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Dialectics of lead: fifty years of Dutch euthanasia and its lessons

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ABSTRACT

Worldwide the Netherlands has the broadest experience with organizing voluntary euthanasia and assisted suicide. Roughly, three phases may be distinguished: in 1968–1985 euthanasia was vividly debated but, as it was illegal, it was at best tolerated. Since 1985, beginning with a verdict of the Supreme Court, euthanasia became officially tolerated and gradually legalized in 2002, after which the numbers stabilized until 2006. The onset of the third phase was in 2007. Since that year, the numbers tripled, new pathologies were accepted as a reason for euthanasia, the number of people with a long life expectancy increased, and mobile euthanizing teams were established that provide euthanasia without a prior doctor-patient relationship. These developments were made possible by a combination of cultural developments, the absence of restrictive legal norms, and a far reaching mandate of the Review Committees.

KEYWORDS

Euthanasia; the Netherlands; review procedure; evaluation

Euthanasia 1968–2006

Decades of discussion preceded the legalization of euthanasia in the Netherlands in 2002. In 1968, psychiatrist J.H. van den Berg commenced the discussion with his book *Medical Power and Medical Ethics* [1]. Using graphic illustrations of severe and needless suffering, the author argued that a medicine that has made such rigorous progress in prolonging life should also have the courage to end it. In 1972 the Dutch Right to Die Society (NVVE) was founded and soon became the largest organization of its kind in the world. Another decade of discussions followed, with an extensive ‘under-the-radar’ practice. In 1984 the Supreme Court acquitted a physician who had performed euthanasia because the physician was in a conflict of duties and had acted in accordance with guidelines set by the Royal Dutch Medical Association (RDMA) [2–4]. In 1985, a report of the State Commission on Euthanasia resulted in an agreement between the RDMA, the Ministry of Health, and the Public Prosecutor: a doctor who performed euthanasia and reported this to the Public Prosecutor would not be prosecuted if certain conditions were met [5]. In 1994, this practice got a legal basis in the form of an appendix to the Burial and Cremation Act. In 1998, five Regional Review Committees (RRCs) were added for the purpose of facilitating the

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Public Prosecutor's task. Finally in 2001 Parliament passed a separate law, the 'Termination of Life on Request and Assisted Suicide (Review Procedures) Act' (henceforth Euthanasia Act) [2]. It was enacted in 2002 and has been unchanged since. The most significant change compared to prior regulations is that the task of the Review Committees was made judicial instead of advisory. By putting the Prosecutor at a distance, the reporting procedure was believed to be less stressful for physicians.

The Euthanasia Act exemplifies a Dutch pragmatism that also underlies other ground breaking laws (such as those regulating gay rights, soft drugs, and prostitution). Rather than leaving certain practices under the radar, the Dutch believe in procedures based on transparency, feasibility, and compromise. Just as in the arrangements of 1985, 1994, and 1998, euthanasia remains a criminal offence and can be punished with imprisonment of up to twelve years. Euthanasia can therefore never be a professional obligation, nor does a physician have an obligation to refer a patient to a willing colleague. To prevent this law from becoming a dead letter, an extensive review apparatus is in place, involving 45 RRC members (lawyers, physicians, and ethicists) and two dozen secretaries and clerks. Annual reports offer statistics in Dutch and English about the numbers, the specialties of the euthanizing physicians, and the pathology in the patients, augmented by case descriptions of ground breaking cases and cases that do not meet the criteria. In an anonymized form most of the RRC's verdicts are accessible on line. Five-yearly evaluations have been published since 1991 [6–11]. The carefulness with which all this is monitored, illustrates the awareness of the Dutch lawgivers that euthanasia is and remains an extraordinary act.

The acceptance of the Euthanasia Act in April 2001 was the beginning of a relatively quiet period, aided by the conclusion of a Governmental Evaluation in 2002 that the numbers had been stable for some years [8]. In 2003, leading Dutch newspaper *NRC Handelsblad* interviewed professors Gerrit van der Wal and Paul van der Maas, both of whom had been involved in three governmental evaluations [12].

