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UVODNI ESEJ / GUEST EDITORIAL

*Judit Sándor**

A LAWYER'S LEGACY: THE SIGNIFICANCE OF THE *DÁNIEL KARSAI V. HUNGARY* CASE

1. Introduction

Dániel Karsai had only 47 years in this world but spent them actively. He was an outstanding constitutional and human rights lawyer. He pursued a successful legal career, earned a black belt in jiu-jitsu, enjoyed life, and liked traveling. In 2021 he started to develop symptoms of a neural disease and a year later he was diagnosed with amyotrophic lateral sclerosis (ALS). ALS is a fatal type of motor neuron disease that features progressive degeneration of nerve cells in the spinal cord and brain. The disease is one of the most devastating of the disorders that affects the function of nerves and muscles. But it does not affect mental functioning or the senses (such as sight or hearing), and it is not contagious. Currently, there is no cure for this disease, which invariantly progresses until the state of complete immobility. This health status results in an undignified state of existence.

Karsai's condition rapidly deteriorated in 2023, and he died on 28 September 2024. He devoted the last year of his life to the promotion of the right to die with dignity. In his interpretation this also included the right for assisted suicide and access to active euthanasia. Until the day of his death, he fought for the recognition and acceptance of end-of-life decisions, not just for himself but for all terminally ill people who are dying from incurable diseases and suffering in their daily existence without remedy. Dániel himself, being very seriously ill, could only experience the largely unsuccessful nature of this legal battle, but he managed to invigorate a society-wide, open discussion of end-of-life decisions.

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Dániel Karsai's request, aimed at having the European Court of Human Rights (ECtHR) declare that the Hungarian laws that do not provide active help when the life is already unbearable for the incurable and suffering patients violates the Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights) was rejected by the court.[1] Karsai argued that by amending the health care law and creating additional legislation, he would be given the opportunity to end his life in Hungary if he decided to die with the help of active, direct, and intentional euthanasia, in order to prevent the slow suffocation that his illness would inevitably lead to. His petition sought to maintain his right to self-determination in the event his conditions become unbearable. Although the ECtHR rejected his claim, his struggle was not in vain. He put a previously suppressed topic on the agenda of constitutional law and human rights debates in Hungary; he provided a legal reasoning for self-determination in the case of an incurable disease, in an accessible way so that even laypeople could understand the positions and stakes. It can be said that Dániel Karsai waged a double struggle: on the one hand, for the recognition of self-determination at the end of life and, on the other, for promoting a human rights stance.

The case was shown special attention by a gesture of the ECtHR in extending the hearing of the case to two days. On the first day, experts were heard and the supporting organizations – the Swiss Dignitas and the European Center for Law and Justice – submitted written comments. On the second day, November 28, the application was accepted, and the case was actually assessed.

The President of the Chamber decided to appoint Marko Bošnjak sit as an *ad hoc* judge (Rule 29). One special element of this case is that the Chamber also decided, of its own motion, to hear evidence from experts (Rule A1 of the Annex to the Rules of Court), namely Régis Aubry and the author of this Guest Editorial, *in camera*.

The ECtHR held, by 6 votes to 1, that there had been no violation of Article 8 of the Convention (right to respect for private and family life) taken alone; furthermore, the ECtHR decided by 6 votes to 1, that there had been no violation of Article 14 (prohibition of discrimination) in conjunction with Article 8 of the Convention.[2] The dissent opinion was formulated by Justice Felici who started his dissent opinion by citing Dworkin: "Making someone die in a way that others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyr-

1 ECtHR, *Dániel Karsai v. Hungary*, No. 32312/23, Final Judgment, of 2 September 2024.

2 *Ibid*.

anny."[3] Felici was the only judge who thought that the Court should have found a violation of both Article 8 and of Article 14 in conjunction with Article 8.

While Karsai lost the legal battle in Strasbourg, and later his life, his legacy is significant and has had a strong impact on Hungarian legal thinking and on bioethics. This Guest Editorial deals with his legacy.

2. Human Dignity at the end of Life

Karsai's main argument for supporting access to active end of life decisions was based on the respect for human dignity. Respecting human dignity in death and dying belongs to basic human rights. At the end of life, if human dignity is impaired and life or its artificial sustainment becomes unbearable, in more and more countries the law allows some form of euthanasia, with appropriate safeguards. It is important to provide every possible form of care to reduce suffering and pain, but there are situations where, despite this, the patient feels that a life full of suffering is intolerable.

