Essays

Advanced Euthanasia Directives. From the "Koffie" judgment to the need for euthanasia beyond reasonable doubt

Alessandro Ferrara*

ABSTRACT: While the ethical legitimacy of euthanasia and assisted suicide is still being debated in Italy and France, in some Northern European countries euthanasia is legitimately carried out on incompetent patients suffering from mental illness, even against their actual will, on the basis of an advanced euthanasia directive. Based on the well-known Dutch "Koffie" case and the principles affirmed by the United Nations Convention on the Rights of Persons with Disabilities, this paper will attempt to review the ethical legitimacy of the practice of anticipated termination of life performed on patients incapable due to mental illness, even against their will, on the basis of advanced euthanasia directives, arguing that in certain cases the performance of euthanasia should be subject to a precautionary principle, such that it is granted only beyond reasonable doubt and that the need for consent is stressed at least until the last moment of life.

KEYWORDS: Euthanasia; bioethics; mental disease; human rights; assisted suicide

SUMMARY: 1. Introduction – 2. The "Koffie" judgment of the Dutch Supreme Court and paragraph 2 of the Dutch Wtl – 2.1. The execution of an advanced euthanasia directive – 2.2 The unbearable suffering of the mental disease – 3. The problem of subjectivity and suffering – 4. The patient's mental competence in the light of the United Nations Convention on the Rights of Persons with Disabilities – 5. Euthanasia beyond reasonable doubt.

1. Introduction

In several European states, the debate on the legality of euthanasia is fervent, especially in France and Italy where the Lambert[1] and Cappato[2] cases (the latter concluded with a historic

*PhD in Theory of Law and European Legal and Economic Order, Magna Graecia University of Catanzaro. Mail: a.ferrara@unicz.it. *The article was subject to a double-blind peer review process.*

[1] C. CASONATO, *Un diritto difficile. Il caso Lambert fra necessità e rischi*, in *BioLaw Journal*, 9, 2015, 489-501.

[2] Cfr. G. RAZZANO, *La Corte costituzionale sul caso Cappato: può un'ordinanza chiedere al Parlamento di legalizzare il suicidio assistito?*, in *Dirittifondamentali.it*, 1, 2019.; F. POGGI, *Il caso Cappato: la Corte costituzionale nelle strettoie tra uccidere e lasciar morire*, in *BioLaw Journal*, 1, 2020, 81-98.

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ruling by the Constitutional Court)[3] have definitively ignited the debate.[4] On 18 March 2021, the Spanish Parliament approved the text of the law that makes the execution of euthanasia legal.[5] Spain is the fourth European country to have legalised euthanasia and assisted suicide, after Holland, Belgium and Luxembourg. In France, following a public consultation on the end of life,[6] a bill for its legalisation is currently pending in Parliament, while in Italy, a bill on medically assisted voluntary death is under consideration in the Senate.[7]

At the same time, while the general legitimacy of euthanasia and assisted suicide is being debated in the rest of Europe, the Dutch Supreme Court, the first country in the world to have made it legal with a law promulgated in 2002, has excluded – with the well-known "Koffie" judgement[8] – the punishability of a doctor who had practised euthanasia on a patient suffering from Alzheimer's disease, and therefore not considered capable of understanding, after having sedated her without her knowledge and without having taken into account her actual will, since she had made a written declaration years earlier in which she had asked for euthanasia precisely in the event of her future incapacity.

The aim of this contribution is to critically analyse the theoretical foundations that appear to permit euthanasia for patients who are no longer capable of understanding and wanting, based on an advanced euthanasia directive, even if the will expressed in the aforementioned declaration is no longer current and is not confirmed immediately prior to euthanasia.

The aim of this contribution, drawing from the grounds of the aforementioned judgment and the Dutch euthanasia legislation, is to critically analyse the theoretical foundations that would seem to admit access to euthanasia for patients who are no longer capable of understanding and wanting on the basis of an advanced euthanasia directive even if the will expressed in the aforementioned declaration is no longer current and is not confirmed immediately prior to euthanasia.

In order to delineate the research perimeter of the present work more clearly, it is necessary to premise that the problematic elements of the application of the law on euthanasia in execution of an advanced euthanasia directive – provided for in section 2 of the Dutch euthanasia law[9] (Wtl) – arise

[3] CONSTITUTIONAL COURT, judgment n. 242 of 2019. With the aforementioned ruling, the Italian Constitutional Court requested the legislative intervention of Parliament and subsequently declared the partial constitutional illegitimacy of Article 580 of the Criminal Code and excluded the punishability of the conduct of assisting suicide when certain conditions were met.

[4] For deepening see, T. CERRUTI (a cura di), *L'elaborazione di un diritto a una morte dignitosa nell'esperienza europea*, Napoli, 2023.

