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The Regulation of Euthanasia: How Successful is the Dutch System?

Govert den Hartogh

Euthanasia¹ and physician-assisted suicide have been legal in the Netherlands since 1984, first by judicial legislation, since 2002 by statute, if enacted by a doctor who meets a number of requirements of due care and makes it possible to assess whether he met them. How successful is this Dutch model?² The answer to that question of course depends on what we understand ‘success’ to mean. In this chapter I will try to assess to what extent the Dutch model is successful *in its own terms*. I will therefore start in § 1 by explaining the underlying morality of the Dutch law which informs both the substantive and the procedural requirements of due care. This will give us the frame of reference we need for judging the success of the system.

Of course many people will not be happy with these moral foundations of the legal system themselves, because on their view they do not sufficiently respect either the sanctity of human life or the autonomy of patients. For such people the system is inherently flawed because it is either too liberal or too paternalistic. Even for them, however, it will be of some interest to have the system evaluated in its own terms, because a common view of foreign observers has always been that it failed as such.^{i,ii,iii,iv,3} In sections 2 and 3 I will discuss the main points of criticism, which concern the reporting rate and the number of cases in which patient’s lives have been ended without their explicit request. In addition in § 4 I will consider the criticism that what doctors consider to be terminal sedation should often be seen as euthanasia (and

¹ Although I am not particularly fond of this piece of verbal legislation, I use the term ‘euthanasia’ in the sense which is by now common in the Netherlands: ending a person’s life on his explicit request. Ending his life in his (assumed) interest but without request is not included.

² I will not explain the model; this has extensively been done in other chapters of this book, see Legemaate (Chapter 2) and Weyers (Chapter 3).

³ All using data from the national survey reports 1991, 1996, 2003, see § 2. Similar judgments have been made by the Canadian Special Senate Committee on Euthanasia and Assisted Suicide 1995, and by the US Supreme Court in *Vacco v. Quill*, 521 U.S. 793 (1997).

reported as such), and in § 5 the criticism that the whole system of monitoring and control is only a façade, because it never leads to the criminal sanctioning of any doctor violating the requirements.

Another criticism is that the actual practice as it has developed since the introduction of the consultation requirement and the regional Review Committees is too restrictive, that it excludes people from access to a relatively humane death who should be eligible in terms of the law itself. I will discuss this problem and proposals to deal with it in the final sections.

1. The moral foundations of the Dutch euthanasia-law

People who defend the justifiability of euthanasia or physician-assisted suicide under certain circumstances, almost invariably argue in favor of and by appeal to some radical revision of common-sense morality. And opponents likewise believe that in addition to pointing out slippery slope concerns their only task consists in defending these same tenets of common-sense morality which the other party wants to revise. In this way it has been argued by most advocates, prominently Ronald Dworkin and the other authors of the 1997 Philosopher's Brief, that the prohibition of euthanasia conflicts with people's right to self-determination which should not only allow a person to end her own life, but also others to do this on her request. It has been argued, for example by Peter Singer, that the prohibition of euthanasia rests on a mistaken belief in the sanctity of life. Others, beginning with James Rachels in 1975, have attempted to show that there is no morally relevant distinction between killing and letting die, hence anyone who allows doctors to abstain from life-prolonging treatment should accept euthanasia under the same conditions. Many defendants of the prohibition, for example John Finnis, have appealed to the distinction between death as a means and as unintended side-effect, the so-called doctrine of double effect. Whether or not one accepts this doctrine or its application to this case as an essential part of common-sense morality, it is clear that something like it is subscribed to by traditional medical ethics, because it allows for palliative treatment with a possible life-shortening effect. Hence this whole family of distinctions has also come under attack, for example from John Harris.^{v,vi,vii,viii,ix}

Studying the underlying morality of the Dutch euthanasia law, we could ask which of these revisions of common-sense morality have been adopted by it. The

answer turns out to be: none. The morality of the Dutch law is a completely traditional one.

This can be shown either in a historical or in a systematic way, by studying the decisions of the courts from 1984 on and the *travaux préparatoires* of the 2002 law, or by reconstructing the most plausible moral rationale of the actual provisions of the law. Both give the same result. The historical account has recently been provided by Esther Pans.^{4,x,33} The aim of this section is to provide the reconstruction.

(1) From the beginning of the Dutch revolt against Spain during the sixteenth century the rebels amongst themselves discussed the justifying reasons of their actions. Did they act *pro religione* or *pro libertate*, to protect the true religion or the ancient freedoms of towns and provinces? A similar discussion has gone on among advocates of the legalization of euthanasia in the Netherlands from the beginning of the discussion about the subject which can be dated exactly, to 1969. This time the battle-cries were self-determination and mercy. During the first ten years, both motives were appealed to more or less equally, occasionally by the same authors. Since that time it has been self-determination which figures most prominently in the rhetoric of advocates, and in public opinion. If you only dare to use the term “mercy”, you will immediately be seen as an intolerable paternalist. I remember well that a lady who asked me a question about a talk I had given, suddenly started to stamp her feet, crying “I don’t want any mercy”. That is a sentiment which many people will recognize.

But there has never been a complete consensus. Notable exceptions include medical authors, in particular those who have been associated with the Dutch Royal Society of Medicine (KNMG).^{5, xi,xii} This is important because the views of the Society, in the Dutch political tradition of finding agreement between elites, tend to be much respected by both the courts and the legislation. Moreover, as we will see, public opinion is not very consistent in stressing everyone’s right to decide the time of his own death. Not even the Dutch Right-to-Die society (NVVE) is fully consistent. For long years every item of its monthly journal contained a sad story of a person who

⁴ Pans summarizes her findings in her chapter in this book. This interpretation of the law is by now more or less generally accepted.