The circumstances of suffering and the dying process are very different for each individual. It is the wider social context, the state of healthcare, the family, and the nature and course of the illness, that matter. Therefore, the dying process and death itself are not only philosophical issues, but also have psychological, medical and legal significance. Poor conditions can falsely distort and increase demand for euthanasia and reduce trust in the healthcare system. Although an advanced healthcare system inspires greater confidence, with more options to alleviate symptoms appropriately, it is precisely these options to extend life that require legal guarantees.

Human dignity and human self-determination in this respect are intertwined in many ways. Preserving human dignity may lead to many different options, for some patients it involves the rejection of artificial and painful prolongation of life, while for the others it gives the opportunity take their own destiny into their own hands, or, if they so wish, to fight to the end or to accept natural death, ending their lives in a way that is nevertheless dignified for them.

Human dignity is most evident in respect of the ultimate self-determination of the dying person.[4] One of the most fundamental elements in

3 Dworkin, R., 1993, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*, New York, Knopf, p. 217.

4 The word dignity used in European languages is etymologically descended from the Indo-European root *dik*, which means "to take, to receive, to welcome, to honor." The Latin word *dignitas* refers both to an ethical concept and to a high social status. This

the fulfillment of human dignity is self-determination. Self-determination in practice means freedom of personal fulfillment. The right to self-determination is granted to individuals regardless of their condition or status, in other words, without discrimination.

The concept of human dignity emerged in numerous international human rights documents immediately after World War II. The European Convention on Human Rights, signed in Rome on 4 November 1950, incorporates some aspects of human dignity in several articles, even though the protection of human dignity is not specifically mentioned as a right in the document. The concept is stated much more clearly and forcefully in the Oviedo Convention, which stipulates already in the first article that "[p]arties to this Convention shall protect the dignity and identity of all human beings."[5] Article 2 on the primacy of human beings goes further in that "[t]he interest and welfare of the human being shall prevail over the sole interest of society or science." The Hungarian Fundamental Law stipulates in Article II that "[h]uman dignity shall be inviolable."

Human dignity is undoubtedly the crucial element that can provide guidance on how to treat patients amidst either the abusive practice of euthanasia, or in the case of artificially prolonged suffering or militaristic circumstances of an epidemic. Human dignity cannot be rationed or precisely defined, yet it is the civilizational minimum on which the respect for human rights, *i.e.*, the primacy and dignity of the human being, even in death or serious illness, is built.

3. Evolution of Legal Changes in the Field of End-Of-Life Decisions

As there are many faces of suffering and death, solutions to this problem vary widely between cultures and legal systems.[6] The term "euthanasia" is rarely used in legal contexts without precision.[7] "End of life decisions", "medical assistance in dying", and "dying with dignity" are

duality is a cause of confusion, and perhaps this is why the complex notion inspiring the concept of human dignity in several European legal systems is problematic when judges interpret it in concrete legal cases.

5 The full title of the Oviedo Convention is The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164).

6 For more see Beširević, V., 2006, *Euthanasia: Legal Principles and Policy Choices*, Florence, European Press Academic Publishing.

7 Sajó, A., Sándor, J., 1995–96, The Legal Status of the "Terminally Ill" under Hungarian law, *Acta Juridica Hungarica*, Vol. 37, No. 1–2, pp. 1–21.

more frequently used to avoid strong emotional reactions that the term euthanasia may provoke, especially because of its historical context. There is not only the confusing and inconsistent terminology, but also the distinction between passive and active euthanasia, the distinction between act and omission, which have different interpretations in law, in ethics, and in medical practice. While in moral terms there is little distinction between deliberately killing someone and deliberately letting someone die, people often feel, psychologically, that non-action is more acceptable.[8] While the development of the Hungarian criminal law goes back to the 19th century, patient' rights started to develop in the last decades of the 20th century. It is also relevant that intensive therapies and life prolonging methods also developed much later than the criminal provisions on homicide and on the assistance in suicide. In the *Karsai* case, the Court relied on the notion of physician-assisted dying (PAD). Aubry clarified this notion in his expert opinion, according to which PAD refers to the fact that a person's death was brought about by medical intervention.[9] In this way PAD covers the concepts of both assisted suicide and euthanasia. Assisted suicide could take the form of medical assistance in suicide and medically assisted dying, where a fatal substance is prescribed following verification that the individual's situation falls within a legally defined framework, but the individual then took the substance themself. The problem with this broad category is that in many legal systems, including the Hungarian one, there are different legal provisions for euthanasia (homicide) and assisted suicide. In the case of euthanasia, it is the physician who administers the lethal substance. The term passive euthanasia is even more confusing and is tending to fall out of use – previously referred to as the refusal or withdrawal of life-sustaining intervention, which ultimately leads to the patient's death.

