

Report on Euthanasia and Physician Assisted Suicide in the Netherlands

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Relevant background, qualifications, and experience of the author

I received a licentiate degree in ethics at the University of Uppsala in 1995, and a doctoral degree in ethics at Utrecht University in 1997.

From 1987 until 2001, I was researcher at the Center for Bioethics and Health Law of Utrecht University.

From 2001 to the present, I have been a senior lecturer of Ethics at the Protestant Theological University in Utrecht, later Groningen (from 2012 on).

From 2005 until 2014, I served as a member of the Regional Euthanasia Review Committee (Region 2 – Overijssel, Gelderland, Flevoland and Utrecht), during which period I personally reviewed 4,000 cases of euthanasia and physician assisted suicide.

Since 2014 I also hold the Lindeboom Chair for Ethics of Care at Kampen University.

I am member of the Board of the Dutch Research School in Philosophy (section Ethics and Practical Philosophy), and was announced ‘most quoted ethicist of the Netherlands’ by the Dutch Association of Ethicists in 2011.

Over the years, I have published extensively on applied ethical issues. Euthanasia and other end-of-life questions have been important themes.

My publications on end-of-life issues include: ‘After the Slippery Slope: Dutch Experiences of on Regulating Active Euthanasia’, *Journal of the Society of Christian Ethics*, 23, 2 (2003), 225-42; ‘Euthanasie: de regel achter de uitzondering’, *Theologia Reformata* 45, 2 (2002), 126-144; ‘La problématique de l'euthanasie aux Pays-Bas: quelques réflexions par un éthicien théologique’, in: Karsten Lehmkuhler en Jean-Gustave Hentz, *Spiritual Care et Fin de Vie*. Genève: Labor et Fides (Lieux théologiques 44), 2015, 55-71; ‘Euthanasia in the Netherlands: An Eyewitness Report’, *The Human Life Review* 41,4 (2015), 61-3; ‘Euthanasia, Ethics, and Theology: A Dutch Perspective’, in: *RES (Review of Ecumenical Studies)* 6 (2/2014), pp. 197-214; ‘De rafelranden van de euthanasiewet.’ *Nederlands Tijdschrift voor Geneeskunde* 2015;159:A8809; Theo Boer, Maarten Verkerk en Dirk-Jan Bakker, *Over (-) behandelen. Ethiek*

van de zorg voor kwetsbare ouderen. Amsterdam: Reed Business Education 2013; ‘Palliative Sedation: An Exploration from a Christian Ethical Point of View’, in: Hendrik M. Vroom, Petra Verdonk, Marzouk Aulad Abdellah and Martina Cornel (eds.), *Looking beneath the Surface: Medical Ethics from Islamic and Western Perspectives*. Amsterdam: Editions Rodopi, 2013, 236-49; ‘Theologisch-ethische kanttekeningen bij de natuurlijke dood’, in: *Kerk en Theologie* 64, 4 (2013), 223-37; ‘Euthanasia in a Welfare State: Experiences from the Review Procedure in the Netherlands’. *Philosophy Study* 2,1 (2012), 51-63; ‘When Family Violence Takes Subtle Forms: A Narrative from a Dutch Context’ (On family pressure in euthanasia), *NGTT* 52 (2011), supplement 1, 37-42; Theo Boer, Aart Hoogerwerf, Wim Golsteijn, Jaap Rebel and Ploni Robbers-van Berkel, ‘Medizinische Entscheidungen im Umfeld des Lebensendes. Seelsorgliche und moralische Erwägungen’. Ins Deutsche übersetzt von Frauke Hayungs, in: Stefanie Schardien (ed.), *Mit dem Leben am Ende. Stellungnahmen aus der kirchlichen Diskussion in Europa zur Sterbehilfe*. Göttingen: Edition Ruprecht 2010; ‘Euthanasia’, in: Joel Green, Jacqueline Lapsley, Rebekah Miles, and Allen Verhey (eds.) *Dictionary of Scripture and Ethics*, Cleveland, OH: Baker 2010; ‘Turning Points in the Conception and Regulation of Physician-Assisted Dying in the Netherlands’. *American Journal of Medicine* 129, 7 (July 2016) (accepted).

1. Foreword

As a professor of Health Care Ethics, I am deeply involved in discussions in the Netherlands about euthanasia and physician assisted suicide. Moreover, as a member of a Regional Euthanasia Review Committee I have witnessed the development of Dutch euthanasia practice over the years. During the period 2005-2014, I personally reviewed 4,000 cases of euthanasia and assisted suicide.

In this report, I accept the invitation of the Health Professions Council of South Africa (HPCSA) to provide information and opinion on the Dutch practice of euthanasia and assisted suicide.

The numbers cited in this report are drawn for the most part from official publications available in hard copy or on the internet and are numbers that have general public acceptance as being correct. Some numbers are drawn from my own research, some of them published, some not yet.

The views I express in this report are my own independent views, based upon my research, knowledge, and experience of euthanasia and assisted suicide in the Netherlands over about 20 years. I do not in this report adopt or present the official view of another person or entity, not of the Regional Euthanasia Review Committee of which I was a member, nor of the universities that I am linked to.

