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A matter of life or death: the euthanasia debate under a human rights perspective

Nesa Zimmermann*

Keywords

Abstract
This contribution examines euthanasia from a human rights perspective. It focuses in particular on passive euthanasia and the right to refuse medical treatment, two aspects that remain under-theorised. Special attention is paid to the interplay of human dignity and human autonomy in the context of euthanasia.

I. Introduction

Long after suicide has ceased to be a criminal offence, euthanasia remains a highly controversial topic. Within the Council of Europe, only four states allow medical practitioners to prescribe lethal drugs enabling a patient to end their life: Belgium, the Netherlands, Luxembourg and Switzerland. Others accept «passive» assistance, while continuing to ban the more explicit forms of assisted death. The matter has however become increasingly pressing over the past years. The advent of modern medical technology and life-prolonging measures, for one, raises important ethical issues. For example, is it always necessary and justified to take all available and technically feasible measures to keep someone alive? Who should be able to decide over an individual’s life and death?

In human rights terms, the question has emerged whether there is a «right to die». In the following, I will take a closer look at this question. After clarifying the most common notions used in relation to euthanasia (II.), I will briefly examine the case law of the European Court of Human Rights (ECHR), focusing on the question of passive euthanasia and the right to refuse medical treatment which has received less attention than assisted suicide. I lay particular emphasis on the key notions of human dignity and autonomy, their interplay and their significance within the edifice of the ECHR1 (III.). The essay ends with concluding remarks and with an outlook (IV.).

II. End-of-life controversies: key distinctions

Modern medicine, with all its technical means and knowledge, has been criticised for its «curative obsession» and «unrestrained urge to intervene and cure».2 This concerns in particular situations where physicians continue to supply curative treatment to a terminally ill patient at a time «when the only outcomes of these treatments and examinations for the terminal patient are discomfort, pain and a meaningless prolongation of

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the dying process».

The relationship between palliative care and euthanasia is however a complicated one. On the one hand, measures aimed at increasing a terminally ill patient’s quality of life are expected to decrease any death wish they may harbour. On the other hand, means aimed at enhancing the quality of life of terminally ill patients may have the side effect of accelerating death. The distinction between palliative care and euthanasia is thus much less clear-cut than it would seem at first glance.

This is especially true concerning indirect euthanasia. «Indirect active euthanasia» designates the administration of medications whose purpose it is to reduce pain and suffering, but whose predictable side effect is to reduce a person’s lifespan. The main focus must however be the reduction of suffering.

Direct euthanasia can be further subdivided into active and passive euthanasia. The latter designates the omission of measures which are necessary to keep someone alive. A common form is the suspension or withdrawal of life-sustaining measures, such as artificial nutrition, hydration or respiration. «Active euthanasia», on the other hand, involves an act that directly causes death, such as the administration of a lethal substance.

From an analytical viewpoint, (physician-)assisted suicide can be considered one particular form of active euthanasia: a professional provides the lethal substance, but the dying person executes the final act of taking the substance. However, commentators consider this being indirect euthanasia since the act itself is executed by the dying persons themselves; this is especially important in Switzerland, where only indirect assistance is permitted.

While active euthanasia, including medically assisted suicide, remains extremely contested, passive euthanasia enjoys a much wider acceptance. Also referred to as «therapeutic abstention», it represents most clearly the idea that better medical technology does not necessarily go hand in hand with a wish to prolong life at all costs. The distinction, while certainly useful, is however ever flawed on several accounts. For one, some scholars have forcefully demonstrated the practical difficulties of distinguishing active from passive euthanasia by asking questions such as «is «pulling the plug» on a respirator really an omission rather than an act?».

For a poignant definition, see Desmedt (fn. 4), 168; see also Claude Rouiller/Leila Rouissianos, Le droit à la vie et le droit de mourir dignement – Esquisse d’une problématique relative aux actes médicaux sur les patients en fin de vie, RJF 142/2006, 938 et seqq., 946.

