To the Social Affairs and Health Care Committee in the Finnish Parliament

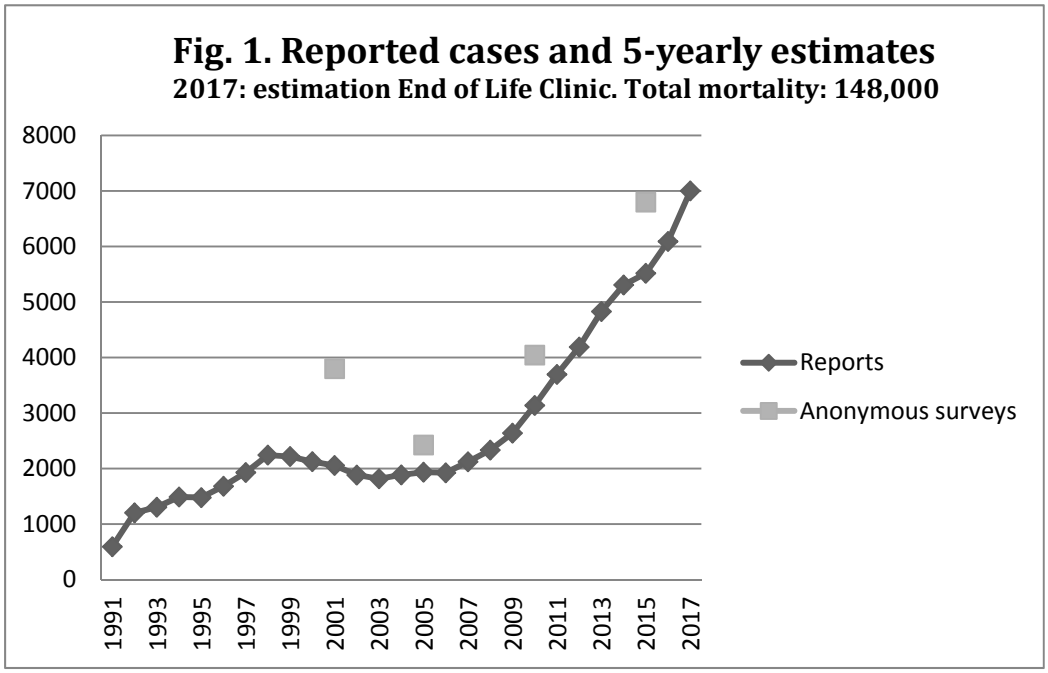
Groningen, March 2, 2018

Ladies and gentlemen,

In this brief paper, on the basis of extensive experience in End of Life discussions in the Netherlands, I would like to ask your attention for the fact that after the legalisation of euthanasia in the Netherlands, we have seen a surge in the numbers, a surge in the medical reasons for euthanasia, and an increasing number of contested cases.

The Numbers

The expectation expressed in Dutch debates in the 1990s and found in international reports well into the early 2010s was that legalising euthanasia would lead to a stabilisation of the numbers, finds no empirical support. After an initial pause in the early 2000s – in which most commentators believed that the stabilisation was the consequence of legalization, the numbers have more than tripled since, with no signs of a slowing down of the rise in numbers. In some regions, euthanasia now accounts for 10% of the mortality.



The Reasons

In the 1980s and 1990s, euthanasia in the Netherlands took place in so called traditional settings: euthanasia in the case of terminal cancer, provided by a patient's own doctor, days or weeks before a natural death was expected. Since about 2007, an increasing number of euthanasia cases take place for non-terminal illnesses: from about 100 reported cases in 2002 to about 700 in 2014, an increase of about 600%. The number of psychiatry and dementia cases went from single-digit numbers in 2002 to 201 cases in 2016.

Increasing Number of Contested Cases

Cases that were accepted by the RRCs, but which continue to stir public debate, concern euthanasia in dementia, in accumulating age-related complaints, in psychiatric illnesses, and in exceptional circumstances such as blindness, autism, loneliness, grief, or 'euthanasia for two.' Dozens of cases have caused societal debate, some more, some less, in part in connection to documentaries and other media attention.

(1) A first example is the euthanasia of Gaby Olthuis, an otherwise healthy 45-year old mother of two who suffers from tinnitus, with a life expectancy that would normally span decades.[1]

(2) Another example is the euthanasia of Hannie Goudriaan, a 65-year old patient who suffers from temporal variant dementia (TV-FTD), also known as semantic dementia, which includes a loss of the meaning of words and eventually of objects. Ms. Goudriaan, who makes a lively impression and manifestly enjoys going to sports events, still drives a car. However, in an advance directive she has indicated that she does not want to enter this stage of dementia, and she has held on to that directive in the first stages of her dementia. When she is about to be euthanized, however, she hardly seems to realize what is happening and even seems to resist being given the injection. The case was televised and the euthanasia was widely criticized for being 'murder,' an 'execution.'[2]

Because euthanasia in the case of a patient who expresses protest, in an unknown but increasing number of dementia cases the patient is being given a sedative before the euthanasia. In late 2016, a case was reported in which the patient was given a sedative in her coffee, yet woke up at the moment of the euthanasia an resisted being injected. She was euthanized with the help of her children, who held her while the doctor injected the life terminating medication. The RRCs rejected the case, but it is not clear whether it was rejected because it is wrong to euthanize an incompetent patient, or because it is wrong to euthanize a patient offering defense (in this last case, the patient should simply have gotten more sedatives).