For convenience, I use the following abbreviations in this report:

NVVE: Dutch Voluntary Euthanasia Society

PAD: Physician Assisted Dying (in the Netherlands consisting of euthanasia and physician assisted suicide)

RDMA: Royal Dutch Medical Association

RRC: Regional Review Committee of Euthanasia and Assisted Suicide

2. The Dutch Law and the Review Committees on Euthanasia

Summary: Since the 1980s, euthanasia and physician assisted suicide have been tolerated in the Netherlands, provided that they took place on the request of a patient whose suffering was unbearable and without prospect of improvement. Negotiations over time between the Public Prosecutor, the Government, and the Royal Dutch Medical Association ultimately resulted in a fully-fledged physician assisted dying law, which was adopted in 2001 and came into effect in 2002. In terms of the 2001 law, a doctor providing physician assisted dying must report the instance of physician assisted dying and will not be prosecuted if it was on request of the patient, the suffering of the patient was unbearable and without prospect of improvement, there were no alternative options to physician assisted dying, a second doctor was consulted with, and the death was brought about in a medically sound manner. Also in terms of the 2001 law, five Regional Review Committees assess each case of physician assisted dying after the fact. When a Committee rules that a case has taken place in accordance with the 2001 law, the decision is final and cannot be overruled, not even by the Supreme Court, unless a third party brings new information to the fore which is reason to reconsider a decision. This has not occurred in the 14 years' that the 2001 law has been in operation. Since 2002, 43,000 cases of physician assisted dying have been reported to the Regional Review Committees under the 2001 law. All in all, 75 cases were referred to the Public Prosecutor, none of which led to prosecution.

Introduction

The Netherlands is one of the few countries in the world where physician assisted dying (that is euthanasia or assisted suicide, henceforth physician assisted dying or PAD) is legal. The legalisation of PAD in the Netherlands was preceded by a process of deliberation and the practice of tolerating PAD in certain circumstances.

In the mid-1980s the Royal Dutch Medical Association (RDMA) and the Public Prosecutor agreed that if certain conditions were met, a doctor performing euthanasia or providing assistance to suicide, would not be prosecuted.

After years of further discussion and deliberation between the RDMA, the Public Prosecutor and the Dutch Government, euthanasia was defined as 'active life termination by a doctor, at the

patient's request'.¹ Whereas earlier definitions contained reference to euthanasia as 'at the patient's request *or* in his interest', with this redefinition the focus shifted onto the voluntariness and competency of the patient's request for PAD. The limitation of PAD to competent patients was a response to, and largely silenced, the international criticism of the Dutch practice of euthanizing incompetent patients. Many critics had compared the last-mentioned to Nazism, where non-voluntary euthanasia in the guise of 'mercy killing' was practiced.

The 1994 law and the Due Care Criteria

In 1994, the practice of physician assisted dying in the Netherlands was formalised in the form of an appendix to the Burial and Cremation Act.² From that time on, and in accordance with that law, it was required that every instance of euthanasia be reported to the Public Prosecutor.

In a report, the doctor concerned had to demonstrate that each of the following six due care criteria were met. The doctor had to demonstrate that:

- a. the doctor was convinced that the patient had made a voluntary and carefully considered request;
- b. the doctor was convinced that the patient's suffering was unbearable, and that there was no prospect of improvement;
- c. the doctor had informed the patient about his or her situation and his or her prospect of recovery;
- d. the doctor had come to the conclusion, together with the patient, that there was no reasonable alternative in the light of the patient's situation;
- e. the doctor had consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above;
- f. the doctor terminated the patient's life or provided assistance with suicide with due medical care and attention.³

¹ Staatscommissie Euthanasie, *Rapport van de Staatscommissie Euthanasie: Advies*. Den Haag: Staatsuitgeverij 1985.

² Dutch "Wet op de Lijkbezorging".

³ In this list of criteria is 'missing' the criterion of a terminal illness. It is largely implied in c. above, and the public had such terminal situations in mind when it supported the legalisation of PAD. However, it

According to this 1994 law, PAD was still punishable. The Public Prosecutor would assess each case in hindsight. Only after the Prosecutor had concluded that the criteria had been met, could a doctor be sure that there would be no (chance of) prosecution. Given the large number of euthanasia cases, the need for specialised knowledge in assessing the reports, and the broadly felt wish to decriminalize the procedure of PAD-reporting, the Government decided in 1998 that most of the Prosecutor's task would be taken over by five Regional Review Committees (RRCs), each consisting of a lawyer, a doctor, and an ethicist. The decisions made by the RRCs had the status of an advice to the Prosecutor, who thus had to make the final decision.

The 2001 Physician Assisted Dying Law

In April 2001, PAD was taken out of the 'Burial and Cremation Act' and put into a separate law. The Dutch parliament adopted a new Act, the 'Termination of Life on Request and Assisted Suicide (Review Procedures) Act'.⁴ In terms of this law, the causing of the death of a patient is still considered an offence, but in its form and tone, the law implies a turn towards 'normalization' of PAD. The new Act (the PAD-Act) came into effect on 1 April 2002.

The biggest difference introduced by the PAD-Act in comparison to prior practice was a change in the role of the Public Prosecutor. Whereas previously every case was sent to the Prosecutor for a final assessment, with the enactment of the PAD-Act only cases that do *not* meet the criteria are sent to the Prosecutor. This change was crucial, as has become clear in recent years. When a RRC judges that a case does *not* meet the criteria, the Public Prosecutor continues to be in charge: it takes over the case and decides about further actions. However, when a RRC judges a case to be in order, the committee's decision is final. The Prosecutor has no access to a report on a case of PAD that a RRC has found to have met the criteria, and is not able to reconsider and overrule the RRC's decision. There is only one exception to this rule, namely, when third parties, such as relatives, bring forward new information that could lead to a reopening of the case. Until today, no such reopening was ever requested. In practice, a positive RRC decision has the status of the verdict of the Supreme Court and cannot be revisited, not even by the Supreme Court.

was never made explicit in the law; this may explain why the PAD-practice has now come to encompass many cases of nonterminal patients.

⁴ Wet Toetsing Levensbeëindiging en Hulp bij Zelfdoding, shortly WTL.

