Submission Prof.dr. Theo A. Boer

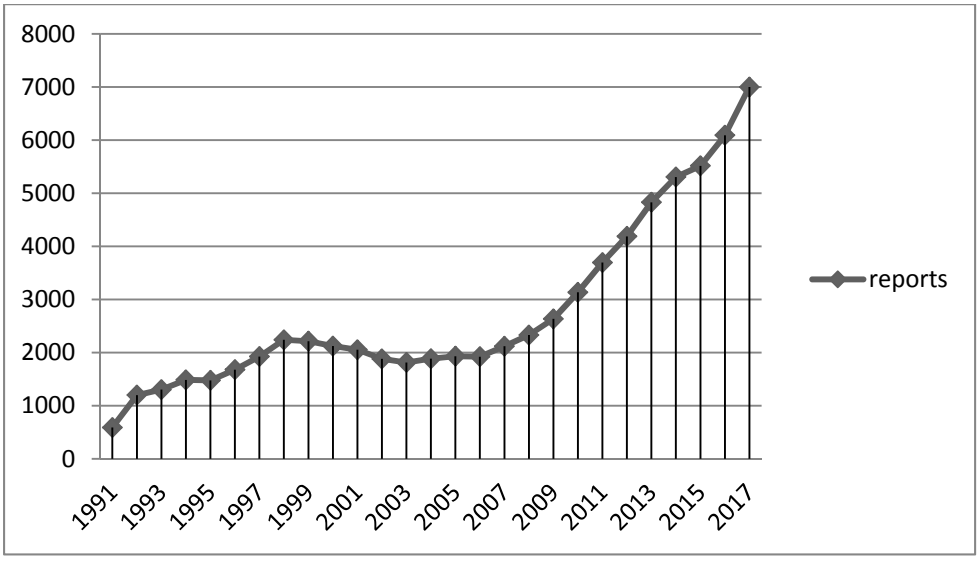
Groningen, March 5, 2018

Ladies and gentlemen,

During 10 years I served on a Euthanasia Review Committee in the Netherlands. In those years I saw 4,000 cases of euthanasia and assisted suicide. Based on my experience, I have become increasingly hesitant to advise countries to legalize physician assisted dying (PAD). Here's why.

Despite mortality rates being constant, the cases of PAD have gone up. From about 1,800 reported cases in 2003[1] to more than 7,000 in 2017,[2] with no sign that the numbers have come to a halt. Moreover, the latest Governmental Evaluation (2017) estimates that as much as 23% of the cases go unreported.[3] This means that we may hit the 9,000 mark in 2018.

The numbers remained stable until about 2007, and until about 2009, my colleagues and I would go into other countries and tell everyone that the situation in the Netherlands really was very much under control. However, from about 2007, the line went up rather steeply, which I think has to do with the fact that we may have needed a couple of decades to get used to the whole idea of euthanasia, and it turned from a last resort to a normal option.



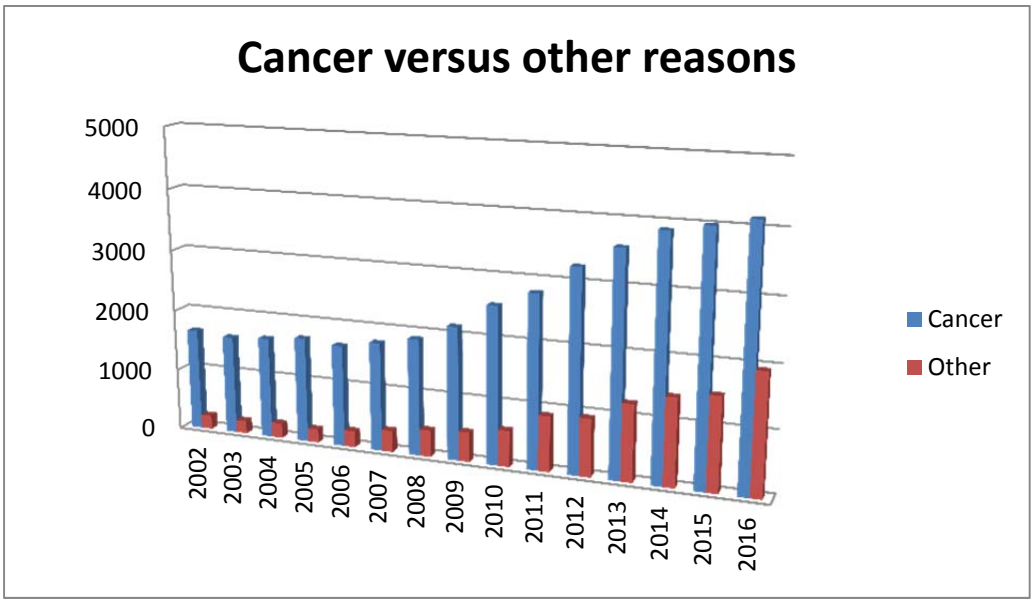
Reported cases since 1991. In 2002 euthanasia was legalized
Source: Regional Review Committees RRCs

