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10 How Legal Euthanasia Continues to be Transgressive

Some Observations from the Netherlands

A. Stef Groenewoud and Theo A. Boer

10.1 Introduction

In his piece, "When Conscience Wavers: Some Reflections on the Normalization of Euthanasia in Belgium," Willem Lemmens argues philosophically in favour of the claim that euthanasia is and remains a transgressive act.[1] First, euthanasia goes far beyond the realm of other medical interventions that are considered transgressive but morally acceptable, such as the use of a scalpel that cuts through a person's skin and the occurrence of relationships of personal proximity. Second, euthanasia is transgressive in that it crosses the border between the existence and non-existence of human beings; in a sense, euthanasia therefore has sacred character. Thirdly, more than in most other medical interventions, euthanasia involves the physician as a person and not merely as a professional; as a human being, in their own moral integrity.

In the second part of his chapter, Lemmens problematizes the process of normalization of euthanasia. The fear is not only that – as a result – euthanasia's weighty dimensions will no longer be discerned (namely, the existential or even sacred character of the act of ending another human being's life), but also that it will further permeate our societies, and will even turn into a collective morality of self-determination. In the end, euthanasia will have become the emblem of a clean, self-desired death, including for those who are not terminally ill. Lemmens concludes with three observations regarding the normalization process of euthanasia: first, the depenalization of euthanasia has increased pressure on the conscience of individual physicians, especially when a patient's death is not reasonably foreseeable. At the same time, and this is his second observation, the transgressive act of euthanasia is reduced to a neutral, and purely procedural act in which existential, moral and professional considerations move to the background. Third, Lemmens addresses that the normalization of euthanasia has strengthened problematic coping

1 When in this piece we use the term, 'euthanasia,' this refers to both euthanasia and physician-assisted suicide. In Belgium and the Netherlands, both forms of assisted dying reside under one law.

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attitudes on the side of physicians as they both (i) hide behind legal procedures, and (ii) pretend that one, as a physician, is motivated by a pure and good will, not contaminated by doubts or afterthoughts.

10.2 Ethics, Law, and the Transgressive Character of Euthanasia

Both Belgium and the Netherlands have laws that allow euthanasia. Compassion and autonomy are the core values underlying these laws but they are not the only ones: the respective legislative bodies also stress the duty to protect human life and the duty to protect vulnerable citizens. Legally therefore, the intentional killing of a human person is a last resort. Given this transgressive character of euthanasia, committees were put in place to assess each reported euthanasia legally and ethically. In the Netherlands five so called Regional Review Committees (RTE) exist, each consisting of one lawyer, one physician, and one ethicist; in Belgium, there is one national committee with a similar composition. The combination of legal, medical, and ethical perspectives has proven to be increasingly enigmatic.[2] The task of ethics is to describe practices in a way that does justice to their moral complexity. In comparison, a legal assessment is simpler: an autonomous patient's request in a situation of unbearable and irremediable suffering are the main requirements. What the legal experts that preside the committees (plus the physicians waiting for their verdicts) have to ascertain, is whether or not a case has met these requirements. The Dutch and Belgian committees' verdicts can go only two ways: affirmation or rejection. If a case meets the criteria, the euthanizing doctor receives an exculpatory notification; if it is defective in one or more of the due care criteria, it is sent to the public prosecutor and the health inspector general for further examination. This happens very rarely: in 2020, only two out of 7,000 cases were rejected, one because the physician used the wrong vein, the other because the consulting doctor was registered as a patient in the euthanizing doctor's practice.[3]

Ethically, however, such affirmative or dismissive verdicts may be less satisfying.[4] It is, for example, very well possible that cases that are found to be legally sound continue to be ethically problematic. What if

2 Berna van Baarsen, "Oordelen toetsingscommissies euthanasie soms onvolledig. Kanttekeningen bij werkwijze regionale toetsingscommissies euthanasie," *Medisch Contact* 39 (2019): 14–17.

3 Regionale Toetsingscommissies Euthanasie, *Jaarverslag 2020* (*Annual Report 2020*) (Den Haag, 2021), https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2020/april/15/jaarverslag-2020/2101423_RTE-jaarverslag-2020_DRUK.pdf.

4 Berna van Baarsen, "De toetsing van euthanasie: zorgen om kwaliteit, argumentatie en normontwikkeling," *Tijdschrift voor Gezondheidszorg en Ethiek* 28(3) (2018). https://www.tijdschrifttge.nl/documenten/archief/tge/tge201803_p79-87_vbaarsen_de.pdf.

a patient partly bases their autonomous request on concerns for their loved ones? What if a patient refuses to consider their loved ones' viewpoints and emotions? What if not the patient but the physician or the relatives bring up the idea of euthanasia? What if feasible alternatives are rejected beforehand? To what extent are a patient's fears of admission to a care facility influenced by the societal imaginary about nursing homes? What if euthanasia, instead of a last resort to prevent a terrible death, becomes a way to prevent a dreaded life? The opposite may also hold: a case can be made that the two cases that were found defective in 2020 were hardly problematic ethically.