[5] Ley Orgánica 3/2021, de 24 de marzo, de regulación de la eutanasia, https://www.boe.es/diario_boe/txt.php?id=BOE-A-2021-4628, (consulted on 19.06.2021).

[6] Convention citoyenne sur la fin de vie, pour une ouverture de l'aide active à mourir sous conditions https://www.lecese.fr/convention-citoyenne-sur-la-fin-de-vie (consulted on 25.01.2024) see also https://www.questionegiustizia.it/articolo/la-convenzione-francese-sul-fine-vita-la-democrazia-deliberativa-per-superare-un-impasse;

[7] Senate of the Republic, Senate Bill No. 104 https://www.senato.it/leg/19/BGT/Schede/FascicoloSchedeDDL/ebook/55281.pdf (consulted 14.10.2024).

[8] Supreme Court of the Netherlands, judgment of 21 April 2020, No. 19/04910 CW, https://uitspraken.rechtspraak.nl/inziendocument?id=ECLI:NL:HR:2020:712 (consulted 18.11.2024).

[9] Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of life on request and assisted suicide law) Art. 2, c. 2: "If the patient aged sixteen or over is no longer capable of expressing his or her wishes, but before reaching that state has been deemed capable of a reasonable assessment of his or her interests in

mainly when the patient is suffering from a mental illness and especially when there is a conflict between the advance request for euthanasia and the actual will.
The term 'mental disease', which is deliberately broad and does not distinguish between psychiatric, neurodegenerative and psychic diseases, is used to refer to all those pathological states that directly or indirectly affect an individual's capacity to make decisions without necessarily leading to a consequent and relevant functional or bodily limitation.

2. The "Koffie" Judgment of the Dutch Supreme Court and paragraph 2 of the Dutch Wtl

In order to explore the relationship between an advance request for euthanasia in the case of mental disease and the contrast with the applicant's current will, it is necessary to analyse the case resolved by the Supreme Court of the Netherlands in judgment No. 19/04910 of 21 April 2020. The case emerged from an appeal by Attorney General Jos Silvis against a ruling by the District Court of The Hague, which declared a geriatric doctor not guilty of euthanasia in the case of a patient suffering from Alzheimer's disease. This was due to the patient having made a written declaration in which she had requested euthanasia in advance in the event that she had reached such a state of health that she had lost her capacity to understand and to be admitted to a nursing home.
Specifically, immediately following the diagnosis of Alzheimer's disease, the patient had drawn up an advance euthanasia directive[10] (AED), in which she requested a peaceful death when she deemed the quality of her life to be unsatisfactory. Following the transfer of the patient in a nursing home, her living conditions exhibited fluctuations, characterised by moments of well-being, especially in the mornings and on visiting days with her relatives and her husband, and other moments of deep suffering, characterised by sleeplessness and fits of rage against the nursing home staff.[11] In any case, when asked whether she wished to be euthanised, she replied "not yet, it's not that bad yet".[12] On the day of the euthanasia – and this is the most controversial element of the case, from which the name "Koffie" (coffee) derives – the doctor, in order to avoid the patient's resistance during the execution of the euthanasia, first administered a sedative in her coffee, without her knowledge, and then injected her with the lethal injection with the help of her relatives who prevented her from moving and getting out of bed.

this regard and has submitted a written statement containing a request for termination of life, which has been completed, the physician may comply with this request. The duties of care set out in the first paragraph shall apply mutatis mutandis" (author's translation).

[10] E.C.A. Asscher, S. van de Vathorst, *First prosecution of a Dutch doctor since the Euthanasia Act of 2002: what does the verdict mean?* In *Journal of Medical Ethics*, 46, 2020, 71-75. The patient's statement was as follows: "I would like to use the legal right to be given voluntary euthanasia, when I think the time is right. I do not want to be placed in a nursing home for elderly people with dementia. I want to say goodbye to my loved ones in a timely and dignified manner. My mother in her time had been in a nursing home for 12 years before she died, so I have close experience of it. I know what I am talking about. I definitely do not want to experience this, it has traumatised me severely and really saddened the whole family. Trusting, that when the quality of my life is so low, that at my request euthanasia will be performed".

[11] For a timely account of every detail of the case, see, D.G. Miller, R. Dresser, S.Y.H. Kim, *Advance euthanasia directives: a controversial case and its ethical implications*, in *Journal of Medical Ethics*, 45, 2019, 84-89.

[12] *Ivi*, 3.

