after birth with congenital defects, with no prognosis that they might ever gain consciousness. Their bodies gradually grow pubic hair, breasts, genitalia, but they are not even aware of their own existence[61]. "They lie for several – over a dozen years, without awareness, e.g. after cardiac arrest, or not breathing as a result of muscular dystrophy", says Elżbieta Rękorajska MD. "You don't just die in a hospital. If resuscitation has been waived, please explain why. No one wants to know why

57. In the matter of Indi Gregory, The High Court of Justice, Fam., 13 Oct. 2023, Case No: FD23P00452: 43.

58. In the matter of Indi Gregory, The High Court of Justice, 8 Nov. 2023 [2023] EWHC 2798 (Fam.).

59. Halliday J: Indi Gregory, baby girl at the centre of a legal battle, dies after life support removed. The Guardian 13.11. 2023. Available from: https://www.theguardian.com/uk-news/2023/nov/13/indi-gregory-baby-girl-at-centre-of-legal-battle-dies-after-life-support-removed.

60. See: Nie rozmawiamy o tym, stoimy obok – rozmowa z Barbarą Kaczmarską, dyrektorką Zakładu Opiekuńczo-Leczniczego im. Sue Ryder w Warszawie. Wysokie Obcasy, 9.07.2011 r.

61. See: Siedlecka E: Kiedy można umrzeć. Polityka 2021; 11: 17–20. Dr. E. Rękorajska: za: ibidem: 18.

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they were resuscitated. The doctor invokes the conscience clause, unwarranted medical procedures escalate. Vegetative states persist for years"[62]. Such biological persistence does not benefit patients in the slightest. So, the question is what value it presents and whom it really serves.

The child says they've had enough

Despite the widely accepted view that futile treatment is inappropriate and even constitutes medical misconduct, on the basis of a review of cases it seems that it is maintained more often in relation to children than in relation to adults. Disputes about this also show that it is not always easy to determine which medical activities should be classified as futile. To consciously demand the cessation of futile treatment, the child must understand that it is indeed futile. This does not mean that there is always a duty to make him or her aware of it. Sometimes, we protect terminally ill children from the painful truth in the hope that they will not realise it and will pass away unexpectedly by themselves, preferably in their sleep. This attitude narrows the number of situations when a child manages to recognise that treatment has no sense. However, deceiving a dying child with "white lies" can have a moral justification only if it remains undetectable – for example, so that it is not exposed by an internet search on a smartphone, or so that it does not insult the intelligence of the patient. When the dynamics of the disease are at an end stage that can be readily identified, it is impossible to pretend that it is not getting worse. This applies especially to the experience of chronic diseases, when the patient spends a large part of their life in hospitals. The starting point for respect for the autonomy of a dying child is the set of criteria from the classic informed consent canon developed by Beauchamp and Childress: disclosure of material information, ability to cope with the decision task (factual competence), awareness and understanding of the situation (competence to understand and decide), understanding of information and recommendation, voluntariness with intention and without controlling influences (intentionality and freedom from pressure)[27: 120–121]. However, this set of criteria should be adjusted to account for specific factors: 1) the case concerns a child; therefore, a negligible factor should be included for the adult patient – the authenticity of the decision – i.e. one expressed in a well-recognised self-interest and without regard to others; 2) the decision is a manifestation of negative autonomy; 3) the treatment in question is futile, but its cessation will accelerate imminent death. It is therefore not a question of considering the pros, cons, and risks of improvement-prospecting treatment, but one of the personal experiences of an intolerable end-stage situation. It is obvious that one should not take seriously a six-year-old running around the haematology ward shouting "I want to die!" while suffering side effects of chemotherapy with a successful prognosis. The focus here is solely on states without hope and without any prospects, and at the same time causing suffering or at least a sense of utter futility of further efforts. This is illustrated by the genuine example of a 15-year-old with Duchenne muscular dystrophy who cried out: "Let me finally fucking die!"[63] after hearing about the planned implementation of parenteral feeding (the dynamics of muscle atrophic diseases is that they gradually deprive the patient of all the pleasures of life, and one of the last is enjoying the taste of food). In the literature, it is pointed out that the child's mental agility, which determines competence, should be seen as a spectrum. According to the scale developed by Priscilla Alderson, four levels of child involvement in decision-making can be distinguished: 1) being informed; 2) being consulted; 3) having views taken into account in decision-making; 4) being respected as the main decision-maker. Achieving the first level of fitness only entitles children to receive appropriate information. Entering the second allows them to express their own opinion on the treatment. The third level allows co-decision on treatment, but only the fourth gives the paediatric patient a decisive vote[64]. The fact that the patient can understand the content of the information provided does not mean that they will be able to use this information effectively. "Children progress through varying degrees of competence as they grow, develop and acquire life experience. Their involvement in decision-making is subject to their level of competence and this must be judged on an individual basis". Although the age criterion is adopted for legal purposes, in practice age is not necessarily a good measure of capacity. As Carol Kendrick's research has shown, nine-year-old children suffering from cancer already understand that a certain type of treatment can cause side effects (such as falling hair or swollen cheeks) and can accept this for its therapeutic purpose. They also understand disease-induced changes in the body, recognise their causes, and quickly learn the right medical terminology[65]. These findings provide strong support for the proposed partnership treatment of child patients, whenever they are able to at least understand the information provided. Achieving this first level of ability should be a clear signal that the child's competence should be viewed as high. It goes without saying that the message should be adapted to the child's cognitive abilities.