Dominique Manaï, Droits du patient face à la biomédicine, 2nd ed., Bern 2013, 256 et seqq.; Rouiller/Rouissianos (fn. 5), 946 et seqq.

Manaï (fn. 6), 258; see also Parliamentary Assembly of the Council of Europe, Resolution 1649, 28/01/2009, § 7.

Rouiller/Rouissianos (fn. 5), 947 et seqq.

Christopher Geth, Passive Sterbehilfe, Basel 2010, 8 et seqq.

In the following, «euthanasia» is to be understood as «voluntary» euthanasia only.


Geth (fn. 10), 8. For a critical take on the distinction between indirect and direct euthanasia, see Florian Jenal, Indirekte Sterbehilfe, ZStrR 134/2016, 100 et seqq.

Geth (fn. 10), 8 with further references.

Rouiller/Rouissianos (fn. 5), 947 et seqq.; Geth (fn. 10), 23 et seqq.

Geth (fn. 10), 12.

Geth (fn. 10), 12.

Rouiller/Rouissianos (fn. 5), 947 et seqq.

See for example Young (fn. 13); Helena Peterková, Sterbehilfe und die strafrechtliche Verantwortlichkeit des Arztes, Bern 2013, 22 et seqq.

See e.g. Stuart Beresford, Euthanasia, The Right to Die and the Bill of Rights Act, Human Rights Research 3/2005, 1 et seqq., 5; Rouiller/Rouissianos (fn. 5), 947 et seqq.

Gregor Puppinck/Claire de La Hogue, The right to assisted suicide in the case law of the European Court of Human Rights, International Journal of Human Rights, 735 et seqq., 736. See also Peterková (fn. 20), 23.

Geth (fn. 10), 24.

Rouiller/Rouissianos (fn. 5), 937 et seqq.

Young (fn. 13), Objection 4. See however Geth (fn. 10), 37 et seqq., for a different distinction between active and passive euthanasia that depends rather on domestic law and legal duties than on the common distinction between act and omission.
moral relevance has also been questioned. According to critics, it is largely hypothetical to attribute the cause of death to the underlying illness in instances of passive euthanasia, since the withholding of nutrition or hydration, and not the patient’s illness, is the immediate cause of their death.26 Thus, despite the fact that passive euthanasia seems much less controversial than active euthanasia, the principles and values governing the debate are the same, as the following will show.

III. Euthanasia in the case law of the European Court of Human Rights

A. Introduction

In recent years, a certain number of hard and soft law instruments have emerged on both the international and the European level in the field of biomedicine. Technological development and ever-increasing possibilities in the medical field, and the advent of «life sciences», have caused a strong call for legal regulation to govern ethically difficult decisions, a tendency that has been described as an «eagerness for lawfulness».27 Normativisation proves however difficult, and sometimes impossible, in areas where there is no social consensus, as in the case of euthanasia. Indeed, with the notable absence of palliative care, international instruments remain silent regarding end-of-life issues.28 In the absence of international instruments explicitly addressing euthanasia, the debate has developed within the framework of existing human rights and general concepts like human dignity and autonomy.29 Particularly relevant are the right to life,30 the prohibition of torture and inhuman and degrading treatment,31 the right to health,32 as well as the right to private and family life.33 The case law of the European Court of human rights is particularly interesting in this context since it shows the important role that such general concepts can play in the interpretation and development of existing rights.34

B. Relevant case law: an overview

To date, there are very few ECHR cases concerning end-of-life decisions, and only a handful of them passed the admissibility stage.35 Some of them have been extensively discussed elsewhere which is why the following overview focuses on the more recent and less analysed question of passive euthanasia and palliative care.