Q: *What was the most surprising outcome for you?*

Van der Maas: "That the number of cases of euthanasia and assisted suicide stabilizes."

Q: *The Netherlands is not on the internationally feared "slippery slope?"*

Van der Maas: "No. Despite the fact that we had expected some growth."

Van der Wal: "That was because the need for a controlled end of life is also determined culturally. After our previous investigation, six years ago, we expected that the need for euthanasia would go up. Because a new, more assertive generation is growing older. This does not show in the numbers."

Q: *Since 1995, apparently, the number of euthanasia cases remained virtually unchanged. What does that mean?*

Van der Maas: "This could mean that this number will not change in the coming years. I actually expect that. That this is about the need for euthanasia in the Netherlands."

The next evaluation, based on data from 2005 and published in 2007, corroborated these findings. The numbers remained stable and there was a significant increase in the willingness to report [9]. Domestically, both euthanasia advocates and sceptics were impressed by the apparent stabilization of the numbers. In international exchanges, many concluded that other countries might usefully follow the example of the Dutch experiment.

Developments 2007–2017

After this initial stability, changes started happening that few people had anticipated. I will concentrate on some of the most statistically obvious: a rise in the numbers, a shift in the pathologies, an expansion of the life expectancies, and the occurrence of euthanasia without a prior doctor-patient relationship. I will do this with my experience as a RRC-member in mind.¹

The numbers

From about 2007, the numbers took an unexpected path: from 1923 in 2005 to 6091 in 2016, a rise of 217% [13]. The anonymous governmental estimates signalled an increase from 2425 in 2005 to 6800 in 2015, or 180% (Figure 1).² The increase in the 1990s was commonly explained by the fact that physicians had become more confident to report a case of euthanasia. For the increase after 2006 there is no such explanation. Without any proof some have argued in the media that the increase only reflects developments in the overall mortality, but that number went up by only 7.7% during those 10 years [14]. Neither can the increase be attributed to a failing level of palliative care: in recent decades, significant progress was made and gradually a level of palliative care was reached that is comparable to the one found in other European countries [15]. The 2007 Governmental Evaluation (based on data of 2005) even attributed the decrease in the euthanasia numbers to improvements in palliative care [9].

The 2017 Governmental Evaluation found that in 2015 4.5% of all deaths in the Netherlands were the consequence of euthanasia. Urban and more secularized regions show higher numbers and suggest that the numbers may continue to rise: in Noord-Holland, home province to the national capital Amsterdam, euthanasia accounts for 7.3% of all deaths, with euthanasia requests being made prior to 11.9% of all deaths [11]. Alongside with euthanasia also palliative sedation is on the rise and accounted for 18% of all deaths

