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MARGINS OF CARE: SILENCE, RISK, AND CONTESTED ETHICS

Judit Sándor, PhD
Full Professor,
Central European University, Vienna – Austria
[sandorj@ceu.edu], ORCID: 0000-0003-0134-4414

Mária Éva Földes, PhD
Assistant Professor,
Erasmus School of Health Policy and Management,
Erasmus University Rotterdam – the Netherlands,
[foldese@ceu.edu], ORCID: 0009-0001-9181-1858

Medicalization of Death and Dying in Post-War Hungary and the Netherlands. *Taboo and Transparency in Legal Thinking*[1]

Abstract: *Medicalization of death and dying after World War II represented a significant shift in both Eastern and Western Europe, with implications for medical law and ethics. Death and dying became subjects of medical decisions and interventions. Increasingly, death occurred in hospitals and was preceded by various medical procedures aimed at prolonging life, sometimes artificially. Along with the process of medicalization, families and communities became less involved in the last phase of their loved ones' lives. In this paper, we explore the repercussions of this process in two post-war societies that took very different paths in addressing doctors' involvement in end-of-life decisions: Hungary and the Netherlands. The Netherlands is widely known for granting access to physician-assisted dying, including euthanasia and assisted suicide, following decades of legal cases, empirical reports, and legislative changes. In Hungary, although the issue has surfaced repeatedly in public discussions, it still constitutes a medical and legal taboo. Patient autonomy in Hungary developed much later and the legal progress has stagnated since 1997. Patients can*

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refuse certain types of treatment, but only through a bureaucratic procedure. To understand the sharp contrast between the current laws in the two countries, we trace and compare legal developments and ethical thinking in both jurisdictions. We examine changes in the approach to the patient-doctor relationship, the role of information disclosure, patient autonomy, transparency, and the obstacles to these. Our analysis shows that striking the right balance between doctors' professional responsibilities and patients' rights remains a challenge in both countries.

Keywords: *medicalization; end-of-life decisions; Hungary; the Netherlands; law; ethics.*

Introduction

This paper examines and contrasts legal developments and ethical debates on end-of-life decisions in post-war Hungary and the Netherlands. After World War II, these two countries followed diverging judicial and medical approaches towards decisions related to death and dying. To understand the sharp contrast between the current rules on this matter, we trace and compare legal and ethical thinking in the two jurisdictions.

Following World War II, medicalization of death and dying become a widespread phenomenon in Europe (on the concept of medicalization, see Conrad, 1992). Some authors argue that medicalization has replaced religious interpretations of illness (Bull, 1990). The development of intensive care and changes in the family structure contributed to the growing practice of hospitalizing the terminally ill. As death and dying became a medical issue, it was mainly institutions that provided nursing and pain relief. Within the debate on medicalization, decisions on who cares for terminally ill patients and how, have become central issues. Specifically, if dying is regarded a medical issue, how are the patients' wishes responded to?

Comparing the legal approach in Hungary and the Netherlands, one can ascertain that at the end of World War II, the situation in both countries was similar. While people were increasingly dying in institutions, physicians' involvement in life-ending acts constituted a criminal offence. Moreover, health professionals were not expected to disclose a terminal diagnosis to patients because telling the truth was regarded cruel and possibly harmful to their condition (on the Dutch experience, see Weyers, 2004, 2006). Death was a taboo topic and the process of dying was to be kept out of sight.

The evolution of the legal norm of informed consent has played an important role in both countries. However, in Hungary, therapeutic privilege was understood very broadly prior to 1990. The bioethics and

legal literature define therapeutic privilege as the withholding of relevant health information from patients if non-disclosure is deemed to be in their best interest (Hodkinson, 2013). In case of a terminal or incurable illness, therapeutic privilege provides an exception to informed consent. As a result of its broad interpretation, doctors in Hungary usually tried to avoid providing full information to the terminally ill until 1990[2] (Sándor, 1991). The practice of secrecy excluded patients from end-of-life decisions. While patients' rights were incorporated into the Hungarian Healthcare Act in 1997, requests for physician-assisted dying were not recognized. The right to refuse medical treatment and the right to leave the medical institution, however, were included as patients' rights. Although there have been very few legal changes in the field of the end-of life decisions since 1997, the issue has been repeatedly discussed in public debates and in Hungarian professional and intellectual circles.