We believe that many of the moral concerns are connected with the transgressive character of active and intentional killing itself. Indeed, this transgressive character was a reason to include an ethical perspective in the review procedures. But although in the past two decades both the annual numbers of euthanasia and the complexity of the cases increased significantly, the Belgian and Dutch committees instead have resorted to more expedient methods to handle the workload. At present, more than 90% of the euthanasia reports in the Netherlands are managed by secretarial staff with legal training.[5] The ethicist- and physician- members have formal access to these reports and may influence the verdicts, but in practice only 10% are discussed in an interdisciplinary setting.

It seems that neither the Dutch nor the Belgians, who both placed euthanasia under the Criminal Code, succeed in upholding a public awareness of euthanasia's transgressive character. This is even more worrisome now that several countries are currently thinking of legalizing euthanasia or physician-assisted suicide outside the Criminal Code, or have already done so (such as Canada). We wonder how under those regimes the transgressive character of the act ('killing a patient at their request') will remain part of the public consciousness.

10.3 A 'Wavering Conscience' or a 'Waiver of Conscious Deliberation'?

Lemmens makes some observations on the apparent normalization of euthanasia from a philosophical perspective. One is that euthanasia in the eyes of many features as "a completely neutral act that is completely independent of any ideology and just meets the patient's right to self-determination."(171) Lemmens argues that the awareness that euthanasia is the outcome of a conflict of values is fading. He claims that this has consequences for the functioning of the doctor's conscience. More in particular, euthanasia laws and practices together tend to silence possible conflicts of conscience in two ways. First, "[physicians] hide completely

5 Regionale Toetsingscommissies Euthanasie, *Jaarverslag 2020*.

behind the law and let the procedures, provided for by the law, take the place of their conscience: 'the papers are filled in correctly, everything is fine'." This point is also addressed by the Dutch philosopher and physician Peter Harteloh in his book *Pondering about Death*.[6] Euthanasia, according to Harteloh, has become a merely procedural practice and lacks a clear vision on "the good death." Furthermore, Lemmens postulates that as a result of this normalization, physicians may be tempted to believe that they are "motivated by a pure good will, not contaminated by doubts or afterthoughts: one's moral self-conception coincides so to say with one's conscience"(168). Indeed, this trust in the doctor's integrity plays an important role in the origins of the Dutch euthanasia law.[7]

At this point, we suggest that we can go even further than Lemmens does. What if the transgressive nature of the euthanizing act is not just ignored; what if the physician's conscience not only undergoes minor changes? Could it be that in the end a physician's conscience not only wavers (i.e., falters, trembles), but waivers (i.e., faces its virtual abandonment)?

The unintended consequences of legal or financial incentives on people's behaviour, and even on their characters have been extensively described in legal, (moral) economical, psychological and (political) philosophical literature, under the header "cultivation and stimulation of desired and virtuous behaviour." Political philosophers from Aristotle to Thomas Aquinas, Jean Jacques Rousseau, and Edmund Burke recognized the cultivation of civic virtue not only as an indicator of good government, but even as its essential foundation. "Legislators make citizens good by forming habits in them," Aristotle wrote in his *Ethica Nichomachea*, and he continues "it is in this that a good constitution differs from a bad one."[8]

Whereas these and other thinkers (such as David Hume, Niccolò Machiavelli, and the theologian Walter Rauschenbusch) argued that good laws can lead to desired behaviour, others, such as Adam Smith, believed that not laws but markets would do so, and even in a better way.[9] We see these views together make their way into liberal democracies in the 1980s. The *New Public Management* is a neoliberal movement intended to reform public sectors such as health care and education. This was reached through a combination of minimal governmental

6 Peter P. M. Harteloh, "Filosoferen over de dood," *Filosofie en Praktijk* 36 (2015): 95–100.

7 Cf. Anne-Mei The, *Verlossers naast God. Dokters en euthanasie in Nederland* (Amsterdam: Thoeris 2009).

8 Aristotle, *Nicomachean Ethics* Book II, section 1 (trans. W.D. Ross). http://classics.mit.edu/Aristotle/nicomachaen.2.ii.html.