⁵ Even though the drafters of the bill were personally sympathetic to the principle of self-determination, by and large they implemented the view of the KNMG.

had to die miserably because no assistance in dying had been given. The primary response such stories aim to evoke in the reader does not seem to be: what a shame that the autonomy of this patient has not been respected, but rather: what a pity that she had to suffer that much.

Nevertheless, with the exception of the doctors, almost every Dutch citizen who has thoughts about the matter, tends to think that the law as it has been codified by the 2002 statute, is founded on the right to self-determination, not on a principle of mercy. Remarkably, the reverse is true. The right to self-determination has, it is true, an essential role to play, but only as a side-constraint, not as the basic justification. Of course it is not acceptable to shorten the life of a competent patient, or a patient who can express any decision at all, if he does not request this action. But that doesn't mean that the law permits the action *because* he requests it.

At first sight it may seem that the euthanasia law puts both principles on an equal footing, each finding its expression in one of the two basic requirements of due care. The requirement that the patient should make a voluntary and well-considered request obviously is made because this is seen as a condition for the request being autonomous. And the requirement of unbearable and irreversible suffering points to the circumstances in which a proper appeal can be made to mercy. However, if the right to self-determination would be more than a side-constraint, the second requirement could not have been made. If you want to respect a person's autonomous decisions, you should do so without any regard to the reasons for which he made them. For example, it follows from a competent patient's right to self-determination that he can refuse any medical treatment, even if it promises to prolong his life. Of course he is allowed to refuse on good grounds, he doesn't need any special right for making that decision. The right implies that his refusal has equal authority in the case his grounds are questionable. To have the authority to decide means that your decision stands, even if it is the wrong one to make. Hence, if the right to self-determination would be the founding principle of the law, it would exclude other substantial requirements besides those concerning competence.

This argument can perhaps be withstood. A first counter-argument could be that seemingly paternalistic requirements can sometimes be justified by of the difficulties involved in establishing competence. In this way the legislator could have insisted on the requirement of unbearable and irreversible suffering because that would be the only case in which no doubts concerning the voluntary and well-considered character

of the request need to remain. This view, however, has never been advanced by any court or during the parliamentary debate about the law. Interestingly, however, it has been advanced during the parliamentary debate about the Belgian 2002 law.^{xiii,6} It is a possible argument, but it carries a burden of proof which no-one until now has attempted to meet, not even in the Belgian case.

Another possible way to show that an additional requirement is compatible with the right to self-determination being the basic justificatory principle would be to argue that it is only in cases in which a person suffers unbearably from a medical condition which cannot be expunged or alleviated, that a doctor can have any task. But this raises the fundamental question why the exception the law introduces to the prohibition on euthanasia and assistance in suicide only applies to doctors. If self-determination is the leading idea, this is hard to understand.

The additional requirements made by the law show that it doesn't take the right to self-determination as its basic justificatory ground. This also tells us something about the rhetorics dominating the debate, for even if some participants to that debate prefer other additional requirements to the ones insisted on by the legislator, for example the irreversible loss of dignity, few participants insist on no additional requirements being made at all.⁷ As for public opinion, 68% of the Dutch people agree with the statement that everyone has the right to decide about his own death, but only 15% agree that the means for ending one's life should be available for everyone who wants to die, whether he is severely ill or not.^{xiv,xv}

{2} The Dutch legal development is deeply influenced by the Supreme Court's path-breaking Schoonheim-verdict from 1984. The court argued that doctor Schoonheim had been in a "conflict of duties" and therefore could appeal to necessity or *force majeure*. In the decision itself the conflicting duties had not been specified precisely, but obviously we should think of the duty of everyone to respect human life and the professional duty of a physician to alleviate or prevent suffering. In

⁶ I suspect that for similar reasons Oregon's Death with Dignity Act (1997) restricts the option of physician-assisted suicide to patients diagnosed with a terminal illness and a life expectancy of less than 6 months. The Swiss organizations which offer assistance in suicide also make additional requirements. For example *Exit Deutsche Schweiz* not only requires that the wish to die is deliberate and stable, but also that the requester suffers from a disease with a hopeless prognosis, and the suffering isn't unbearable or unreasonable disability is present (Exit statutes, article 2).

⁷ See § 8 below.

succeeding decisions this has been made explicit. The duty opposing the duty to respect human life could not have been a duty to respect autonomy, for that is a negative duty only: not to interfere with the execution of someone's self-regarding decisions. Such a duty can always be completely fulfilled by doing nothing at all. Hence it cannot conflict with any other negative duty. The right to self-determination by itself does not imply a duty of assistance for anyone, and in any case a *duty* to assist anyone in fulfilling his wish to die has never been recognized in Dutch law. (It is debatable whether it has been recognized in Belgian law.^{8,xvi})

{3} In order to derive even the permission to assist we have already to go beyond the right to self-determination itself. This is something advocates of the right, for example within the Dutch right-to-die society, seldom realize. The additional premise which we need is the Volenti-principle: *Volenti non fit iniuria*, the consenting person cannot be wronged. However, within Dutch law (and European law generally) the Volenti-principle is not taken to apply to the most fundamental, the so-called inalienable human rights: the right to life, to bodily integrity and to personal freedom. In respect to these rights the law subscribes to a form of *indirect paternalism*^{9,xvii,xviii}

As for the right to life, this is clear from the two articles of the criminal code, 293 and 294, which still forbid taking someone's life on his explicit and earnest request, and assisting to kill himself. The euthanasia law has left both articles in force, only adding an exception for physicians who satisfy the requirements of due care. If the Volenti-principle applied to the right to life, it would have been impossible to restrict the exceptions to physicians. Accordingly, the duty which is supposed to be possibly in conflict with the right to life is not a general moral duty but only a professional duty of doctors.