Despite this, the doctor who performed the euthanasia was found not guilty by both The Hague Tribunal and the Supreme Court because - in contrast to the Dutch euthanasia review committee (RTE) and the Attorney General's Office - they considered that the diligence requirements of the Dutch euthanasia legislation had been met. Compliance with these requirements leads to the non-punishment of the doctor.[13]

The Dutch End of Life and Assisted Suicide Act[14] (Wtl) establishes the exclusion of the punishability of the physician who has performed euthanasia, if the latter has complied with the criteria of due diligence laid down in Art. 2(1), namely: (a) is convinced that the request is voluntary and is well-considered; (b) is convinced that the patient is unbearably suffering and that there is no prospect of improvement; (c) has informed the patient of his condition and of the various alternatives; (d) has reached the conclusion together with the patient that there are no alternatives in the light of his condition; (e) has consulted at least one other independent doctor who has given a written opinion on the existence of the diligence criteria provided for in the preceding points; (f) has ended the patient's life by giving due care and through medical treatment. At the same time, subsection 2 provides that the doctor may also take into consideration and execute a written request for euthanasia received from a patient over the age of sixteen who is currently not capable of consent if, at the time of the request, he or she is considered to be capable of consenting and aware of his or her request, provided that the requirements of subsection 1 apply *mutatis mutandis.*

One of the most debated issues in doctrine, which this paper will address, concerns the possibility, which seems to have been recognised by the Dutch Supreme Court, of performing euthanasia even against the patient's current will, and despite their unconsciousness, if the patient is no longer capable of understanding.

The analysis will commence with the Supreme Court's judgment, which seeks to address the most contentious aspects of subsection 2 of the Wtl by proposing an interpretation of the legislation that touches on critical issues that warrant in-depth reflection.

It must be emphasised that the intention of this paper is not to limit itself to the analysis of the Dutch case, but to use it as a starting point to explore some relevant ethical issues and to provide useful food for thought for the ongoing legislative activity in many European parliaments, including the Italian one.

Prior to proceeding with the analysis of the Supreme Court's decision, it is appropriate to briefly reconstruct the case in question, highlighting some essential elements to support the subsequent conclusions.

[13] *Ivi*, 4. The requirements for diligence that were not fulfilled according to the RTE related to the voluntariness and sufficient weighting of the request and the necessary implementation through compliance with the principles of medical activity.

[14] Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Act on Termination of Life on Demand and Suicide Assistance, https://wetten.overheid.nl/BWBR0012410/2020-03-19 (consulted 20.06.2024).

2.1. The execution of an advanced euthanasia directive

In order to pronounce the doctor's non-punishability, the Dutch Supreme Court focuses its attention on the recurrence – *mutatis mutandis* – of the same requirements of diligence as provided for in paragraph 1 of art. 2 Wtl,[15] irrespective of whether the patient's current incapacity is attributable to mental disease. The Court clarifies that, in order to execute a previous written request for euthanasia, it is appropriate to exclude any doubt as to the patient's present capacity; the fact that the patient is able to express herself verbally does not prevent the doctor from carrying out an assessment as to her capacity in any event.

The onus, therefore, falls upon the physician to interpret the content of the written request for euthanasia and any subsequent declarations (even those expressed in a general condition of incapacity) in order to assess the correspondence between the current situation and that envisaged in the advance request. On this point, a particularly salient excerpt from the ruling merits attention:

> "This requirement also implies that the doctor must establish that the current situation in which the patient finds himself is (also) envisaged in the written request for euthanasia and that the conditions for which the patient has asked in writing to end his life are therefore fulfilled. This requires first of all determining the content of the written request. The diligence required consists in the investigation made by the physician in order to know the patient's intentions. In doing so, he must consider all the circumstances of the case and not just the literal terms of the request. Ambiguities or inconsistencies of a substantial nature may prevent the fulfilment of a written request for euthanasia. However, this does not apply to every ambiguity or contradiction. The written declaration must always at least indicate that the patient requests euthanasia in the event that he/she is no longer able to form and express a will related thereto as a result of dementia. If the patient wishes the declaration to be implemented also in cases where unbearable physical suffering is not involved, the request must also show that the patient considers the (intended) suffering resulting from advanced dementia to be unbearable and that this is indeed the basis for his or her request. In this context, it is important that the doctor carefully determines and assesses the patient's current situation, so as to be able to compare that situation with the one to which the written request refers".[16]

The passage reveals one of the most problematic aspects of the judgment and probably highlights one of the most critical aspects of the very hypothesis of euthanasia as a consequence of mental disease. The Dutch Minister of Health had previously raised the issue in a memorandum addressed to the President of the House of Representatives of the Parliament. The memorandum concerned cases in which the will of a patient who had expressed their written request for euthanasia in advance and had meanwhile become incapacitated could be considered current or not when the conditions indicated in the written request came true. This is especially problematic when the patient's current behaviour does not align with their previous written request and the conditions indicated in the declaration have been met.