9 Adam Smith, *An Inquiry into the Nature and Causes of the Wealth of Nations* (Oxford: Oxford University Press, 2008, reissued paperback version 1776).

legal prescriptions, accountability procedures, and (oftentimes financial) incentives. The assumption in all this is that legal as well as financial incentives leave the objects of interest (i.e., those to whom these incentives apply, as well as their character and motivation) unchanged: unchanged both in terms of its intrinsic value, as well as in terms of the deepest motivations and character traits of those involved.

But this assumption may not stand experiential evidence, as we will now illustrate with examples from the field of education and health care. Before we do so, however, we want to stress that, of course, not all laws or incentives are bad, even if they may have negative unintended consequences that can reasonably successfully be dealt with. But our concern is that some laws may negatively change people's behaviour and, even more consequential, their characters. Sometimes the cure may turn out worse than the disease, in which case we may consider to reverse the rules and abandon the incentives.

In a famous TED-talk,[10] related to his book, *What Money Can't Buy: The Moral Limits of the Market*, Michael Sandel recounts an experiment in the US city of Dallas where children were paid US$ 2 for each book they read. Indeed, these children started reading more books. They also read thinner books however. It was found that in the long run they developed a wrong idea about the intrinsic value of reading books. Sandel concludes:

> if you pay a child to read a book, as some schools have tried, you not only create an expectation that reading makes you money, you also run the risk of depriving the child forever of the value of it. Markets are not innocent.[11]

Obviously, not all incentives (non-intrinsic stimuli) are neutral, since they may change the way people think about the intrinsic value in the things they do. They may be tempted to act in a certain way, not because this is good or right to do, but for the reward they will receive afterwards. The result is an excavation of people's virtuous characters.

A second example of the intricate relations between incentives and moral behaviour comes from health care. In 2015, Dutch General Practitioner Chantal van 't Zandt received a letter from one of the largest insurance companies in the Netherlands. The company wanted to pay her a visit because they found her to be in the top 50 of high-volume prescribers and referrers of all contracted GPs. Especially the amount of

10 Michael Sandel, "Why We Shouldn't Trust Markets with Our Civic Life" (TEDGlobal 2013), accessed February 23, 2022, https://www.ted.com/talks/michael_sandel_why_we_shouldn_t_trust_markets_with_our_civic_life#t-342423 (min 5:00 and onward).

11 Ibid.

care she provided to terminally ill patients had attracted attention.[12] In a way, the insurance company merely did what the *Health Care Insurance Law* wanted them to do: promoting the use of appropriate care through control mechanisms, and decrease utilization of low-value care. Then why is this a disturbing narrative? Because the insurance company's intervention affected this doctor's deepest feelings of integrity, questioned her motives as a family doctor, and challenged her principles as a virtuous person. If the company had persisted in its claims, and if the physician had complied, this could have had a serious impact on the way she acts and reflects as a professional. She reports how the insurance company forced her to either unveil patient–doctor confidentialities – thus to breach her professional code of ethics – or to change the way she cared for her patients in the future – which would have also meant an external interference in her professional acting as a physician. This illustrates that rules and procedures are not neutral. They do affect the way people act and think, touch upon their moral convictions, and sometimes lead to conflicts of conscience. One would expect that as a physician she would act in accordance with her professional values, guided by her conscience. But what if such conduct will have long-term financial or professional consequences? Will she continue to be a conscientious doctor?

A third example is the closest to our subject: the way legal euthanasia procedures may impact the moral deliberation between and within physicians. It is taken from a interview with Odette Schouten and Marieke de Brouwer, who are both general practitioners. After performing a euthanasia together, Schouten and De Brouwer were summoned to attend an RTE-meeting and answer questions that had risen on the basis of their euthanasia report.[13] Schouten remembers, "My first thought: I have done something wrong. I panicked. I associated it with the Inspectorate – shaming and blaming." Her colleague describes herself as ...

> ... emotionally affected. Angry. You do what is best for your patient. And then you get this. All kinds of scenario's crossed my mind: 'this

12 Chantal van het Zandt, "De 'materiële controle' van de verzekeraar," *Medisch Contact* 12 (2015): 288–90.

13 Martijn Reinink, " 'Ik voel me kwetsbaar.'Op gesprek bij de Regionale Toetsingscommissie Euthanasie," ("'I feel vulnerable.' On interview with the Regional Euthanasia Review Board.") *Arts en Auto* (October 2020): 18–21. https://www.artsenauto.nl/op-gesprek-bij-de-regionale-toetsingscommissie-euthanasie/. Quote in Dutch: "Mijn eerste gedachte: ik heb iets fout gedaan. Ik was in paniek. Ik wist niet wat zo'n gesprek zou inhouden, maar associeerde het met de Inspectie, shaming & blaming." Translation by Stef Groenewoud.