The high status of RRC decisions would not be problematic if the interpretation of the due care criteria to concrete PAD-cases were a matter of simple logic (similar to ruling that the speed limit has been exceeded). But the requirements for a lawful act of PAD contained in the PAD-Act are far from being as concrete and unambiguous as one might expect. In fact, the open-norm character of the criteria of PAD-Act is the reason for establishing RRCs in the first place. Some of the vexed questions in interpreting the PAD-Act include: what are the content and limits of ‘unbearable suffering’? What if a patient refuses treatment that could have eased the suffering? What if the suffering is the consequence of psychological, spiritual, or financial factors, or of social factors such as grief and loneliness? Is a doctor-patient relationship prior to a euthanasia request needed? Should a physician have specialised knowledge about palliative care? What does it mean that a request must be well-considered? What is the relationship between a person’s request and his earlier views on euthanasia? And what if a patient has an advance directive reading that he wants to have euthanasia in case of dementia, but seems not to be suffering once the dementia has occurred?

The RRCs are expected to review cases of PAD ‘in the light of current medical ethical norms’.⁵ Because these norms shift over the years, this means that the RRCs may adopt new policies or approaches in interpreting the law. The many extensive and careful discussions that have taken place within the RRCs alter nothing about the fact that an important part of these discussions never reaches the outside world – the RRCs have no minutes of their meetings –, nor about the fact that the RRCs’ decisions cannot be overruled. This lack of transparency and this impossibility to overrule an RRC-decision are a serious systemic failure of the Dutch system.

There is another systemic complexity in the review procedures: physicians have to report their own actions. Reporting a case of PAD that may not have met the criteria would become a form of self-indictment, in which a physician would provide arguments for a RRC to eventually reject the case. No doubt this paradoxical situation may keep a physician to reveal all the necessary details (such as family pressure, or partial incompetence), which makes it hard for a RRC to access all the facts. Moreover, an RRC has very limited means (if any) to check the veracity of all the facts of a report.

⁵ “De commissie overweegt of er naar heersend wetenschappelijk verantwoord medisch inzicht en naar in de medische ethiek geldende normen aan de zorgvuldigheidseisen is voldaan”, Regionale Toetsingscommissies Euthanasie, *Jaarverslag 2014*. Den Haag: 2015, 24.

In recent years, physicians, patients, patient organizations, and RRCs have become increasingly aware of the many loose ends of the Dutch PAD-Act.⁶ Others have considered these openings as opportunities for further liberalisation of Dutch PAD-practice.⁷

In the period 2002-2015, roughly 43,500 cases of PAD have been reported to the RRCs.⁸ Of the 38,000 cases that were reviewed during the period 2002-2014, 75 cases were referred to the Prosecutor, equalling an average of 0.19%, or one out of 500 cases.⁹ This average went down to one in 1,000 cases in 2013 and 2014.

In the great majority of these cases, the problem was of a procedural nature: either the medication did not meet the criteria established by the RDMA and its pharmaceutical counterpart the Royal Dutch Pharmaceutical Association (RDPA), or there was no proper consultation with a second physician. Only in a small number of cases were one or more of the other criteria violated. In some cases a patient was no longer competent at the moment of the life termination, in other cases a RRC was not convinced that there were no alternative options to relieve the suffering. If a RRC rules that a case of PAD does not meet the legal requirements, the case is referred to the Public Prosecutor who decides whether or not to prosecute. Not any of the 75 cases referred to the Prosecutor has led to prosecution. This is mainly because the omissions or

⁶ Cf. Theo Boer, 'De rafelranden van de euthanasiewet.' *Nederlands Tijdschrift voor Geneeskunde* 2015;159:A8809

⁷ "Met het aldus toegankelijk en kenbaar maken van hun 'jurisprudentie' willen de RTE's duidelijkheid scheppen over de mogelijkheden die de wet aan artsen biedt", Regionale Toetsingscommissies Euthanasie, *Jaarverslag 2013*. Den Haag: 2014, 5; "Volgens de onderzoekers worden de zorgvuldigheidseisen door de commissies steeds meer ingevuld, waarbij ook de ruimte die de WTL biedt voor euthanasie bij patiënten met dementie, psychiatrische aandoeningen of een stapeling van ouderdomsklachten steeds duidelijker wordt", Regionale Toetsingscommissies Euthanasie, *Jaarverslag 2012*. Den Haag: 2013, 6.

⁸ 37,688 2001-2014, added by an estimated 5,500 in 2015.

⁹ 2002: of the 1,882 reported cases 5 cases, i.e., 0.20%, did not meet the criteria; 2003: of the 1,815 reported cases, 8 cases, i.e., 0.45%, did not meet the criteria; 2004: of the 1,886 reported cases, 4 cases, i.e., 0.21%, did not meet the criteria; 2005: of the 1,933 reported cases, 3 cases, i.e., 0.15%, did not meet the criteria; 2006: of the 1,923 reported cases, 1 case, i.e., 0.05%, did not meet the criteria; 2007: of the 2,120 reported cases, 3 cases, i.e., 0.14%, did not meet the criteria; 2008: of the 2,331 reported cases, 10 cases, i.e., 0.42%, did not meet the criteria; 2009: of the 2,636 reported cases, 9 cases, i.e., 0.34%, did not meet the criteria; 2010: of the 3,136 reported cases, 9 cases, i.e., 0.28%, did not meet the criteria; 2011: of the 3,695 reported cases, 4 cases, i.e., 0.10%, did not meet the criteria; 2012: of the 4,196 reported cases, 10 cases, i.e., 0.23%, did not meet the criteria; 2013: of the 4,829 reported cases, 5 cases, i.e., 0.10%, did not meet the criteria; 2014: of the 5,306 reported cases, 4 cases, i.e., 0.07%, did not meet the criteria.

mistakes were not considered to be serious enough to justify prosecution and the physicians involved were committed to not making the same error again. It is no secret that the Dutch Government, the RRCs, the RDMA, and the Public Prosecutor have a shared preference to avoid complex and protracted lawsuits about cases of PAD.

