Communicating Concerns

Reviewing the Review Procedure in Dutch Euthanasia Law

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Abstract: The Dutch Euthanasia Act seems to be set in stone. Since it took effect in 2002, it has not seen any significant amendments. Recent developments, however, indicate that a major component of the act—the review procedure—is due for revision. The review practice of the regional euthanasia review committees—responsible for applying and interpreting the law—now also extends to instances of euthanasia and assisted suicide for special categories of patients: psychiatric patients, patients with early-stage dementia, and patients whose suffering is derived from a combination of medical and existential causes. In this article, it is argued that a reconsideration of the review practice for these new cases is necessary primarily because review committees lack the legitimacy needed for the development of policies with such a large impact on society.

Keywords: Dutch Euthanasia Act; euthanasia; physician-assisted suicide; review procedure; special categories of patients; legitimacy

Introduction

The Dutch Euthanasia Act (officially named the Termination of Life on Request and Assisted Suicide [Review Procedures] Act) seems to be set in stone. Since it took effect on April 1, 2002, it has not seen any significant amendments. In Dutch law such immunity to change is extremely rare and is shared only with the Constitution. However, anyone critically following recent developments, especially the practice of the regional euthanasia review committees (RTEs), must conclude that a major component of the act—the review procedure—is due for revision.

Dutch Euthanasia Law and the Facts

The basic idea of the Euthanasia Act is very simple: physicians who complied with a request to terminate a patient's life or who assisted with a patient's suicide are protected from prosecution if they acted with due care according to an RTE. In contrast to what is often believed, terminating a life on request (euthanasia) and assisting with suicide are punishable offences under Dutch law.[1] In the Criminal Code a special ground for exemption from criminal liability has been created for physicians, and only physicians. Physicians who comply with a patient's request for euthanasia or assisted suicide do not have to fear prosecution if they (1) reported the request for euthanasia or assisted suicide in the correct way to the correct agency and (2) acted with due care according to the criteria specified in the Euthanasia Act.[2]

Whether the physician's actions did fulfil these criteria is examined in retrospect by one of the five RTEs in the Netherlands. If an RTE concludes that due care was exercised, then the public prosecutor, who is solely responsible for prosecution

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under Dutch law, is not informed of the case. If the examining RTE decides that one or more due care criteria were not met by the physician, then it notifies the public prosecutor, who can decide to bring the case to criminal court. Along with the public prosecutor, the Dutch Health Care Inspectorate is also informed.

The RTEs publish annual reports of their activities. In 2012 they received 4,188 reports of euthanasia and assisted suicide, an increase of 13% over the number of reports received in 2011 (3,695). Of this total, 3,965 cases involved euthanasia; 185 cases involved assisted suicide, and 38 cases involved a combination of the two. The reporting physician was a general practitioner (GP) in 3,777 cases. In 3,251 cases, cancer was the underlying condition. The termination of life took place at the patient's home in 3,335 cases. In 2012 the committees ruled in 10 cases that the physician had not followed the due care criteria.[3] According to the last Dutch national death certificates study, it was estimated that euthanasia was responsible for 2.8% of all deaths and that 0.1% of all deaths involved assisted suicide.[4]

In contrast to what is sometimes assumed, the Dutch Euthanasia Act does not give patients a *right* to euthanasia or assisted suicide. Physicians can refuse to comply with the request on any grounds. The act only provides for the possibility of being protected from prosecution. The public prosecutor is not informed by the RTE if, according to that RTE, the physician (1) was convinced that the patient's request was voluntary and well considered; (2) was convinced that the case involved unbearable suffering for the patient, with no prospect for improvement (hopelessness); (3) had explained the situation and his or her prospects; (4) had come to the conclusion with the patient that there was no other reasonable solution for his or her situation; (5) had consulted at least one other independent physician, who had examined the patient and given a written evaluation of the due care criteria, as specified under the preceding points 1–4; and (6) had carried out the termination of life or assisted suicide with due medical care.[5]

The legal due care criteria are abstractly formulated. This makes interpretation by the RTEs inevitable. The question of whether to modify the review procedure is raised as a result of the review practice of the RTEs, which now extends to instances of euthanasia and assisted suicide for special categories of patients; these patients are "special" because they raise specific moral questions: they bring about controversy.