> is going to last for years,' 'Do I have to quit my profession? Search for a different job?'[14]

They describe how the forms they had to complete when reporting the euthanasia felt like a straightjacket and did not match their (moral) considerations:

> I really struggled with the form. It did not enable me to tell my story, because questions were solely somatically oriented. Then I consulted a colleague. He said: 'keep it short, otherwise you raise all kinds of questions.' And therefore I decided to stick with the main diagnosis: pathological mourning.

This procedural and legal focus is reinforced by lawyers who assist physicians who are invited by the RTE: "We explain what doctors may expect, we look over their shoulder: are all forms filled out correctly, are all the files complete? What parts of the report may raise questions?" When Schouten finally received a phone call from the committee that her euthanasia was judged to be 'in accordance with the legal requirements, "[t]his was reason enough to open a bottle of champagne."[15] Still, her experiences were enough to decide not to perform euthanasia anymore. "At least, not for now. That is the downside of the whole story. I feel vulnerable. We had been working so meticulously. And still… it went wrong."[16] Schouten and De Brouwer thus narrate how the euthanasia procedures, in forcing them to comply with the legal requirements, undermined their moral involvement. Again, we have to conclude that the way these legal procedures work, may seriously affect the moral functioning of the medical professional.

From different vantage points, these three examples show that incentives, rules, and procedures are not neutral. Not only the moral values of the phenomenon that is supposed to be incentivized, legalized, or formalized, may be silenced or overlooked, but also the involved persons (their moral characters, habits, and motivations) may be affected. According to Michael Sandel, some incentives "erode certain moral and

14 Ibid. Dutch quote: "Maar toch was ik aangedaan, boos. Je doet wat het beste is voor je patiënt. Vanuit je hart. Je bent ervan overtuigd dat je zorgvuldig hebt gehandeld. En dan krijg je dít op je dak. Dan gaan er allerlei scenario's door je hoofd. Van: dit gaat misschien wel jaren duren. Tot: moet ik mijn dokterstas erbij neergooien en van baan veranderen?" Translation by Stef Groenewoud.

15 Ibid. Dutch quote: "Al snel na het gesprek met de commissie krijgt zij te horen dat de uitgevoerde euthanasie aan alle zorgvuldigheidseisen voldoet. "Dat was wel reden voor een fles champagne." Translation by Stef Groenewoud

16 Ibid. Dutch quote: "We zijn zó zorgvuldig geweest, juist door het met z'n tweeën te doen. Hebben alles gecontroleerd en dan kan het tóch misgaan." Translation by Stef Groenewoud.

civic goods worth caring about."[17] The first effect is stressed by Samuel Bowles when he adds to Sandel that there is "evidence that incentives (non-intrinsic stimuli) may finally crowd out ethical and generous motives" of the people involved.[18]

10.4 An Empirical Study on the Experiences of Relatives

We now turn to some of the empirical ethical research that was conducted under our auspices, and that illustrates from the inside that euthanasia continues to be not only medically and ethically complex, but also transgressive. In collaboration with a number of funeral directors, we collected 43 stories in which relatives tell about their experiences with euthanasia for a loved one.[19] We mention five of those positive sides here, after which we will turn to five experiences about the dark sides.[20] Quotes are taken from the book's reflection section (pp. 215–28).

Firstly, the experience that serious and/or senseless suffering has come to an end is positive and makes relatives grateful. "I have always supported my mother's choice. I also thought it best if she could be spared the worst suffering." For many, preserving dignity means, in addition to the mode of death by euthanasia, the certainty to be ahead of suffering, loss of independence and loss of mental faculties. Past experiences often play a role.

> With her father, she had seen how badly he wanted to die and had even pulled the ventilator and IVs a few times because he didn't want to go on. He was tied up by the doctors. A long agony followed, eventually resulting in death. Since then, my mother has been a strong supporter of euthanasia.

And another: "The urge to control her own life was very deep. The misery and pain she saw from the death of her son and many others around her only reinforced that urge." A relative of one author is initially sceptical because of her faith, but says: "The scales tipped for me to the concept of mercy." Compassion, of course, is an old Christian virtue. There

17 Michel. J. Sandel, "Market Reasoning as Moral Reasoning: Why Economists Should Re-Engage with Political Philosophy," *Journal of Economic Perspectives* 27 (2013): 121.

18 Samuel Bowles, "The Moral Economy: Why Good Incentives Are No Substitute for Good Citizens," *Journal of Economic Sociology – Ekonomicheskaya Sotsiologiya* 17 (2016): 100–28.