(3) In a considerable number of cases loneliness constitutes part of the suffering. An example is the euthanasia of Ans Dijkstra, a 100 year old woman who is relatively healthy, who suffers from age-related complaints and bereavement (her son has recently died), and who complains that her 'brains are still doing so well.' Some days before her euthanasia, she is taken out by a relative to visit the coast. When, after a beautiful day, she returns home and is asked about her euthanasia wish, she replies, 'This has been such a wonderful day. I don't feel like discussing euthanasia now.' On the day of her death, she drinks a last glass of Port wine, lays down on her bed and before the doctor euthanizes her, says, 'I'm on my way to my son now.'[3] All these cases were approved by the RRCs.

In my own ongoing research, I have found that in at least 276 of the 2,260 cases (or 12.1%) reviewed in the period 2010-2014 loneliness played an essential role in a patient's suffering. If we select only the reports in which the patient had at least one year to live, the loneliness factor was 40.9% (89 out of 218 cases).

(4) Euthanasia for two: in my reports, I found 11 patients who had euthanasia together with their spouse, with the first case occurring in 2010. A recent example was in November 25, 2017, when the largest national newspaper *De Telegraaf* opened on the front page with the story of two patients, Jack and Puck, both in their late sixties, who have decided to have euthanasia together. Jack has cancer in a terminal stage; his wife Puck has a slowly progressing form of dementia and 'could become a hundred years old.'

The reason for referring to these and other narratives is not to question the integrity or the suffering of anyone involved, but to point to their potential effect on public views. In the case of Jack and Puck, they stress that 'they are not missionaries.' Still, the newspaper brings the story in commendable terms, adding that the couple has never ever received any negative judgment from those around them, and quoting them: 'Perhaps other people wrestle with similar things as we. Perhaps for them it is a comfort that it is possible. That for a loving couple it is possible to make this last journey together at a moment of your choice…'. The article proceeds: 'Puck's older sister has the same illness and lives in a caring facility. […] "Never ever for me," [was Puck's reaction when she received her diagnosis].' This is just one example out of hundreds that shows that ground breaking narratives of euthanasia are likely to have a formative effect on our views about dependency and dignity.[4]

(5) In at least 53 cases I saw, mourning played an important role in the suffering of a patient. Grief can be all the more serious when a patient has no prospect of a natural death. How this can develop, is illustrated in the Australian documentary film 'Allow Me to Die'.[5] It features an 84-year-old Belgian woman, Simona de Moor, who, upon receiving the report of the unexpected death of her daughter, decides that she wants to have euthanasia. After failing to help her with an antidepressant – about which Simona remarks that it will not bring her daughter back – the doctor decides to grant her request.

Three months after the death of her daughter, Simona eats her last breakfast and rides her last miles on a home trainer before going to sleep: 'I am ready to meet my daughter.' Her life expectancy could well exceed ten years. But who would contest the seriousness of becoming a widow, losing a daughter, and being estranged from the other daughter?

Conclusion

I supported the euthanasia law back in the early 2000s, not only because I could well imagine that a physician in extreme cases would help a patient die, but also since it reflected the will of a majority of citizens. However, I now consider it proven that a euthanasia law is not only the closing part of discussion, but is also the beginning of something much bigger, namely a development towards the normalization of death on request, with an increasing pressure on doctors and patients to accept euthanasia as *the* form of dignified dying. I now fear that important expertise about palliative care will leak away. Up and until it has become cleared how such a slippery slope can be prevented, I strongly urge legislative bodies to not legalize euthanasia and, instead, to put all possible effort into exploring the alternatives.

Sincerely,

Theo Boer
Professor of Health Care Ethics
Member of Regional Review Committee for Euthanasia 2005-2014
The Netherlands
taboer@pthu.nl

The views in this paper do not represent the views of any institution and are the author's own views, based on extensive research

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NOTES

[1] https://www.youtube.com/watch?v=HGcUJ2Dg3uo, with English subtitles.

[2] Https://ww.youtube.com/watch?v=bJ_GvyA5AI8.

[3] *Ibid*.

[4] In an analysis of thirty documentary films on the topic, Dutch journalist Gerbert van Loenen found that all productions he reviewed commend euthanasia in ground breaking cases. Van Loenen, Gerbert (2015), *Lof der onvolmaaktheid: waarom zelfbeschikking niet genoeg is om goed te leven en te sterven.* Utrecht: Ten Have. Van Loenen has personal experiences in this: during the ten years in which he took care of his partner who had serious brain damage after surgery, several people around him suggested that euthanasia would be the better option. Hence the title of his earlier book: 'He would be better off dead,' Van Loenen, Gerbert (2009), *Hij had beter dood kunnen zijn*. Amsterdam: Van Gennep 2009.

[5] See http://www.sbs.com.au/news/dateline/story/allow-me-die.