Because of the wide and incoherent use of the term "euthanasia" it has become practically useless from a legal perspective, as it is understood to mean many different kinds of actions and inactions.[10] First and foremost, it is worth differentiating between self-inflicted actions and those inflicted by others. Not only in legal theory, but also in practice, many find that individual autonomy is better expressed by self-inflicted action, namely when an incurable, agonizing patient ends their life themselves, and the emphasis is on the legal assessment of participation. Involvement in suicide is also a criminal act under Hungarian law; moreover, the

8 Rachels, J., 1975, Active and Passive Euthanasia, *New England Journal of Medicine*, Vol. 292, No. 2, pp. 78–80.

9 *Dániel Karsai v. Hungary,* para. 48.

10 For example, Section 241.1 of the Canadian Criminal Code, uses the term "medical assistance in dying" (MAiD).

involvement of a doctor is not a privileged form of participation. In Hungary, the Health Care Act introduced the right to refuse medical care in 1997, although this was confined to narrowly delineated cases. The circumstances of ending life are always personal. Patients who are about to depart this life arrive here in different conditions, after various treatment and symptom reduction options. Everyone has a different concept of life and death. This intimacy provides a worthy backdrop for the end of one's life. In most cases, medical support, pain relief and an earnest battle for life are indispensable. In the wake of the medicalization of dying, it seems that, at this important point in life, ensuring dignity has slipped from the hands of those most affected.

With the development of intensive care, the demands for the suspension of mechanical ventilation and later artificial nutrition gradually emerged, followed by active forms of euthanasia, which meant not only the discontinuation of treatment but also active medical intervention to shorten life. The Netherlands, Belgium, Luxembourg and Switzerland have embarked on this path, but the patient's request to shorten their life has been accepted in many parts of the world, including Columbia, Canada, the states of Oregon and California, as well as the Australian state of Victoria, under different conditions and with different labels. The increased number of legal cases also shows that the range of euthanasia is gradually expanding for different types of treatment and patients of different ages and health conditions. In France, the notion of so-called symptom relieving sedation has also become established.[11] The question is that under what circumstances and for what medical conditions should patients be allowed to undergo assisted premature death in order to reduce physical and mental suffering?

The evolution of patient rights has resulted in an increasing degree of patient rights in decisions about their treatment, but this has not automatically affected the criminal laws that apply to healthcare professionals. This dual system of norms, which can be observed in many places, has resulted in doctors who, even if they follow their patient's requests faithfully, may still be found liable in court or before the medical board. From the patient's side, the main question is whether they can expect their doctors to carry out their autonomous decisions in the name of individual freedom.

All this shows that deliberation about euthanasia is highly context-dependent, with its naming, assessment, acceptance, extent, and breakdown of the necessary legal guarantees depending largely on the current capabilities and capacities of the health care system, respect for the elderly,

11 "La sédation palliative", see ECtHR, *Lambert and Others v. France*, No. 46043/14.

alternative options for pain relief and symptom reduction, and the societal receptiveness to human rights.

No one can be spared the pondering that one day they or their loved ones will have to make such decisions. Even if the decision on euthanasia or the termination of a life-sustaining treatment seems to be within the individual's self-determination only, it influences the whole society. Euthanasia cases are, therefore, very emotional, which makes the decision even more difficult.