19 Theo A. Boer, A. Stef Groenewoud, and Wouter D. de Jonge, *Leven met Euthanasie. Geliefden vertellen over hun ervaringen* (Utrecht: Kok Boekencentrum, 2021).

20 The following quotes are taken from Boer, Groenewoud, and De Jonge, *Leven met euthanasie*, 215–28. Translation Stef Groenewoud.

are also references to what would have happened if euthanasia had not taken place: "Astrid would have faced a short but difficult and painful death struggle." Sometimes the medics involved also clearly indicate that they find euthanasia a palpable solution.

> Jan made the decision early in the process to talk to his physician about euthanasia. He didn't have to think for a moment, it was clear to him that you don't have to wait for the entire process with such an illness.

And:

> One day after [her] death, I was contacted by telephone by her doctor. He assumed that Astrid would have lived another week, but that that week would have been a very heavy and difficult week for her and her loved ones. According to him, the euthanasia had been on time and this was the best solution in Astrid's situation.

Secondly, there is the positive experience of dying itself: a peaceful, certain and desired death without serious suffering and in the presence of loved ones. "We wished her a good journey. It felt like a nursery," writes one person, "there was a loving, clear atmosphere. Almost sacred." "Bye all, thanks," a dying person is quoted as saying, "Oh, I can feel it coming." "It all went very smoothly and quietly. No breathlessness, no panic, just falling asleep peacefully as envisioned. When I think about euthanasia, I now see that moment before me." "Our mother died a sweet death at the age of 94, thanks to the Euthanasia Clinic." "In the end, an enormous sense of gratitude has remained, that we could experience and finish this so very close together." "The euthanasia itself is special: while I hold her hand and my mother looks at everyone in the room again, she falls asleep. […] She lies quietly and peacefully in the pillows. The euthanasia was successful." "Are you sure this is the time?" the doctor asked. "Yes," was her firm reply. With our son close to us she fell asleep on a beautiful summer day […]. Her last words were, "I'm so proud of you." As the moment itself can be beautiful, so are the memories: "We look back on the entire process with great satisfaction. There were no second thoughts." "I didn't find the euthanasia scary at all" writes a young person, "It has a sad, yet fond moment in my memory."

> The moment of euthanasia was right. His children were there, we listened to Chopin and he went full of surrender. It was a liberation. After that, we never had a moment of remorse or regret. A deep gratitude that we live in a country where euthanasia is possible.

Someone who saw three euthanasia cases writes: "In all three of these deaths, I, and I think I can speak on behalf of the rest of the family, have been grateful that euthanasia is possible." These experiences also have the indirect benefit of reducing the relatives' own fear of a dreadful death. "My son told me later in the evening that he wouldn't be afraid of death at all now that he had experienced this. Because dying can be peaceful and quiet."

A third kind of positive experience concerns the ability to plan and foresee death coming. There is a "dot on the horizon," illness and death do not last indefinitely. "We did not know what his life expectancy was at that time," writes the wife of a man with Parkinsonism, "At least I couldn't have continued to take care of him." That waiting period allows for impressive memories. "I could take her in my arms and felt that she completely surrendered to me" writes one author, and another: "As soon as the decision was made, Jan became calmer and he was no longer afraid." The planning prompts people to prepare: "Because euthanasia always has to be planned," one writes, "I was given time to prepare, which helped tremendously in processing afterwards." A conscious farewell can be prepared; last words can be spoken. This also applies to the preparation of the day itself.

> We as daughters made her beautiful that morning for the moment she was looking forward to. For us this was a nice way of saying goodbye: we painted her nails, did her hair and put her on the nicest clothes.

The planned ending brings loved ones closer together: "We were invited as a group of friends to attend this event," writes one person, "I found this gathering intimate and of great significance." The realization that the end is near also makes humour possible. "At eleven o'clock the ambulance nurse came to put the IV on. 'You still look very good, sir,' the nurse said rather clumsily. 'Yes, but you look even better,' was the witty reply."

A last positive side of euthanasia is that it fulfils someone's last wish. "When my husband told me he wanted to die, I couldn't help but feel that this was the autonomous wish of an autonomous man." "His choice was completely in line with his character," wrote another. And although euthanasia may now be a natural option to many – this is also clear from many stories – it is not always an easy choice. "Euthanasia also requires a certain courage and confidence," one writes, "unbelievable how strong you were." It is experiences like these that sometimes make relatives decide to want euthanasia for themselves. "I am grateful and have experienced the value of self-determination even more. I notice that because of this I cannot rule out euthanasia for myself either." In one of the stories, a euthanasia is described for two people at the same time.

Someone writes in response to this happening in her parents: "My father said, 'Now this is still an issue, in ten years people will find this very normal'." Obviously, the self-determination of one person may produce the desire for self-determination in the other.

