

Development of Euthanasia and Physician-Assisted Suicide in the Netherlands

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Reports on the use of voluntary active euthanasia (VAE) and physician-assisted suicide (PAS) in the Netherlands have been released since 1991. After gaining statutory force in 2001, the rate of VAE and PAS is reported to have dropped¹. It has also been reported that compliance with guidelines for VAE and PAS have improved and reporting has become more effective. These conclusions may be drawn from a preliminary reading of the Dutch reports. However, much can also be said of the end-of-life decisions that don't receive much coverage such as long-term palliative sedation and other forms of non-voluntary euthanasia. These end-of-life decisions are often overlooked because the Dutch definition of 'euthanasia' has been interpreted narrowly to include only explicitly requested acts. Embracing a wider definition, which includes all intentional life-shortening by act or omission and with or without request (including the intentional termination of neonates), reveals a more extensive practice of euthanasia and assisted suicide in the Netherlands.²

Guidelines allowing doctors to carry out VAE in certain circumstances were set down in Dutch courts long before being passed by the Dutch legislature. In 1981 guidelines set out by the Rotterdam court included:

1. The patient must be experiencing unbearable pain
2. The patient must be conscious
3. The death request must be voluntary
4. The patient must have been given alternatives to euthanasia and time to
5. There must be no other reasonable solutions to the problem
6. The patient's death cannot inflict unnecessary suffering on others
7. There must be more than one person involved in the euthanasia decision
8. Only a doctor can euthanise a patient

¹ see 'Euthanasia, Assisted Suicide Drop in the Netherlands after Law' by Elizabeth Lopatto, Bloomberg News Online 05/09/07

² Keown, John, 2002. *Euthanasia, Ethics and Public Policy: An Argument Against Legalisation*, Cambridge University Press, Cambridge, 133.

9. Great care must be taken in actually making the death decision³

It has since become evident, however, that these guidelines were neither followed nor enforced.⁴ This was largely due to the fact that they were not legally enforceable. It was not stipulated whether the guidelines were requirements or merely recommendations. Doctors were at liberty to interpret the guidelines themselves, which meant they were held accountable to nothing more than their own integrity for the procedure of self-reporting.

The first Rummelink Report was released in 1991 in an attempt to shed light on the 'extent and nature of medical euthanasia practice'⁵ in the Netherlands. A committee appointed by the Dutch government conducted this report, along with a second report examining practice in 1995, and produced a wealth of valuable data. The results of the first report presented that:

1.) 2,300 people died as a result of voluntary active euthanasia

2.) 400 people died as a result of physician-assisted suicide

3.) 1,040 people died from involuntary euthanasia

14% fully competent

72% never expressed a desire to die

In 8% of cases involuntary euthanasia was performed despite the fact that other alternatives were still available and yet to be exhausted

4.) 8,100 patients died as a result of doctors giving overdoses of pain killers with the intention of ending life, not reducing pain

In 61% of cases this occurred without the patient's consent

5.) 11,840 were killed by lethal overdoses or injections

The total number of deaths reported in the survey and resulting from either VAE or PAS totaled 2,700. However, the Commission's definition of euthanasia: 'intentional action to

³ Gomez, Carlos, 1991. *Regulating Death*, New York: Free Press, 32.

⁴ Fleming, John and Hains, Michael G and Fisher, Simon, 1996. *Submission to Select Committee on Voluntary Euthanasia Bill 1996*, Southern Cross Bioethics Institute, Plympton.

⁵ van der Maas, P.J. et al., 1991. *Medische beslissingen rond het levenseinde. Het onderzoek voor de Commissie onderzoek medische praktijk inzake euthanasia*, s'Gravenhage: SDU Uitgeverij Plantijnstraat, 3.

terminate a person's life, performed by somebody else than the involved person upon the latter's request'⁶ excludes any act of euthanasia that is non-voluntary (NVAE). As points 3 to 5 (above) represent involuntary acts, they are not included in the overall calculation, which masks the reality that people are being killed without giving consent.