Euthanasia and Psychiatry

In June 2014 the Dutch parliament held a hearing on the topic of euthanasia and psychiatry. The meeting was prompted by the sharp increase in the number of reports of euthanasia and assisted suicide of patients with a psychiatric disorder: from just 2 in 2009 and 13 and 14 in 2011 and 2012, respectively, to 42 in 2013. Of these 42 reports, 32 were evaluated by the RTEs in 2013. In all of the cases, they ruled that the reporting physician had met the legal due care criteria.[6] The most common explanation for this increase is the greater willingness of physicians to comply with euthanasia and assisted suicide in psychiatric cases.[7]

Under Dutch law, there is no doubt that psychiatric patients should also be permitted this kind of assistance. Already in 1994, in the Chabot case, the Dutch Supreme Court ruled that the suffering that must be evident does not have to derive from a somatic disease or condition.[8] There is also no doubt that patients

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with a psychiatric disorder are special in view of the Euthanasia Act. The question of whether the criteria of a voluntary and well-considered request, a situation in which the suffering is hopeless, and a lack of any other reasonable solution are met will, of course, not always be easy to answer.

With psychoses, for instance, the patient is often not fully aware of his or her disorder, and the patient's wish to die could be the result of irrational convictions. How well considered is any request for assisted suicide then? Severely depressed patients are not by definition less legally competent. During certain periods these patients may be very capable of coming to a well-considered decision for suicide. But when is such a death wish sustained over time? How voluntary is the request for assisted suicide of a patient who was involuntarily admitted to a psychiatric hospital? Suffering is hopeless when, in the practitioner's professional opinion, there are no realistic treatment options. There is often more certainty about the impossibility of treating somatic conditions (e.g., advanced cancer). With psychiatric conditions, the future course is much less predictable. Spontaneous recovery cannot always be ruled out, and alternative treatments are often still available. When are those alternatives reasonable, and when are they not?

The RTEs state that with requests for euthanasia and assisted suicide from patients with a psychiatric disorder, physicians are required to proceed with great caution.[9] Through the Dutch Psychiatric Association (NVvP), psychiatrists have defined this caution in a guideline by setting additional, primarily procedural criteria of due care. For example, there is a stricter consultation requirement. If the treating psychiatrist comes to the conclusion that assisted suicide is justified and that in his or her opinion the due care criteria have been met, then the recommendation is to consult two colleagues, not one (as required by law): one who is an expert in the field of the patient's psychiatric disorder and a second consultant-psychiatrist who checks in a general sense that the due care criteria have been met and who preferably has experience as a SCEN (Support and Consultation Project Euthanasia Netherlands) physician. The treating physician is also emphatically advised to consult previous caregivers, the GP, the treating team, and the patient's loved ones.[10]

Euthanasia and Dementia

The second special group consists of patients who are diagnosed with dementia. Whereas with psychiatric patients the objective component of the criterion of suffering, the hopelessness, is the primary source of questions, in patients with incipient dementia, the subjective component of that criterion is considered more problematic. The suffering of these patients is without a doubt hopeless. Their condition will worsen, and medical science does not offer any consolation. Physicians are unlikely to deny that this suffering is hopeless. But the unbearableness of that suffering is another matter. In practice, physicians are not willing to accept readily that element of suffering. Whereas the unbearableness is primarily something that the patient experiences personally and claims publically, the Euthanasia Act makes the subjectivity of that element more objective. The act states that the physician must be convinced that there is unbearable suffering. This means that the unbearableness of the patient's suffering must be something the physician can imagine.