But there are also dark sides, and this is important given the fact that they feature even in the narratives of those who overall welcome the euthanasia in their loved ones. Firstly, euthanasia is not always what it is expected to be. One relative says she had expected the euthanasia "a little more romantic." Rather than falling asleep organically, the patient dies abruptly and the speed overtakes the bystanders. "The transition from our serene farewell to a situation in which death suddenly became visible was [...] abrupt." One relative experienced the speed as "awful." Sometimes patients themselves react fearfully to the impending termination of life. "I regularly see this in front of me," someone writes, "The look in my father's eyes, cheerful at first, until the moment just before it changed into a frightened cry. It completely upset me." Another:

> I want to describe one moment of the euthanasia, because it was so special and confusing. At one point I shifted a bit to look him in the eye one more time, but he didn't look back. I was shocked, shifted again, but no, I couldn't get in touch with him anymore.

"We returned home orphaned. [...] cried a lot afterwards. Probably also because of the tension beforehand, because I found it scary to be so aware of someone who dies." Things can also go wrong medically. There is the story in which the euthanasia had to be postponed because no usable vein could be located. "I was angry and also very sad," writes one bereaved, "You consciously say farewell and then this happens." Some relatives have difficulty accepting the timing of a euthanasia on the day.

The advantage of plannability also creates stress: "setting a date," "calendars that must be coordinated," waiting for "the moment." Someone writes,

> You're in a kind of weird waiting position, between when the date is set and the moment when life ends [...] The tipping point is the most difficult when making a decision to euthanasia. If there is [...] a time when you know: from now on there is no going back.

Another side of this plannability is that because euthanasia is not a normal procedure, professionals act with extreme caution. Too cautious, according to some. The family regularly assumes that a doctor will perform the euthanasia whenever the patient is ready, only to find out that physicians also need time. In addition, any intention to euthanasia must also pass a second doctor's assessment. One scribe calls the interview

with this physician "a job interview" and "a horror." A survivor is upset when a consulting doctor comes to visit unannounced.

> [The doctor] visits my mother unannounced and finds her in one of those rare moments. She sits upright in her wheelchair and is playing bridge with three friends. My mother feels caught, especially when the doctor notes that he has never seen anyone wanting to die so much, while having so much fun.

Patients and their families sometimes try to use conscious skills to show themselves from their "best" side. When a planned or expected euthanasia is postponed, it can be a bitter disappointment for the patient and their loved ones. Paradoxically, an experience that would not have occurred if euthanasia was not possible at all.

Thirdly, some relatives are not at peace with the euthanasia and some find themselves hard-hitting afterwards: "Where was I myself?" This sometimes manifests itself in physical or psychological complaints afterwards. "Euthanasia is a redemption, a solution for the person who is very ill," someone writes, "but in my view it is an emotional burden on the grieving process of the loved ones." And another: "Dad, it's your life, you're in control. If you want that, I support your choice," only to add: "[But] my feeling screamed, 'Don't go!'" One survivor says: "[The euthanasia intention] took over her life and eventually there was no room for anything else." There is the story from a best friend:

> When you chose it, I wasn't ready. But a person has to make his own choices – that is what they say. But I don't know about myself. […] Your choice made my world collapse. I'm still not completely healed. I still carry the despair and fatigue with me.

Fourthly, relatives have doubts whether the euthanasia was necessary, or in place yet: did caregivers and loved ones give up too easily? Did the deceased leave too soon? "Was this the right way?" "Shouldn't I have taken mother in my house?" Another doubt is whether this is what the person really wanted: "Because even though she said many times a day that she wanted to die and she could cry pitifully, when visitors came she became happy and she could easily forget her death wish," writes someone, who continues to be convinced of the correctness of this euthanasia. In several stories, relatives run into their own and unexpected negative emotions. Someone writes after a euthanasia, which had been planned and desired for a long time:

> After that I was very confused. Was this really what she wanted? I felt that I had let her down. As if I was responsible for how things had gone. Rationally I knew I wasn't, but it felt desperately different.

A fifth drawback is that an intended euthanasia sometimes leads to disagreement between family members. In one narrative, a surviving relative had a serious clash with his now deceased mother and other family, and afterwards with his mother's doctor, about euthanasia. In another story the euthanasia was cancelled for this reason. The euthanasia decision and process are often experienced differently by relatives of one and the same patient. Where one supports this choice, others are angry. Such instances may put a serious strain on the relations between the relatives.