However, this does not provide an unambiguous answer to the question whether a decision to refuse treatment at the end of life requires more or less competence. Initially, it can only be assumed that this competence is very different from positive autonomy. For example, the ethical guidelines adopted at the Royal Children's Hospital Melbourne provide that decision-making during palliative care requires: 1) the ability to understand one's illness in physiological terms and to conceptualise death as an irreversible

62. From care and treatment facility with mechanical ventilation in Konstancin-Jeziorna.

63. This example was given by a doctor during a discussion at a legal-medical conference in Białystok, Poland, in March 2023.

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phenomenon; 2) the capacity to reason and consider future implications (formal operations stage of cognitive development); 3) the ability to act autonomously and not acquiesce to the authority of doctors and parents[66].

This results in increased requirements for the actual ability to cope with the decision-making task. On the other hand, the end-stage condition and futility of further treatment of the child require, in my opinion, greater than usual trust and respect for the child's individual feelings, as long as they are fixed and internalised feelings, rather than merely impulsive reactions. Consequently, the decision to discontinue futile treatment does not fall within the scope of all the criteria for the precise determination of competence set out in the literature. In particular, the assessment of rationality, in the sense of logical-cognitive competence, should not be a decisive criterion. To a greater extent than usual, it is worth taking into account so-called emotional intelligence. If it is possible to feel the suffering of a completely incompetent child and decide to withhold intensive care, it is all the more necessary to respect the will of a child suffering in the same way, but who is able to consciously express their needs. This is especially true for chronically ill children. Priscilla Alderson saw a high probability that children who have experienced chronic illness and hospital more clearly felt the limitations of treatment or its failure, and this enabled them to make a more realistic assessment of their situation[64: 15–16]. In turn, Anna Tyborowska's team has shown that under conditions of severe stress – perhaps caused by poor health – children's intellectual performance increases significantly thanks to the accelerated development of certain brain structures observed at such moments[67].

For this reason, it is possible, in my opinion, to relax some of the criteria for the effectiveness of opposition to futile treatment and to reduce them to an informed understanding of the health situation – including its inevitability and the implications of a faster death, the intentionality of the decision, and assurance that it is authentic and free – that is, only taken for one's own sake. The demand to stop futile treatment declared as intolerable may just as well result from the conviction of being a burden for parents or siblings or from the desire to meet someone's expectations. I reiterate that this is not a question of abandoning mandatory activities dictated by positive medical indications, but of suspending procedures that prolong agony and *de facto* interfere with dying – such as, in particular, mechanical ventilation and CANH in the terminal phase of the disease.