1. Suicide and euthanasia under the right to life

Although the current debate evolves around the question whether and to what extent the ECHR guarantees a «right to die», the first question to be addressed in this context is whether states can allow the practice of voluntary euthanasia without violating the right to life guaranteed by Article 2 ECHR. In this context, it should be recalled that Article 2 ECHR does not only prohibit the intentional killing of persons by state agents, but also requires states to take appropriate measures to protect the lives of those within their jurisdiction.36 States have a positive obligation to set up an adequate legal framework, including criminal law remedies against the inten-
tional taking of life, and to conduct prompt, effective and independent investigations when faced with suspicious deaths. In some cases, there is a positive obligation to protect individuals against threats to their life emanating from other individuals or from themselves. The latter applies notably in the case of prisoners. Indeed, being placed under the absolute control of state authorities, they are in a situation of particular vulnerability, which calls for enhanced protection. Outside this very specific context, the right to life «obliges the national authorities to prevent an individual from taking his or her own life if the decision has not been taken freely and with full understanding of what is involved». The Court has emphasised on several occasions that the general principles developed under Article 2 ECHR also «apply in the public health sphere». They require states to regulate the activity of public as well as private hospitals, and oblige them to «adopt appropriate measures for the protection of their patient’s lives». The Court’s rulings in Haas and Gross indicate that a domestic legislation allowing euthanasia or assisted suicide does not violate the right to life ipso facto. The Court has however insisted on several occasions on the need to create necessary safeguards, especially to protect vulnerable persons against abuse.

2. Active euthanasia and assisted suicide

Having established that states can tolerate or legalise euthanasia without violating the ECHR, provided the necessary safeguards are in place, the next question naturally is whether individuals can claim a «right to die». The Court’s findings on Articles 2 and 3 ECHR in Pretty v. the United Kingdom remain valid today. The applicant in this well-known case suffered from a degenerative and terminal illness affecting her muscles known as motor neurone disease (MND). Wishing to commit suicide, but not being able to do so on her own, she requested an undertaking from the British authorities that her husband would not be persecuted for assisting her. The Court famously stated that the right to life could not, «without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die».

According to the Court’s position, which was not altered by subsequent case law, Article 2 ECHR protected life itself, and thus could not be interpreted as a «right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life». Concerning Article 3 ECHR, the Court stated unequivocally that no positive obligation to administer a lethal substance to a person wishing to end their life could be derived from Article 3 ECHR, a finding that has not been altered by subsequent judgments.

Hence, while there seems to be little room for the development of a «right» to die under either Article 2 or Article 3 ECHR, later case law suggests that things are different within Article 8 ECHR. In Pretty already, the Court accepted cautiously that the choice to end one’s life might fall within the ambit of the right to private life. In this context, the Court stressed the importance of self-determination and personal autonomy as guiding principles. The Court was particularly sympathetic to the fact that domestic law prevented Mrs Pretty «from exercising her choice to avoid what she considers will be an undignified and distressing end to her life». Despite that, it refrained from deciding whether this constituted an interference with her right to private life, considering that in any case the restriction conditions of Article 8 par. 2 ECHR were fulfilled. Almost ten years later, the Court famously held in Haas v. Switzerland (2011): «In the light of [its] case-law the Court considers that an individual’s right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention.»