A second Rummelink Report was released in 1995 to provide the opportunity for further scrutiny. The report did show better compliance with the guidelines. Doctors reported 41% of VAE and PAS as opposed to 18% in 1990. The report also indicated that there had been a decrease in the amount of competent persons being euthanized. The 1990 studies indicated that 37% of patients were fully competent as opposed to 21% in this report.⁷ However, one must not be uncritical of the report's summary. Regarding the increase in reporting, John Keown, a senior lecturer in the law and ethics of medicine, points out that this still leaves 60% of cases unaccounted for.⁸ There was also a marked increase of deaths in several areas. General requests for euthanasia increased by 800. While the number of PAS remained the same (400) VAE increased by 900 to equal 2.4% of the total number of deaths in the Netherlands.⁹ Again, these figures are records only of explicit requests and thus exclude any non-voluntary end-of-life treatments. According to the survey, the greatest increases in deaths were related to cases even where no request was made:

The intensification of pain and symptom treatment – taking into account the probability that life will be shortened (14,400 in 1990 and 15,150 in 1995)

The withdrawing/withholding treatments, including the removal of tube feeding (22,500 in 1990 and 27,300 in 1995)

The intentional termination of neonates (0 recorded in 1990 and 90 recorded in 1995) as well as the first official records of PAS of psychiatric patients (2-5).¹⁰

⁶ van der Maas, P.J. et al., 1992. *Euthanasia and Other Medical Decisions Concerning the End of Life*, Amsterdam, Elsevier, 11.

⁷ Editorial, 1999. 'Few Euthanasia consultants in the Netherlands act as independent evaluators of the patient's situation.' *Medical Journal of Australia*, 179:351-352
<http://www.mja.com.au/public/issues/apr19/hendin/hendin.html> (last accessed, July 2007)

⁸ Keown, John, 132.

⁹ van der Wal, G. and van der Maas, P.J., 1996. *Euthanasia and other medical decisions concerning the end of life. Practice and reporting procedure*. Den Haag: SDU Uitgevers.

¹⁰ van der Wal, G. and van der Maas, P.J., 1996.

Both the 1990 and 1995 Remmelink Reports indicated a lack of control over VAE, PAS and NVAE in the Netherlands. While certain improvements were noted in the 1995 reports, the situation was not yet meeting the guidelines fully. Failure to recognize this indicates Dutch complacency, emanating from an uncritical reading of the reports. Consider the words of the Dutch Ambassador who claimed that cases of euthanasia were rare and must be reported to the Public Prosecutor.¹¹ Even the base number 2,700 (reported number of VAE and PAS cases in first report) cannot be labeled 'rare.' Such claims show a fundamental misreading of the facts.

In 1999 another study, funded by the Dutch Ministry of Health, Welfare and Sports and the Ministry of Justice, was carried out 'to investigate how often physicians act as a consultant in the review of intended euthanasia and assisted suicide (EAS), by whom physicians are asked to act as a consultant, and the consultant's reasons for not agreeing with the intended performance of EAS.'¹² A stratified random sample of Dutch physicians concluded that 42% of physicians had been a consultant for euthanasia or assisted suicide and 11% more than three times. Whilst many had had some experience, there was not a structure present to enable physicians to gain necessary expertise in the area in order to make clear and accurate consultations. Other difficulties were inherent, such as doctors consulting patients face-to-face only 12% of the time.¹³ Overall, this report reflected an insufficiency in appropriate care to patients considering end-of-life decisions.

In 2001 the Netherlands officially legalised euthanasia and physician-assisted suicide. This law outlined that:

VAE must be performed in accordance with 'careful medical practice.' Requests must be voluntary, well considered, persistent, and emanate from patients who are experiencing unbearable suffering without hope of improvement, and the doctor and the patient must agree that VAE is the only reasonable option. At least one physician must be consulted, who must see the patient and give a written opinion on the case.¹⁴

¹¹ Letter from Dutch Ambassador, Mr J. H. R. D. van Roijen, dated 24 April 1995 (in) Keown, John, 139.

¹² Onwuteaka-Philipsen BD, van der Wal G, Kostense PJ, van der Maas PJ, 1999. 'Consultants in cases of intended euthanasia or assisted suicide in the Netherlands' *Medical Journal Australia* 170: 360-363 <http://www.mja.com.au/public/issues/apr19/onwuteaka/onwuteaka.html> (last accessed, July 2007)

¹³ Onwuteaka-Philipsen BD, van der Wal G, Kostense PJ, van der Maas PJ, 1999.

¹⁴ Keown, John, 88.