Typical procedure

Most cases of PAD (still) take place within an established doctor-patient relationship. Of the 5,306 cases reported in 2014, 88% of the PAD cases were provided by general practitioners/home health doctors.

Although the law makes possible both euthanasia (a doctor inducing a coma and then administering a muscle relaxant) and assisted suicide (the patient drinking a lethal drink), 96% of patients choose euthanasia. This preference for the doctor in this highly active role is typical for both the Netherlands and Belgium. Between 2003 and 2015 the numbers in the Netherlands went up from 1,800 to 5,550¹⁰, in Belgium between 2003 and 2014 from 235 to about 2,300.

For a physician, a request for assisted dying will normally not be unexpected. Many patients have an advance directive in their medical files containing their views about resuscitation, (non-) treatment, euthanasia, or a refusal of euthanasia. When a patient contracts a serious, potentially terminal disease, many patients ‘refresh’ their directive and others who have not yet written one, will do so. Often, patients who consider making a euthanasia request, will discuss this with their physician. When a disease becomes terminal or comes close to being terminal, arrangements are usually already in the process of being made for assisted dying and a second doctor is invited to assess the case. Although the approval of this second doctor is not needed (only the consultation is needed, not the approval), almost no physician will provide PAD without the approval of at least one consulting colleague.

Between the visit of the second doctor, and the PAD lie on average between 2 days and 3 weeks. In the event that it is longer, the second doctor may be invited a second time in order to make sure that the conditions are still met. In a considerable number of cases – that is somewhere

¹⁰ The 2015 numbers were presented by RRC official Sjef Gevers on March 17, 2016 on a RDMA conference on PAD. The 2015 annual report will be published later in 2016.

between 15% and 45% – an assisted death proves not to be possible or necessary in the end, either because the patient withdraws his request, or because a natural death has occurred before a PAD could take place. After a case of PAD has occurred, the coroner is invited to establish the fact of an unnatural death. The physician sends a written report with all the necessary documents to a RRC, which has to review the PAD within 6 weeks. Although most cases of PAD take a preparation time of weeks or months, there are cases in which the procedure takes much longer – years, in the case of, e.g., a psychiatric disease – or shorter, e.g., in the case of an acute and unexpected deterioration of the patient’s condition.

Although euthanasia without the patient’s request is illegal, it was estimated in 2012 that it occurs in about 0.2% of all deaths in the Netherlands, i.e., about 280 cases. This number is down from 0.7% in 2001 and 0.4% in 2005.¹¹ PAD is possible for children aged 12-17 years. However, of a total of 38,000 reported cases between 2002-2014, only six cases of PAD fell within this age group, most of which were aged 16 years and older. This equals 0.01% of all reported cases.

¹¹ Agnes van der Heide, Johan Legemate, Bregje Onwuteaka-Philipsen, Eva Bolt, Hans van Delden, Eric Geijteman, Marianne Snijdewind, Donald van Tol, and Dick Willems, *Tweede Evaluatie Wet Toetsing Levensbeëindiging op verzoek en hulp bij zelfdoding*. Den Haag: ZonMw 2012, 108.

3. The numbers of Physician Assisted Dying

Summary: Despite mortality rates being constant over the past decade, the cases of PAD have gone up considerably since 2005. Overall, from 1,883 reported cases in the year 2002 there was an increase to 5,550 in 2014, i.e., 195%, with numbers continuing to rise. PAD now accounts for one out of every 25 deaths in the Netherlands, making PAD an increasingly ‘normal’ death. If the PAD-Act is supposed to bring about a stabilization of the numbers, this stabilization is yet to occur.

In this section we will take a more detailed look at the numbers of PAD. It is necessary to do this, because there is some ambiguity about the frequency of PAD in the Netherlands, the way the figures develop, and different interpretations of the data are offered. For instance, some publications as late as 2012 speak consistently of a ‘stabilisation’ of the numbers. On international forums, some Dutch ethicists, politicians, and physicians continue to assure the public that the situation is ‘stable’. The Dutch Voluntary Euthanasia Society (NVVE) sees an increase in the numbers, but explains the increase in terms of an increase in the overall mortality rate.

Well into 2016, however, it is beyond any doubt that the numbers have increased considerably. This increase cannot be attributed merely to a rise in mortality rates.

In the section below, I deal with the numbers with a view to assisting the reader to reach an understanding of them.

(1) Regional Review Committee data

There are two recognized sources of the numbers of PAD in the Netherlands (i.e. two ‘ways’ to count). The first source, or set of sources, are the annual reports of the RRCs, published yearly in about September, and describing the numbers in the preceding year. Physicians have an obligation to report every case to the RRCs, so the numbers published in their annual reports are

supposed to account for all deaths that were the consequence of PAD (euthanasia and physician assisted suicide). These numbers remained level until 2006, and then went up sharply:

2002: 1,882 reported cases
2003: 1,815 reported cases
2004: 1,886 reported cases
2005: 1,933 reported cases
2006: 1,923 reported cases
2007: 2,120 reported cases
2008: 2,331 reported cases
2009: 2,636 reported cases
2010: 3,136 reported cases
2011: 3,695 reported cases
2012: 4,196 reported cases
2013: 4,829 reported cases
2014: 5,306 reported cases
2015: +- 5,550 reported cases

(2) Anonymous five-yearly surveys

At the same time, it is unclear whether all cases are reported, or which percentage of the cases are reported. This uncertainty is one of the reasons why five-yearly representative surveys are conducted in the Netherlands on behalf of the Government. The five-yearly reports are the second source.