4. Is It a Private Life Decision?

During the last year of his life, Karsai developed a regular conversation with the public through recurrent appearances in the media and at conferences, and through his daily posts on the social media (titled *Post Mortem*). He also revealed the inconvenient truth about the gradual decline of his body. He showed what it means to live, eat, and speak while having ALS. This public demonstration also paradoxically showed that it is only the individual who can decide how far they could go and when it becomes unbearable – because it is a private matter. Dying is an essential part of life. It is enough just to look up a biography on Wikipedia or elsewhere to recognize that even if celebrities had outstanding achievements, their biographies often mention the way they died. In other words, the way people die is the final chapter of their life. It can be tragic, peaceful, or involve a lot of suffering. Since it is their life, they should receive assistance in determining their way of death as much as possible, in a way that is in harmony with their concept of life, religion, beliefs, and their psychological, moral and other commitments.

Karsai was not the only activist patient who fought for the rights of the terminally ill, but he was unique in that he maintained his attitude as a human rights lawyer while being ill and even being limited by ALS. In the United States Brittany Maynard was battling a severe and incurable brain tumor when she decided to ask for assistance in ending her life.[12] Her case triggered strong emotions because she was just a young, happily married woman when she was diagnosed with the disease. When the subject of dying is raised, most people still imagine an old, frail person. There is nothing more humiliating than when this last, glimmering desire is ignored or dismissed with just a wave of the hand. Brittany insisted on her

12 Eleftheriou-Smith, L. M., 2014, Brittany Maynard: Terminally Ill euthanasia campaigner dying of cancer ends her life by assisted suicide, *Independent*, 3 November, (https://www.independent.co.uk/news/people/brittany-maynard-dead-terminally-ill-cancer-patient-ends-life-by-assisted-suicide-9834808.html, 10. 11. 2024).

decision: she traveled from California to Oregon, where she passed away on 1 November 2014, from a lethal dose of a substance prescribed by her doctor, at a time she had chosen.

5. Lessons Drawn From Similar European Cases

The coexistence of the autonomous expression of the individual and the criminal liability of the doctor or the assisting relative usually results in lengthy legal proceedings. One of the most well-known European examples was the *Pretty* case, which addressed the legal assessment of assisted suicide and was heard by the ECtHR in April 2002.[13] Dianne Pretty's petition was the first time that the European Court of Human Rights faced a different legal interpretation of individual autonomy and assisting in suicide. The 43-year-old woman's severe neurological condition and paralysis meant that she could not carry out the suicide she had planned, but if her husband helped her, he could be convicted under English law.

The suffering woman argued that the right to privacy and human life, as well as non-discrimination, would be violated if, in such cases, a dying person could not be assisted in committing suicide. Of course, it is debatable whether the right to self-determination can also apply to life and death.

The judges in Strasbourg found that an individual does not have the right to death, or to life, at least not in the sense that the right to participate in suicide is universally accepted in the legal system.[14] Differences in opinion among relatives and disputes over the discontinuation of critical treatment for children and unconscious patients have led to numerous human rights-related legal disputes.[15]

The *Pretty* case shows a lot of similarities with the *Karsai* case. In the *Pretty* judgment, the Court established that the notion of personal autonomy is an important principle underlying the guarantees of Article 8 of the Convention. The ECtHR considered that, in an era of growing medical sophistication, combined with longer life expectancies, "many people were

13 ECtHR, *Pretty v. the United Kingdom*, No. 2342/02, Judgment of 29 July 2002.

14 Orentlicher, D., Sándor, J., 2021, Decisions at the End of Life, in: Orentlicher, D., Hervey, T. K., (eds.), *The Oxford Handbook of Comparative Health Law*, Oxford, Oxford University Press, pp. 1073–1107.

15 *Pretty v. the United Kingdom*; ECtHR, *Gard and Others v. the United Kingdom*, No. 39793/17, declared inadmissible on 28 June 2017; ECtHR, *Haas v. Switzerland*, No. 31322/07, Judgment of 20 January 2011, Final Judgment of 20 June 2011; ECtHR, *Gross v. Switzerland*, No. 67810/10, Judgment of 14 May 2013, Grand Chamber Judgment of 30 September 2014; ECtHR, *Lambert and Others v. France*, No. 46043/14, Judgment of 5 June 2015; ECtHR, *Koch v. Germany*, No. 497/09, Judgment of 19 July 2012, Final Judgment of 17 December 2012.

concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude." By way of conclusion, the ECtHR was "not prepared to exclude" that preventing by law the applicant from exercising her choice to avoid what she considered would be an undignified and distressing end to her life constituted an interference with her right to respect for private life, as guaranteed under Article 8 §1 of the Convention.