What these positive and negative experiences with euthanasia have in common is that they all illustrate that from the perspective of relatives and friends euthanasia is not a normal medical treatment. No matter how good memories or experiences are, all story-tellers would have preferred a natural, peaceful, and pain-free death for their beloved one, if this would have been possible. Even most positive experiences have a (less positive) flipside, which stresses the need for thorough and multi-perspective moral deliberation upon the transgressive act of euthanasia.

10.5 Practice Variation

A second phenomenon that illustrates the transgressive, and therefore controversial character of euthanasia is the great diversity in its incidence throughout a country such as the Netherlands (but also in Canada), which is partly caused by considerable regional diversity in (moral) views on euthanasia.

In January 2021, we published a study of regional variation in the incidence of euthanasia in the Netherlands.[21]This resulted into two coherent findings: a large variation in practice and a locally very high incidence of euthanasia. When it came to euthanasia performed by general practitioners, which accounted for 85% of the Dutch euthanasia cases, we found a regional difference of a factor 25. That is, in municipalities with a high incidence euthanasia accounted for a 25 times higher percentage of total mortality than in municipalities with a low incidence. If we adjusted this factor score for possible explanations on the part of the care user – church attendance, political preference, socio-economic status, and the presence or absence of volunteers – an unexplained score of seven was left. In other medical procedures, the international literature on the subject of regional (or: practice) variation hypothesizes that if demographical, medical, and preferential factors have been taken into account (as we did in our study), an unknown (but probably considerable) part of the remaining variation may be supplier induced. This

21 A. Stef Groenewoud, Femke Atsma, Mina Arvin, Gert P. Westert and Theo A. Boer, "Euthanasia in the Netherlands: A Claims Data Cross-Sectional Study of Geographical Variation," *BMJ Support Palliative Care* 14 (January 2021). doi:10.1136/bmjspcare-2020-002573.

means that this variation may be caused by differences in the type and amounts of treatments that are offered by doctors. After a careful deductive analysis, our study concludes that it may vary from region to region whether doctors (the suppliers) bring the option of euthanasia forward, as in some regions doctors may refuse to discuss euthanasia altogether. Other supplier-induced explanations for regional variation in euthanasia that we mention in our conclusions may be that reasonable alternative options for euthanasia, such as appropriate palliative care, are not equally accessible or available in all the country's regions.

Our second finding was that, measured at a more detailed zip code level, some euthanasia rates were even higher – and the differences correspondingly larger. We found residential areas where euthanasia by general practitioners accounted for 18% of all deaths. We should consider that this is a percentage of the total mortality which includes sudden deaths, accidents, and deaths in incompetent patients, in all of which cases euthanasia cannot be considered. Moreover, euthanasia by medical specialists is not included in this research, meaning that an additional 18% more euthanasia cases could not be taken into account. Considering all this, the conclusion is that in parts of the Netherlands euthanasia has become a more or less default choice when people are fatally ill. At the same time in other regions it continues to be practically absent. Thus whereas in some other neighbourhoods euthanasia is in the process of becoming a normal, uncontested medical practice, it features in other neighbourhoods as a highly transgressive act.

10.6 Attitudes and Experiences in the Pastorate

A third empirical study that underpins the claim that euthanasia still is a transgressive act, is a recent study among pastors who provide pastoral care and counselling for parishioners who face end-of-life decisions, and also euthanasia.

We found that pastors in the Protestant Church in the Netherlands (PCN – the largest Protestant denomination) have broad experiences with euthanasia. Given the widespread conviction that religious people, generally speaking, are opposed to euthanasia, this finding may be surprising to some. However, positions held by mainstream Dutch Protestants tell a different tale. In the 1970s and 1980s, the two largest Reformed denominations in the Netherlands issued reports that advocated the possibility of ending a patient's life in the face of unbearable suffering. Many influential Protestant theologians and physicians supported this stance.[22]

22 Theo A. Boer and A. Stef Groenewoud, "Dutch Reformed support for Assisted Dying in the Netherlands 1969-2019: An Analysis of the Views of Parishioners, Pastors, Opinion Makers, and Official Reports of the Protestant Church in the Netherlands," *Journal of the Society of Christian Ethics (JSCE)* 41 (2021): 125–47.