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The problem with incipient dementia patients, at least according to the Dutch Right to Die Society (NVVE),[11] is that physicians will find it hard to imagine that their suffering is unbearable, seeing that in the initial stage of the disease the patients still have almost all mental faculties. They will even find it hard when patients tell them they are already suffering unbearably from the prospect of progressive dementia. Only when the disease has progressed so far that the patient can no longer live independently and has to be institutionalized are physicians then willing to acknowledge the unbearableness of the suffering. However, as the disease progresses, the patient is less likely to still be considered legally competent.

Among the 42 reports handled by the RTEs in 2012 in which a dementia syndrome was involved, in two cases physicians were judged to have been negligent. Of the other reports, the vast majority involved patients in the initial stage of a dementia process—that is, in the phase when they still had insight into their disease and the symptoms, such as loss of orientation and personality. Patients were considered legally competent because they could (still) contemplate the consequences of their request.[12] In 2010 there were 25 reports of termination of life or request for assisted suicide of patients with incipient dementia. In 2009 there were 12 reports, and in 2008 there were none.[13]

As with psychiatric patients, the RTEs state that in cases of dementia a physician has to proceed with greater caution regarding a request for termination of life. In such a situation physicians must be able to demonstrate to the committee that they were especially cautious when making that decision. With respect to patients in the early stages of dementia, the RTEs consider it advisable to consult one or more experts as well as the physician acting as the independent consultant, preferably a geriatrician or psychiatrist.[14]

Euthanasia and Completed Life

Since 2010 the issue of voluntary termination of life has been in the spotlight of Dutch societal debate. This is due to a legislative proposal put forward by a citizen's action group called Uit Vrije Wil (Of Free Will). The Royal Dutch Medical Association (KNMG), the national physicians' organization, also took a stand regarding the role of the physician in voluntary ending of life.

For the "completed life" discussion, the Brongersma ruling by the Supreme Court is particularly relevant. After a failed suicide attempt, Edward Brongersma, an 86-year-old former member of the Dutch Senate who claimed to be "weary of living," asked his GP to help him end his life. In 1998 the latter complied with the request. Initially, the case against the physician was dismissed.

The facts of the Brongersma case occurred before the act became law; the ruling of the highest Dutch court of law came afterward. It stated that the suffering must originate to a great extent in a medically classified disease or condition. In the view of the Supreme Court, which referred to the history of the Euthanasia Act, the physician did not have the required expertise to evaluate the suffering derived from "weariness of living." This expertise does not fall within the medical domain.[15]

Uit Vrije Wil is the name of a citizens' group campaigning for assisted suicide of elderly people with a "completed life." This group launched the citizens' initiative Completed Life in 2010. The aim of the initiative was "legalization of assisted

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suicide of elderly people who consider their life completed, to be carried out at their express request and under conditions of due care and testability."[16]

This citizens' initiative was launched in February 2010; just 14 days later, the 40,000 endorsements required to force parliament to look at the case had already been received. When the citizens' initiative was submitted to parliament in May 2010, there were almost 117,000 signatures. The parliamentary committees for safety and justice and for public health, welfare, and sport arranged an open discussion with the citizens' group in February 2011. At this opportunity, the citizens' group presented parliament with a model act.

The basic principle of the model was self-determination. Uit Vrije Wil proposed assisted suicide on the basis of a voluntary, well-considered, and sustained request, with completed life being seen as a subjective concept. Suffering from life would be given an individual meaning by the elderly person him- or herself. Therefore, a definition of "completed life" was not given. According to the model, the lethal drugs would have to be supplied by a certified provider of assistance with dying. The elderly person would remain responsible for actually taking them. The model concerned those 70 years old and older who consider their life completed, and who suffer from continued living. The choice of an initial age limit was meant to reassure the elderly that if they consider their life completed, they can receive assistance with suicide from the age of 70. The providers of assistance with dying could, after all, be a broader group than just physicians; they could be chaplains, nurses, psychologists, and so on.[17]