One could argue, however, that more than twenty years have passed since the *Pretty* case and since then a lot of new cases have nuanced the legal situation, and that, furthermore, several European countries have moved towards a broader acceptance of the end-of-life decisions. Austria, France, Italy, Germany, Portugal, and Spain also moved to this direction – not only the Benelux states and Switzerland. In addition, PAD involves more guarantees than in cases when the action is in the hands of relatives.

In the *Haas* case,[16] the applicant, who had been suffering for a long time from a serious bipolar affective disorder, wished to end his life and complained of being unable to obtain the lethal substance required for that purpose without a medical prescription; the ECtHR held that there had been no violation of Article 8.

In the *Koch v. Germany* case, the applicant's wife, who was suffering from complete quadriplegia, had unsuccessfully applied to the Federal Institute for Pharmaceutical and Medical Products for authorization to obtain a lethal dose of a drug that would have enabled her to commit suicide at home in Germany.[17] In *Koch*, the applicant alleged that the refusal to allow his wife (who was paralyzed and required artificial ventilation) to acquire a lethal dose of medication, for the purpose of taking her own life, had violated her right, and his, to respect for their private and family life. He also complained against the national courts' refusal to examine his complaints on the merits, and the ECtHR found a violation of Article 8 on that point only. In February 2005 they both went to Switzerland, where the wife committed suicide with the help of an association. In April 2005 the applicant unsuccessfully brought an action to obtain a declaration that the Federal Institute's decisions had been unlawful. His appeals to the administrative court, administrative court of appeal, and the German Federal Constitutional Court were declared inadmissible. The applicant complained that the domestic courts' refusal to examine the merits of his complaint had infringed his right to respect for private and family life. Taking into consideration, in particular, the exceptionally close relationship between the applicant and his wife, and his immediate involvement

16 *Haas v. Switzerland*.

17 *Koch v. Germany*.

in the fulfilment of her wish to end her life, the ECtHR considered that he could claim to have been directly affected by the refusal to grant her authorization to acquire a lethal dose of the medication. The court held that, in the present case, there had been a violation of the applicant's procedural rights under Article 8 of the Convention (right to respect for private and family life), in respect of the German courts' refusal to examine the merits of his complaint. Regarding the substance of the applicant's complaint, the ECtHR considered that it was primarily up to the German courts to examine its merits, in particular in view of the fact that there was no consensus among the Member States of the Council of Europe as to the question of whether or not to allow any form of assisted suicide.

In the case of *Lambert and Others v. France* there was a disagreement between the relatives regarding their views on making end-of-life decisions.[18] Vincent Lambert had suffered a head injury in a traffic accident and as a result he was tetraplegic. The applicants were his parents, a half-brother and a sister. They complained about the judgment of the French Conseil d'État. Based on the medical opinion it was considered lawful to withdraw artificial hydration and nutrition. The applicants submitted that in the given case the withdrawal of artificial nutrition and hydration would be in breach of the State's obligations under Article 2 of the Convention. In their view, depriving him of nutrition and hydration would constitute ill-treatment, amounting to torture within the meaning of Article 3 of the Convention.

6. The Relevance of Legal History and Culture

Based on the history of the legalization of certain forms of euthanasia and assisted suicide, it is important to note that countries had taken very different paths and procedures prior to reaching the point of legalization.[19] The gradual piecemeal legislation process usually started with the legalization of some forms of passive euthanasia, realizing the inconsistencies based on different courses of the disease, and then taking the next step. Looking at the European countries one could immediately observe that the applied terminology is vastly diverse, and that even among them, where some forms of assistance in dying is allowed, the legal guarantees vary greatly.[20]

18 *Lambert and Others v. France.*

19 See more in Beširević, V., Mission (Im)Possible: Defending A Right to Die, in: Himma, K., Spaić, B., (eds.), 2016, *Fundamental Rights: Justification and Interpretation*, The Hague, Eleven Publishing International, pp. 166–176.