As for the right to bodily integrity, it is clear that the Volenti-principle applies to relatively minor infringements of it, as for example taking a sample of your blood in the course of a criminal investigation, or even for living donation of a kidney. But it does not apply to major infringements, and, moreover, it does not apply to medical

⁸ Nor in Belgian law, although there has been some debate about this, see Adams in Griffiths.

⁹ In my chapter of *Medical Ethics at the Dawn of the 21st Century*, I have discussed whether indirect paternalism is subject to the same objections as direct paternalism (as Feinberg asserts).

action generally. The so-called law on the contract of medical treatment¹⁰, in spite of talking the language of contract, is clear about this: a competent patient always has the right to refuse any treatment, but he cannot demand any treatment which in the professional opinion of the doctor is harmful to him on balance. The doctor, as the law states, has always to conform to the professional standard. If only for this reason all talk about health care as a market like any other and patients as care-consumers, is basically mistaken. Similarly for including a person in a medical experiment his consent is not enough. The risks involved should always be minor, and in proportion to the importance of the experiment, and the consent of the participant is no defense for infringement of these requirements. Lastly, as a matter of unwritten law, consent is not a defense for a crime against personal freedom either. If a person is found chained in your cellar, you will not escape a prison sentence if you can show a signed document confirming that person's consent to his treatment. Anyone who believes that a voluntary and well-considered request should be sufficient to justify euthanasia, can be asked the question: should a person also have the power to sell himself into slavery, if he does so voluntarily? If not, what is the difference?

That the Volenti-principle does not apply to the most basic human rights, has clearly been stated by the European Court for Human Rights in two landmark British cases: the Spanner-case regarding bodily integrity, and the Diane Pretty-case regarding the right to life.¹¹ Such rights do not only aim to protect spheres of personal sovereignty.

The recent euthanasia law presented itself as a codification of the court-made law in place before, nothing more and nothing less. For that reason the ministers who proposed the law at first did not even find it necessary to explain the moral foundations of the law, though in the course of the extensive parliamentary debate they provided that explanation.^{10,16} Of course the conflict of duties ceased to function as a relevant legal figure, because this had only been a specification of *force majeure* as a general justificatory basis for making exceptions to any legal norm, and for these

¹⁰ Wet op de Geneeskundige Behandelingsovereenkomst (WGBO), in force since 1995.

¹¹ Laskey, Jaggard & Brown v UK, 19./2/1997; Pretty v UK, 29/4/2002. Article 2 of the European Convention on Human Rights, recognizing the right to life, is said in this last verdict to be "unconcerned with issues to do with the quality of living or what a person chooses to do with his or her life."

exceptions the law did now provide a general formulation. Even in this respect the law in a way did not change the legal situation, for a paradoxical aspect of the court-made law had been that the courts had already build a system of norms, including requirements of due care, on this essentially casuistic foundation. But except for this formal aspect which the courts had already given up *de facto* and which the new statute necessarily had to give up *de iure*, the notion of a conflict of duties has a substantial aspect which the codification has left fully intact.

This is most prominently apparent in the fact that euthanasia is not considered to be “normal medical action”. Normal medical action is covered by the so-called medical exception: the provisions in the criminal code about violation of bodily integrity have an unwritten reader saying: ‘doesn’t apply to physicians acting in accordance with the professional standard’. If a doctor amputates your leg in order to prevent gangrene from spreading through your body, he is not supposed to be fulfilling the delict-description of severe bodily injury, not even with a justification. The norm forbidding such injury simply doesn’t apply. The medical exception can be relevant to the prohibition of killing as well. For a physician can use pain-killing medicine and other palliative means in order to relieve the suffering of a dying patient, even when this foreseeably will, or may shorten that patient’s life. In evident cases it may be his professional duty to act that way. Such an action doesn’t count as euthanasia or murder, it is covered by the medical exception, and the death of the patient will be classified as a natural one.¹²

But in the case of a conflict of duties neither of the conflicting norms is set aside by the other, both norms are supposed to continue to apply, even if only one can be satisfied. That even the norm which will not be satisfied, is still valid and applicable in a sense, is shown by the existence of substitute duties, in this case in particular the duty to report one’s action and thereby to submit it to external evaluation. But most prominently it appears in the fact, which I already referred to, that it can never be a professional duty of the doctor to grant a patient’s request for euthanasia. It is at best a justifiable result of weighing the conflicting duties, the alternative way of weighing them being equally acceptable under the law. That euthanasia is not a form of normal medical action also explains why this form of action is subjected to a special system of evaluation which does not involve only physicians, but lawyers and ethicists as

¹² As we will see in § 2, this cannot be explained because in such cases the doctor doesn’t ‘intend’ the death of the patient.

well. Euthanasia is not only subject to professional standards but also to special societal regulations.

When a doctor chooses palliative means which may shorten a patient's life he should, if possible in dialogue with the patient, consider the best interest of the patient. What is more important to this patient, suffering less or living longer? If it is euthanasia he considers, the weighing he is required to make is a different one: the patient's suffering should be unbearable and irreversible. Other interests of the patient, for example his interest in avoiding to be a burden on others, do not count at all. One could say that all medical action is a form of beneficence, but it would be odd to call it a form of mercy. To act from mercy one must be moved by the suffering of someone else which is directly experienced. The justification of euthanasia doesn't follow from the normal professional duty to act in the interest of the patient, for this duty conflicts with another one, and this means that more is needed to tip the balance.