The Netherlands followed a different path. In the early 1950s, Dutch courts began developing jurisprudence on end-of-life decisions by examining cases from medical practice. Small-scale studies conducted during the 1980s showed that despite the criminal law prohibitions, Dutch physicians sometimes complied with patients' life-ending requests (Weyers, 2006: 805). In ruling on such cases, judges created the possibility for physicians to be exempted from prosecution under specific conditions. In doing so, they were willing to be guided by the views of the medical profession (Buijsen, 2024). For decades, physicians could not rely on statutory provisions to justify life-ending acts, but the courts ensured that the Dutch legal system did not remain entirely unresponsive. Judges helped lift the taboo and paved the way for increased transparency. By shifting the focus from the threat of prosecution to procedural justice and patient autonomy, the courts laid the groundwork for the adoption of Dutch statutory law enabling physician-assisted dying under due care.

It is thought-provoking that while some form of end-of-life decision (euthanasia, assisted suicide, or physician-assisted end-of-life planning) is accepted in several Western European countries and particularly in the Netherlands, the issue remains taboo in Central and Eastern Europe, including Hungary. However, this does not mean that such decisions are not made in practice. Rather, it reflects that the practice of

[2] Parliamentary Act No XII. of 1990 modified Section 45.(1) of the Healthcare Act of 1972.

self-determination is less established and the situation is "resolved" differently. Our paper highlights these differences and contrasts the approaches to the patient-doctor relationship, the role of information provided to patients, autonomy, transparency, and the obstacles to achieving these.

In this paper, we use the term *euthanasia* to denote the act of deliberately ending another person's life with the intention of relieving suffering. The term *assisted suicide* (or *assistance in suicide*) refers to a life-ending act carried out by the individual with the help of another person who provides medication or other assistance. *Physician-assisted dying* covers both euthanasia and assisted suicide and was used in this way in the judgment delivered by the European Court of Human Rights in 2024 in the case *Dániel Karsai v. Hungary* (see Sándor, 2024 for analysis of the case). Furthermore, we use the term *patient autonomy* to refer to the capacity to decide for oneself and to pursue one's chosen course of action in life. Respect for autonomy is listed among the four major principles of bioethics (Childress and Beauchamp, 2001). We argue that information and autonomy are essential to the development of patients' rights, including the rights of dying patients, and that patients cannot act autonomously in the absence of adequate information about their medical condition.

After World War II, Hungary and the Netherlands experienced significantly different trajectories in the development of political, religious, and societal factors. These divergent socio-political developments left their mark on both the legal and healthcare systems, and the broader societal changes influenced approaches to patients' rights and options concerning end-of-life decisions. Notably, between the late 1960s and mid-1970s, the Dutch society underwent significant political, religious, and social transformations described as a process of "de-pillarization" (*ontzuiling*), which involved secularization (see for example, Thurlings, 1979) or as a gradual transition from the ideals and practices of "heavy" communities to those of "light" communities (van Dam, 2015). These societal changes paved the way for breaking the taboo surrounding death and dying. Nevertheless, religious arguments continued to be present in the Dutch debates even after the 1970s, while such arguments were virtually absent in the Hungarian context during the state-socialist decades. Whilst we acknowledge these broad societal differences, in this paper we focus on legal developments and contrast the underlying legal and ethical arguments.

Death and Dying in Hungary: Ethical and Legal Debates

There has been a longstanding debate in Hungary about death with dignity, and polls conducted at various times have indicated that people prefer to decide for themselves whether or not to have medical treatment at the end of life. Respect for human dignity involves recognition of personal decisions and implies that no patient can be treated as a mere object of a medical procedure. Opinion polls show that if suffering cannot be alleviated, many people would seek active help in hastening death (Europion, 2024). Yet, when it comes to legislation in Hungary, and generally in Central and Eastern Europe, modesty, caution, or simple avoidance tend to prevail.

Human dignity is a basic constitutional legal concept in Hungarian law (Constitutional Court decision 8/1990. (IV.23.)). The current Fundamental Law stipulates that "human dignity is inviolable" and "every human being has the right to life and human dignity". This principle demands that we regard another human being not as a means but always as an end. It has a passive and an active element: every human being is entitled to equal respect, and human dignity demands respect for the person's autonomy. In the context of end-of-life decisions, this means that society should respect the dignity of dying persons, including their wish to avoid suffering and their decisions on how to cope with a terminal illness.

The issue of end-of-life decisions has appeared repeatedly in Hungarian public debates, although usually as isolated incidents lasting only for a few days or weeks. Authors like Béla Blasszauer (1984), Alaine Polcz (1993), László Bitó (2014), József Kovács (1997), Gábor Vadász (2020), Mihály Filó (2015), Albert Takács and Ildikó Kmetty (2003), András Sajó and Judit Sándor (1996, 1995), and many others have taken part in these public debates. The topic also features in literary works and films. In 1994, István Jelenczki made a multi-part documentary titled *The Right to Die* (Haláljog), which was shown not only in cinemas but also on television. In 2021, thirty Hungarian writers expressed their opinions on the dignity of death in a book (Demény et al, 2021). Nevertheless, no debate or awareness-raising campaign has generated as much attention and influence in Hungarian media and public discourse as that initiated by the legal case of the terminally ill human rights lawyer Dániel Karsai in 2023 and 2024 (European Court of Human Rights, 2024; see also Sándor, 2024).