20 Orentlicher, D., Sándor, J., 2021.

If one looks at the European map of the countries where some form of physician-assisted dying is allowed and where it is not, one inevitably thinks of the Cold War, as if Europe still has this old political division. What could be the reason for this difference? One explanation is that in the legal transformation of the political and economic system norms on bioethics and medical law was not a priority. The other possible explanation could be that the implementation of the right to self-determination has still not been embedded in health care; even if patient rights have been adopted, still the old paternalistic patterns continue to shape the doctor–patient relationship. The third possible explanation could be the fear of legal consequences and the lack of practice of interpreting legal norms. This is also true for the patients, as self-determination requires responsibility and some legal knowledge. In this context it is not surprising that the applicant in the case in question is a prominent lawyer. Since his case received media attention, his fight has for months been in the center of public attention and has generated broad debates on human rights, which is rarely seen in Hungary.

In the regulation of end-of-life decisions, the example of Netherlands is perhaps the best known worldwide. Based on several decades of jurisprudence, the Dutch law gradually reached the legalization of both active euthanasia and assisted suicide.

The argument of clandestine forms of euthanasia were the major argument in favor of regulating euthanasia and allowing some forms of it under strict legal control. Before drafting a law on euthanasia, the so-called Remmelink Report was launched.[21]

It is important to note that in the Netherlands euthanasia and assistance in suicide are both (still) criminal acts, in accordance with Articles 293 and 294 of the Dutch Penal Code. However, when euthanasia or assistance in suicide are performed by a physician who fulfils the due care criteria of the Termination of Life on Request and Assisted Suicide Act, and the acts are reported to the municipal coroner, they are exempt from punishment. A review committee assesses in every specific case whether physician-assisted dying has been carried out in accordance with the due care criteria. Only if the committee finds that the physician did not fulfill one or more due care criteria, is the case handed over to the Public Prosecutor who in turn judges whether there are grounds for prosecution.

Significant case law in the Netherlands has contributed to the debates on what constitutes "assistance" by clarifying what action (involving friends or relatives) is considered as assistance, in accordance with Article 294–2 of the Penal Code. When the assistance means the distribution of means to commit suicide, it is clearly an offense, provided that the helper

21 Delden, J. J. M. van, Pijnenborg, L., Maas, P. J. van der, 1993, The Remmelink Study Two Years Later, *The Hastings Center Report*, Vol. 23, No. 6, pp. 24–27.

knows that the involved person will commit suicide using those means. Assistance that falls under the scope of the provision involves: giving instructions, carrying out concrete actions, and actively taking or directing initiatives to commit suicide. Actions that are not considered assistance include: giving general information, having conversations, being present during the suicide, and offering moral support. Furthermore, assistance in suicide is not only assistance given during suicide; preparatory acts also fall under the scope of the provision.

The Belgian Euthanasia Act requires that the disorder is serious and incurable, and that it causes unbearable physical or mental suffering of the patient, but the patient does not necessarily have to be terminally ill.[22] No distinction is made between active and passive euthanasia. Austria is also a recent example of introducing legal changes in the field of the end-of-life decisions, with assisted suicide being allowed since 2022.[23] Parliament approved the new law following a Constitutional Court ruling on the issue. The practice will be tightly regulated, with each case assessed by two doctors – one of them being a palliative medicine expert.

The Spanish law on the assistance in dying (*prestación de ayuda para morir*) consists of providing the necessary means to a person who suffers a serious and incurable disease or a serious, chronic and incapacitating illness that causes them unbearable and continuous physical or psychological suffering that cannot be alleviated, and who has expressed their previous and informed request to die, either through the direct administration of a substance by a health care professional, or the prescription or supplying them with a substance by a health care professional, so that it can be self-administered to cause their own death.[24]

In Portugal a new law was adopted on assisted dying, which regulates the conditions under which medically assisted dying (*morte medicamente assistida*, MMA) is not punishable in Portugal.[25] This law was drafted after a long legislative process, spanning more than one parliamentary term and featuring the particularity of having been the subject of four Assembly of the Republic decrees, four presidential vetoes, two Constitutional Court rulings and one parliamentary confirmation of a vetoed decree prior to the 2023 presidential promulgation.[26] These recent legal changes in Europe indicate the trend of the broader acceptance of PAD.

22 Belgian Euthanasia Act of 28 May 2002.

23 Sterbeverfügungsgesetz (StVfG), *Bundesgesetzblatt* (BGBl, Federal Law Gazette), I Nr. 242/2021.

24 La Ley Orgánica de Ley de Eutanasia despenaliza la ayuda médica para morir en personas con una enfermedad en fase terminal o una dolencia irreversible con limitaciones en su autonomía física (LORE), 18 March 2021.