These considerations also tell us something about the other conflicting duty, the duty to respect human life. I have already argued that a right like this one does not protect a sphere of personal sovereignty, for then the Volenti-principle should apply to it. But it now turns out that what is protected by the right to life is not merely a personal interest in continued living, for then some form of weighing this interest against other interests should be allowed. In protecting human life the law is not only concerned with the personal value of the life, the value it has for the person living that life, it is also concerned with an impersonal element.¹³ I will refer to this as the taboo on killing.

This taboo is extremely important in the experience of doctors, of Dutch doctors who do not *a priori* reject euthanasia in all cases no less than of any other doctor. Even if such doctors are convinced that it is in the best interest of a patient to die, they have to overcome considerable inner resistance in order to accept a request for euthanasia of that patient, it will usually cost them sleepless hours during the night. The reason is that they really experience the situation as involving a conflict of duties. If they could achieve the same result by abstaining from treatment or by an

¹³ On this point my interpretation of the law differs somewhat from Pans (Chapter 4). She points to statements of the drafters of the bill during the parliamentary debates suggesting that it is the personal rather than the impersonal value of human life which requires protection. But in that case there would not be a conflict with the duty of the doctor to mitigate suffering.

action which they could, perhaps with a certain amount of self-deception, interpret as a form of palliative care, they would greatly prefer such an alternative.¹⁴ For similar reasons most doctors prefer terminal sedation to euthanasia, even if from the perspective of the patient the result of both decision is essentially the same: the end of his conscious life. And as far as we know no doctor will end the life of a patient in an advanced stage of dementia, even if she has clearly requested this in an advance directive which is recognized as valid by the law.

It is both a difficult and a neglected task of ethics to explain the taboo on killing in secular terms.^{15,xix,xx} For some authors it is nothing but an atavistic remainder of a theistic world-view which still has some grip even on people who have given up that world-view. On my view only two attempts to explain it without explaining it away deserve serious consideration. On the first view the taboo is implied in the recognition of the moral status of the human being, in a similar way as it is incompatible with the dignity of the person to become a slave, even if this would be, which is hard to imagine, both a person's choice and his interest.^{xxi,xxii,xxiii} I am not so sure that it is really incompatible with the dignity of man to be granted death if this is both one's choice and one's interest.^{xxiv,20} I would therefore prefer the second account. According to this account such taboos are not so much a matter of the rightness or wrongness of certain actions, but rather of the authority to make certain decisions. The prohibiting norm intends to take away the power to involve the life of another human being in a weighing of interests, any weighing of interests, and the reason may be that we don't trust each other to exercise that power.^{xxv,xxvi,xxvii} This is confirmed by the fact that doctors who are prepared to accept a request for euthanasia are often accused of "playing God", and to some extent may have similar feelings themselves. There are dangers involved in having the option to kill another person, even in his interest and with his consent, and we tend to believe that these dangers are more important than the risks involved in not having that option.

If this is correct, it can explain another characteristic of the Dutch euthanasia-law: that euthanasia and even assistance in suicide are only allowed to doctors. If it is dangerous to have people decide about life and death, we can restrict the danger by

¹⁴ See below, § 3.

¹⁵ According to Fred Feldman, "this...is one of the most notorious scandals of moral philosophy: moral philosophers have not managed to explain why it is wrong to kill people."¹⁹

restricting the category of people who have that power. Doctors do not normally have any personal interest in the death of their patients and in executing their professional duties they already often have to weigh the interest of the patient in continued living against other interests. Indeed, the very fact that doctors have the authority to decide on palliative care with possible life-shortening effects should already be seen as a first inroad on the taboo on killing. The second step is then only a short one, in particular if the action allowed by it is not seen as normal medical action and is subject to a strict system of evaluation.

Some time ago I had to explain the underlying morality of the Dutch euthanasia law to a group of Poles who had come to the Netherlands on the invitation of the Ministry of Foreign Affairs in order to get inside-information about both the euthanasia law and the practice regulated by it. When I had finished my argument, one of my guests threw his arms in the air in a gesture of despair, crying: “here we have a representative of the most liberal legal system in the world, and he talks like a Polish Catholic priest.” He had got the message.

In order to assess the Dutch model one other point of view is very important. In almost all countries in the world, including even some of the few countries which have legalized euthanasia or physician-assisted suicide, the majority of doctors is opposed to such legalization. That doesn't mean, however, that all of them believe that they are never morally justified in making such decisions, many doctors recognize that exceptionally there may be cases in which no other humane alternative exists. But on their view that is only a matter of their personal conscience, and the law should simply look away. And in many countries the law does. In Belgium, for example, before the introduction of the euthanasia legislation no physician had ever been prosecuted for either euthanasia or PAS (or the ending of a patient's life without request), although those practices occurred regularly.¹⁶ In other countries, for example the UK or Canada, in the few cases which have come to court, doctors have been acquitted or given very light sentences. The main function of the legal prohibition in such countries seems to be to send a moral message, to reinforce a norm which is commonly known to allow for exceptions.

¹⁶ In pages 511-2 of Griffiths, Weyers, and Adams¹⁶ it is argued that this is the main reason why Belgian doctors opposed the euthanasia law: it imposed regulation on them where they had absolute freedom before.

The approach of the Dutch model is the opposite. One of the main aims of the law is to ensure that the behavior of doctors in this area should be open to view, ‘transparent’ as it is usually called.¹⁷ This is seen as a requirement of integrity in itself, but also as a precondition of a monitoring and control system which ensures that doctors take account of the criteria of due care which have been derived from the underlying morality of the law.