Thinking about death and dying and the need to recognize patients' rights directs end-of-life decisions in two different ways: towards claiming medical assistance in dying if life has become unbearable, and towards maintaining control with the aim of preserving life for as long as possible. We have found evidence for both positions: while in public debate people have often claimed the right to decide on the withdrawal of medical treatment when the terminally ill patient suffered, in court cases relatives have often sued hospitals when they lost loved ones due to negligent care (Sándor, 1997). Despite many debates and initiatives, the Hungarian legislature has never accepted medical assistance in dying, whilst several Western European countries, starting with the Netherlands, have made significant changes and gradually accepted euthanasia and assisted suicide. The Dutch example was a frequent reference in the Hungarian debates on euthanasia and the Dutch experience was extensively analyzed by Hungarian authors, such as Bérczes (Bérczes, 2016).

Although the term euthanasia has been repeatedly used in Hungarian legal debates, it has become virtually useless from a legal point of view, since it is now used to cover so many actions and inactions that shorten life (Sajó and Sándor, 1996). As noted above, within end-of-life decisions it is worth distinguishing between self-inflicted actions and those carried out by others. In both legal theory and practice, many consider autonomy to be better expressed through self-inflicted actions or by incurable, agonizing patients ending their life themselves, with the legal focus placed on participation. Due to their condition, many dying patients are unable to commit suicide without some form of medical assistance and prescription, unless they and their relatives are forced to resort to shocking, inhumane acts. An illustrative example for the desperate acts that those who do not receive medical help might resort to is the *Binder* case. In this tragic case from Hungary, a mother killed her sick child at the child's request, after several unsuccessful attempts at home, and then went to the police, reporting the crime herself (Fedor, 2017). Involvement in suicide is also a criminal act under Hungarian law, and a doctor's involvement is no exception.

Parliamentary Act No CLIV of 1997 (the Hungarian Healthcare Act) introduced the right to refuse treatment, albeit limited to narrowly defined cases. However, the circumstances of ending life are always personal. Patients who are about to leave life face different conditions after various treatment and symptom-reduction options. The combina-

tion of autonomous acceptance by the individual and the criminal liability of the doctor or assisting relative usually leads to legal issues. In most cases, medical support, pain relief, and some form of a life sustaining treatment are indispensable. In the wake of the medicalization of dying, it seems that, at this important point in life, the possibility of ensuring dignity has slipped from the hands of those most affected. The medicalization of dying has often even distanced family members from the final struggles of their relatives' lives.

Therefore, the question is what legal solutions can assist in restoring the autonomy and dignity of persons nearing death. The right to refuse treatment, as the term suggests, only gives the patient the right to refuse certain interventions in a narrow range of cases. Explicitly patient-centered end-of-life planning would be more effective if it were allowed not only the refusal of certain interventions, but also the request and consent to end-of-life treatments, which could lead to medical interventions aimed at reducing suffering. But as long as only certain treatments can be waived (in a very complicated way), the autonomy of the incurable patient remains compromised. In 2017, a representative study was conducted on knowledge of the right to refuse medical treatment and was analyzed by lawyers (Kussinszky & Stánicz, 2022).

End-of-life decisions have had a prominent role in the development of Hungarian bioethics. Thanatology is now a recognized field of research and discipline, with its Hungarian periodical titled "Kharón, Thanatology Review", launched in 1997 by Alaine Polcz, Péter Berta, and János Pilling as the first professional, scientific Hungarian forum in the field. The influence of thanatology and suicidology has broadened the context of end-of-life debates in Hungary. At Semmelweis Medical School in Budapest, the bioethics curriculum includes a session on "suicide, euthanasia, and "terathanasia". Suicide, assisted suicide, and euthanasia have become leading topics in Hungarian bioethics and medical law. The high number of committed and attempted suicides in Hungary has led to several sociological research projects on the causes and prevention of this phenomenon (Buda, 2001). Although the number of suicides dropped just after World War II, it began to rise rapidly again in 1957. Subsequently, Mihály Gergely's work on suicide was published in the Journal "Kortárs" in 1969 and later in a book (Gergely, 1972). Since 1958, the Central Statistical Office has been regularly collecting data on suicides and suicide attempts. As health conditions have not been the focus, it is difficult to establish a connection between potential requests for euthanasia and suicide. In the early

1960ies, László Cseh-Szombathy conducted interviews with relatives of 100 people who had committed suicide (Cseh-Szombathy, 1963). Later, Béla Buda referred to the possible connection between acceptance of suicide and euthanasia (Buda, 2001).