Indeed, it is noteworthy that in the event that the patient, having become incapacitated, expresses a contrary opinion to that of euthanasia, the memorandum states that there is no certainty that the

[15] See *supra* note 7, par. 4.4.1.
[16] See *supra* note 7, par. 4.5.2.

patient, even if the conditions indicated in the declaration were to be fulfilled, would still be in favour of terminating his life.
The issue has been addressed by the Court, which has determined that the patient's current will is not relevant. This decision seems to indicate that the patient who has become incapacitated loses the right to modify his or her own will and, consequently, the right to control his or her own life, at the same time as he or she meets the conditions set out in the written request drawn up by him or her. The Court determined that, as the patient has lost the capacity to consent, the responsibility and authority to evaluate the fulfilment of the diligence requirements stipulated in Article 2 of the Wtl, and the potential justifications for denying the written request for euthanasia, will be entrusted exclusively to the physician. The reasoning of the Court further elucidates that the words of an incapacitated individual cannot be considered in either the context of requesting euthanasia or the revocation of a previously made request.
The "Koffie" judgment in essence – by excluding the punishability of the doctor who had administered a sedative to the patient in the coffee in order to be able to perform euthanasia without any 'hindrance' on the part of the patient himself – tends to affirm that, even when the patient's right to life, dignity and health is at stake, it is not necessary to investigate their actual will if one considers them incapable of coherently assessing their own interests. It therefore follows that one can act against the patient's will, even if they are unconscious.

2.2. The unbearable suffering of the mental disease

The Supreme Court further stated, applying *mutatis mutandis* the requirements of art. 2 par. 1 of the Wtl, that euthanasia can only be administered in the case of mental disease if the patient is suffering unbearable and present suffering with no future hope of obtaining any clinical improvement. The existence of such unbearable suffering, according to the ruling, is difficult to determine precisely in this type of disease, and therefore this assessment–to be made on a case-by-case basis–must be the sole responsibility of the doctor.
The responsibility for determining if an individual, no longer in a state of sound mind, is in fact suffering unbearably, lies with the attending physician. The Court proposes that the assessment of unbearable suffering may be informed by the presence of additional pathologies, or physical discomfort, or alternatively, in their absence, by the existence of concomitant conditions (for example, despondency, food refusal, or a cessation of drinking), which correspond to those delineated in the euthanasia request, and which are deemed to result in the conclusion that the patient is in an unbearable state of suffering.
The Court further asserts that the correspondence merely between the elements stipulated in the written request and those of actual occurrence does not constitute a sufficient condition for unbearable suffering to be deemed present. Rather, it is submitted that this correspondence may be considered a useful indicator by the physician.

> "Since in these cases it is established that the patient is no longer able to form a relevant written statement and to make a current correlated position on his suffering, the doctor will have to establish the severity of the patient's suffering, based on certain deductions from the patient's actual condition. For

this reason, too, the physician must always carefully and traceably ascertain that the patient is actually experiencing unbearable suffering".[17]

The Supreme Court's judgment appears to acknowledge that the assessment of unbearable suffering in a patient may be derived from the analysis of clauses included in the written statement, from conversations with close relatives, and from the current observation of the patient and their life circumstances. In essence, this may be deduced from circumstantial elements. In the present case, the evidence of unbearable suffering was deemed sufficient to establish such suffering from observation of the patient. "It was observed that the patient showed signs of agitation, restlessness, stress, fear, sadness, anger and panic for most of the day. He cried a lot, often said that he hated this condition and that it would eventually destroy him and said almost daily (up to 20 times a day) that he wanted to die".[18]

Affirming the criminal liability of the doctor is certainly a different matter from the absolute certainty that the patient was actually suffering unbearably at the time euthanasia was administered. In any event, in applying the rule, the assertion that the patient suffered unbearably does not seem convincing. While the physician's acquittal may be substantiated by the prevailing principles of the criminal justice system, the ruling underscores several deficiencies in the Wtl as well as in the very idea of euthanasia administered to mentally ill patients.

With regard to the further requirements of diligence – such as, for example, informing the patient of his condition and of the various alternatives to euthanasia or arriving with the patient at the conviction that there was no alternative but to end his life – the Court merely states that the requirement must be applied to the extent that the factual situation permits, essentially acknowledging that in cases where the patient is incapable of understanding some requirements cannot be met at all.[19] The question of whether the requirement of unbearable suffering must be permanent has also arisen, or whether it is sufficient that the patient suffers unbearably at certain times of the day and others does not. In response to this query, the regional euthanasia review commissions (RTE), as delineated by the Dutch discipline as entities established to verify the standard of euthanasia procedures *ex post*, stated that the requirement for unbearable suffering need not be constant at all times of the day, but just enough to be considered unbearable. In addressing this issue, it is imperative to recognise that the evaluation of a patient's condition necessitates a multifaceted approach, encompassing diverse assumptions. The existence of every human being is marked by more or less positive periods, periods of depression and suffering, sometimes even unbearable suffering, but in order to determine when the burden of suffering is such as to justify the interruption of life, a more in-depth evaluation[20] would be required, or at least the establishment of objective or at least more rigorous requirements.