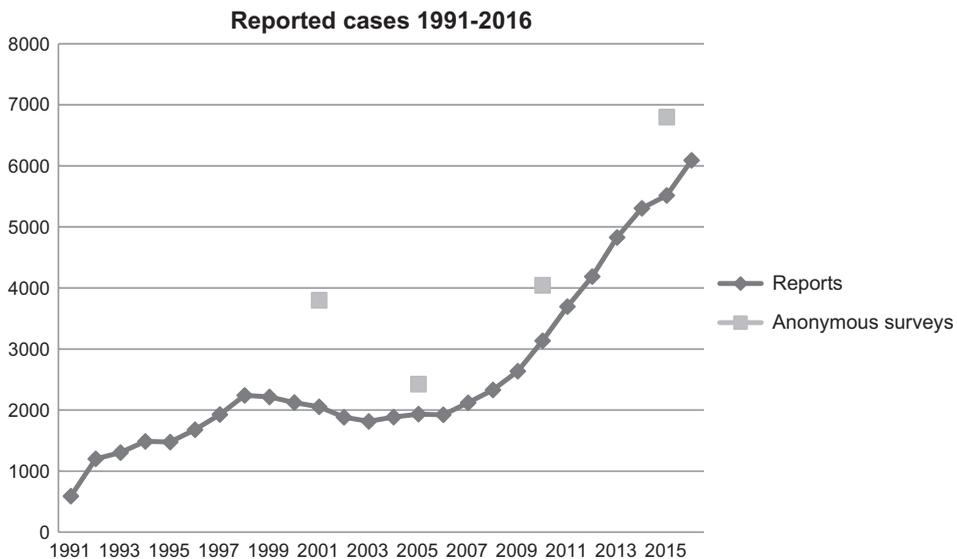


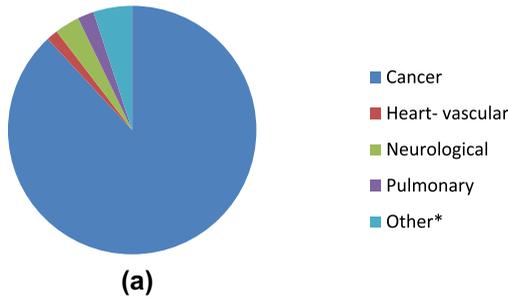
Figure 1. Reported cases 1991–2016.

in 2015 [11]. The medical influence in the Netherlands on the manner and the moment of dying is probably higher now than it has ever been before. The evaluation recommends research into causes of the increasing number of euthanasia cases and on the practice of palliative sedation [11].³

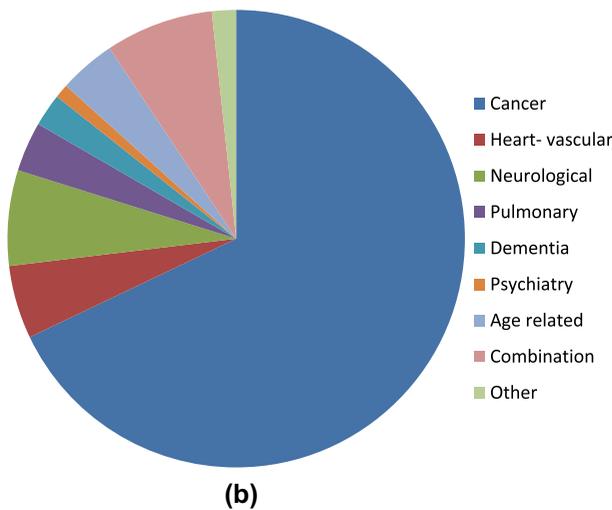
The pathology

In the early years of Dutch euthanasia practice the lion’s share of cases took place in a context of terminal illness (cancer, AIDS, progressive neurological diseases), days or weeks before a natural death would have incurred, and with the patient’s family doctor performing the act. In the review procedure, these were referred to as ‘traditional euthanasia cases’, cases which roughly belong to the categories of patients for whom legal euthanasia is under consideration in other countries worldwide. As can be seen from Figures 2(a) and (b), the Dutch have now entered a different phase, one in which the relatively biggest increase is non-cancer patients:

Medical context 2002 (1,883 cases)



Medical context 2016 (6,091 cases)



Figures 2 (a) and (b). Medical pathology underlying euthanasia in the Netherlands, 2002 and 2016*.⁴
 *Category ‘other’ in 2002 may include incidental cases of psychiatric illness and dementia.

Life expectancy

Traditional euthanasia cases formed the major part of the reports until 2007. The context for the public acceptance of euthanasia in the pioneering years was the conviction that euthanasia may sometimes be a justifiable option in patients whose natural death is expected within days or weeks. But there were some notable exceptions. A number of legal rulings since the 1970s, notably the Wertheim and Chabot cases, concerned patients whose deaths were not reasonably foreseeable [2]. In as early as 1986, the two largest Protestant denominations emphatically discussed the existence of a ‘psychologically terminal stage’ [17,18].⁵ And although some local guidelines may have been different (e.g. in hospitals), a foreseeable death was never part of the national guidelines. For the rare exceptions in which a patient was not close to dying a natural death, there was a broadly shared trust that physicians would act with restraint. In the review procedure in the beginning of the 2000s, a foreseeable death functioned as a background criterion in the review procedure: neither official nor crucial, but nevertheless of importance in the assessment of a report. If a euthanized patient had had longer than some months to live, there was a reasonable chance that an RRC would ask additional questions.