Despite this view found in church bodies and amongst Protestant thinkers, we found that parishioners continue to hold very diverse – and mutually conflicting – views about the topic. Within the PCN, the incidence of euthanasia varies. As reported by pastors, in the Orthodox-Christian parts of the church, 5% of the deaths was preceded by euthanasia, which is roughly the same as in the Netherlands as a country. This number was reported to be 13% in the more liberal part of the PCN.[23]

Of PCN-pastors, 21% state that euthanasia conflicts with their Christian convictions, with again considerable internal differences: 66% of orthodox pastors reject euthanasia, whereas this is 3% for liberals. Younger pastors appear more reticent than their older colleagues, and in their pastorate these younger pastors report a lower euthanasia incidence than their colleagues. The acceptability of euthanasia for PCN-pastors also depends on the type of disease or suffering: on average 66% of the pastors find euthanasia acceptable in a terminal illness, whereas this number is 20% in "completed life," i.e., when elderly persons have an active death wish in the absence of a serious disease. It thus seems that amongst PCN-pastors euthanasia has gained broad acceptance but younger pastors, especially in the orthodox modalities, continue to hold strong moral and religious reserves.[24]

Notwithstanding the broad acceptance of euthanasia among PCN-pastors, they still report that they experience serious problems during their pastoral care in cases of euthanasia. A recent survey among parishioners resulted into a list of more than 600 topics and situations that they mention as 'difficult' in case of euthanasia.[25] In a follow-up study, using concept mapping as a hybrid qualitative/quantitative method, this large number of themes could be narrowed down to ten clusters of 'difficulties' pastors experiences when delivering pastoral care in case of euthanasia: (1) *pastors' doubts and concerns* (especially in controversial cases, e.g., where terminal illness is absent); (2) *parishioners' controversial choices* (e.g., when the pastor does not share the judgement 'unbearable suffering'); (3) *conflicting opinions about suffering and treatment* (when do we stop medical treatment and how does the concept of suffering fit into that?); (4) *family and relatives* (e.g., if family interferes to a great extent); (5) *image of the pastor* (parishioners and their relatives have certain expectations regarding the pastor's attitude, e.g., that they will reject euthanasia); (6) *communication and timing* (how and when is the pastor informed, and about what?); (7) *tension between pastoral*

23 Ibid., 133.

24 Ibid., 133.

25 Theo A. Boer et al., "Legal Euthanasia in Pastoral Practice: Experiences of Pastors in the Protestant Church in the Netherlands," *International Journal of Public Theology* 14 (2020): 41–67.

proximity and professional distance (e.g., if the time that is shared with a dying parishioner exceeds the acceptable amount of time); (8) *communication with involved physicians;* 9) *the pastor personally* (dealing with their own emotions, convictions and doubts); and (10) *pastoral colleagues* (if colleagues have different moral convictions and opinions).

Again, these empirical findings underpin the claim that was postulated by Lemmens, that euthanasia is still in its character a transgressive act. The increasing incidence, also in the practices of Protestant pastors do not change that character. Our findings that we brought forward in this section underline once more that – in spite of its increasing acceptance, also within the church – the action itself is still seen as transgressive and brings all kinds of moral difficulties.

10.7 Concluding Remarks

In his article, Lemmens describes exactly the phenomena we have just been taking a closer look at. He states that it is

> undesirable to reach as a society a point where doctors are no longer appealed in their conscience – and either reduce euthanasia to a purely procedural semi-therapeutic act, or sacralize it as a highly moral intervention. If this point of normalization is ever reached, it is also done with the freedom of conscience of the doctor. (172–73)

Furthermore, "as a transgressive act, euthanasia should always remain controversial and possibly embarrass the doctor's conscience and by extension the entire society. This embarrassment cannot and should not be eliminated by any law or procedural decision." (173) Lemmens' plea to continue regarding euthanasia as a transgressive act also resounds in a recent interview with chief public prosecutor in the Netherlands, Rinus Otte. In the aftermath of the groundbreaking coffee-euthanasia case (where an elderly woman suffering from dementia received euthanasia while she was visibly resisting) he argues that there is need for additional information about the euthanasia practice, more than is found in the RTE's annual reports, because "euthanasia should remain a worrisome theme."[26]

The question is however: have countries that have legalized the practice of euthanasia not already set sail in the direction of a partial abandonment of the doctors' conscience? If we should believe philosophers such as Sandel and Bowles, who criticize the assumption that laws and other

26 Marten van de Wier, "OM-topman Rinus Otte legt uit waarom euthanasie volgens hem een tobberig thema moet blijven," *Trouw,* July 28, 2021. https://www.trouw.nl/binnenland/om-topman-rinus-otte-legt-uit-waarom-euthanasie-volgens-hem-een-tobberig-thema-moet-blijven~ba159233/. Translation by Stef Groenewoud.

non-intrinsic-stimuli leave the people ('s characters) unaffected, and if we look at the examples and empirical research results given above, we must conclude that the special moral character of the act of euthanasia, as well as some doctors' ethical receptivity have already started to be affected. They may have already started to waiver (with an 'i', meaning that in case of an ethical appeal some doctors' consciences seem not to be inclined to actively reflect). We suggest that in the near future we need more research and empirical evidence for or against these claims.

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