As a distinct issue related to death and dying, the term *terathanasia* (Giagounidis et al., 1997) has a clear connection with the legacy of eugenic thinking and medical paternalism. The term refers to the withdrawal of medical care from newborns based on their health condition. The issue has not been discussed in public, and until the recognition of patient's rights, medical decisions did not involve relatives. A shocking criminal case from the city of Tatabánya (Hungary) revealed how medical decisions based on hierarchy and workplace loyalty could lead to the death of a prematurely born baby who was deliberately left without proper nursing and medical care (case No BF-III-640-1984). In this case, several doctors were charged with neglecting the baby. So far, this has been the only reported case in Hungary where the term terathanasia was mentioned.

Since euthanasia was, and still is, prohibited in Hungary, we could not find legal cases using this term, although several medical malpractice cases have questioned treatments provided to seriously ill patients with the effect of hastening death. There have been some controversial cases of the alleged killing of the terminally ill, such as the so-called Black Angel case, which resulted in criminal charges against a nurse (Frenkl, 2001). In this case, the actual number of deaths remained unclear, partly because of the lack of transparency regarding medication given to patients at the end of life. Unlike in the Netherlands, Hungarian cases have not contributed to legal development, although they strongly argue for greater transparency. As in other Central and Eastern European countries, Hungary has not decriminalized any form of physician-assisted dying. During the COVID-19 pandemic, hospitals became black boxes and decisions made at the end of life were not transparent (Munk, 2020). Opinion surveys (Europion, 2024) and scholarly debates, however, call for change.

Death and Dying in the Netherlands: Pragmatic Approach with Focus on Procedural Justice

Similarly to Hungary, in the Netherlands, the criminalization of euthanasia and assistance in suicide dates back to the 19th century. The 1886 amendment of the Dutch Penal Code inserted two relevant provisions. Article 293 addressed killing on request, i.e., depriving another

person of life "at the person's explicit and earnest desire", and set a sentence of up to 12 years' imprisonment. Article 294 addressed assistance with, or inducement to commit suicide, or providing means thereto, and set a punishment of up to 3 years' imprisonment if the suicide followed (Penal Code, 1886, Title XIX: 'Crimes against life'). The criminal ban is still in force.

After World War II, legal developments in the Netherlands took a very different path from those in Hungary. In the absence of any societal consensus that could have enabled legislative initiatives for decades, Dutch courts gradually filled the legal vacuum through judgments concerning doctors who complied with their patients' life-ending requests. An analysis of post-1950 case law reveals a lenient approach by Dutch courts to violations of Articles 293 and 294, as shown by the relatively light sentences imposed.

The first court case involving a physician dates to 1952. Acting upon his patient's repeated request, a medical doctor from Eindhoven terminated the life of his brother suffering from tuberculosis. The doctor invoked necessity (*noodtoestand*), meaning a conflict between the simultaneous duties of preserving life and ending unbearable suffering, and the need to follow his conscience. Although the doctor was found guilty of deprivation of life on request, the sentence imposed was a one-year suspended prison term (District Court of Utrecht, 1952; upheld by the Court of Appeal of Amsterdam, 1952; see also Buijsen, 2024; Weyers, 1998; 2004).

The lenient approach of Dutch courts continued for years. Another example is the 1966 *Mia Versluis* case, in which an anesthetist doctor recommended the removal of the *trachea cannula* to hasten the death of a 21-year-old girl in irreversible coma. Although the Medical Disciplinary Tribunal fined the doctor for "undermining trust in the medical profession", the public health inspector appealed the decision arguing medical negligence instead. As a result of the court cases that followed, the doctor was acquitted of the original charge and fined only for insufficient reporting (Court of Appeal of Amsterdam, 1969).

In a 1973 landmark case, Dr Postma, a general practitioner, was sentenced to one-week suspended prison for complying with her severely ill mother's request to administer a lethal dose of morphine. The ruling constituted a turning point because, for the first time, the court considered the possibility of impunity for a life-ending act on request (District Court of Leeuwarden, 1973; see also Buijsen, 2024). The court followed the expert opinion of the health inspector and held that the

defense of necessity could be accepted in the following cases: the patient was incurable, experienced unbearable suffering, had clearly expressed a wish to die, the act was performed by a physician, and a second doctor was consulted and agreed to the proposed action. In the legal and ethical debate that followed the *Postma* ruling, the patient's self-determination was invoked for the first time in the context of end-of-life decisions. The ruling was followed by civil society action, notably the creation of the Dutch Association for Voluntary Euthanasia (NVVE) in 1973.