From about 2007 on, a shift in the life expectancy of people receiving euthanasia became apparent. In 1991, the five-yearly governmental evaluations estimated that in 1990 only 1% of those who died from euthanasia had more than half a year to live [6,19]. Twenty-five years later, this percentage had increased to 8%.⁶ In absolute numbers, this was an increase from 27 to 544 per year. Whereas the evaluations do not specify this category more precisely, my own anonymized notes do. Of all the patients whose dossiers I saw in the period 2005–2014, and whose life expectancy exceeded six months, the average life expectancy was 4.2 years. Of the patients whose dossiers I saw, 41 had a life expectancy of ten years or more (Figure 3).

>half year	a <2 years <1	<5 years	<10 years	10 years or more	Total
4	98	76	40	41	259
(1.5%)	(37.8%)	(29.3%)	(15.4%)	(15.8%)	(100%)
(avg. 251 days)	(avg. 376 days)	(avg. 3 years)	(avg. 5.6 years)	(avg. 13 years)	(avg. 4.2 years)

Figure 3. Patients with a longer life expectancy than half a year, specified $N = 259$.

Mobile euthanizing teams

Traditionally, almost all euthanasia cases took place within a doctor-patient relationship in which the physician had known and treated the patient before a euthanasia request was made. The Dutch system of family doctors with their personal and geographical proximity to the patient and his family was long seen as a warrant for a careful euthanasia practice. The physician could judge whether a request was made autonomously and was in harmony with a patient’s values, could fathom the patient’s suffering, and had a range of treatment

options at his disposal. Just like the foreseeable death criterion, the doctor-patient relationship criterion functioned as a background criterion for the RRCs. In the exceptional cases in which a patient's own doctor was unable to perform euthanasia – e.g. during absence or because of religious objections – the patient would be transferred to a colleague.

That all changed when NVVE founded the End of Life Clinic in 2012. The Clinic employs a network of mobile teams who visit patients in their homes or institutions and who perform euthanasia on site. In only 6 of the 53 cases of euthanasia provided by the Clinic that I reviewed, was the patient's own doctor principally opposed to euthanasia. The vast majority of doctors of these patients were not against euthanasia and did occasionally provide euthanasia, but refused to do so for a specific patient in a specific situation. (1) Some had objections to perform euthanasia in non-terminal patients. (2) Others objected to euthanasia for patients with psychiatric illnesses. (3) Some physicians were not convinced that the suffering of the patient was without prospect of improvement. (4) In addition, some doctors referred a patient to the Clinic because the pressure or the emotional stress of performing euthanasia was too much to handle.

The founding of the Clinic in 2012 marked a major shift in Dutch practice, for two reasons. Firstly, its doctors have no patient-doctor relationship prior to a euthanasia request. Secondly, its doctors provide euthanasia only and have no other treatment options. The Clinic neither has the license nor the funding to provide palliative care or to discuss and advise on alternative options. The RRCs decided that there were no legal criteria that would justify the rejection of the Clinic's euthanasia reports. In 2012, the year in which the Clinic opened, 53 patients received euthanasia. In 2016 that number had gone up to 498 patients [20]. The Clinic's doctors euthanized 747 patients in 2017 alone (Figure 4) [21].⁷

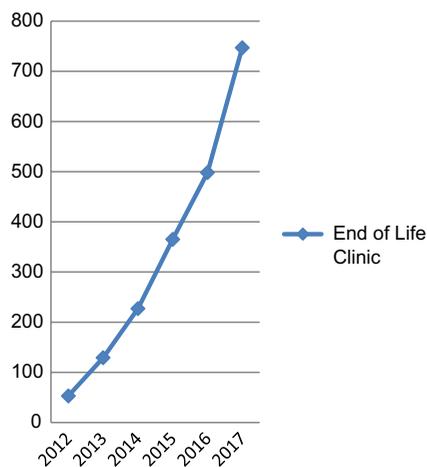


Figure 4. End of Life Clinic Numbers.