As a result of the citizens' initiative, in May 2011 the aforementioned committees also held hearings with ethicists, scientists, experts, publicists, and relevant organizations. The plenary debate took place in March 2012. Ultimately, only the representatives of two smaller parties agreed with the proposal from Uit Vrije Wil. In March 2012 it was decided not to proceed with the citizens' initiative any further.[18]

The physicians' organization KNMG rejected the citizens' group's proposal immediately. It did not condone tampering with the existing legislation and practice concerning euthanasia and assisted suicide in the Netherlands. However, the KNMG did initiate an internal discussion about the role of physicians with patients who were ready to die. In June 2011 it published its position paper.[19]

The organization repeated the observation that suffering without a medical basis falls outside the domain of medicine, and thus outside the area of expertise of physicians and outside the scope of the Euthanasia Act. But it added that physicians need to consider the broader well-being of the patient by supporting the patient struggling with existential questions arising because of disease, by showing empathy, and by providing palliative care, terminal care, and comfort. According to the KNMG, the physician always has the task of exploring a patient's level of suffering and what the suffering consists of, regardless of the origin of the suffering or the manner in which the patient describes his or her suffering—even when the patient's wish to die is founded on a feeling that life has been completed. In addition, the paper stated that no one other than individual persons can judge whether their life is completed, assuming that a life can be completed. Physicians do not have a role or task in judging whether a life is completed.[20]

When physicians evaluate suffering in the context of termination of life, the KNMG point of view assumes that there is *also* a medical basis, or a condition that can be considered a disease or a combination of diseases/symptoms. A medical

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classification can help with the evaluation of suffering. In the KNMG's opinion, the different dimensions of suffering that a patient experiences as unbearable are not straightforward to distinguish in practice and can augment one another. A request for euthanasia is one of the most intrusive and burdensome questions that a patient can ask of a physician, according to the physicians' organization. Physicians in general find it difficult to carry out euthanasia or satisfy a desire for assisted suicide. The difficulty is amplified if there is no terminal illness underlying the suffering. According to the position paper, to comply with a termination of life or assisted suicide request in that case, the physician must clarify or help to clarify the suffering and must be convinced that the suffering is unbearable and *also* has a medical basis. To clarify the various dimensions of the suffering, it is necessary to make and discuss systematic inventories. To the extent that other (nonmedical) causes of the level of suffering become prominent, other experts should be involved.[21]

Finally, the KNMG interprets the current legal framework and the term "suffering" more broadly than many physicians currently do when they apply them. In the organization's view, vulnerability—including dimensions like loss of function, loneliness, and loss of autonomy—may be incorporated into the physician's evaluation of a request for euthanasia. This nonlinear summation of medical and nonmedical problems, which are primarily not individually life threatening or fatal, can, in its opinion, lead to hopeless and unbearable suffering within the meaning of the Euthanasia Act.[22]

In other words, in 2011 the KNMG, which represents all physicians in the Netherlands, clearly took a broader view on the legal definition of suffering. Suffering without any medical basis still falls outside the domain of medicine, but now "an accumulation of ailments," which are mostly not individually life threatening or fatal, can lead to suffering within the meaning of the Euthanasia Act. This position is consistent with earlier rulings of the RTEs on reports of euthanasia or assisted suicide of patients whose suffering derived from a combination of somatic, mental, and existential causes.

For example, in the 2010 annual report, an account was given of a case of euthanasia involving an 86-year-old woman who lived independently, used the Internet, and loved reading and discussing philosophy, politics, and art. Her body was deteriorating, however, which meant she was increasingly restricted in all the things that for her made life worthwhile. Her vision had diminished in the last few years, her hearing was poor, and she suffered from dizziness and incontinence. She felt like a prisoner in her deteriorating body and considered it a gift to use euthanasia to leave her life behind and not become dependent. She claimed her life was completed.[23]