In these five-yearly surveys, a representative selection of physicians is asked to report anonymously whether they have performed PAD in the past year. Traditionally, the numbers resulting from these surveys reach a higher level than the numbers of the RRCs. The anonymous surveys show the following results:

2001: 3,800 estimated cases¹²

2005: 2,425 estimated cases¹³

2010: 4,045 estimated cases¹⁴

These numbers differ from the first source, in that (1) they are higher than the RRC-numbers which refer to the same years and (2) unlike the RRC numbers, they show a ‘dip’ in 2005.

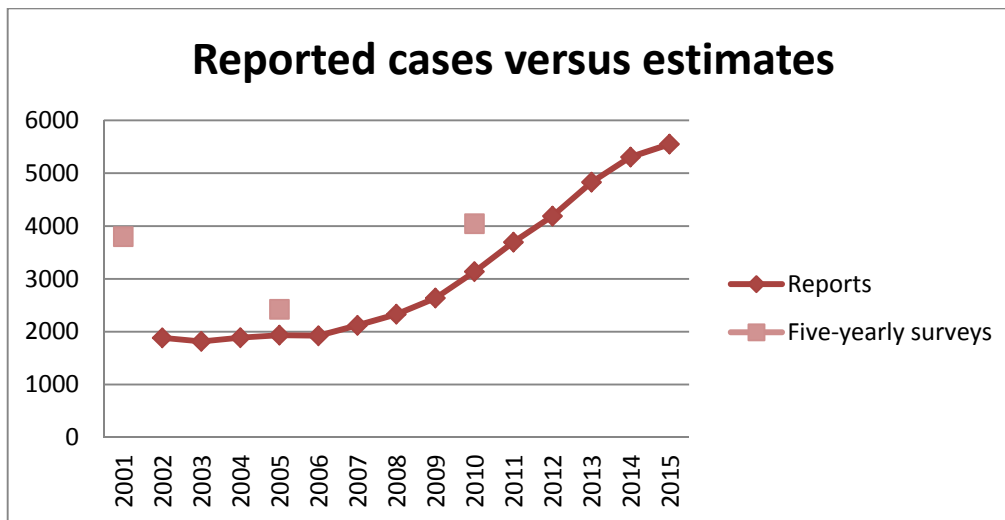


Table 1: Reports in relation to the estimated PAD-totals. Source for reported cases: RRCs annual reports. Estimates: anonymous surveys 2001, 2005, 2010. (Euthanasia advocates consistently ignore the numbers from the reports and only refer to the five-yearly surveys, the last of which occurred in 2010.)

¹² G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen, and P.J. van der Maas, *Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie*. Utrecht: De Tijdstroom 2003.

¹³ B.D. Onwuteaka-Philipsen, J.K.M. Gevers, A. van der Heide, J.J.M. van Delden *et al.*, *Evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*. Voorburg: Centraal Bureau voor de Statistiek, 2007.

¹⁴ Bregje D Onwuteaka-Philipsen, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J F de Jong-Krul, Johannes J M van Delden, Agnes van der Heide, *Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey*. *Lancet*. 2012 Sep 8;380(9845):908-15; Agnes van der Heide, Johan Legemate, Bregje Onwuteaka-Philipsen, Eva Bolt, Hans van Delden, Eric Geijteman, Marianne Snijdwind, Donald van Tol, and Dick Willems, *Tweede Evaluatie Wet Toetsing Levensbeëindiging op verzoek en hulp bij zelfdoding*. Den Haag: ZonMw 2012.

Combining the figures

One reason for the discrepancy between the two kinds of statistics may be that the definition of ‘euthanasia’ in the anonymous surveys is wider than the definition used by the RRCs. Whereas the RRCs give a narrow definition of euthanasia, i.e., the injections of a doctor to kill the patient instantly, the anonymous surveys are said to include even actions in which the intention of the doctor is not to kill, but to alleviate suffering, but in which death is nevertheless welcomed.

Another reason may be that some physicians feel free to fill in an anonymous survey, but may still feel hesitant to report because, in principle, a RRC could decide that a reported case does not meet the due care criteria and will refer it the case to the Board of Procurators General and to the Healthcare Inspectorate. Yet another reason is that physicians consider euthanasia or physician assisted suicide as too ‘intimate’ to be reported to a committee such as a RRC.

The 2005 anonymous survey numbers, which were published in 2007, showed a 36% decrease in comparison to the 2001 anonymous survey.¹⁵ One reason for the decrease may have been a better awareness of doctors of the fact that the administration of large doses of pain killers is not by definition euthanasia; another reason may have been the corresponding rise in the numbers of palliative sedation that was found. The 2005 report concluded that “*The euthanasia law has not led to unwanted developments. The frequency of euthanasia and PAS has decreased, probably as a consequence of the increased focus on medical care and treatment in the terminal phase*”. Many, including myself, shared this view.¹⁶ Another conclusion that was drawn was that the preparedness of doctors to report had gone up from an estimated 45% in the early 2000s to 80% of the euthanasia and PAS cases (1,933 reported out of 2,424 estimated cases) in 2005.

However, the anonymous survey published in 2012 and based on data collected in 2010, showed the reverse: a surge in the numbers from 2,424 to 4,050 cases of euthanasia and PAS, meaning

¹⁵ B.D. Onwuteaka-Philipsen, J.K.M. Gevers, A. van der Heide, J.J.M. van Delden *et al.*, Evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding. Voorburg: Centraal Bureau voor de Statistiek, 2007, 14. In the same period, the number of life terminations without a patient’s request (not covered by the Euthanasia Law) had gone down from 950 to 550.