2. The problem of the reporting rate

In 1990 the Dutch government commissioned a group of social health care researchers led by Prof. Paul van der Maas to study the frequency and circumstances of medical decisions with a possible life-shortening effect. Their report, published in 1991, showed that the number of cases of euthanasia and physician-assisted suicide was lower than most observers had expected: 2.1% of all deaths (annually 2700 cases). Quite similar results have been reported at about the same time in the doctoral dissertation of Gerrit van der Wal who had concentrated his research on the province of North-Holland. In 1996, 2003 and 2007 similar reports have been published, based on research (in 1995, 2001 and 2005) by the combined research groups of van der Maas and van der Wal (Universities of Rotterdam and of Amsterdam. In the meantime similar research projects have been undertaken, though not quite on the same scale, in Belgium and a number of other European countries, which gives us some basis for international comparison.^{xxviii,xxix,xxx}

Though the results of the first report had been received in the Netherlands mainly with sighs of relief, these same data provided critics of the Dutch euthanasia model elsewhere with heavy ammunition. The same is true of the data of the second report and to a lesser extent of the third one.¹⁸ These criticisms often have not been fully fair, in the first place because they did not (and could not) compare the Dutch data with similar data for other countries, the authors often tacitly assuming that in their own countries actions which are forbidden by law do not happen either, and in the second place because they suggested causal relations between the data without

¹⁷ This is rightly stressed by Kennedy (Chapter 1).

¹⁸ To my knowledge they have not been revised by any of the critics after the publication of the fourth report which, remarkably, drew very little international publicity anyway.

offering any evidence in proof. From the beginning the most scandalous data concerned the reporting rate and the number of cases in which a patient's life had been ended without his explicit request. It seems reasonable to interpret these data as failures of the system in its own terms. A low reporting rate means that the aim of transparency has not been achieved, and hence, that we cannot be sure about the extent to which the requirements of due care are being met. Indeed, we should be suspicious that they often are not, for why not report if they are? And if patients are killed without having made a request at all, let alone a voluntary and well-considered one, that seems to point to an even more alarming disregard for the notions of due care underlying the system. That figure has therefore widely been used as proof of the existence of a slippery slope.

As for the reporting rate, i.e. the percentage of cases of euthanasia and PAS which had been reported to the proper authorities as cases of unnatural death, this rose from 18% in 1990 to 80% in 2005. During that time two major events will have influenced the percentage. In 1998 the government installed a reporting procedure which required doctors to report directly to one of five regional Review Committees, consisting of a lawyer, a doctor and an ethicist (or their deputies).¹⁹ And in 2002 the euthanasia law took legal force which largely gave statutory recognition to the legal situation as it had been developed by the courts since the epochal Schoonheim case of 1984, but at some minor points clarified this legal situation. From this time on the Review Committees did only report their decisions to the public prosecution in cases in which they had concluded that the doctor had not satisfied the criteria of due care laid down in the law.²⁰ The first change may have been responsible for the (disappointing) rise of the reporting rate from 41% to 54% between 1995 and 2001²¹, the second for the (rather spectacular) rise to 80% in 2005. Although the legal situation had not really changed, apparently many doctors only trusted 'the law' when its rules had the authority of statute, not only of case law.

¹⁹ See Kimsma/Van Leeuwen (Chapter 12).

²⁰ From 1998-2002 in no case which had been reported as "careful" by the committees prosecution took place.

²¹ It is even possible that this change by itself had no direct positive impact on the reporting rate at all, because doctors at first wanted to know how the committees would proceed.¹⁶

However, all these reported reporting rates, including the last one, require some scrutiny. Starting from 1990 the researchers have always used their own classification system of the relevant medical decisions, based on the following questions to the physician: (1) has the death of the patient been caused by the use of a drug which has been given by you with the explicit aim of shortening the life of the patient (or to assist the patient in doing so himself), (2) has the decision to do so been taken on the basis of an explicit request of the patient? If the answers to both questions were positive, the case was classified as one of euthanasia, or PAS. Hence, given a life-shortening effect of the action (as assumed by the doctor) and a request of the patient, it was the “explicit aim” of the doctor which made the difference.²² If the doctor reported that he had merely taken into account the possibility of the effect, but had not aimed at it, the action was classified as alleviation of symptoms with a foreseeable life-shortening effect. (15% in 1990, 24% in 2005) To complicate affairs, the researchers also gave the physician the option to state that he made the decision with the shortening of the patient’s life as a second, additional aim. (4% in 1990, 1% in 2005). These cases were also classified as alleviation of symptoms rather than of euthanasia.²³

It is an odd fact of the Dutch discussion that for more than a decade these definitions have hardly been criticized, not even by lawyers.^{24,xxx} It has been quite common during that period to say that the definition of euthanasia was based on ‘the’ principle of double effect.^{25,xxxii} In recent years, however, it has been almost generally

²² Keown³ claims that all cases in which the doctor had stopped or not started treatment “with the explicit aim of shortening the life of the patient” should be classified as cases of euthanasia. He doesn’t pause to consider whether these decisions are in any respect, including patients’ refusal of treatment, medical futility or even the intention of the doctor, different from the decisions to stop or not to start treatment made by doctors in the UK and elsewhere.

²³ A minor problem is that the questions are not mutually exclusive: a second aim can be as explicit as the first one.

²⁴ An exception is Griffiths, Weyers, and Bood³¹, in particular chapter 4. Part of the explanation may be that during this period almost no expert in criminal law wrote on the subject.