25 Law No. 22/2023, of 25 May 2023.

26 *WAML Newsletter*, No. 59 on medically assisted dying.

7. The Relevant Hungarian Laws

The euthanasia debates have a long history in Hungarian legal tradition. The Hungarian Constitutional Court received several petitions concerning the right of patients with terminal illnesses to end their lives with dignity. None of these petitions were successful. Still, the opinion surveys show a strong support for euthanasia in Hungary.

In 1997 the new Health Care Act included the right to refuse medical treatment, even including the refusal of life-saving and life-sustaining treatment, however the laconic legal solution and bureaucratic procedure did not result in actual accessible practice.[27] The applicant also argued that the law allows the refusal of medical care in certain cases of terminal illness, but refuses the help when only active assistance could end the suffering. Similar to in many countries, prior to legislative changes Hungarian law criminalized both active euthanasia and assisted suicide.

The current Hungarian legal source is the Act C of the 2012 on the Criminal Code. Chapter XV of the Code includes criminal offences against life, physical integrity, and health. It is important to emphasize that there is no mercy killing in the current Hungarian Criminal Code. Assisted suicide is a crime under Section 162. (1) "A person who induces or provides assistance for another person to commit suicide is guilty of felony and shall be punished by imprisonment for one to five years if the suicide is attempted or committed."[28]

One should note that the request for allowing assisted suicide and other forms of PAD involves the collision between the criminal provisions originating in the 19th century and the patients' rights to self-determination, developed in the last 20th century. Similar conflict has been recognized in the American *Glucksberg* and *Vacco* cases.[29] It is not unique that while patient rights have developed significantly during the past several decades, criminal provisions have not followed this development.

During the hearing of the *Karsai* case, much attention was paid to the extraterritoriality of the Hungarian Criminal Code. While assisted suicide is available in some other European countries, such as Switzerland, it does not exempt those who help the petitioner in committing assisted suicide from criminal liability. This is due to the so-called extraterritoriality of the Hungarian Criminal Code. Section 3(1) of the Hungarian Criminal Code applies not only to cases of criminal offences committed in Hungary

27 Act No. CLIV of 1997 on Health.

28 Translated by author.

29 SCOTUS, *Vacco v. Quill*, 521 U.S. 793 (1997); SCOTUS, *Washington v. Glucksberg*, 521 U.S. 702 (1997).

but also to "(c) acts committed by Hungarian nationals abroad if the act constitutes a criminal offence under the Hungarian law," and "(2) The Hungarian criminal law shall apply to [...] [b] acts committed by persons other than Hungarian nationals abroad against a Hungarian national [...] that are punishable under the Hungarian law."[30]

The Hungarian Criminal Code does not recognize mercy killing or special circumstances under which the above-mentioned crimes are not punishable. There are specific historical reasons why Hungarian criminal law punishes complicity in suicide so severely. The high suicide rate in Hungary and the fact that an earlier approach remains unchanged are reflected in the current criminal justice regulation.[31]

Criminal law in itself cannot respond to the needs of the suffering terminally ill person. The change usually comes from the human rights norms and from the rights of the patients. In many countries where some forms of PAD are allowed, criminal provisions are still maintained and criminal procedure will not be initiated provided that the PAD meets certain legal criteria, such as unbearable suffering, lack of medical remedy, request by the patient, etc.

In Hungary the specific law that encompasses patient rights is Act No. CLIV of 1997 on Health Care. At the time when this Act was adopted, it represented a significant and progressive step in many fields. This Act included explicit patient's rights for the first time.

Section 20(3) of the Act stipulates that "[b]y allowing the natural course of the disease, it is only possible to refuse life-sustaining or life-saving intervention if the patient is suffering from a serious disease which, according to the current state of medicine, leads to death within a short time – even with adequate health care – and is incurable. Further condition is that the patient wants to refuse life support. If the patient does not agree to the examination by the medical committee, their statement of refusal of treatment cannot be taken into account."[32]

As a conclusion, I should emphasize that the Hungarian law provides assistance only when a patient is suffering from an incurable disease and requests the withdrawal of life-saving or life-sustaining treatment. When a patient's suffering cannot be diminished by the mere withdrawal, then there is no legal remedy. The right to self-determination and dignity has nevertheless been recognized by the Hungarian Health Care Act.