Between 1978 and 1981, Dutch courts delivered four judgments in assisted suicide cases (see Weyers, 2004 for details). Among these, the 1981 *Wertheim* ruling is most relevant for the due care and reporting requirements developed therein (District Court of Rotterdam, 1981). Mrs. Wertheim, a 76-year-old (non-medical) activist, was charged with helping a 67-year-old woman end her life. The Rotterdam District Court ruled that if specific due care criteria were met, the interest of the persons wishing to end their life outweighed the legislature's interest in criminalizing assistance in suicide. The court raised the possibility of accepting the necessity defense and referred to the criteria set in the *Postma* ruling. Although Mrs. Wertheim had not met most of the criteria, a lenient sentence was imposed (6 months suspended prison with a one-year probation).

The 1984 *Schoonheim* case reached the Dutch Supreme Court. The ruling confirmed the possibility for physicians to invoke the necessity defense and thereby provided a legal ground for their involvement in voluntary euthanasia (Supreme Court, 1984). It emphasized that physicians could successfully invoke the necessity defense if they had rigorously weighed the duties and interests involved, acted consistently with medical ethics and professional standards, and made an objectively justifiable decision. Later, in the *Rademaker* case, the Supreme Court held that euthanasia could never be regarded a natural cause of death (Supreme Court, 1987). Furthermore, as ruled by the Leeuwarden Court of Appeal, only a physician could successfully invoke the necessity defense; other healthcare professionals, such as nurses, could not (Court of Appeal of Leeuwarden, 1995).

Following the case law, a set of due care criteria was incorporated into the first procedural rules. Other stakeholders also made a significant contribution to the development of Dutch policy on physician-assisted dying. Notably, the Royal Dutch Medical Association (KNMG) called for the removal of legal uncertainty and the establishment of rules

enabling physicians to report life-ending acts performed under due care. By setting out their position on how physicians could professionally address patients' life-ending requests, the Dutch Medical Association helped develop the due care criteria into elements of a professional standard (KNMG, 1984).

The associated legal and ethical debates prompted further momentum for legislative action. In 1982, a State Commission was established to produce a report on the definition of euthanasia and the criteria for its justification. Published in 1985, the State Commission report concluded with a call for statutory rules (Groenhuijsen and van Laanen, 2006). Official, nationwide empirical studies followed to explore the frequency and characteristics of reported euthanasia cases (Remmelink report, Ministry of Justice and Ministry of Welfare, 1991). Following several unsuccessful legislative proposals, an agreement was reached in 2001. The *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* – hereafter, the Euthanasia Act[3] – entered into force on 1 April 2002.

The Euthanasia Act sets out the due care and reporting requirements (notification procedure). Unlike other jurisdictions that differentiate between euthanasia and assistance in suicide, the Dutch act treats them alike, as it subjects both to the same requirements. However, it distinguishes them from other medical decisions on ending life – such as withdrawing/withholding life-prolonging medical interventions, or refraining from performing a procedure deemed medically pointless – which remain outside its scope.

As in Hungary, euthanasia and assistance in suicide still constitute criminal offences under Dutch law. Further to the Euthanasia Act, a physician's involvement constitutes a *justifiable and non-punishable exception if and only if the due care and reporting requirements are met.* This exception does not extend to other medical professionals (e.g., nurses) or to non-medical persons (relatives, friends, other laypersons) who risk prosecution, as in Hungary.

The scope of the Euthanasia Act is limited to the termination of life upon the patient's personal request. Actively ending life without the patient's explicit request is outside the scope of the Euthanasia Act, although some borderline cases remain debated, such as situations of extreme urgency, patients unable to express their wishes, and children younger than 12. (The Act also applies to minors aged 12 or older. For

[3] Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Wtl) (2002).

details on parental involvement and consent, see Verhagen and Buijsen, 2023). Furthermore, a life-ending act can only be justified if the patient's condition has a medical dimension. Initially this encompassed only somatic conditions. Later, in the *Chabot* case, the Dutch Supreme Court ruled that non-somatic (mental) suffering could also be considered, albeit with extra caution. What mattered was the unbearable and hopeless nature of the suffering (Supreme Court, 1994). At present, a medically classifiable illness or disorder must be diagnosed, which may include psychiatric disorders, dementia, and other age-related conditions. However, "tired of life" situations are not considered justifiable exceptions, as ruled by the Supreme Court in the *Brongersma* case (Supreme Court, 2003; on the "tired of life" debate, see Buijsen, 2018).