(2) The fact that PAD is made legal, may have contributed to a gradual paradigm shift from PAD as a last resort to PAD as a default way to die. The fact that the quality of palliative care has become much better in the past 15 years, has not prevented the numbers from going up. PAD is increasingly seen not as a last resort but as 'a good death after a trajectory of excellent palliative care'. To illustrate: in some Dutch cities, such as Alkmaar and Almere, euthanasia now accounts for about 9% of the total mortality rate. Within these cities, there are postal code areas in which euthanasia accounts for up to 15% of deaths.[4] The consequence may be that valuable knowledge in the field of palliative care will leak away.

I conclude that the legalization of euthanasia is not only the end of discussions and not only the official recognition of hitherto unrevealed practice, but also creates new realities.

(3) Pressure on doctors increases. According to a survey conducted in 2015 by the Royal Dutch Medical Association (KNMG), a majority of physicians in the Netherlands experiences this pressure as problematic.[5] Most doctors continue to see PAD as very burdensome, both emotionally[6] and professionally, and think the public underestimates this[7].

(4) The reasons for having euthanasia continue to expand. In the beginning it was almost exclusively cancer in a terminal stage (95%). This number is now down to 68%, the rest of them being PAD in, e.g., early dementia, accumulating age related complaints, psychiatry, and exceptional cases such as blindness, autism, and grief etc. Hundreds of patients yearly receive euthanasia who could have lived for years or decades.



Cancer versus other reasons 2002-2016

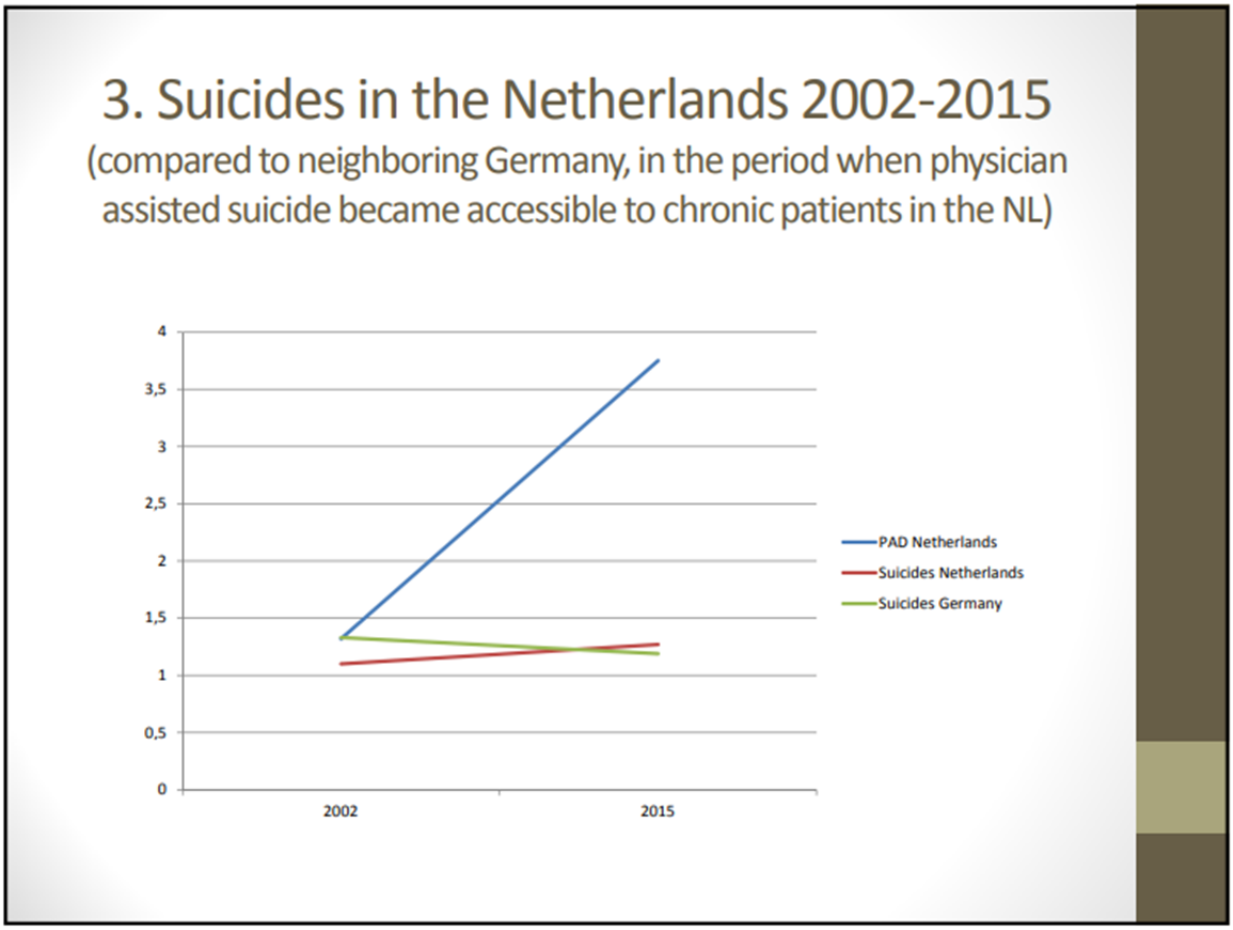
As we write, new grounds are being explored and discussed: euthanasia for infants, euthanasia for people with advanced dementia, and euthanasia for people who have no diseases but who are 'tired of life'. Similar developments can be found in Belgium. Although these discussions take place in a well-mannered way, they illustrate the fact that a PAD-law does not come alone: it adds a new dynamic to