²⁵ It is highly debatable whether there is really one such principle. In most cases in which it is invoked the primary aim of the action and the merely foreseen side-effect concern different people. In such multi-person cases the principle is closely related to the Kantian injunction not to treat people as a mere means but always also as ends in

recognized that this definition of euthanasia differs from the legal one.^{26,xxxiii} To be sure, one requirement for an action to be punishable to the full extent in Dutch criminal law is that its deplorable result should be ‘intended’. But in any case in which the actor is aware, or can reasonably be held to be aware that the result will occur, he is supposed to intend it, whether it is his primary aim, a means of achieving this, or only a by-product of his action which he was merely prepared to take into the bargain.

Nevertheless, the law does not take all cases in which a medical action has foreseeably resulted in a shortening of the patient’s life to be cases of euthanasia. The criterion for making the relevant distinction, however, is not the subjective intention of the doctor, but the existence of a medical indication. In any case in which the medical action is justified by a palliative aim, and the possible life-shortening effects cannot be considered to be disproportional, the case is not a case of euthanasia. In such cases what the doctor did is held to be ‘normal medical action’, which is not only permitted by the law (the so-called ‘medical exception’), but may even be a professional duty.

It will turn out to be relevant to my discussion in one of the next sections to point out an implication of these definitions. If the doctor either uses dosages of medicine beyond what is indicated for a palliative aim, or uses even proper dosages in a case in which the life-shortening effects of his action should be considered disproportional (in relation to that aim), the action, given a request of the patient, should be classified as a case of euthanasia.²⁷

themselves.³² In the case of actions with life-shortening effects, however, both effects concern the same person which makes it difficult to understand why they cannot be balanced. Significantly, pain relief seems to be the only one-person case in which the principle is standardly being invoked.

²⁶ The point has not yet been recognized, however, by the researchers themselves,³³ with a mistaken appeal to the authority of the Report of the State Commission 1985, and Onwuteaka-Philipsen, chapter 7 in this book. In the legal chapters of the 2007 report, on the other hand, written by or under the supervision of J.K.M. Gevers, the point has been fully recognized, see in particular pp. 238-39, proposing to include the definitions of the State Commission into the law. This same definition is being used since 2006 in the Guidelines for the Proceedings of the Review Committees.

²⁷ See § 4 on the borderline between euthanasia and terminal sedation.

If we now look at the number of cases, classified as euthanasia in the 2007 report, we find that in 74% of these cases (roughly 1800) the doctor used muscular relaxants and/or barbiturates. For these cases, taken as a separate category, the reporting rate is 99%, which, given the margin of error of such figures, is indistinguishable from 100%. On the other hand, in 18 % of the cases (roughly 400) the doctor had used morphine or one of its derivatives, and these cases had almost never been reported.²⁸ The same is true, of the 1350 cases in which the doctor reported to have had two aims. How many of these (400+1350=) 1750 cases should we count as cases of euthanasia under the proper legal definition?²⁹ Only in 28% of the 400 cases in which the doctor reports to have had an explicit life-shortening intention, and besides in 11 % of the 1350 cases in which he reports to have had both aims, together about (100+150=) 250 cases, he reports to have used a higher dosage than necessary for the aim of symptom-alleviation. Hence, as far as we know, the other (1350-250=) 1100 cases are covered by the medical exception. The next question is in how many of these 250 cases the doctor did not only think that he shortened the life of the patient but actually did so. The answer is: we don't know.³⁰ What we do know, however, is that doctors still tend to overrate the life-shortening effects of morphine. In order to remain effective, the dosage of morphine should normally be increased regularly because of a habituation effect. (This also means that we cannot read off a life-shortening effect from the final dosage reached.) It has now been established that even quite substantial increases of

²⁸ In addition in 7% of the cases benzodiazepines have been used. These cases are never being reported either, and probably indicate a mistaken belief concerning the possibly lethal effect of these drugs. (Some of these cases might, however, conceivably be cases of terminal sedation which really should be considered cases of euthanasia, see § 4.) The percentage of cases in which morphine had been used to execute an explicit intention to shorten life was 41% in 1995 and 23% in 2001 (= 1550 and 875 cases).

²⁹ It could be objected that subjective intention, even if not legally, is morally relevant, either as a matter of professional or at least of personal ethics. I don't think it is, though I cannot argue the point here. It is worth observing, however, that intention reports are very unreliable. It is particularly hard to say of two effects of one's action which are both welcome whether or not both were intended.

³⁰ One intriguing datum from the 2007 report is that the average dosage of morphine used during the last 24 hours is much higher (265-285 mg) than the median dosage (180 mg), which suggests a small number of exceptionally high dosages. When the time lag between the administration of a higher dose of morphine and the death of the patient is more than several hours, as it is in most cases, it is particularly difficult to ascertain a causal link.

the dosage do not have the life-shortening effect traditionally attributed to them, perhaps even the contrary.^{31,xxxiv,xxxv,xxxvi,xxxvii}

So we may conclude that the number of cases in which morphinee has been used and which should properly be classified as cases of euthanasia is decreasing and lower than 250, possibly much lower. It is reasonable to assume that both these facts can, at least partly, be explained by the secure legal availability of the option of euthanasia. Another part of the explanation probably is the increased awareness of the availability of the option of terminal sedation. Doctors who want to end the suffering of their dying patients do no longer need to go for the morphinee-route and know this. Why then do they still occasionally use this route? Recent research has suggested an interesting explanation. The use of morphinee is often not followed by death immediately, and even if it is, there is still room for doubt about the causal nexus. This is probably the very reason why doctors do not classify their own actions as euthanasia. It allows them (albeit with some amount of self-deception) to entertain two thoughts at the same time: I am doing something for my patient, I am not letting him down, and: I am not killing him (“at the needle”).^{32,xxxviii,16} Doctors may occasionally still be attracted to this grey area precisely because of its grayness. One other conclusion is worth mentioning: the reporting behavior of doctors is as good as we can possibly expect it to be. It therefore makes no sense to call for further improvement of the reporting rate. The cases in which proper euthanatica have been used are all being reported, the others are never reported and will never be reported. Even if doctors realized that cases in which they think they have shortened the life of the patient by using a clear overdose should be classified as euthanasia and hence reported, they would not do so, because they would then also realize that they had not acted in a professionally responsible way.^{33,xxxix,xl} We should not call on these doctors

³¹ Hence it is something of a mystery why the number of cases in which doctors ascribe a life-shortening effect has increased.