CONCLUSIONS

In the analysed cases, doctors often emphasised the suffering of small patients under medical care and used it as a crowning argument for stopping intensive care, although they sometimes exaggerated this argument due to their lack of perception of simple pleasures that prevailed over the ailments. The nurses' accounts cited in several judgments were more nuanced and provided information about the daily feelings of young patients, including their enjoyment of life. Day-to-day observation at the bedside were also reported by parents, but their objectivity was sometimes undermined by wishful thinking. Many times, they saw what they wanted to see, and they supplanted unfavourable knowledge. In a child, the individual benefits of life predominantly take the form of simple pleasures: warmth, respite from convulsions, closeness and contact with loved ones, positive sensory sensations from the environment, lack of pain, shortness of breath or anxiety, the ability to breathe without difficulty, eat well, digest and excrete well without painful interference, absence of persistent vomiting, no hunger or thirst. In older and more self-aware children, it may also be important to look forward to a promised pleasure or a new experience. With the prospect of improving or maintaining health, suffering and pain can be considered explicable, but suffering and pain before death have no justification. In the Judeo-Christian cultural circle, suffering is of extreme importance, and this hinders the rational weighing of pros and cons: to sustain a dwindling life in suffering for as long as possible – or to end suffering at the expense of shortening life in the face of imminent death. It is rightly repeated that the decision-making criteria for further treatment and intensive care must be adapted to the individual condition of the child concerned. The starting point, however, is at least the hypothesis of a successful prognosis, or a reasonably stable clinical condition that is bearable. Charlotte Wyatt spent a long time balancing on the verge of death, mentally disabled and malnourished, but gradually achieving improvement. Due to persistent respiratory problems, the moment of cessation of efforts was considered a respiratory crisis requiring the use of a ventilator because, according to doctors, Charlotte's weak body would not be able to survive it anyway. The court-approved attitude of waiting in readiness for rescue was adopted, but without using the most invasive method – in this case, considered ineffective. Medically justified consent to death was therefore by refraining from connecting the ventilator. Alexandra, who had Down syndrome, received surgical clearing of the intestines, her condition otherwise justified a positive prognosis. Robert Houle was in a much worse situation, but the surgery to close the fistula was ordered by a court in the name of "everyone's right to life" rather than based on a comprehensive consideration of the prognosis. Madzia Słabiak passed away in peace, as the prognosis for two coexisting heart defects was so poor that the parents were "allowed' to make this decision. However, if they had insisted on treatment, operations would have been carried out. In the case of M, the court ordered the temporary maintenance of mechanical ventilation and medical nutrition because the patient, although completely inert, still enjoyed life in his own modest way. The court decided, in opposition to the doctors, that the benefits of life outweighed the ailments, although the moment would come when the ailments would prevail and resuscitation should not be performed. The critical moment would therefore be cardiac arrest in the course of SMA.

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In the case of K, the court found that this moment had already occurred. The disease was fatal as in M's case, but K suffered such severe ailments with virtually no life benefit that withholding TPN nutrition was considered an act of mercy. In the Chazan case, such a severe form of anencephalia condemns the patient to inevitable death immediately after birth, so any intervention would only prolong dying. In my opinion, the most humane way to treat this boy would have been to use appetite suppressants and not connect him to feeding tubes. The moment when life-sustaining care should have been abandoned was the moment of birth. Charlie Gard, Alfie Evans, and Indi Gregory suffered from terminal mitochondrial diseases. Each of them was in a state of deep collapse and at the stage when medicine had nothing to offer but palliative care, so the decisions taken to stop mechanical ventilation were justified. Indi received life-saving intestinal surgery at an early stage, before she developed all the dysfunctions and when the prognosis of her condition was not yet known, so it was justifiable to carry out the procedure. The 15-year-old with Duchenne dystrophy, who understood his situation, should have had the right to refuse invasive care when in a terminal state – provided he was not acting on a momentary impulse, but was refusing intentionally, freely, and solely for his own sake. The same should apply to all children who meet the material criteria of "mature minors".

A child patient is at the beginning of the path of life, which, as a rule, should not be closed. However, this path can be blind, short, and so thorny that no one should be condemned to walk it. In states of imminent death, it may, in my opinion, be considered inhumane to allow a child to feel the full extent of their suffering, so it is better to put an end to it before it truly begins. It may even be necessary to comprehensively consider the desirability of palliative surgery as well as discharge from the hospital – so that the actual decision does not fall exclusively into the hands of parents. Such children should only live for themselves and not for others, and the quality of life should be assessed solely from their point of view: the pleasures of living in such a state. From this perspective, it should make no difference whether the intervention involves treatment in the strict sense, medical nutrition, or mechanical ventilation. The assessment is hindered only by a rigid attachment to the principles of so-called primary care and instinctive opposition to allowing death from starvation and dehydration. The argument is used that feeding the hungry is one of the simplest gestures of concern and a symbol of the fact that human life is always embedded in the life of the whole society and community(65). The caring symbolism of nutrition, however, is not an argument in itself: it can be considered justified only if nutrition brings benefits to the patient. In my opinion, therefore, it is reasonable to consider its futility. The position of any nutrition as part of mandatory primary care results from a top-down assumption, so as an unshakable care principle, it does not yield to rational persuasion. However, if, at a given stage of medical care, nutrition and hydration do not bring the patient any real or perceived benefit from life but only follow an arbitrarily adopted principle – then, from the point of view of the patient's good, it is superfluous, and this is the main argument in favour of legal cessation because its value is purely abstract. Feeding a person for whom it is not necessary undermines their interests, ceases to serve them, and becomes an empty act. In fact, it works for the benefit of third parties instead. It provides carers with positive reinforcement and moral satisfaction that they are "doing their job". The insistence of parents to continue such care more satisfies their own emotional need and can be judged as a violation of the child's privacy – the right to pass away in peace and dignity. Maintaining life at all costs through medical intervention reduces the patient to the role of a doll in a game of feeding and changing.