To meet the due care criteria set in the Euthanasia Act, the doctor must be satisfied that: the patient's request is voluntary, based on appropriate information about his/her condition and prognosis, and carefully considered; the suffering is unbearable with no prospect of improvement; and the patient's condition allows for no reasonable alternative. Furthermore, the doctor must consult at least one other independent physician and ensure due medical care during the life-ending act. For transparency and accountability reasons, the doctor must comply with the notification procedure – meaning they must immediately report the death to the medical examiner (coroner) using a standard form. The medical examiner must investigate the cause of death, verify the completeness and accuracy of the doctor's report, and notify one of the five Regional Review Committees operating in the Netherlands. Comprising lawyers, medical doctors, and ethicists, these Committees review all euthanasia cases. If unmet due care requirements are found, the Committees refer the case to the prosecutorial authorities. Although criminal prosecutions are extremely rare (Groenhuijsen and van Laanen, 2006), other sanctions (e.g., disciplinary) may be imposed.

Dutch case law shows that historically, the defense of necessity (balancing the simultaneous duties to preserve life and alleviate suffering) was pivotal in justifying physicians' life-ending acts. However, some commentators have voiced concerns about assigning to doctors an entirely instrumental role and expecting them to comply with their patients' euthanasia requests whenever the law permits (Kouwenhoven et al., 2019: 46). In this context, it is important to note that the current Dutch legal framework does not create a patient's right that imposes a corresponding obligation on doctors to comply with euthanasia requests. Doctors have a legal right to refuse assistance in dying. They

may refer the patient to another physician but are not legally obliged to do so. While patient empowerment to take and maintain control is emphasized in the legal and ethical debate, the challenge remains to find the right balance between the physician's professional responsibility and the patient's autonomy (see also Kouwenhoven et al., 2019: 48).

Taboo and Transparency in Hungary and the Netherlands

As emphasized in bioethics, fair and proper provision of information and respect for self-determination constitute the basis of other health-related rights. If the former is delayed or poorly developed, other rights are also violated.

In Hungary, patient information emerged first not in the form of a legal right but as a duty imposed on physicians. The Hungarian Doctors' Deontology Code was adopted in 1959.[4] Article 9 prescribed an exception: if patient information could provoke serious reaction in patients or their relatives, doctors could withhold information or share only some necessary details. Thus, therapeutic privilege was convenient for medical staff as they did not have to communicate the serious diagnosis and face the patient's reaction. It was believed that it was better to tell lies or simply remain silent so as not to cause any psychological distress to the patient. Doctors often used coded language or exchanged envelopes among themselves containing the real diagnosis (Konkoly Thege, 1974).

The first comprehensive Hungarian Healthcare Act was adopted in 1972 (Act II of 1972). Section 45(1) stipulated that the doctor had to inform the patient, the relatives, or – if necessary for the patient's medical treatment – the caregiver, about the illness and the patient's condition in an appropriate manner. In justified cases, the physician could waive this in the interest of the patient. This provision was usually applied in cases of incurable disease, not merely as an exception but as a standard practice. Prior to 1990, information given to patients suffering from incurable diseases was thus considered a case when physicians could withhold information (Sándor, 1991). In 1990, an amendment by Parliamentary Act No XXII of 1990, Section 35(1)(a), invalidated this exception. Since 15 March 1990, all patients must be given full information. This was the first step towards opening up the communication between a dying patient and the doctor. Consequently, once the diagnosis was communicated to patients, they had more opportunities to ask

[4] Az orvosi rendtartásról szóló 1959. évi 8. tvr.

questions and decide on their treatment. Until then, without proper information, end-of-life decisions could not even be discussed.

While Act II of 1972 specified the obligations of doctors, since 1997, Parliamentary Act No CLIV of 1997 has included patients' rights, among them the right to refuse treatment, including lifesaving and life-sustaining treatment. The regulation was, and still is, very laconic on this matter. Because it has not been given sufficient publicity, there is little awareness of the opportunities for these end-of-life decisions. In practice, very few people seem to avail themselves of this option, and doctors are uncertain about how to implement the law (Busa, Zeller, Csikós, 2018).