the debate. Rather than being the end of a discussion, a PAD-law is bound to be the onset of new discussions.

(5) The criterion of 'unbearable' suffering – one of the cornerstones of the Dutch euthanasia law – will in the long run prove to be unmanageable: who are others to say that a person who claims to suffer unbearably, in fact does not suffer seriously enough? In the end, we will have to rely on a person's request. This is illustrated by the fact that, of 55,000 PAD cases in the Netherlands, only a handful were dismissed by the committees on the basis of the argument that the suffering was unbearable.

(6) I have special doubts about laws that include heavy involvement of doctors. To be sure, euthanasia (i.e., by doctors) will help patients who are in a terminal stage of cancer and who can no longer swallow a poisonous drink. (Otherwise these patients may have to request the assistance in dying earlier.) However, medical involvement also lowers the barriers: of all Dutch patients (even those who can still eat, drink, walk, etc), 97% prefer the doctor to 'do the act'.[8] The involvement of doctors in the Netherlands and Belgium may be the main, or even sole explanation for the enormous difference in the number of assisted deaths between Oregon and the Benelux countries. Between 2003 and 2016 the reported cases in the Netherlands went up from 1,805[9] to 6,091[10] and in Belgium from 235 to 2,021[11] . In the same period in Oregon, the number of assisted suicide deaths went from 42 to 135[12]. Whereas assisted suicide accounts for about 0.4% of all deaths in Oregon[13], euthanasia accounts for about 2.1% in Belgium[14] and 4.3% in the Netherlands[15].

(7) The claim is often made that if we want to prevent violent suicides, we should provide people a way out. The availability of PAD is said to be an alternative for patients who want to have a suicide. This may be true for some. But as for the Netherlands, despite the wide availability of PAD and despite the numbers rising from 1,800 to 6,091 in the period 2007-2016, the number of suicide cases went up by 40%.[16] The rise was all the more significant since in exactly that same period we made assisted dying possible for the categories of people that do commit suicide. I see two reasons for the increase in suicides. First, PAD-procedures (especially for patients with a psychiatric condition) are bound to take weeks and months, which is way too long for a patient with an acute death wish. Second, the ever ongoing discussions and media attention for death as a solution to suffering may contribute to a cultural climate in which death is seen as a solution to any form of severe suffering. This mechanism (‘speaking about assisted dying leads to more death wishes’) was officially suggested by Spokesperson Jan Latten of the Dutch Bureau of Statistics (CBS) in June 2017, when he presented the latest suicide figures.[17]



(8) A considerable number of people ask for PAD out of concern for their loved ones. (In my last 500 dossiers, I counted: 'family' was a factor in about 10% of these cases.)

(9) I have come to believe that euthanasia is a danger for vulnerable people – not in the sense that people are forced externally, but in the sense that they feel that society no longer provides hope to go on. I have become painfully aware that the possibility of euthanasia and assisted suicide increasingly contributes to a culture of death. A recent example is the announcement of the Minister of Health, Edith Schippers in 2016,[18] that assisted suicide should be available for anyone who has a 'Completed Life': elderly people who have no sickness, but who are suffering from loneliness, bereavement, disconnection, and they should be a minimum age of 70 or 75 years old. Although the new Government that is in place since October 2017 is less certain about 'Completed Life' (it consists of a coalition of Christian Democrats and Liberals), it was agreed that nothing would stand in the way of a Completed Life Bill if Parliament, after thorough investigation, would take the initiative and adopt this Bill. I am deeply convinced that this leaning towards death increasingly influences severely impaired, deeply suffering, and elderly people to consider active killing as their only way out.