Discussion

It would require extensive discussion to identify the backgrounds and the reasons for these developments.⁸ No doubt there is truth in the observation of Professor Van der Wal in

2003 that there is an increased need for a ‘controlled end of life.’ The 2017 Governmental Evaluation may also be correct in suggesting that there is a diminishing tolerance in society for suffering [11]. This does not imply a diminishing degree of compassion, but rather that compassion increasingly includes the preparedness to end a life.

Now that euthanasia and assisted suicide are on the way to becoming some of the most important ways to die, was this the original intention of the Dutch legislators? Indeed, some legislators in 2001 may have anticipated the developments discussed here, and welcomed them. But others in the Dutch landscape, including politicians, physicians, and other citizens, are all too aware that the Euthanasia Act originates from the wish to provide a painless death to dying patients. Some may argue that what has happened in the Netherlands is bound to happen in any country that legalizes euthanasia or assisted dying. This conclusion cannot be ruled out beforehand, which is why, e.g. developments in Oregon (U.S.A.), Canada, and Victoria (Australia) should also be closely monitored. I would like to suggest another possibility here: if it is not legalization in itself that leads to these developments, it may be the way in which the Dutch have set the rules: the enormous liberties of the RRCs, in combination with the open character of the due care criteria.

Prior to the 2002 Euthanasia Act, the decision whether a physician had acted in accordance with the due care criteria (see below) was made by the Public Prosecutor, since 1998 aided by five RRCs. This changed when in 2002 the RRCs got a final say in the cases that they decided met the criteria. In the latter case their decision is final and thus judicial, and not even the Prosecutor has access to the dossier. Only if an RRC rules that a case does not meet the criteria, is the dossier sent to the Prosecutor’s office. In the years after 2006, several ground breaking reports were received: psychiatric patients, patients with accumulated age related complaints, otherwise healthy persons suffering from blindness, people with autism, people in early stage dementia, people in an advanced stage of dementia and, after 2012, people who had received help from the End of Life Clinic. After often extensive discussion, most of these cases were approved. The RRC meetings take place behind closed doors, no minutes are made, no societal debate takes place before a decision is reached and the final verdict at best only describes part of the concerns of the committee members. Their decisions subsequently have jurisprudential status and, in effect, have the status of a verdict of the Supreme Court. There is no doubt that the Committees act carefully. But the enormous rise in the number of reports, some of which were about very complex cases for which a committee previously would have needed hours or days to discuss, may have overburdened the committees. By the time the committees had gained the necessary personnel reinforcement, most of the ground breaking cases had already passed.⁹ The most important decisions in the history of the Dutch euthanasia practice since the 1980s were made behind closed doors by overstrained committees.¹⁰

All this would not have been so consequential, if the criteria contained in the Euthanasia Act had been more precise. According to the 2002 Euthanasia Act a physician must...

- (1) be convinced that the patient’s suffering is unbearable, and that there is no prospect of improvement;
- (2) have informed the patient about their situation and their prospect of recovery;
- (3) have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient’s situation;
- (4) have consulted at least one other, independent physician;

- (5) have terminated the patient's life or provided assistance with suicide with due medical care and attention;
- (6) A patient should be at least 12 years of age. When a patient is under 16, the parents should consent before a euthanasia can take place.