³² See Willems (Chapter 13). This also explains why these doctors do not classify their own action as euthanasia, even if they report the explicit intention to shorten the patient’s life. See also Onwuteaka-Philipsen, (Chapter 7). I do not deny that some of these doctors may be mistaken about this.

³³ For a case in which a doctor who used morphin has been judged by a Review Committee not to have satisfied the criteria of due care, see Annual Report 2004, 30-32 (case 15); Annual Report 2005, 35-36 (case 15).

to come forward and report^{34,xli}, but rather to change their behavior: to alleviate symptoms and shorten life both by proper means in proper dosages.

3. Ending lives without request

The other scandalous figure of the national survey reports has always been the number of cases of life-shortening actions without request. This is a very heterogeneous category of cases, including termination of life of severely defective newborn babies.³⁵ But the largest group seems to concern dying patients who are too ‘far away’ to be able to communicate clearly with the doctor and have not made a request before, but are still in a state of severe suffering. Often this figure has been interpreted as a corroboration of slippery slope fears: doctors do this because their moral aversion of killing has been eroded by the practice of euthanasia.^{36,3} But no evidence for this causal nexus has ever been offered. It could as well be that the figure would have been substantially higher but for the legal availability of the option of euthanasia, which enables the doctor to communicate openly and timely with his patient about the use of that option. This explanation is to some extent confirmed by data from research in other countries, in particular in nearby Flandres.^{37,29,30,xlii,xliii,16} Before the introduction of the euthanasia law in 2002 the number of cases in which the doctor ended the life of a patient without his explicit request was relatively much higher than the same

³⁴ As Onwuteaka-Philipsen does (Chapter 7). In recent years the number of reported cases of euthanasia and PAS has risen, from 1815 in 2003 to 2636 in 2009. One possible explanation suggested by the Annual Report of 2008 is that the number of doctors using morphine in stead of muscular relaxants has further decreased. But that number was already so small in 2005 that it can at best explain only a small part of the increase in reported cases.

³⁵ See van der Heide, Chapter 8.

³⁶ For an example see Keown³, or the evidence presented by the Linacre Centre for Health Care Ethics to the Select Committee of the House of Lords on the Assisted Dying for the Terminally Ill Bill, Report ii, Evidence, p. 705, accessible on: www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/5020336.htm

³⁷ In a comparative study of six European countries van der Heide et al.²⁹ found higher rates of ending patients lives without request for Flandres (1,5) and Denmark (0.67) than for the Netherlands (at the same time, 2001: 0.6). Seale³⁰ found a rate of 0.3 for the UK, slightly lower than the Dutch rate (0.4) in 2005. For the relevance of these comparative data see Otlowski⁴², Smith⁴³, and Griffiths, Weyers, and Adams.¹⁶

number in the Netherlands (and also much higher than the number of cases of euthanasia). Perhaps the explanation is also confirmed by the substantial decrease in the Netherlands of the figure between 2001 and 2006, from 900 to 550 cases, although this can also be attributed to the increased awareness of the availability of the option of terminal sedation as an alternative.

But there is one other point about this figure to be made, and this again concerns the means used—in 1995 muscle relaxants in 18%, morphine in 59% of the cases, in 2005 muscle relaxants in 23%, morphine in 59% of the cases.³⁸ That in the majority of the cases morphine has been used, invites the same comments I made about euthanasia: we cannot be sure that a life-shortening effect actually occurred and have reason to be somewhat skeptical about that. And even if it did, we cannot be sure either that an overdose has been used, i.e. a dosage exceeding the existing indications for symptom alleviation.^{39,33}

I do not suggest that the figure after all does not indicate any problematic practice at all. If there is no explicit request of the patient to have his life ended or to be assisted in ending it, in the dying stage (and at least 81% of the 550 cases concern cases in which the patient had a life-expectancy of less than one week) normally only palliative measures should be considered to end severe suffering, including terminal sedation as the means of last resort. Ending the life of the patient could only be an option in the very few cases in which the patient is out of the reach of communication but still has a life expectancy which excludes terminal sedation as an option, or in the even fewer cases in which terminal sedation cannot be used for medical reasons.^{40,16} So there is still a real problem here, but it is of very modest proportions. And this problem, like the problem of the unreported use of morphine generally, should probably not be seen as the dire result of legalizing euthanasia, but rather as a relic of a pre-legalization practice.

³⁸ The mysterious figures of 2001 (2% use of muscle relaxants) warn us that we are in an area of very small numbers which doesn't allow strong conclusions anyway.

³⁹ Accordingly, in 91% of the cases classified by the researchers as termination of life without a request, the doctors involved do not use that classification themselves.³³ Most of them may be right about this.