Sustaining life in the end-stage of a terminal illness can be considered harmful if it brings nothing but prolongation of suffering. Based on the review of cases, it is therefore worth summarising when interventions including medical nutrition and hydration can be considered futile.

1. When there is no benefit in remaining in a certain state without any hope of improvement – e.g. with severe and lethal Edwards or Patau syndromes in the very short term[64], or in an irreversible vegetative state resulting from birth defects.
2. When there is an established inability to live and the prospect of imminent death. The inability to live can also be the sum of many defects – as suggested by the Baby Houle Case.
3. When it causes or prolongs torment in the absence of any chance of improvement, delaying the inevitable death – as was the case with the incranial newborn in the Chazan case. In other words, "in circumstances where the end is postponed only for a short time"[65].
4. When it only brings additional suffering before inevitable death. This might include pressurised air pumping by a ventilator or pain caused by numerous injections, drips, and catheters, the meticulous description of which occupied a lot of space in the Indi Gregory judgement.
5. In the terminal state of a terminal disease with a longer course, when the only sensation felt is pain.
6. When the possibility of survival depends on mechanical surgical correction – such as clearing the intestines, ballooning critically narrowed blood vessels, or implanting a valve reducing hydrocephalus – the appropriateness of the procedure should be weighed against the general condition of the child so as not to unnecessarily prolong suffering. Let us remember that this applies only to the context of a clearly lethal defect, with no prospects for the future, where the treatment itself brings additional ailments and may not even provide relief.

64. See: *Re L* (a child) *(medical treatment: benefit)* [2004] EWHC 2713; follow: Huxtable R: Law at the limits of life: children, welfare and best interests. In: Huxtable R: Law, Ethics and Compromise at the Limits of Life: To Treat or not to Treat? Routlege, London 2013: 46.
65. *Re B (a child) (medical treatment)* [2008] EWHC 1996 § 18.

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7. When death by starvation through appetite suppression means such as dihydrocodeine is more tolerable (i.e. causes less suffering) than dying in agony caused by incurable defects or fatal deformities. In the case of baby girl K with congenital myotonic dystrophy, the court's authorisation stated that medical personnel could remove the intravenous line providing parenteral nutrition and begin palliative care, since the expert neonatologist placed K's condition somewhere between "no chance" and "no purpose" situations. In turn, the judge concluded that it would not only be merciful, but also in K's best interest to stop administering TPN while she was still clinically stable, so she could die peacefully and in a relatively short period of time.

Under such circumstances, further treatment should be considered futile, because it neither achieves the therapeutic goal nor benefits the patient. Not only is it permissible to be discontinued through a collegial decision of a team of medical specialists, without the need to appeal to the court, but the Code of Medical Ethics, in its updated version, states categorically that a doctor is not allowed to administer futile treatment. Professional guidelines, on the other hand, recognise futile treatment as a medical malpractice. In this way, the laws of medical knowledge and medical ethics form a model for the proper handling of clinical situations "without purpose and without exit". These documents mark an effort to somehow flesh out the criteria that justify the cessation of treatment in accordance with medical knowledge, and to create reasonably clear ethical principles. In the absence of specific legal regulations, ethics and professional guidelines supplement the overly laconic law, and are mandated by the reference in Article 4 of the UZL. The same directives should guide the courts, once they have undertaken the moral effort of issuing rulings authorising the withdrawal of treatment. It has been shown that a substantive legal basis exists, as does a legal interest on the part of the doctors or the treatment entity. The status of the applicant in such a proceeding allows them to take an active part in it as the "host" of the proceeding, provided they take the trouble to specify this interest in the application and are not deterred by a refusal.