The bill extended VAE decisions to persons as young as 12 years old provided that there be parental consent. At the ages of 16 to 18 teenagers can make their own choices regarding their own end-of-life decisions so long as a parent is *made aware* of their situation.¹⁵ Points also included in this bill related to the compulsory reporting procedures.

The United Nations Human Rights Committee, fearing that the law could be subject to abuse, had voiced its concerns six months before it came into effect.¹⁶ Euthanasia for minors was another major criticism made by the UN. It was thought that minors were unable to make fully autonomous decisions given their age and possible third party intervention. Such vulnerable persons are not protected under the statute, which retains the broad terms of earlier guidelines. For example, the term ‘unbearable suffering’ may continue to be interpreted to incorporate psychological suffering and even depression. An example of this abuse was in *Chabot’s case*¹⁷ where the court held that mental distress, experienced by a woman whose marriage had ended and two sons had died, constituted “unbearable suffering.”

In 2005 researchers from Amsterdam’s University Medical Centre carried out another Dutch government-sponsored study regarding physician compliance with euthanasia and assisted suicide guidelines. The report held that ‘physicians report compliance with the official requirements for accepted practice.’¹⁸ The focus in this study was on deaths by explicit requests, not surprisingly overlooking non-voluntary deaths. Of these explicit requests the results presented that 44% of cases were carried out by a general practitioner, 13% of patients died before treatment was administered, 13% of patients died before the doctors gave the final consent, 12% of requests were refused by doctors and 13% of patients requesting euthanasia or PAS changed their minds.

Susan M. Wolf J.D., of the Minnesota Law School, raises questions about what year the data for this report was collected. She reveals that the timing (2000-2002) coincides with

¹⁵ *International Task Force on Euthanasia and Assisted Suicide* ‘Holland’s Euthanasia Law’ <http://www.internationaltaskforce.org/hollow.htm> (last accessed, July 2007)

¹⁵ Van der Heide et al., 2007 "End-of-Life Practices in the Netherlands under the Euthanasia Act," *New England Journal of Medicine*, 5/10.

¹⁶ U.N., 2001. *International Covenant on Civil and Political Rights, Concluding Observations of the Human Rights Committee: Netherlands*, 7/20.

¹⁷ *New York Times*, 4/5/93, p.A3, and *Washington Times*, 4/22/93, p.A2.

¹⁸ Jansen-van der Weide et al., 2005. “Granted, Undecided, Withdrawn, and Refused Requests for Euthanasia and Physical-Suicide,” *Archives of Internal Medicine*, (11/08) 165.

the Dutch preparations ‘to pass and enact the new euthanasia statute, created, in large part, to solve the huge problem of non-compliance.’¹⁹ Her findings show that:

[A]ll physicians being surveyed were either recently trained in the [euthanasia] law rules as consultants or the target of a project to encourage them to use these consultants and follow the rules. There was no control group, and retrospective self-report was the only data collection method. This is hardly an adequate basis for assessing whether physician practice actually complies with the rules.²⁰

Wolf casts further doubt on the validity of this report by suggesting that if the Dutch had an effective reporting system, they would not have any cause to introduce a statute.²¹

2006 brought forward a new dimension to the problem of palliative care. The Remmelink Reports revealed that it was not unheard of for doctors to implement VAE even when they had not accessed all reasonable and available palliative treatments. In 2006 the Dutch government, frightened by the increasing use of costly medical treatments ‘out spacing economic growth’²² announced health cuts. The fear remains that these costs may further influence VAE being an alternative to palliative care. John Keown writes: ‘the opinion of the Supreme Court, the Ministers of Justice and Health, and the KNMG, that VAE is impermissible when treatment alternatives are available, even if the patient refuses them, has clearly not prevented its administration in such circumstances.’²³ Such administration has even given rise to the defense of ‘necessity’ (Alkmaar case), deeming palliative care ‘medically meaningless’ in some cases.

More recently in May 2007, the New England Journal of Medicine published a report titled: ‘End-of-Life Practices in the Netherlands under the Euthanasia Act.’ This report boasts a ‘modest decrease’ in acts of VAE and PAS between 2001 and 2005, since both practices were formally legalised.²⁴ The report shows that VAE was the cause for 1.7%

¹⁹ *International Task Force on Euthanasia and Assisted Suicide*, 2005 Vol. 13, No. 3., “Dutch studies don’t tell whole story about euthanasia practice” <http://www.internationaltaskforce.org/iaa34.htm> (Last accessed July 2007)

²⁰ Wolf, Susan, 2005. “Assessing Physician Compliance with the Rules for Euthanasia and Assisted Suicide,” *Archives of Internal Medicine* (22/08) 1677-1679.