39 PETERMANN (fn. 38), 214 et seqq.
40 ECHR, Renolde v. France, 5608/05 (2008), §§ 80 et seqq.; see also ECHR, Keenan v. the United Kingdom, 27229/95 (2001).
41 ECHR, Haas v. Switzerland (fn. 35), § 54.
42 ECHR, Calvelli and Ciglio v. Italy, 32967/96 (2002), § 49; ECHR, Burke v. the United Kingdom, 19807/06 (2006), 7. See also PETERMANN (fn. 38), 232 et seqq.
43 ECHR, Calvelli and Ciglio v. Italy (fn. 42), § 49.
44 ECHR, Widmer v. Switzerland (admissibility), 20527/92 (1993); ECHR, Haas v. Switzerland (fn. 35), §§ 50 et seqq.; Gross v. Switzerland (fn. 35), §§ 50 et seqq.
45 E.g. ECHR, Haas v. Switzerland (fn. 35), §§ 37, 58.
46 ECHR, Pretty v. the United Kingdom (fn. 35), § 39. See also the strong wording in the dissenting opinion of ECHR, Lambert and others v. France (fn. 35), at pt. 2.
47 ECHR, Pretty v. the United Kingdom (fn. 35), § 39.
48 ECHR, Pretty v. the United Kingdom (fn. 35), § 56.
49 ECHR, Pretty v. the United Kingdom (fn. 35), § 67.
50 ECHR, Pretty v. the United Kingdom (fn. 35), §§ 67 et seqq.
51 ECHR, Haas v. Switzerland (fn. 35), § 51.
Some commentators have interpreted this as a significant shift since *Pretty* and as recognition, by the Court, of a «right to die». This needs to be relativized to two accounts. First, rather than a shift, this development constitutes a slight evolution which is perfectly in line with the landmark case of *Pretty*. Second, careful reading of the Court’s wording in *Haas* reveals that the individual’s right to decide how and when to end their life depends not only on the capacity of reaching a free decision, but also on «acting in consequence». This is precisely the crucial point: a person in the situation of Mrs Pretty could not «act in consequence» without any help. The question, then, was essentially whether the state was required to provide a medical substance in order to relieve (palliative) care available could violate Article 3 ECHR. Conversely, the question arises whether the administration of unwanted medical treatment could be considered as a violation of Article 3 ECHR. The difficulty lies in the fact that for a treatment to be degrading within the meaning of Article 3 ECHR, some element of humiliation must be involved. Wicks has argued that treatment which is against the patient’s express will violates his or her autonomy and, hence, human dignity, thereby involving an element of humiliation. The Court did not endorse this view, indicating on the contrary that «a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading». The prospects of invoking Article 3 ECHR in order to refuse medical treatment thus seem rather dire.

3. Passive euthanasia and palliative care

While it has been made abundantly clear that Article 3 ECHR cannot found a claim to active euthanasia or assisted suicide, matters might be different concerning palliative care and passive euthanasia. The Court’s ruling in *Pretty* already indicates that a failure to make pain-relieving (palliative) care available could violate Article 3 ECHR. The Court considered whether the administration of unwanted medical treatment could be considered as a violation of Article 3 ECHR. The difficulty lies in the fact that for a treatment to be degrading within the meaning of Article 3 ECHR, some element of humiliation must be involved. Wicks has argued that treatment which is against the patient’s express will violates his or her autonomy and, hence, human dignity, thereby involving an element of humiliation. The Court did not endorse this view, indicating on the contrary that «a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading». The prospects of invoking Article 3 ECHR in order to refuse medical treatment thus seem rather dire.

In contrast, the Court has unequivocally recognised that «the imposition of medical treatment without the consent of a mentally competent adult patient would interfere with his or her right to physical integrity and impinge on the rights protected under Article 8 of the Convention». This is the case even «where the refusal to accept a particular treatment might lead to a fatal outcome». The Court deduced the «freedom to accept or refuse specific medical treatment» directly from the principles of self-determination and personal autonomy. It emphasised in particular that this meant that a competent adult’s decision must be respected, «regardless of how irrational, unwise or imprudent such choices may appear to others». It should however be stressed that this reasoning belongs to a case examining the refusal of a life-saving blood transfusion by Jehovah’s witnesses. This is relevant since the case clearly reveals that the Court was particularly mindful of individual autonomy as an expression of religious beliefs. Indeed, the Court explicitly stressed that the question at stake was not that of committing suicide, or of refusing treatment altogether, but of refusing specific treatments contrary to the person’s beliefs. It remains to be seen, then, whether the Court will ascertain the right to refuse medical treatment as firmly when no religious beliefs are at stake.
The question is a different one altogether where the patient lacks capacity to consent. This was the case in Glass v. the United Kingdom concerning the administration of diamorphine to a severely impaired and terminally ill child against his family’s wishes. The difficulty of the balancing exercise is shown by the case’s outcome: at the admissibility stage, the Court ruled that there was no violation of the Convention, due notably to the fact that the doctors did not intend to kill the boy, or to hasten his death, but only to reduce his pains. When ruling on the merits, however, the Court found that the medical staff had not respected the safeguards put in place by domestic law, especially by failing to apply to a Court to resolve the dispute between parents and health professionals.