The patient's poor vision was the result of macular degeneration. This condition was not stable, and her eyesight had deteriorated drastically in a short period of time. The existence of the macular degeneration formed the reason why her physician wanted to comply with the euthanasia request. The RTE ascertained that macular degeneration must be defined as a medically classifiable condition. There is no effective treatment for this condition, nor is there hope of improvement. The committee felt that this case was not an instance of a completed-life situation, and that the action fell within the medical domain. The mix of factors led to unbearable suffering for this patient, at her advanced age and with her history and character. In its judgement, the RTE stressed that unbearableness in the framework of the

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Euthanasia Act must be explained subjectively and can only be tested marginally. According to the committee the physician in this case could reasonably come to the conclusion that there was unbearable and hopeless suffering. It ruled that the physician had carried out the euthanasia with due care.[24]

The similarities to the facts of the Brongersma case are striking. The outcomes are very different, however. The physician who complied with assisted suicide for the 86-year-old Edward Brongersma was ultimately found guilty. Mr. Brongersma also suffered from age-related ailments. Every elderly person becomes frail. It is evident that the RTEs have tacitly moved the boundary set by the Supreme Court in the Brongersma case.[25]

Complexity and Legitimacy

Two reasons prompt a reconsideration of the review practice for these new categories of cases. To start with, there is unusual complexity. It is somewhat surprising that although the RTEs—rightly—urge physicians to exercise great caution, this same caution is not found in the RTEs' own review practice. For requests from psychiatric patients, the RTEs demand—again, rightly—that the reporting physicians consult a psychiatric expert. But the RTEs themselves (consisting of a lawyer, an ethicist, and a physician) generally lack this expertise. Geriatric expertise is also absent. We must remember that when an RTE rules that a physician acted with due care, the matter is brought to an end. This assessment, given in more than 99% of all cases,[26] is sacrosanct. If an RTE judges that a physician acted without due care, then and only then will the public prosecutor, the Health Care Inspectorate, and—depending on the prosecutor's decision—a judge be shown the file.

But there is something else. Euthanasia and assisted suicide for psychiatric patients, people suffering from early-stage dementia, and people who consider their life completed are sufficiently disturbing to society that they invariably lead to questions in parliament.[27] RTEs make policy, and that policy undoubtedly influences physicians' behavior. The increase in the number of cases of euthanasia and assisted suicide among these special patient groups is a result of the fact that in the past few years, several cases were reported and judged to have involved due care. The ultimate question is whether the margin of discretion, which is only and solely derived from the abstract wordings of the due care criteria, provides the current RTEs—just a limited number of appointed officials, after all—with sufficient legitimacy to develop policies with such a large social impact.

What should be done?

A Central Euthanasia Review Committee

Why not submit euthanasia files that are considerably more complex, or those that bring about controversy and that could force a change in policy, to a central review committee with a greater range of expertise? This committee, if the right people are chosen as members, would be able to advise the RTEs in such cases or be asked by them for a ruling.

The composition of this national committee requires careful consideration, but a psychiatrist, a specialist in geriatrics, and a psychologist seem required. And why not include one or more laypeople? The relationship of this central

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euthanasia review committee (CTE) to the RTEs must also be considered carefully. However, such a constellation of committees in healthcare does have a precedent. The Dutch law regulating medical-scientific research involving human subjects provides for a national committee, alongside the local institutional review boards, that is competent to review certain research proposals—namely, the ones involving study subjects that are more complex and/or morally controversial: for example, research on reproductive cells, research involving genetic manipulation, or the use of xenotransplantation.[28]

The establishment of a CTE would not lead to more administrative red tape for a reporting physician. The working of a CTE could only have a favorable effect on the time taken by the RTEs to come to a judgement. According to the RTEs' own latest annual report, the time between receiving a report and issuing the judgement in 2012 averaged 127 days![29] Legally, the RTEs are meant to inform the physician concerned within six weeks.[30] But more than that, a CTE would not have to have a different relationship with the public prosecutor and the Health Care Inspectorate than the RTEs. So there is no basis on which to fear a reduced willingness to report among physicians.