These criteria, the core of which has remained unchanged since the first agreements in the 1980s, were often described as 'strict'. Following the RRC's rulings in ground breaking cases, the 2012 Governmental Evaluation observes that 'open' is a more appropriate way to describe the criteria. Indeed, much of the initial strictness of the criteria was based not on the criteria themselves, but rather on specific interpretations by physicians, RRC members, and patients. In the course of time, the RRCs have increasingly stressed that what is not forbidden by law, is permitted. In that process, a patient's role in deciding whether or not the criteria are met has gained importance. This applies especially to the criterion of unbearable suffering. Is not a euthanasia request in itself proof that a patient suffers unbearably? Who are others – doctors, consulting doctors, RRC members – to say that a person who claims to suffer unbearably, does not suffer 'seriously enough'? For what other reason would any competent and well-informed patient request to have their life ended in the first place? Doctors with a long lasting or intense doctor-patient relationship may come closest to discerning the true character of a patient's suffering, but even their assessments may be inaccurate. Outside such relationships an assessment is likely to be even harder, so why in the end not rely on a person's request? Moreover, experiences of suffering largely depend on individual factors. For some it is the physical symptoms, for others it is meaninglessness, shame, loneliness, or lack of control. 'I have problems understanding my patient's request', a physician writes, 'I have had patients in a much more serious situation who were determined to go on'. The elusive nature of the criterion of unbearable suffering is illustrated by the fact that, of the 89 cases that were sent to the Prosecutor between 2002 and 2016, there was only a handful of cases where the suffering was not accepted as convincing. In practice, the criterion of unbearable suffering is bound to coincide with the criterion of a well-considered request.

Further, the criterion of the absence of a prospect of improvement – the most objective criterion – and the absence of a reasonable alternative are subject to the patient's individual preference. Over the years I have seen about 60 dossiers (in a total of 3722) in which a patient had a death wish prior to a fatal disease and refused to accept lifesaving or life-prolonging treatment ('Patient refuses treatment. This is what makes her situation without prospect of improvement', a consulting doctor writes.) Some others dismiss palliative options that could have offered relief: antidepressants, painkillers, sedatives, admission to a nursing home or to a hospice. Most physicians do not take such refusals for granted and will try to convince a patient. RRC practice requires that a physician must have explored alternative options together with the patient. In the end, however, the autonomous right to refuse treatment has to be respected.

That a physician's preparedness to perform euthanasia may also depend on the patient's ingenuity is illustrated in an article in the RDMA's weekly journal *Medisch Contact*, called, 'Euthanasia for Beginners. Ten Suggestions for a Successful Death Wish' [24]. The authors argue that patients who stress the physical aspects of their suffering, who refrain from referring to being a burden to their relatives, who refrain from referring to hobbies, joys, and future plans, who stay in bed when a (consulting) doctor visits instead of opening the door themselves, etc., have a better chance of getting euthanasia performed. Convincing

a physician may thus become a game, a process of negotiation, in the absence of more objective criteria.

In the process of tolerating, regulating, and legalizing euthanasia, the Dutch have made choices. In that process, some other potential criteria were not included in the Dutch Act:

- (1) *A lasting patient-doctor relationship*: the trade mark of the Dutch euthanasia in the pioneering years. It functioned as a background criterion even under the present Act but faded away with the introduction of the End of Life Clinic in 2012.
- (2) *Dutch citizenship and proper medical insurance coverage*: a criterion that was self-evident and therefore unnecessary in the pioneering years. Since these are not legal requirements under the Act, it is possible that the End of Life Clinic will one day open up to patients from abroad, similar to the way Dignitas and Exit offer their services to non-Swiss citizens.
- (3) *The physician should be able to provide alternative options and not only euthanasia*: even this criterion was self-evident prior to the founding of the End of Life Clinic, but it was not made a formal requirement.
- (4) *Consulting a specialist in palliative care*. A criterion that has been suggested in various law proposals outside the Netherlands. It would be an extra safeguard in cases in which the patient and his physician fail to discuss 'state of the art' alternative options.
- (5) *The patient should (if possible) administer the drugs him- or herself*. Dutch euthanasia advocates have stressed the value of a person ending his own life if possible. It would have lessened the burden on physicians and would have highlighted the significance of the patient's autonomy [25].
- (6) *Consciousness and full competence in the patient when the euthanasia is administered*. Until about 2010, the RRCs used this as a background criterion. Following the 2002 Euthanasia Act which explicitly accepts an advance directive as a substitute for a present and actual request, this is no longer a (background) criterion.
- (7) *A natural death is expected in a foreseeable future*. That euthanasia was administered only to dying patients formed an important factor in the societal acceptance of euthanasia. Within the RRCs it functioned for a long time as a background criterion. In 2009, the question about the patient's life expectancy was taken out of the standard reporting form.
- (8) *The request must be a lasting request*. A criterion that was officially used in the 1980s, but since in some very acute circumstances there was no time for lengthy preparations, it was abandoned. It continues to function as a background criterion in the RRCs.
- (9) *Family members should be consulted or informed*. A criterion that was officially used in the 1980s. It continues to function as a point of attention.
- (10) *A physical illness*. This criterion has never been made official, but in practice, euthanasia in people with a psychiatric condition was considered too risky for decades.