²¹ Wolf, Susan, 1678.

²² *International Task Force on Euthanasia and Assisted Suicide* ‘Dutch cost cutting could prove fatal’ <http://www.internationaltaskforce.org/iaa38.htm#14> (Last accessed July 2007)

²³ Keown, John, 134.

²⁴ van der Heide et al., 2007. "End-of-Life Practices in the Netherlands under the Euthanasia Act," *New England Journal Medicine* (5/10), 1962.

of deaths in 2005 as opposed to 2.6% in 2001. PAS rates also dropped by 50% from being 0.2% of deaths in 2001 to 0.1% in 2005. However, the authors admit the introduction of alternative life ending procedures: 'In our study, we found that euthanasia and assisted suicide were to some extent replaced by continuous deep sedation.²⁵' This 'deep continuous sedation' is often disguised by the gentle term 'palliative sedation,' yet in practice is actually 'terminal sedation.' According to the International Task Force on Euthanasia and Assisted Suicide, it often coincides with the withdrawal of feeding tubes.²⁶

While in 2005 DCS (deep continuous sedation) was responsible for 7.1% of deaths (as opposed to 5.16% in 2001), it is not considered euthanasia on account of its involuntary and gradual process. Similar occurrences were reported in 1990 when the Institute for Bioethics in Maastricht, Holland, reported that 30 patients per year were induced into a coma "by means of a morphine injection" at the Netherlands Cancer Institute. The Institute also indicated that this was not 'euthanasia' as it was 'non-voluntary.'²⁷

According to the latest report the percentage of NVAE (written in the report as Involuntary Active Euthanasia or IAE) occurred four times more than PAS, with a total percentage of 0.4%: 'In 2005, the ending of life was not discussed with patients because they were unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%).'²⁸ This confirms the fears expressed by the United Nations Human Rights Committee prior to the VAE/PAS guidelines receiving statutory force. Understandably, the evidence for NVAE has created caution amongst the elderly and disabled persons in the Netherlands. A Dutch disability group created cards to be placed in their wallets, indicating that if they should be admitted to hospital they do not wish to be euthanised.²⁹

It has become evident that euthanasia and physician-assisted suicide are regular medical practices in the Netherlands. On average, doctors 'receive about 9700 requests per year,

²⁵ *International Task Force on Euthanasia and Assisted Suicide*, 2007 Vol. 21, No. 2., 'New Dutch Report shows terminal sedation deaths on the rise.' <http://www.internationaltaskforce.org/iua41.htm> (Last accessed July 2007)

²⁶ Capron, Alexander M., 1992, 'Euthanasia in the Netherlands--American Observations', *Hastings Center Report* (March, April), 31.

²⁷ Van der Heide et al., 2007 "End-of-Life Practices in the Netherlands under the Euthanasia Act," *New England Journal of Medicine* (5/10), 1962.

²⁸ van der Heide et al., 1960.

²⁹ Marker, Rita L, 1993., *Deadly Compassion -The Death of Ann Humphry and the Truth About Euthanasia*, New York; William Morrow and Company, p. 156.

and 77% of them have at some time had such a request.’³⁰ The definition of euthanasia remains narrow, with terms such as ‘unbearable suffering’ continuing to be interpreted widely. There is not adequate protection for the disabled, elderly, children or anyone with reduced autonomy and little appreciation for the fact that people can come out of suffering. An alarming reality is that non-voluntary euthanasia has been justified as ‘necessary’ or in some cases even good palliative care. Palliative care, whilst improved, is still not sufficiently provided. This is indicated partly by a cut in funding. Reporting, also improved, remains inadequate. Whilst there has been an improvement of compliance with guidelines it remains as John Keown wrote: ‘The reassuring picture of the euthanasia landscape portrayed by the Dutch is surreal.’³¹

³⁰ Griffiths, John et al., 1998, *Euthanasia and Law in the Netherlands*, Amsterdam University Press, Amsterdam, 253.

³¹ Keown, John, 147.