¹⁶ Theo A. Boer, ‘Recurring Themes in the Debate about Euthanasia and Assisted Suicide’, *Journal of Religious Ethics*, 35, 3 (2007), 529-555.

that in 2010, 77% (3,136 of an estimated 4,050) of all cases were reported.¹⁷ In hindsight, many have expressed doubts about whether the 2005 anonymous survey was reliable. Rather than considering the strong increase between 2005-2010 to be alarming, the 2010 numbers were compared to the 2001 numbers – and the 2005 numbers were interpreted in terms of ‘slight decrease in the euthanasia frequency’ after 2002.¹⁸

What are the real numbers?

When the Dutch situation is said to be ‘under control’ and ‘not on the rise,’¹⁹ this view is based on two mistaken pillars. First, it is based on data obtained in 2010, without taking into consideration the sharp and uncontested increase in the number of PAD-reports since 2010: from 3,136 to 5,550 in 2015 (an increase of 76%).

Second, the view accepts the arguments of some – like the NVVE – who argue that the rise in the numbers is related to the increase in the mortality rates, based on an ageing population. However, in these 13 years, the overall mortality rate in the Netherlands has remained about the same, about 138.000 p.A., with year to year deviations of only 1,5%.²⁰

If we accept that the real number of PAD cases is higher than the number of reported cases, the real number may well be more than 6,000 in 2015. All in all, this means that the expectations expressed by many Dutch opinion makers, politicians, and physicians, that legalising PAD will

¹⁷ Bregje D Onwuteaka-Philipsen, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J F de Jong-Krul, Johannes J M van Delden, Agnes van der Heide, Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet*. 2012 Sep 8;380(9845):908-15; Agnes van der Heide, Johan Legemate, Bregje Onwuteaka-Philipsen, Eva Bolt, Hans van Delden, Eric Geijteman, Marianne Snijdwind, Donald van Tol, and Dick Willems, Tweede Evaluatie Wet Toetsing Levensbeëindiging op verzoek en hulp bij zelfdoding. Den Haag: ZonMw 2012.

¹⁸ Bregje D Onwuteaka-Philipsen, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J F de Jong-Krul, Johannes J M van Delden, Agnes van der Heide, Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet*. 2012 Sep 8;380(9845):908.

¹⁹ An example of this optimism is the article mentioned above, Bregje D Onwuteaka-Philipsen, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J F de Jong-Krul, Johannes J M van Delden, Agnes van der Heide, Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet*. 2012 Sep 8;380(9845):908-15; another is RDMA-official Eric van Wylick’s analysis for the Canadian Medical Association in August, 2014; see <https://webcasts.welcome2theshow.com/cma2014/end-of-life>. Last visited Sep 17, 2014.

²⁰ E.g., the mortality numbers in 2004 were 136,553, in 2014 139,223, i.e., an increase of 1,9%. See <http://statline.cbs.nl>.

lead to a stabilisation of the numbers rather than an increase, is in strong contrast with empirical evidence. With the already high numbers having tripled since the introduction of the 2001 Law, and with no end to the rising of the numbers in sight, the Dutch experience is a strong indication that a law legalising PAD is not the end of a trajectory, but rather the beginning of much more to come.

The numbers of PAD for psychiatric patients have increased from approximately 4 p.A. in 2005 to 50 p.A. in 2015. An even greater increase has been found in cases of PAD for patients with (commonly early stage) dementia: from approx. 1 p.A. in 2005 to over 100 in 2015.²¹

Cases that were accepted by the RRCs, but which continue to stir public debate (both for and against) concern PAD in dementia, accumulating age related complaints, psychiatry, and exceptional cases such as blindness, autism, loneliness, grief, or unemployment in combination with a medical condition. Finally, also a number of cases of ‘euthanasia for two’ have been reported.

As I write, new grounds are being explored and discussed: euthanasia for people with advanced dementia, euthanasia for people who have no diseases but who are ‘tired of life.’ In my opinion, part of the reason for the widening of the reasons is found in the fact that the criterion of unbearable suffering – one of the cornerstones of the Dutch PAD-Act – has proven to be difficult to handle, if not outright unmanageable, in the case of competent patients with a persistent euthanasia request. In these cases, the criterion of unbearable suffering inherently begs the question: who are others – doctors, consulting doctors, RRC-members – to say that a person who claims to suffer unbearably, in fact does not suffer ‘seriously enough’? Doctors with a long lasting and/or intense doctor-patient relationship may come the closest to discerning the seriousness of the suffering in a patient, but even their assessments may not be accurate. For all other doctors, this is likely to be much harder, and so in the end reliance is placed on a person’s request. Moreover, the experience of ‘unbearable suffering’ strongly depends on individual factors. The problematic nature of the criterion of unbearable suffering is illustrated by the fact that, of the 75 cases that were sent to the Prosecutor, only five were rejected by the RRCs on the basis of the argument that it was not made convincingly clear that the suffering was unbearable. Since in practice the criterion of unbearable suffering is identical to the criterion of a well-considered request, the criterion will apply to anyone, irrespective of the seriousness of his medical condition, who insists on having his life terminated.

Apart from the widening reasons for competent adults to request euthanasia, discussions are also going on about allowing people with mental handicaps and children age 1-11 to have euthanasia.

²¹ Numbers 2015 presented on March 17, 2016 by RRC official Sjeff Gevers. Annual Report 2015 to be published later in 2016.

This latter development – the Dutch Parliament has recently²² held a ‘round table discussion’ about euthanasia for young children – is especially concerning. If accepted, an inclusion of young children could undermine the longstanding Dutch consensus about ‘euthanasia being on request only,’ and may mark a move back to euthanasia as ‘mercy killing,’ the form in which it entered the Dutch discussion in the late 1960s.²³ In April 2016, a discussion has started about the possibility of euthanasia for people with mental handicaps in an unbearable and unbearable stage of their lives.

²² 22 January 2016.