[17] *Ivi*, par. 4.6.3.
[18] *Ivi*., par. 5.3.3.
[19] J.J. VAN DELDEN, *The unfeasibility of requests for euthanasia in advance directives*, in *Journal of Medical Ethics*, 30, 2004, 447-51.
[20] D.G. MILLER, R. DRESSER, S.Y.H. KIM, *op. cit*., 84-89.

3. The problem of subjectivity and suffering

The analysis of the Dutch Supreme Court's ruling, with particular reference to its justificatory elements, provides a foundation for ethical and philosophical reflection on the execution of euthanasia in the case of persons with mental disease.

In the following examination, we will start from the assumption that the requirements of art. 2(1) of the Wtl may theoretically be acceptable, at least when we are not referring, according to the definition set out above, to mental disease. On the other hand, there are different problems with respect to performing euthanasia on patients suffering from this type of illness.

The first point of criticism of the rules providing for the possibility of euthanasia for patients suffering from mental diseases consists precisely in ascertaining the requirement of unbearable suffering.

The balancing of values and fundamental rights underlying the recognition of the possibility of access to euthanasia involves consideration of the relevance of the right to self-determination and human dignity as opposed to the state's duty to protect the lives of its citizens, especially those considered to be in a weak or fragile state, such as the sick or people living with disabilities.

The rationale of the rules on euthanasia rests on the recognition of the existence of certain special situations in which the patient's objective conditions are such as to give greater weight to the need to protect the dignity of the human being and his right to self-determination than to the general duty to protect the lives of fellow citizens. This inversion of values, which is based on a feeling of solidaristic compassion towards the sick person, requires certain requirements in order to be effective.[21]

One of the particular conditions that permits the inversion of the hierarchical scale of the principles of the legal system is precisely the unbearable suffering of the patient. The discussion of suffering and intolerability naturally gives rise to evaluations that transcend objectivity, necessitating, as the "Koffie" judgment acknowledges, that the physician's assessment be anchored to the specific case.

It is important to acknowledge that suffering is inherently subjective and not an objective phenomenon. This subjective nature of suffering is further compounded by the concept of intolerability, which introduces an additional layer of subjectivity to any assessment.

In addition to the patient's subjective experience of suffering, the physician's perception of the suffering of others must also be considered. In the context of mental disease, which does not appear to be associated with other physical illnesses or obvious functional limitations,[22] the assessment of suffering and its intolerability requires even greater rigour and places the evaluator in a position of greater uncertainty, especially in the case of an advance request for euthanasia based on a forecast of future intolerable suffering.[23] This is a particularly controversial aspect of the ethical acceptability of AED.

In cases of advance euthanasia directives, the individual anticipates the onset of one or more specific conditions, which are regarded as harbingers of unbearable suffering. The request for euthanasia is made upon the occurrence of these conditions. The individual does not, however, have the ability to

[21] J.J. VAN DELDEN, *op. cit*., 449.

[22] Reference is made to the case in which the certainty of unbearable suffering can be derived from the obvious functional limitations associated with the illness, such as the inability to perform any movement or particularly severe limitations.

[23] D.G. MILLER, R. DRESSER, S.Y.H. KIM, *op. cit.*, 6, "It is not easy to predict the experience of mental decline or its future effects on one's quality of life".

predict their own future suffering, despite anticipating it, as they have not yet experienced the condition that will cause it. It is therefore important to note that an anticipated request for euthanasia, expressed at a time when the patient is unable to imagine or empathise with their own condition, may have limited validity. Indeed, the absence of awareness can fuel prejudice towards illness and disability by making one imagine unbearable conditions of suffering instead of a more balanced idea that also includes moments of joy and pleasure.[24] It is evident that predicting the experience of cognitive decline and its future effects on quality of life is challenging.[25] Anticipating the emotional burden is also complicated because people often underestimate their ability to adapt to their state of health after developing an illness or disability.[26]