Communicating Concerns

The responsibility must sometimes be a heavy burden for individual RTE members. Not only is their social mandate flimsy and not only is it impossible to correct RTE rulings, but their possibilities for consultation and requesting advice are extremely limited.

What is more important is that a CTE would be able to share with society the moral deliberations concerning a change in policy for termination of life on request or assisted suicide by physicians. Not only would an expert committee with more expertise be better equipped to review complex cases, but that committee could be legally obliged to publish and clarify its moral deliberations.

The current situation—in which certain decisions by doctors suddenly appear to be morally acceptable, or not—cannot be sustained. In cases that raise questions the RTEs publish their rulings immediately on their website, but the texts accompanying those judgements are very brief and provide no insight into the moral considerations. That is not the transparency Dutch society has a right to and demands.

Notes

1. Dutch Criminal Code, section 293, para. 1, and section 294, para. 1.
2. Dutch Criminal Code, section 293, para. 2, and section 294, para. 2.
3. Regionale Toetsingscommissies Euthanasie. *Jaarverslag 2012*. Den Haag; 2013, at 64.
4. ZonMw. *Tweede Evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*. Den Haag; 2012, at 284.
5. Euthanasia Act, section 2, para. 1.
6. See *Aanhangsel Handelingen II*; 2013/14, no. 1168, at 1. See also Regionale Toetsingscommissies Euthanasie, *Jaarverslag 2013*. Den Haag; 2014, at 9.
7. *Aanhangsel Handelingen II*; 2013/14, no. 1168, at 1.
8. HR 21 June 1994, *NJ* 1994, 656.
9. See Regionale Toetsingscommissies Euthanasie website: http://www.euthanasiecommissie.nl/uitspraken-en-uitleg/p/psychiatrische-aandoeningen/ (last accessed 8 April 2016).
10. NVvP. *Richtlijn omgaan met het verzoek om hulp bij zelfdoding door patiënten met een psychiatrische stoornis*. Utrecht; 2009, at 30–9.

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11. See the Levenseindekliniek website: http://www.levenseindekliniek.nl/ (last accessed 28 July 2014).
12. See note 3, Regionale Toetsingscommissies Euthanasie 2013.
13. Regionale Toetsingscommissies Euthanasie. *Jaarverslag 2010*. Den Haag; 2011. Regionale Toetsingscommissies Euthanasie. *Jaarverslag 2009*. Den Haag; 2010. Regionale Toetsingscommissies.
14. See note 3, Regionale Toetsingscommissies Euthanasie 2013, at 15–16.
15. HR 24 December 2002, *NJ* 2003, 167.
16. See Uit Vrije Wil. *Burgerinitiatief voltooid leven*; available at http://www.uitvrijewil.nu/index.php?id=1000/ (last accessed 29 July 2014).
17. *Kamerstukken II*; 2011/12, 33 026, no. 1.
18. *Handelingen II*; 2011/12, no. 68, at 36–7.
19. KNMG. *De rol van de arts bij het zelfgekozen levenseinde*. Utrecht; 2011.
20. See note 19, KNMG 2011, at 39–40.
21. See note 19, KNMG 2011.
22. See note 19, KNMG 2011.
23. See note 13, Regionale Toetsingscommissies Euthanasie 2011, case 11, at 31–4.
24. See note 13, Regionale Toetsingscommissies Euthanasie 2011, case 11.
25. Zwanenburg E. Toetsing euthanasie stilzwijgend versoepeld. *Medisch Contact* 2011:2128–30. See also den Hartogh G. Voltooid leven: Binnen of buiten het wettelijk kader. *Nederlands Juristenblad* 2011:224–30.
26. See note 4, ZonMw 2012, at 222.
27. See *Aanhangsel Handelingen II*; 2013/14, no. 1168.
28. See the Medical Research Involving Subjects Act.
29. See note 3, Regionale Toetsingscommissies Euthanasie 2013, at 64.
30. See the Euthanasia Act, section 9, para. 1.

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