²³ The starting point for the Dutch discussion on euthanasia was the book *Medische macht en medische ethiek* (Nijkerk: Callenbach 1969) by psychiatrist J.H. van den Berg. Van den Berg’s book contains graphic photo’s of incompetent patients in severe suffering.

5. End of Life Clinic

Summary: In 2012 the ‘End of Life Clinic’ was established on the initiative of the Dutch Voluntary Euthanasia Society. The End of Life Clinic operates in teams of travelling doctors. The numbers of PAD at the hands of the End of Life Clinic went from 53 in 2012 to 365 in 2014. The numbers of patients and teams continue to increase. The End of Life Clinic provides PAD to patients without there being a doctor-patient relationship prior to the euthanasia request, and offers no palliative care.

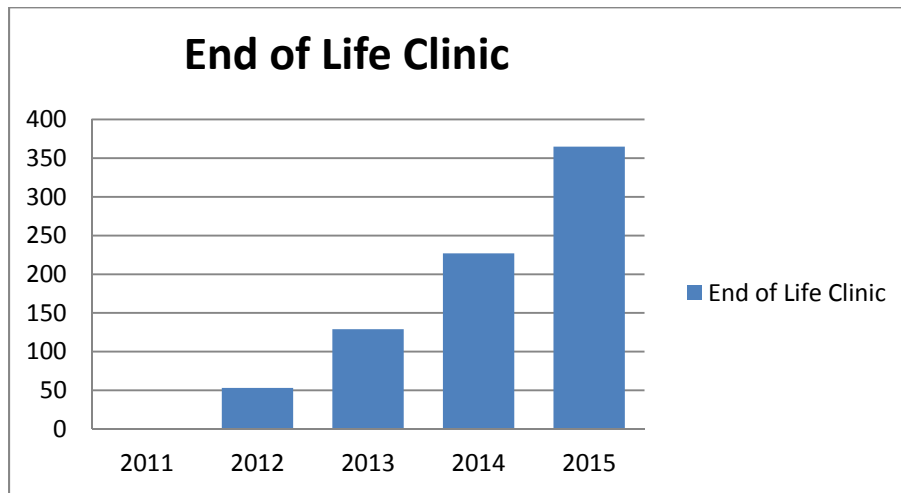
Traditionally, PAD in the Netherlands was considered to be an intimate act that could take place only within a long standing doctor-patient relationship. Given the fact that a considerable number of physicians continue to refuse to provide PAD, either as a matter of principle (they never perform the act) or because they will not perform the act in *a particular* situation, the Dutch Voluntary Euthanasia Society (NVVE) founded the End of Life Clinic in The Hague. The Clinic opened its doors in early 2012. There is no reason to doubt the motives of the doctors involved: the End of Life Clinic is not a commercial initiative and merely has to generate enough income in order to cover the expenses.

The teams of the End of Life Clinic typically have no patient-doctor relationship prior to a euthanasia request. The relationships are established solely for the purpose of PAD. Close to 50 teams now operate nationwide; the term ‘Clinic’ does *not* refer to the presence of a building where PAD is provided. On most occasions the PAD is provided at the patient’s home. End of Life Clinic teams see the patient at least once (sometimes more than once) before making a ‘go’ or ‘no-go’ decision. The most problematic aspect of the Clinic’s work is the fact that its doctors cannot provide any form of palliative treatment. Although the Clinic provides PAD to terminal patients also, a relatively large part of clients are patients suffering non-terminal conditions and could have lived years, some even decades, before dying a natural death.

In 2014 and 2015, the RRCs ruled that four cases were not conducted in accordance with the PAD-Act. The Committees, however, questioned neither the absence of a doctor-patient

relationship, the absence of any form of palliative expertise in its doctors, nor the institutional setting in which death was being administered. Paradoxically, an advantage of the Clinic is that it takes the burden of providing PAD from ‘ordinary doctors’.

In 2012, the year in which the Clinic opened its doors, 53 individuals were euthanized by the End of Life Clinic. In 2015, this number had risen to 365 patients.²⁴



²⁴ www.levenseindekliniek.nl.

6. Pressure on doctors and patients

Summary: The majority of Dutch doctors experience pressure to provide assisted dying: Societal pressure, pressure from patients, pressure from a patient's relatives. Pressure on patients to request PAD is likely to take the form of a patient's internalised concern for the wellbeing of loved ones.

A concerning feature of Dutch euthanasia practice is the phenomenon of pressure on doctors and patients. With the increasing 'normalisation' of PAD, this pressure has increased. According to a survey conducted in 2015 by the RDMA, the majority of physicians (70%) in the Netherlands experience pressure to perform PDA. In addition, the majority (64%) have experienced an increase in such pressure.²⁵ 87% of the physicians hold the view that the (Dutch) society should be more aware about how emotionally burdensome providing PAD can be. Only 25.6% of the physicians hold the opinion that patients are sufficiently aware of the fact that there are limits to PAD. And 50% of physicians indicate that they have occasional sleepless nights because of a case of PAD. While 75% of the doctors are convinced that 'considering and providing' PAD comes with being a physician, they view it as very burdensome, both emotionally and professionally, and believe the public underestimates this.