The recent case of Lambert and others v. France was another instance of a patient unable to consent. Following a road accident, 32-year-old Vincent Lambert was tetraplegic and in a chronic vegetative state since 2008. Four years later, a medical procedure resulted in the decision to withdraw the patient’s artificial nutrition and reduce his hydration. While his wife, who had been associated to the decision-making process, and some of his family favoured the decision, his parents and two of his siblings fiercely opposed it. Their claims having been dismissed by the Conseil d’État, they filed an application with the Court.

Concerning the merits of the case, the main question before the Court was whether the withdrawal of artificial nutrition and hydration violated Article 2 ECHR. Instead of providing an abstract answer to the question, the Court focused on the decision-making process and the safeguards provided for by domestic law. Referring to the state’s margin of appreciation, particularly in view of the lack of consensus amongst state parties, the majority of the Court concluded that the domestic procedure had provided sufficient safeguards and thus respected the right to life. Interestingly, the Court stressed that the «issue before it in the present case is not that of euthanasia, but rather the withdrawal of life-sustaining treatment». As this falls clearly within the generally accepted definition of passive euthanasia, one must suspect that the reasons for the Court’s emphasis were of a strategic, rather than legal, nature. One reason could be that the Court wanted to stress the specificities of the case and avoid creating too strong a precedent.

C. Underlying values and principles

The interest of the Court’s case law on end-of-life decisions goes beyond the immediate question whether there is a «right to die» or not. Indeed, this topic has allowed the Court to engage with both autonomy and human dignity, which has in turn led to a better understanding of these two foundational concepts.

Human dignity has been described as a «cornerstone», and «shaping principle», of bioethics and biomedical law. In the realm of human rights, human dignity can be considered as a source and foundation of all human rights. The Court, for its part, has qualified the «respect for human dignity» as the «very essence of the Convention». While the inspirational importance of human dignity is undeniable, in biolaw and human rights alike, its normative value is much less clear. The criticism of human dignity as being too vague and effusive is a recurring theme in human rights scholarship.

This is particularly evident in the context of end-of-life decisions, where human dignity is frequently appealed to by holders of diametrically opposite views. This does

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66 ECtHR, Glass v. The United Kingdom (admissibility), 61827/00 (2003), 16.
67 ECtHR, Glass v. The United Kingdom (merits), 61827/00 (2004), § 83.
68 ECtHR, Lambert and others v. France (fn. 35).
69 An important part of the case concerned issues of admissibility, see ECtHR, Lambert and others v. France (fn. 35), §§ 82 et seqq.
70 ECtHR, Lambert and others v. France (fn. 35), §§ 142 et seqq.
71 ECtHR, Lambert and others v. France (fn. 35), § 181.
72 ECtHR, Lambert and others v. France (fn. 35), § 141.
74 See also Jacob Dahl Rendtorff, Basic ethical principles in European bioethics and biolaw: Autonomy, dignity, integrity and vulnerability – Towards a foundation of bioethics and biolaw, Medecine, Health Care and Philosophy 2002, 235 et seqq.
76 Roberto Andorno, Human Dignity and Human Rights as a Common Ground for a Global Ethics, Journal of Medicine and Philosophy 2009, 4 et seqq.; Rendtorff (fn. 74), 235 et seqq.
77 Di Stasi (fn. 75), 8 et seqq.
78 ECtHR, Jehovah Witnesses of Moscow and others v. Russia (fn. 62), § 135.
79 Di Stasi (fn. 75), 6 et seqq., with further references.
80 See e.g. Christopher McCrudden, Human Dignity and Judicial Interpretation of Human Rights, EJIL 4/2008, 655 et seqq. In the field of bioethics, see e.g. Andorno (fn. 76), 6 et seqq.
not mean that dignity is just an empty rhetoric; rather, it shows that dignity is a concept with variable, competing and sometimes mutually exclusive understandings.82