Moreover, the time elapsing between the moment of the advance declaration of euthanasia and its execution runs the risk of bringing out the so-called *then-self versus now-self problem*.[27] That is, the idea that the individual at the time of the AED and the individual at the time of the illness are different subjectivities that develop simultaneously with the progress of the illness itself. The idea is that in these cases there is doubt as to whether the anticipated euthanasia directive made by one subject is actually being performed with respect to a substantially different subject. In reality, the arguments in support of this idea are that the individual against whom euthanasia is performed is not a different subject from the one who made the advance directive, but is simply not a complete individual, by which is meant – using a Lockian definition – a thinking, intelligent being, capable of reasoning and reflecting who perceives himself as the same thinking entity in different times and spaces[28] in which self-determination is a decisive element.[29]

Moreover, an individual's personality due to mental illness can vary and also allow him to experience moments of absolute lucidity in which his 'old-self' can emerge.[30]

In addition to the patient's awareness of their future suffering and its intolerability, a further problematic issue relates to the ascertainability of the suffering at the time it occurs. Indeed, the physician is obligated to verify the presence of the unbearable suffering at the time of the euthanasia procedure, thereby confirming that the condition stipulated in the advance declaration has materialised.

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[24] *Ivi*, p. 5; See also P.T. MENZEL, B. STEINBOCK, *Advanced Directives, Dementia, and Physician-Assisted Death*, in *Journal of Law, Medicine & Ethics*, 41, 2013, pp. 484-500; A. ASCH, *Recognising death while affirming life: can end of life reform uphold a disabled person's interest in continued life?*, In *Hastings Center Report*, 35, 2005, 31-36;

[25] *Ivi*, p. 6.

[26] P. MENZEL, P. DOLAN, J. RICHARDSON, ET AL., *The role of adaptation to disability and disease in health state assessment: a preliminary normative analysis*, in *Social Science & Medicine*, 55, 2002, 2149-2155.

[27] P.T. MENZEL, M.C. CHANDLER-CRAMER, *Advance directives, dementia, and withholding food and water by mouth*, in *Hastings Center Report*, 44, 2014, 23-37. See also E. WALSH, *Cognitive transformation, dementia, and the moral weight of advance directives*, in *The American Journal of Bioethic*, 20, 2020, 54-64; D. DEGRAZIA, *Advance directives, dementia, and 'the someone else problem'*, in *Bioethics* , 13, 1999, 374: "One concern about the use of advance directives is distinctively philosophical: the possibility that, in certain cases in which a patient undergoes massive psychological change, the individual who exists after such change is literally a (numerically) distinct individual from the person who completed the directive. If this is true, there is good reason to question the authority of the directive in question, since it is supposed to apply to the individual who completed it, not to someone else. This may be called 'the someone else problem".

[28] J. LOCKE, *An essay concerning human understanding*, In *The works of John Locke*, London, 1824.

[29] C. KORSGAARD, *Self-constitution. agency, identity, and integrity*, Oxford, 2009, 25.

[30] P.T. MENZEL, B. STEINBOCK, *Advance directives, dementia, and withholding food and water by mouth*, *op. cit.*, 34.

To ascertain this, as the "Koffie" ruling states, the doctor must resort to presumptions, clues and evaluations that are clearly fallible since they refer to highly subjective conditions and above all often drawn directly from verbal confrontation with the patient, whose condition of capacity or incapacity cannot but affect the evaluations themselves.

The experience of suffering and its associated intolerability, which is even more subjective, necessitates direct communication or transfer by the patient experiencing it. However, this need for communication is subject to limitations, as the subjective state of the patient, influenced by their current illness and its potential impact on their cognitive abilities, can hinder the clarity of their message.

Furthermore, advance euthanasia directives are subject to less rigorous scrutiny regarding the fulfilment of criteria than an actual request for euthanasia, thereby rendering subsequent assessments particularly uncertain. The application of an advance request for euthanasia in the case of a patient suffering from mental disease is problematic, as illustrated above. The high degree of subjectivity and unawareness that characterises all the steps of the procedure risks making the execution of euthanasia illegitimate precisely because the legal requirements are not met.

This problem, which is directly related to the problem of determining intolerable suffering, arises because, in order for the requirements of diligence to be considered met, it is necessary for that intolerable suffering, if it exists, to be present, as well as the other requirements.

The requirement for the request for euthanasia to be voluntary and well considered on the part of the patient may present a challenge in the case of an early request for euthanasia, perhaps dating back several years. Indeed, the physician tasked with evaluating the fulfilment of these criteria may lack the means to ascertain with absolute certainty that the request in question was written without any external conditioning.[31]

Moreover, with regard to the individual's possibility of establishing *a-priori*, and therefore without any phenomenal experience capable of giving him certainty, the conditions that in his opinion would produce unbearable suffering in the future, two questions emerge: on the one hand, as already mentioned, it is problematic to admit that a prognostic judgement on possible future unbearable suffering can be considered a sufficient condition for determining the reversal of values – outlined above – necessary for the execution of a euthanasic practice. On the other hand, the temporal context in which the subject's future will is manifested is relevant. In fact, the moment in which the request for euthanasia is drawn up does not seem to have any relevance either in the legislative framework or in the interpretation of it provided by the Supreme Court.