30 Translated by author.

31 Filó, M., Kiss, M., Az öngyilkossághoz nyújtott orvosi segítség büntetőjogi megítélése, in: Filó, M., (ed.), 2022, *Autonómia, életvédelem, jogbiztonság*, Budapest, ELTE Könyvkiadó, pp. 153–164.

32 Translated by author.

8. Concerns About the Risk of Abuse

During the preparation for the *Karsai* case, several worries and argument against the decriminalization of assisted suicide and PAD were addressed. One of these issues was whether a terminally ill patient, seriously depended on their caregivers could give a free and voluntary consent or refusal. I argued that the consent and request by the patient – not just in case of euthanasia but in case of other decisions – may involve not just the patient's needs but the concerns for others, especially for family members. Countries that have moved towards a wider recognition of the patient's self-determination in case of end-of-life decisions have had extensive public debates and established carefully designed and elaborated guarantees without which the law could not be applied. In addition, it must be ensured that terminally ill persons will receive all necessary care. Euthanasia should not be used as a way out of poverty and disenfranchisement, and when there is room for improving health care services, including palliative care. If euthanasia were regarded as a cheaper and more convenient alternative to high-level palliative care then, of course, this could distort the free and voluntary will of the patient. The recent Austrian law, for instance, prescribes that financial support for palliative care should be increased following the decriminalization of assisted suicide.

The argument could be formulated also the other way around; some patients may wish to die because of unbearable suffering, however, their relatives may not be ready to accept their death, so the patients continue to struggle even if it is against their wishes.

Consent and refusal of certain medical care certainly have elements that are beyond the individual's own reflection on their self-determination. Perhaps the best guarantee against pressure and misunderstanding is a very considerate end-of life planning process, which also includes alternatives and palliative care.

In the case of physician-assisted dying, one of the main concerns is whether the doctor complies with the autonomous wish of the patient. In the case of unconscious patients, it is more difficult to establish the assumed intention of the patient based on their previously expressed wish; in the case of ALS, the patient is able to express their concerns as they will preserve the mental capacity to decide. In case of PAD, several legal guarantees have to be established. One condition is that the patient had received all the necessary information for their decision. Furthermore, having access to pain management and other medical treatment may diminish their suffering. One should also note the existence of so-called existential suffering: the fear of becoming vulnerable and dependent, and the experience of losing the capacity for self-determination – which is an essential element of human dignity.

9. Conclusions

While the Hungarian law criminalizes the active form of euthanasia and assisted suicide based on legal provisions that were developed in the 19th century, patient rights were born only after the political transition at the end of the 20th century in Hungary. These norms were built on the recognition of the patient's dignity and autonomy. The Parliamentary Act on Health Care includes a section on self-determination. Furthermore, the Hungarian Fundamental Law endorses human dignity. It should be noted that while patients can make decisions regarding trivial operations or health care services, they cannot make decisions in cases of terminal disease.

In cases where the patient is no longer capable of expressing their wish, the debate on euthanasia is complex because it tries to reconstruct the patient's actual intent. When the patient is capable of expressing their wish and suffers from an incurable disease, there is no need to interpret their earlier statement in a living will or assume the best interest of the patient. In the case discussed here – given the progressive nature of the disease – the only solution would have been to travel abroad and seek assistance in dying, and the legal restrictions that aim to protect right to life may infringe the right to life itself and the right to respect private life, by urging the applicant to take a step as early as possible when he still did not need active help in ending his life. It was clear from Karsai's application that it was not what he wanted. He was fighting for the possibility of self-determination and his aim was to live a dignified life as long as possible. Given the progressive nature of the disease, he understood that he would eventually lose many of his physical abilities but not his mental capacity, which, ultimately, represented his personhood. In the case of a serious and incurable disease, the loss of physical abilities results from the illness, while the loss of self-determination is the consequence of the legal norms. The fear of losing dignity and self-determination was Dániel Karsai's main concern. He fought for this right until the very last day. Although he lost his legal battle, he won enduring public support for the rights of the terminally ill. This is his true legacy.

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