My ten years of service on the RRC confirms that pressure, on the doctor and the patient, is a problem. To be sure, this problem of pressure was seen from the beginning: this is the reason why the standard reporting form contained a question with regard to pressure from relatives. The question on the form serves the purpose also of alerting physicians to the possibility of pressure, particularly family pressure. In a number of reports, physicians do indicate that they experienced pressure prior to granting a PAD request. Referring to this pressure may serve as an indication that doctors have *not* acted in accordance with this pressure, e.g., by postponing assistance in dying. However, it is highly unlikely that physicians that have given in to family pressure are prone to report this to a RRC. Firstly, pressure may come in such a way (either by being subtle, or by emotionally or psychologically overwhelming a physician) that not all physicians may be

²⁵ <http://www.knmg.nl/Nieuws/Overzicht-nieuws/Nieuwsbericht/147880/Euthanasie-hoort-bij-het-artsenvak-maar-is-emotioneel-belastend.htm>. The data from this section are taken from this RDMA source.

able to recognize it as pressure. Moreover, even physicians who are aware that they acted upon family pressure are not likely to make this explicit in a PAD report. Not only would they admit a personal (or professional) defeat, but mentioning the occurrence of pressure is also likely to have the RRC make a request for more information. In that case, a report would be a form of self-indictment. Nevertheless, family pressure on the physician and the patient can be read between the lines of a report. Overt pressure is more difficult to prove.²⁶

In the last 500 reports that I reviewed in the year prior to stepping back as a RRC member, ‘family’ featured as a factor in the decision to request PAD in at least about one out of ten cases. Notably, in the majority of these cases, the patient has expressed concern for the wellbeing of his or her loved ones as one of the reasons (among others) behind a PAD-request. It is remarkable that in a considerable number of cases (50% or more, in my estimation) in which help is asked from the End of Life Clinic, a patient’s relatives take the initiative. Sometimes this pressure is direct: relatives insist that the patient and the doctor should consider the option of PAD. In other cases, family pressure is internalized. I have seen hundreds of cases in which one of the reasons for a request for PAD is a patient’s wish to protect his relatives from the burden of having to take care, or having to witness the suffering of a loved one. Often the problem is not overt pressure on the side of the relatives; it is the absence of the positive reassurance of relatives to the patient that they (as relatives) will take care of the patient as long as needed, and that there is, on their part, no reason to seek assisted dying.

Another sign of how pressure is a feature of the practice of PAD in the Netherlands is a law that will be presented shortly to the Dutch Parliament obliging doctors who do not want to perform euthanasia to refer the patient to a ‘willing’ colleague.²⁷

²⁶ One example of pressure (details changed so as to not reveal any confidential information) is documented in my article; ‘When Family Violence Takes Subtle Forms: A Narrative from a Dutch Context’, *NGTT* 52 (2011), supplement 1, 37-42.

²⁷ *Voorstel van wet van de leden Dijkstra en Voortman tot wijziging van de Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding in verband met de invoering van een verwijsplicht voor de arts*, 2015.

7. Concluding Remarks

It is my opinion that the fact that PAD has been made legal has contributed to a paradigm shift from PAD as a last resort to PAD as a default way to die. The marked improvement in the quality of palliative care over the past 15 years²⁸ has not at all prevented the numbers from going up. PAD is increasingly seen not as a last resort but as ‘a good death after a trajectory of good palliative care’. Similar developments can be found in Belgium.

Although discussions in the Netherlands take place in a well-mannered way, they illustrate the fact that a PAD-law does not come alone: it introduces new dynamics to society, and to the debate of life and death in society. Rather than being the end of a discussion, a PAD-law causes or fuels new discussions.

In many publications offered by advocates of a more liberal government policy on PAD, PAD is said to be an alternative for patients who otherwise would choose to have a suicide. This may be true for some. However, despite the wide availability of PAD and despite their numbers rising from 1,800 to 5,550 in 10 years, the numbers of suicide have gone up by 36% in the past 7 years. There are two discernible reasons for this. First, PAD-procedures (especially for patients with a psychiatric condition) are bound to take weeks and months, which may be experienced as too long a period for a patient with an acute death wish. Second, the ongoing discussions and media attention for death as a solution to suffering contributes to a cultural climate in which death is seen as a legitimate solution to any form of serious suffering.

I respect the situation in which the Dutch find themselves. I do not question the moral and personal integrity of those who are involved in providing PAD, of the RRCs and their members reviewing these cases, nor of those who press for further liberalisation. However, with hindsight, in my view the Netherlands may have made a mistake in giving PAD the official legal status that it has. If there is one lesson to be learnt from the pioneering experiences in the Netherlands, it is that a law on PAD is bound to create its own, new dynamics, instead of closing old discussions. Despite the fact that palliative care in the Netherlands has reached an historically unprecedented

²⁸ Chambaere K, Bernheim JL, ‘Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience’, *J. Med Ethics* doi:10.1136/medethics-2014-102116.

quality, the preoccupation with death and with PAD is larger than ever before. The categories of cases in which PAD is seen to be a solution continue to be pushed ever broader. The increasing pressure placed on doctors to perform PAD, and on patients to opt for PAD, is a problem, a worrying feature to say the least, of a PAD system that had its beginnings in tolerating acts of euthanasia for humanitarian reasons in limited terminal cases. The developments of the past 10 years are even more remarkable with view to the fact that the quality of palliative care was improved considerably in comparison to the 'pioneering years' of PAD. There is medication available for pain, dyspnoea, fatigue, anxiety, and other symptoms of terminal illnesses that significantly ameliorates these conditions.

Reflecting in 2016 on the experience and current practice of PAD in the Netherlands it is my view that patients who write the word autonomy with a capital 'A' should perhaps consider the consequences of the exercise of the kind of autonomy they seek to assert: rather than asking the doctor to provide death and insist on a change in law, these persons should make their own provisions, or else consider less radical alternatives. For it is preferable that those who insist on dying sooner look for ways to find such a death without involving their physician and changing the law in their society that prohibits euthanasia and physician assisted suicide. Confronted here in the Netherlands with a culture in which physician assisted dying is increasingly becoming a patient's right, a default way to die, and a default way to deal with life's difficulties, I am now convinced more than ever before that what a society faced with calls for the legalisation of PAD should do, is protect the lives of its members and provide the best possible care, affordable to all who need it. A society should not be involved in organizing the death of its citizens.