It could be argued, however, that this moment should be taken into account in view of the evolution of the human psyche and soul in the course of life. Indeed, the same individual, in going through the different stages of life, tends to change his or her conceptions, on dignity, life, death and illness, to such an extent that he or she may also change his or her judgement and will with regard to the performance of euthanasic treatment or the conditions under which it is required.[32]

A final critical element, which will be explored in more detail in the next section, concerns the assertion that the conditions laid down in art. 2 Wtl should be applied *mutatis mutandis* to patients suffering

[31] J.J. VAN DELDEN, *op. cit*., 448.
[32] *Ibid*.

from certain pathologies and in any case no longer capable of understanding, highlighting the legitimacy of a different treatment – probably less precautionary – towards even more fragile subjects who, in addition to their pathology, also suffer from a limitation of their capacity to understand and to make decisions.

4. The patient's mental competence in the light of the United Nations Convention on the Rights of Persons with Disabilities

The elements highlighted thus far concerning the problematic nature of AEDs performed on incapacitated patients are matched by further arguments that certain justifications for the Supreme Court's judgment may potentially infringe fundamental human rights. Those who have expressed disapproval of the Supreme Court's judgment have asserted that the interpretation of the rules is primarily informed by an analysis of the parliamentary proceedings that took place during the drafting, discussion and approval of the Dutch Euthanasia Act. At the time the Wtl came into force, however, the Convention on the Rights of Persons with Disabilities (CRPD) had not yet been signed.[33]

The most useful provision of the CRPD is contained in article 12, in which it is stated that persons with disabilities enjoy the same legal capacity as other persons in all aspects of life, thus requiring states to take the necessary measures to make this equality effective.[34]

As stated by Klaas Rozemond[35] on the other hand, the right of the mentally ill patient to express his or her wishes and to decide when and whether to end his or her life, was absolutely violated by the conduct of the defendant doctor in the "Koffie" judgment, who did not even inform the patient that he or she had decided to perform euthanasia. The most serious thing, according to Rozemond, is that the doctor's conduct was approved by the Supreme Court, which did not consider it necessary to consult with the patient or to inform him about the execution of euthanasia, precisely because the patient was incapacitated.

Also according to Rozemond, a differentiation of human rights based on the condition of illness or disability seems absolutely unjustifiable since the CRPD did not specifically state any new rights of the sick or disabled, but merely sanctioned the need for fundamental human rights, already in force, to be ensured also and above all for the weakest and most disadvantaged.

The application of the principles enshrined in Article 12 of the CRPD thus establishes that an individual's disability cannot be used as a justification for withholding information about decisions made, or

[33] United Nation, Convention on the Rights of Persons with Disabilities (CRPD), 2007, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html, (consulted 22.06.2021).

[34] CRPD, Art. 12: "States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity".

[35] K. ROZEMOND, *Euthanasie bij mensen met dementie volgens het supported decision-making regime van artikel 12 van het Verdrag inzake de Rechten van Personen met een Handicap*, in *Handicap & Recht*, 6, 2021, 3.

for the administration of sedatives without the patient's consent, with the aim of performing euthanasia.[36]

On this point, moreover, it is impossible not to take into account the different difficulties in determining a person's capacity to make a decision, especially in view of the broad temporal scope of reference. In the "Koffie" judgment, the Court in fact considers relevant the written request for euthanasia of a patient already suffering from Alzheimer's disease insofar as at that particular moment he was considered capable of understanding and willing, and considers, on the other hand, the subsequent expression of will as irrelevant insofar as, at a later stage of the disease, it was considered to come from a person incapable of understanding. Well, it is clear that the determination of the moment at which the patient crosses the threshold of incapacity can make the difference between life and death.

Lastly, taking into consideration that the doctor who performs euthanasia and assesses the patient's present capacity is not always the same one who assessed the patient's capacity at the time the written request for euthanasia was drawn up, and in any case, the unnecessary correspondence between the advance request and the present will,[37] it is possible to argue that the termination of a patient's life in a condition of frailty and weakness such as that of the mentally ill patient is subject to excessive discretion and lacks the necessary caution that the overturning of a right as important as the right to life would instead require. Evidently, accepting the idea that the patient who has become legally incapacitated no longer has the right to express his or her will would tend to exclude the problem of actuality through a legal fiction that considers external manifestations of the patient's will irrelevant, but in reality, as we have already seen, this interpretation has several weak points.