I would urge the New Zealand Parliament to take experiences from the 'guiding countries' seriously, especially the experiences from the last 10 years. One suggestion is that, *if* a law is formulated, this law should contain very precise criteria and to leave out the open-ended criteria such as 'unbearable suffering'. Moreover, a constituency should consider keeping medical involvement as low as possible. However, the best solution may be to refrain from legalizing PAD altogether, since we do not know whether additional safeguards will, in the long run, hold.

Sincerely,

Theo Boer
Professor of Health Care Ethics, Kampen University
Lecturer of Ethics, PThU, Groningen
Associate, Ethics Institute, Utrecht University

Notes

[1] Regional Euthanasia Review Committees (2004, April 1). *Annual report 2003*, p.8. Available at https://www.euthanasiecommissie.nl/uitspraken/jaarverslagen/2003/nl-en-du/nl-en-du/jaarverslag-2003.
[2] Based on data that leaked out in January 2018. Definitive data expected in June, 2018.
[3] According to the official statistics there were 7,254 deaths with the 'explicit intention of hastening death' in 2015, but only 5,516 were reported to the Regional Committees. That means about 23% were not reported to the Review Committees. In StatLine. (2017, May 24). Deaths by medical end-of-life decision; age, cause of death. Available at https://opendata.cbs.nl/statline/#/CBS/en/dataset/81655ENG/table?ts=1520174905967.
[4] Based on data obtained from Dutch health insurance companies. Expected to be published in 2018 under authorship of T.A. Boer and A.S. Groenewoud.
[5] 69.97% of doctors who received at least one request for euthanasia during the previous 10 years said they experience pressure to perform euthanasia (Question 10) and 63.98% said this pressure has increased in recent years (Question 11). In KNMG (2014, December 11). *Helder communiceren over euthanasia met de patient: belevingsonderzoek arts en euthanasie*. Available at the link "Uitkomsten belevingsonderzoek euthanasie" at https://www.knmg.nl/actualiteit-opinie/nieuws/nieuwsbericht/euthanasie-hoort-bij-het-artsenvak-maar-is-emotioneel-belastend.htm
[6] 57% of doctors who received at least one euthanasia request during the previous 10 years rated the emotional burden of euthanasia as 8 out of 10 or higher (Question 9.4). 49.39% of doctors who received at least one euthanasia request during the previous 10 years said that they sometimes lie awake because of euthanasia and 27.74% said that they don't (Question 15.7). *Ibid*.
[7] 77.81% of doctors who received at least one euthanasia request during the previous 10 years thought that the public should pay more attention to the fact that euthanasia can be burdensome for doctors (Question 15.1). *Ibid*.
[8] Regional Euthanasia Review Committees (2016, April 26). *Annual report 2015*, p. 16. Available at https://www.euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2015/april/26/jaarverslag-2015
[9] Regional Euthanasia Review Committees (2004, April 1). *Annual report 2003*, p.8. Available at https://www.euthanasiecommissie.nl/uitspraken/jaarverslagen/2003/nl-en-du/nl-en-du/jaarverslag-2003
[10] Regional Euthanasia Review Committees (2016, April 26). *Annual report 2015*, p. 16. Available at https://www.euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2015/april/26/jaarverslag-2015
[11] News24. (2016, January 27). Belgian euthanasia cases hit record high. Available at https://www.news24.com/World/News/belgian-euthanasia-cases-hit-record-high-20160127
[12] Oregon Health Authority. (2017, February 10), Oregon Death with Dignity Act Data Summary 2016, p.4. Available at http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf
[13] During 2017 the estimated rate of DWDA deaths was 39.9 per 10,000 total deaths, or 3.99% of all deaths. Oregon Health Authority. (2018, February 9), Oregon Death with Dignity Act 2017 Data Summary, p.5. Available at http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year20.pdf
[14] Out of 110,508 total deaths in Belgium during 2015. In Statista. *Total number of deaths in Belgium from 2006 to 2016*. Available at https://www.statista.com/statistics/516846/number-of-deaths-in-belgium/
[15] Out of 147,134 total deaths in the Netherlands during 2015. In Statista. *Total number of deaths in the Netherlands from 2006 to 2016*. Available at https://www.statista.com/statistics/520011/total-number-of-deaths-in-the-netherlands/
[16] Source: Central Bureau of Statistics, https://www.cbs.nl/en-gb
[17] Van de Wetering, Kim (2017), 'Waarom neemt zelfdoding onder ouderen toe?', *Trouw*, June 28, 2017, https://www.trouw.nl/home/waarom-neemt-zelfdoding-onder-ouderen-toe-~aa84d98f/
[18] NOS. (2017, March 10). Schippers: wet voltooid leven liefst in volgend kabinet. Available at https://nos.nl/artikel/2162303-schippers-wet-voltooid-leven-liefst-in-volgend-kabinet.html