Patient information and involvement are prerequisites for end-of-life decisions. Yet, as shown above, until 1990, doctors in Hungary were allowed to refrain from providing information to incurable patients. Although the current law requires proper provision of information in all cases, disclosure of an incurable disease is often inadequate or insufficient, as many treatment options and alternatives need to be discussed. This preparation is called end-of-life planning. It entails longer, multi-stage communication between the doctor, other health professionals, and the patient. As the last stage of a patients' life can last for months or even years, during which their condition may change, information should be given more than once. As it is now rare for someone to die following the natural course of the disease, the onset of a hopeless condition is usually preceded by countless medical interventions, which in some cases attempt to prolong life but also inadvertently increase suffering. For this reason, doctors should not abandon their patients in this last phase, even if they feel helpless. Reducing suffering and accompanying the patient through the last stage of life is not incompatible with a healing role. The lesson of the Binder case from Hungary, mentioned above (Fedor, 2017) is that abandoned patients and their relatives can find themselves in a hopeless situation. This case shows that acts by laypersons can cause unnecessary suffering due to a lack of professionalism, and that assistance provided by a relative may resemble murder committed in the absence of medical help. It can also be a source of conflict among relatives with radically different views on the matter.

As shown above, the current Dutch system strives for transparency and accountability pursued through due care criteria and the notification procedure. It values patients' and doctors' joint involvement in end-of-life planning. Some commentators argue that doctors should be

trained in and equipped for end-of-life planning, and that life-ending acts can only take place in the context of a standing relationship between the patient and the physician (Fontalis et al., 2018). In the Netherlands, it is mostly in the context of general practitioner (GP) care that standing patient-physician relationships develop (Janssens and ten Have, 2001), and GPs perform most life-ending acts. For example, in 2015, 93% of euthanasia cases were performed by GPs (van der Heide et al., 2017). Patients may formulate their request in an 'advance directive', and GPs must include these in the medical records. Furthermore, end-of-life care is often provided at the patient's home. Studies have shown that 65% of cancer deaths occur in the patient's home environment (Cohen et al., 2008; Rietjens et al., 2009). Nevertheless, the law strictly requires the involvement of physicians, and the current legislative framework has kept death and dying within the realm of medical care.

Transparent and joint end-of-life planning is seriously obstructed in Hungary and other jurisdictions with no legal ground for physician-assisted dying. Research shows that in such countries, patients also request for their life to be ended (van der Heide et al., 2003), yet physicians remain largely untrained regarding professional responsibilities and the challenges posed by end-of-life decision-making (Fontalis et al., 2018). Yet, there has been no significant development in this field in Hungarian health law since 1997, while criminal law continues to strictly prohibit physicians' assistance in dying. Hungarian criminal law also applies to acts committed abroad that are considered criminal offences in Hungary, even if they would not constitute criminal offences under the law of that country.[5]

Heroic struggle and dignified endurance of suffering are to be honored in the same way as when someone feels they can no longer fight or maintain dignity. When the hospice movement started in Hungary, Poland served as a good example. Later, Hungarian experts went to Georgia and Bosnia to teach hospice care.[6]

In Hungary, the work of Alaine Polcz and Katalin Muszbek[7] helped hospice care become established. In the field of bioethics, Katalin Hegedűs has been most involved in hospice care (Hegedűs, 2006). The textbook on palliative care was edited by Ágnes Csikós (Csikós, 2014).

[5] Section 3(1) of the 2012 Hungarian Criminal Code.
[6] Interview with Katalin Muszbek on 15 February 2024.
[7] *Ibid.*

Developing the hospice movement required great effort in Hungary. As part of our Leviathan Project, we conducted several interviews with experts, including a long interview with Katalin Muszbek on 15 February 2024. She pointed out how much resistance she initially encountered when talking to oncology patients. Doctors believed that patients' expressions of emotion were an obstacle to their recovery. They found it easier to treat a patient who was disciplined and unemotional. Later, when hospice care was launched in Hungary, it was modelled on the system already in place in Poland. However, hospice care is still focused only on oncology patients, with many other dying patients not receiving such care.

The process of dying varies greatly, and palliative and hospice care are not effective for everyone. Not only physical suffering, but also emotional suffering is experienced differently by different people. It is important, however, that whether assisted suicide or some form of euthanasia is permitted by law, palliative care must first be available and meet an adequate standard.

Conclusions

Having examined the differences between Hungary and the Netherlands, we note the divergence in the development of the patient-doctor relationship during the second half of the 20th century. At the end of World War II, a paternalistic and hierarchical physician-patient relationship was dominant in both societies. In Hungary, the various forms and manifestations of paternalism created and maintained throughout the following decades an aura of secrecy around medical decisions concerning the end of life. On the one hand, paternalistic healthcare was provided by the state to patients free of charge at the point of delivery, but it did not encourage them to make autonomous decisions for themselves. Moreover, healthcare was often difficult to distinguish from social care. On the other hand, the recorded malpractice cases indicated that patients and their relatives attempted to challenge this paternalistic allocation of rights.