The retrospective nature of advance euthanasia requests in allowing a doctor to act on the basis of his or her personal judgement on such a controversial issue probably requires a more thorough evaluation and a characterised by enhanced formality,[38] thereby conferring legal significance on the patient's present wishes and well-being, particularly in instances of conflict with prior advance euthanasia directives.[39]

Indeed, in accordance with the principles set out in the CRPD, it would be expected that legal systems would provide a series of additional safeguards for persons who, by their nature, are in a state of extreme weakness and fragility, particularly in circumstances where there may be doubt as to whether the necessary conditions for access to euthanasia are met.

[36] See A. ARSTEIN-KERSLAKE, E. FLYNN, *The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law*, in *The International Journal of Human Rights*, 4, 2016, 479-484.

[37] S.Y.H. KIM, D. MANGINO, M. NICOLINI, *Is this person with dementia (currently) competent to request euthanasia? A complicated and underexplored question*, in *Journal of Medical Ethics*, 2020, https://pubmed.ncbi.nlm.nih.gov/32792345/ (consulted 26/11/2024).

[38] J.J. VAN DELDEN, *op. cit*., 451.

[39] See also, R. DRESSER, *On legalizing physician-assisted death for dementia*, in *Hastings Center Report*, 47, 2017; R. DRESSER, *Dworkin on dementia. Elegant theory, questionable policy*, in *Hastings Center Report*, 25, 1995.

5. Euthanasia beyond reasonable doubt

The recent examination has identified several issues that require thorough examination when discussing the possibility of carrying out euthanasia on the basis of an advance request from persons suffering from certain types of illness who are incapacitated.

The justification for the infringement of the individual's right to life in such cases necessitates a higher degree of certainty, particularly when the harm is inflicted against the explicit wishes of the patient, who is deemed incapable of understanding. The evaluation of the criteria for access to euthanasia, therefore, faces the risk of being excessively subjective, with the result that the foundations upon which the justification for euthanasia is based may become shaky.

The advance request for euthanasia in the case of mental illness is drawn up on the basis of a future idea of unbearable suffering characterised by a high degree of unconsciousness.

The patient's perception of suffering and its intolerability is also highly subjective, as is the perception and assessment by the doctor who must establish whether the patient is suffering unbearably and from what point in time he or she is no longer capable of understanding and therefore from what point in time the expressed will no longer has any value.

The margin of error seems to be too high, and although the recognisability, in certain situations, of a right to access euthanasia seems now out of the question, the evolution of the disciplines that will regulate its implementation necessitates the application of high standards of certainty and guarantee of protection of human rights.

Indeed, although some authors, including Dworking,[40] have expressed the view that the interest of the able-bodied person in securing a death consistent with his or her personal values should take priority over his or her future care interests, it is felt that one can agree with those who argue that determining the relationship between the burden of an early euthanasia request and the patient's current welfare and interest is a difficult task that probably cannot be left to the individual judgement of a physician.[41]

This assertion may be considered a bold comparison with a fundamental principle of criminal law, which stipulates that the restriction of an individual's personal liberty – a right of inestimable value, yet undoubtedly inferior to the right to life – necessitates the ascertainment and provenance of the defendant's guilt to a degree that is beyond reasonable doubt. Consequently, it can be affirmed that even in circumstances where the infringement of the patient's right to life is justified by the acceptance of euthanasia, particularly when it is contrary to the patient's actual will, the existence of the stipulated requirements and prerequisites as outlined by the pertinent legislation must be substantiated beyond reasonable doubt.

Just as the ultimate task of the penal system can be seen as that of attempting, not to punish all offenders, but to prevent even one innocent person from being punished, so a law on euthanasia that respects fundamental human rights should set itself the goal – not to necessarily allow access to euthanasia to all those who may qualify for it – but to prevent euthanasia from being performed even on

[40] R. DWORKIN, *Life's dominion: an argument about abortion, euthanasia, and individual freedom*, in *Vintage Books*, 1993.

[41] J.J. VAN DELDEN, *op. cit*., 451.

one who does not have it, especially if against his or her will, in order to protect the right to life of all human beings.

Otherwise, one would run the risk of violating the fundamental rights of the weakest and most fragile individuals, which the laws allowing euthanasia and the United Nations Convention on the Rights of Persons with Disabilities aim to protect more than any other.

As stated by the *Euthanasia review committee* in the "Koffie" case, the subject involves concerns matters of life and death and the termination of life is irreversible, which is why it would be better to ensure a higher level of certainty and to maintain a narrower interpretation of the rules.[42]

[42] D.G. MILLER, R. DRESSER, S.Y.H. KIM, *op. cit.*, 12.

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