In adjudicating, the court's task will first be to determine whether the medical opinion is consistent, complete, and free of inaccuracies. As a review of British rulings shows, courts there make extensive use of independent expert opinions to make sure that all the advantages and disadvantages of continuing treatment have been thoroughly analysed, and no important factor has been overlooked. They also give careful consideration to parental opinions, emphasising great respect for the devotion of the parents standing by the child's bedside and declaring sympathy for their suffering. One can see a certain diplomacy in this, but at the same time one can sense sincere empathy on the part of the judges, evident in the stylistic layer of the justifications. Regardless, the court's verdict is guided by the criterion of the child's best interests, including the individual benefits of medical care and their relation to burdens and ailments. This balance is made in each recognised case and with the indication that the court does not make a subjective and top-down valuation of the patient's quality of life, but rather tries to empathise with the patient's condition and assess how THAT child perceives his condition.

The best interest test finds a statutory basis in British law; nevertheless, it is simultaneously explained that it is an expression equivalent to the criterion of child welfare. The British use the terms "child welfare" and "best interests" interchangeably, with equal effect of assessing the multi-factor balance. The concept of child well-being is capacious enough to include such an expansion. The evaluation thus breaks away from any principlism in favour of the interests of that child taken personally: it requires empathy with the patient's position and enjoyment of life. While there is a strong presumption in favour of life, this can be rebutted if continued treatment or a new intervention is deemed futile. The best interest test is both comprehensive and pragmatic. It provides a well-established analytical framework that has evolved over decades in the British judiciary and allows for the consideration of a broad context of various factors, including possible harm[68], and at the same time has been practiced and passed the test also in very unusual cases. If the case goes to court, there should be a balancing act, taking into account all the factors that count for and against, not just medical ones[based on: 52]. Whatever name you give it, in determining the welfare of a child, it is always necessary to collate all those interests of the child that can be established and then balance them. This is an obvious course of action from a pragmatic point of view. It is also obvious that in this balancing act there is no room for the parents' own views on what they personally consider "good" for the child. As Beauchamp and Childress point out, "quality of life estimation" does not refer to the social value of individuals (in particular, it does not promote the opposition "useful" – "not useful"), but rather to their individual lives[27: 193]. One assesses the value that life represents for a particular person, not for the general public or from the point of view of third parties. In other words, one balances what benefits that particular person derives from staying alive. Rather, it is a matter of determining all the benefits and inconveniences, and then comparing what prevails, or at least whether the inconveniences are worth enduring for the sake of the pleasures experienced. Under ordinary circumstances, the drastic nature and invasiveness of medical measures used are outweighed by the prognosis for improvement of the condition. However, when the prognosis is inauspicious – nothing justifies the drastic measures and invasiveness anymore, especially when the pain is felt until the very end. The argument raised in the British verdicts that human dignity is being violated by sustaining the body's vital functions by force is based on the conviction that remaining in such a condition without any chance of improvement makes such continuance unworthy of a human being in light of the image it presents. The argument relating to respect for the "dignity

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of the human being" serves both supporters and opponents of life support by means of advanced technology. The former argue that dignity will be violated by disconnecting mechanical ventilation and feeding by probe, because it condemns a person to suffocation and death by starvation, while so-called primary care is one of the chief humanitarian duties. The other group argues that most people would not want to be kept in a condition that not only serves them in no way, but also exposes them to a deplorable view as an entirely externally powered facility. Very young children are indifferent to this, while it will be important to feel any pleasure from living in such a state.

In the *Bland* case, the House of Lords ruled in favour of discontinuing life support when the balance of value of less than or equal to zero. The best interests criterion is objectified and thus well suited for use in cases of patients who are incapable of making decisions and, at the same time, unable to express their preferences in any way. However, deciding according to the quality of life criterion is sometimes seen as an "undoubted flaw" in the objective test[66]. It is significant that the objectification of references was considered an unquestionable flaw merely because of the reference to the criterion of quality of life. This suggests some kind of misunderstanding or a programmatic closure to a particular message. Therefore, it should be emphasised once again that the quality of life is evaluated in the subjective perception of it by the patient in question. The well-being of the child as a patient undergoing intensive and highly invasive life support requires a positive outcome of all factors signifying a benefit, that is, a satisfactory quality of life for the child. Of crucial importance is the quality of life as perceived by that child, particularly when it turns out to be "unbearable". The suffering factor should be one of the more relevant indications.