From one viewpoint, human dignity is closely intertwined with the «sanctity», or inviolability, of life. According to this position, euthanasia, by making death acceptable, would diminish the value of human life and, thus, attack our inherent human dignity.83 Closely related is the fear that the acceptability of euthanasia in certain circumstances, but not in others, constitutes a value judgment, implying that some lives would be less worthy than others. This criticism of euthanasia is very strong within disability studies.84 The opposite viewpoint consists of emphasising the importance of the quality of life, and tends to link human dignity to the absence of suffering, hence the notion of «dignified death».85 In this second approach, human dignity is closely intertwined with self-determination and personal autonomy: respect for human dignity signifies respect for the individuals’ choices, even if it is to end their life.86

Both approaches can be found in the ECtHR’s reasoning. Already in Pretty, the Court famously held:

«Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.»87

Despite this recognition, the Court accepts that the blanket ban on assisted suicide and, hence, limitation of Mrs Pretty’s autonomy, could be justified by the need to prevent abuse and protect vulnerable persons. According to Mills, «the dignity of humanity expressed in its most universal and objective form so as to protect life is given force over and above the individual and subjective dignity of the person seeking assistance to terminate a state of personal suffering».88 It would however be an overstatement to say that the «sanctity of life»-approach prevailed: rather, the case’s outcome was decided by the large margin of appreciation left to the state.89

Later cases have put even stronger focus on personal autonomy as an aspect of the respect for human dignity. While in most instances, personal autonomy has been referred to as a «principle», in some cases it has been qualified as a «right».90 Within the right to private life, personal autonomy includes the individuals’ right to decide what they consider to be an «undignified» life, and to act accordingly by ending a life that they do not wish to pursue, but also the right to refuse any medical treatment.91 Importantly, the emphasis on personal autonomy is not limited to cases on end-of-life questions, but has, on the contrary, spread into other areas. In a case concerning forced sterilization of a Roma woman, for example, the Court stressed the paramount importance of informed consent for «promoting autonomy of moral choice for patients».92 In the same case, the Court considered the medical staff’s acts to be both against her basic human dignity and in violation of the patient’s «right to autonomy».93

IV. Conclusion and outlook

The Court has been adamant: the right to life does not have as corollary a «right to die». On the contrary, Article 2 ECHR obliges states to prevent persons from taking their lives if the decision is not reached freely or if they cannot understand its implications. Nor is there a right to end one’s life, however painful, to be derived from the prohibition of inhuman and degrading treatment. However, under the right to private life, some aspects of a «right to die» or, more accurately, a «right to choose the time and manner of one’s death» have come to be protected under the right to private life (Article 8 ECHR). This includes the individuals’ right to decide what they consider to be an «undignified» life, and to act accordingly by ending a life that they do not wish to pursue.

This choice is, however, limited by a certain number of factors, above all the need to protect persons against...
a choice that is not made freely and knowingly. This means not only that such a choice can only validly be made by competent adults. It also signifies that even a state which allows euthanasia can restrict access in order to protect vulnerable individuals. More importantly even, this choice is preconditioned by the individuals’ ability to act upon their choice, since it does not oblige states to provide persons wishing to commit suicide with the necessary means to do so. When it comes to suicide, then, personal autonomy is real only for those who cannot only decide freely, but act accordingly. Such an approach seems discriminatory towards persons who have their entire mental capacity, but do not have control over all their bodily functions. However, in view of today’s context, where assisted suicide and active euthanasia are prohibited in all but four countries within the Council of Europe – the Court lacks a solid basis for recognising a right, even conditioned, to be provided with a lethal substance.

For the foreseeable future, matters of life or death are therefore likely to remain largely not only a matter of personal autonomy, but also a matter within each state’s margin of appreciation. The discussed case law is however also of relevance outside the context of euthanasia. Indeed, it has contributed to be more generally to the emergence of a «right to autonomy». As an inherent aspect of human dignity, such a «right» encompasses an array of other choices essential to personal identity, in the health care sector and beyond.