But are we in need of more objective criteria? My argument here is that the Dutch experience shows that we are. As I have argued, the original acceptance of Dutch euthanasia was based on the widely shared view that people who are close to their death, who are in severe suffering, and for whom no other relief can be given, should have the option of active life termination. The failure to anchor this in the form of unambiguous criteria went hand

in hand with a broad trust in the wisdom and integrity of physicians. In reality it is not only physicians who decide about the interpretation of the law, but also society as a whole. Apparently, not even the most careful euthanasia monitoring system in the world has halted developments which many find reason to refer to as a slippery slope.

The Dutch example was followed only by neighbouring Belgium and Luxembourg. Some other countries that are discussing euthanasia and assisted dying have taken measures to prevent an unintended widening.¹¹ Let us hope that these systems will be more sustainable than the Dutch: no society can afford open-ended laws when it comes to killing citizens on their request. Given each person's unique and inestimable value, the intentional killing of a human being is and remains an intrinsically problematic act. The killing of deeply unhappy human beings at their request may also have societal consequences. Some patients may be strong enough to make that decision in total freedom. But the Dutch example gives reason to conclude that, just as with other human actions and needs, supply may have created demand. The rule that human life needs protection needs better safeguards than those the Dutch have chosen.

Notes

1. During my own membership of an RRC in the period 2005–2014, I reviewed almost 4000 cases. Of more than 3700, I made anonymized notes about age, illness, life expectancy, etc. and, in addition, about ethically significant features. I was therefore able to follow these changes personally and intensely.
2. The difference between the numbers in the five-yearly evaluations and those of the committees may constitute a grey zone of cases that took place but were not reported. That grey zone has also increased: from 493 cases in 2005 to 1284 in 2015.
3. In a recent book, chairman Wim Distelmans of the Belgian Federal Control and Evaluation Commission discusses the increase in the numbers of palliative sedation [16]. Given the similarities, Distelmans advocates a reporting procedure for palliative sedation which would be similar to the one required in euthanasia.
4. The numbers in 2002: cancer 1658, heart-vascular 28, neurological 61, pulmonary 40, other (including occasional cases of psychiatry and dementia) 95. In 2016: cancer 4137, heart-vascular 315, neurological 411, pulmonary 214, dementia 141, psychiatry 60, age related 244, combination 465, other 104.
5. Indeed, Dutch Calvinistic Protestantism probably has contributed significantly to the acceptance of euthanasia [18].
6. Of the 2,111 'ordinary' cases (cases that my committee was the first to assess) that I saw in 2010–2014, 8.7% (184 patients) had a life expectancy of more than six months.
7. All this does not mean that the Clinic just provides euthanasia to anyone: in 2016, the Clinic received about 1796 requests for euthanasia, which means that the Clinic has refused euthanasia in 72.9% of the queries.
8. One of the other developments is a 39% increase in the suicide numbers in the Netherlands in the period 2005–2016, significantly higher than in the surrounding countries [22].
9. One example: in 2012, the RRCs received dozens of unusually complex dossiers from the End of Life Clinic. These were thoroughly debated in a plenary RRC meeting only in early 2013, i.e. after 29 reports had already passed.
10. In April 2017, RRC chairman Jacob Kohnstamm decided to ask the Dutch Parliament to consider the possibility that not only rejected cases, but also affirmative verdicts of an RRC may be presented to the Supreme Court in order to make an open discussion possible and to establish more solid jurisprudence [23].
11. See, e.g. the legalization of euthanasia in Victoria, Australia [26]. It remains to be seen whether this much more stringent legislation will contain all the necessary safeguards.

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