Quality of life assessment is a criterion commonly considered in the application of various treatment methods. For example, it often favours a sparing method over a radical one and opposes a disproportionately invasive one. Foreign judgments present the argument that an incompetent patient should not be exposed to a futile treatment that an informed patient would most likely reject for the sake of quality of life in that condition. An alternate decision requires adopting the same criteria(3: 635–636). An individual's life is of good quality when an analysis of interests – benefits, burdens, and hardships – allows one to conclude that the person (and not someone else) derives a tangible benefit from this life. This is how the best interests should be understood, taking into account individual factors. The criterion of quality of life according to best interests is not universal for everyone. It is useful only when the preservation of life requires medical maintenance or highly invasive procedures, while the individual concerned is not competent enough to decide for themselves(69).

The second major issue is how to choose the right moment to stop intensive care. No human being, let alone an unintelligent child with profound injuries, has an obligation to endure suffering, and adults should not avoid decisions that shorten it in declining states. On the child's side, it is possible to note at most a survival instinct that causes another aggressive resuscitation to have a positive effect for a short time. The right to die in peace and dignity is, of course, also held by newborns and infants, because they too feel pain, cold, or loneliness. Pain is a primitive response, so in the cases of Charlie Gard and Alfie Evans it was implicitly assumed that it was felt by them, and this was taken into account when refusing to transport patients pointlessly from place to place. Before there was an unexpected improvement in Charlotte Wyatt's condition, doctors testified that "she only feels pain". When the perceived stimuli are limited to unpleasant ones with no chance of any improvement, one may argue that keeping the patient in pain is undignified. When suffering is not relieved by medication – one can ask the rhetorical question whether it is better for a person to remain in this state longer or shorter. The desirability of palliative care is not disputed by anyone, but one should also consider its limits. This is because some of the medical activities carried out under its banner – including feasible but not always necessary corrective surgery, artificial ventilation, and continued nutrition until the very ned – are still questionable. The gastric probe feeding of the "Chazan newborn" made him suffer longer than he had to, because as the parents observed – the morphine did not work, presumably because he had developed purulent inflammation. In my opinion, we should not have waited for this to happen, because the child's death was inevitable and imminent anyway. This case in particular makes one wonder whether the recommendation included in the 2011 Paediatric Guidelines to continue feeding for neurological conditions with dysphagia is appropriate to the clinical condition of a child born without a skull. Such a severe lethal defect means that the baby is born only to die imminently. Artificial nutrition delays "natural" death. When death arrives with unbearable agony, the problem arises as to what purpose is served by delaying it. One principled prohibition blocks individual and comprehensive evaluation of such cases, and this is presumably what it was formulated for. Thus, any "but" will be equated with a violation of the order. This is wrong because it is arbitrary and unreflective. Such a generally formulated recommendation has nothing to do with current medical knowledge. It is harmful and leads to the multiplication of suffering. The argument that "because they will starve" rises to the status of a taboo halting all further thought. Meanwhile, force-feeding interferes with the usual course and decline of an incurable disease. If nothing else, the conscience clause should deter fierce treatment and life support at all costs, especially at the expense of prolonging agony. It is sufficient not to insert a feeding probe, but to administer drugs to relieve and abolish the feeling of hunger. The patient's interest in

66. Śliwka M: Prawa pacjenta w prawie polskim na tle prawnoporównawczym. 2nd ed., TNOiK, Toruń 2010: 367.

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abandoning nutrition is to shorten unmeasurable torment if it accompanies a congenital lethal defect or in the hopeless condition of an incurable disease. Appetite suppressants then make starvation death come gently and shorten other forms of suffering. One can find examples when this is, in my opinion, morally justified. I aim to distinguish whether the dying process is of "bearable" quality (as in the case of Madzia Słabiak), or whether it takes place in agony.

Death-inducing discontinuance of care may be the subject of an objection only if it is possible to establish duty of action on the part of doctors. Positive indications for treatment depend on what it improves and for how long. Treatments are advisable if they improve the comfort of life, or at least alleviate the process of dying. They are not advisable if they only serve to "do something" that is technically possible but will not bring the patient any benefit. This principle applies equally to feeding and hydration – although here we touch on the global taboo of so-called "primary care". The mechanism of judicial review of decisions in such cases is valid, but as long as the body actually remains independent and unaffected by external ideological pressures.

Conflict of interest

The author does not report any financial or personal connections with other persons or organisations which might negatively affect the content of this publication and/or claim authorship rights to this publication.

Author contribution

Original concept of study; collection, recording and/or compilation of data; analysis and interpretation of data; writing of manuscript; critical review of manuscript; final approval of manuscript: MB.

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