The legal assessment of end-of-life decisions is a particularly sensitive area. While it is linked to important moral and cultural issues, it also requires a combined assessment of many factors. There are differences in the course of diseases, the evolving possibilities of medicine, the degree of trust in the legal system, the status of bioethics, and the availability and quality of palliative care. It is also difficult to assess the

relationship between regulation and actual medical and nursing practice. One consequence of the taboos surrounding death and dying is that we do not know how and in what way medical decisions are made in intensive care units and other wards, where such decisions may partly replace self-determination. The threat of prosecution poses obstacles to the open debate in Hungary. Despite rich literature and opinion surveys, Hungarian medical law developed the right to refuse (certain types of) treatment only in 1997, and neither euthanasia nor assisted suicide have been legalized ever since. Providing information, even in case of the incurable disease, is the first step towards opening the discussion with the patient about choices. In Hungary, therapeutic privilege constituted an obstacle for decades, and although it was legally eliminated in 1990, open communication at the end of life was not followed by recognition of physician-assisted dying. Unlike in the Netherlands, where transparency was an explicit aim of legal reforms, in Hungary, end-of-life decisions remain opaque, and the current challenge of insufficient access to public healthcare makes it even more difficult to reinforce patients' rights in cases of terminal illness.

In the current Hungarian debate, legitimate doubt has been raised as to whether euthanasia or assisted suicide could be appropriately implemented in the present deteriorating healthcare environment with long waiting lists and many patients who have paid public healthcare premiums for decades only to receive timely treatment at private providers. Such concerns are justified, but it must also be recognized that a patient who is suffering now cannot wait for the health system to improve. Elsewhere, euthanasia debates have been used to bring greater attention to the care of dying patients, palliative care, and hospice care, and have served as catalysts for improvements in these areas. Paradoxically, the taboo on end-of-life decisions can also hasten them, as shown in the *Dániel Karsai v Hungary* case, where many questions were raised at the court hearing about the consequences of the applicant travelling to Switzerland to request assisted suicide there (Sándor, 2024). If the overall situation of patients improves, a wider range of end-of-life decisions could be made available to individuals whose condition becomes incompatible with human dignity and unbearable despite receiving help.

In the Netherlands, the Euthanasia Act was adopted following judicial decisions, empirical studies, and initiatives by healthcare professionals and civil society. Together, these contributed to lifting of the

taboo on end-of-life decisions. A gradual shift occurred from a predominantly paternalistic approach towards an emphasis on joint decision-making. It took decades for this shift to materialize. Without attempting any causal inferences, we can highlight several factors in this context. Our analysis has focused predominantly on legal elements, and specifically on case law developments guided by medical ethics, which paved the way for the adoption of professional standards and statutory rules. Clearly, legal developments tell only part of the story, and several authors have discussed why euthanasia was first permitted in the Netherlands and not elsewhere (see for example, Kennedy, 2002, Weyers, 2004). Legal change occurred against the background of broader societal shifts. Since the 1960s, changes characterized by secularism and growing individualism have loosened the taboos on several aspects of life including death and dying. Patient autonomy has become emphasized, together with rights to information and to (refusal of) consent. These developments laid the foundations for the general acceptance of physician-assisted dying as a legitimate topic for debate, which in turn created room for empirical studies providing better evidence-base for policy and legislative action.

The Dutch approach to end-of-life decisions has been characterized as very specific and pragmatic (Groenhuijsen and van Laanen, 2006; Buijsen, 2024[8]). It has also been widely challenged due to the inconsistencies resulting from the compromises it involves: criminalizing whilst making exceptions, ensuring some recognition of patients' self-determination while granting physicians the right to refuse their patients' life-ending requests (Buijsen, 2024: 11). Even so, the Dutch case shows that, with guidance from the medical profession, the judicial system has lifted end-of-life decisions from the realm of taboos, treated them as facts of life, and focused on ensuring procedural justice. The current Dutch system strives to ensure due care, accountability, and transparency of physicians' life-ending acts. Nevertheless, the current legislative framework upholds medicalization and keeps death and dying within the realm of medical care, since physicians may comply with their patients' life ending requests (under regulated conditions) but may also refuse them. Finding the right balance between the physician's professional responsibility and the patient's autonomy remains a challenge in the Netherlands as well as in Hungary.

[8] An example for Dutch pragmatism is provided by Buijsen (Buijsen 2024: 8): between 1994 and the 2002 enactment of the Euthanasia Act, the legal prohibition of euthanasia co-existed with an official regulation on the method of reporting cases.

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