⁴⁰ In such cases the doctor should use proper euthanatica, and have the courage of his conviction to report his action, on a plea of necessity. In the case of newborns some doctors have done this and have been acquitted by the courts, see Sauer and Verhagen (Chapter 19) and Griffiths, Weyers, and Adams.¹⁶

4. The borderline between euthanasia and terminal sedation

In addition to this traditional grey area in recent years a new grey area has developed, on the borderline between terminal sedation and euthanasia. Before discussing it, I have to defend my use of the very term 'terminal sedation', which has been outlawed in the Netherlands, because some people seem to have confused it with 'terminating sedation'. The problem is that the alternative term 'palliative sedation' has been officially defined in a broad way, which includes any form of sedation at the end of a patient's life, whether deep or superficial, whether temporary, intermittent or permanent. The problem with sedation I want to discuss, however, arises only in cases in which sedation is deep enough to induce a coma, and is intended to last until the end of a patient's life. Because we need a word for this particular form of sedation I will stick to the internationally common and appropriate term 'terminal sedation'.^{xliv} Terminal sedation is properly done by using benzodiazepines, in particular midazolam (dormicum), and midazolam has no life-shortening effect, when used in proper dosages or even larger ones. Therefore terminal sedation by itself does not shorten a person's biological life, even if it ends his life as a conscious subject. However, if the decision has been made to start terminal sedation, the question arises whether the patient should be given artificial hydration, and the usual policy in the Netherlands is not to do so. If the patient dies within a few days afterwards, this will be a result of his illness, not of dehydration, but if death takes longer to arrive, this is no longer sure. In such cases one could suggest that the combined policy of terminal sedation and abstaining from hydration amounts to the shortening of a patient's life and hence, if it happens on the request of the patient, to euthanasia.

Mainly because of this worry the Dutch Royal Society for Medicine KNMG has developed a guideline for "palliative" sedation. One of the requirements for starting terminal sedation formulated in the guideline is that the patient should have a life expectancy of no more than 1 à 2 weeks. Of course, the estimation of a patient's life expectancy beyond 2 or 3 days is very unreliable, so, even if doctors tend to overestimate rather than underestimate life expectancy, the requirement does not

make sure that no terminally sedated patient will ever die from dehydration.⁴¹ This is justified in the guideline by the argument that, if the decision to start terminal sedation is made on good grounds –that it is the only way to end ‘refractory symptoms’- artificial hydration would be a futile treatment. I agree that it would be, because it would not add anything to the life of the patient of which he is the conscious subject. But the argument mistakenly assumes that in deciding about the first step of the procedure, terminal sedation, we can abstract from the second step, abstaining from futile hydration, and vice versa. There is no problem with terminal sedation because it has no life-shortening effects by itself, and is justified by refractory symptoms, and there is no problem with abstaining from artificial hydration because it is only a form of letting die, justified by futility. Neither of the actions is a form of killing, so the combination of the two cannot be a form of euthanasia. But if that is a valid argument, it is hard to see why a requirement concerning the maximum life expectancy of the patient is needed at all.^{42,xlv,44}

There is no doubt that if we sedate a healthy person, and from that moment on do not artificially provide him with fluids, we kill that person. We should consider both actions together as elements of one policy. If the effect of that policy is the shortening of the person’s life, on the killing/letting die divide the combined action falls on the side of killing. The same is true if the person is fatally ill, but does not die from his illness (alone), but as a result of dehydration.

It is true that if a patient with a neurological disease, who cannot swallow, refuses artificial hydration, the doctor who accedes to his refusal does not kill that patient. But in that case the patient is dependent on artificial hydration as a result of his illness, not because of anything the doctor has done. In the case of terminal sedation, however,

⁴¹ This means that without dehydration death would have occurred later, not that the underlying illness is not a causal factor at all in causing death at the time it occurs.

⁴² The Report of the AMA Council on Ethical and Judicial Affairs on Sedation to Unconsciousness in End-of-Life Care of 2008⁴⁵ argues in a similar way: sedation does not shorten life, and patients or their surrogates “with guidance from their physicians should separately decide whether they...want to maintain, withhold or withdraw life-sustaining interventions (including nutrition and hydration).” The report states a requirement of proportionality, but does not apply it to the extent of life shortened by the combined decision to sedate and not to provide hydration. Consequently it formulates no restriction on life-expectancy; it only restricts sedation into unconsciousness to “terminally ill patients”. If my argument in this section is sound, the report justifies a form of euthanasia, contrary to its stated intention.

the patient needs artificial hydration for survival (for more than 1-2 weeks) because of the sedation. That is why the two actions have to be considered together.

But we have seen (§ 2) that other forms of palliative care which, however exceptionally, have life-shortening effects, should be seen as falling on the ‘killing’ side of the killing/letting die divide as well. They may be justifiable nevertheless. This particular form of palliative care with possible life-shortening effects should be assessed in exactly the same way. It may be justified when there is no other way to alleviate severe suffering, and when the life-shortening effect, no more than a few days at most, cannot be considered disproportionate.⁴³

If that argument is accepted, however, it follows that if the patient’s life is foreseeably shortened by a substantially longer period, the policy should be counted as a form of euthanasia, or, if the patient has not consented to it, as ending his life without his request. Admittedly, the borderline between these classifications can only be a matter of stipulation. This is precisely what the guideline provides. If this is the real reason for the requirement concerning the life-expectancy of the patient, it should have been made clear that if the policy of sedating the patient and withholding artificial hydration is started (on the request of the patient) when the patient has a life expectancy of more than 1-2 weeks, this should be classified and reported as euthanasia. (The doctor would then be judged not to have acted in a medically careful way.) Unfortunately, the guideline doesn’t say this explicitly.

How sure can we be that the requirement concerning the maximum life expectancy is respected in practice? There are some reassuring data.⁴⁴ On the other hand, members of regional Review Committees report that it is not uncommon for reports of euthanasia to show that terminal sedation has been discussed with the patient as an alternative to euthanasia (and euthanasia is chosen in the end) in cases in which the life expectancy of the patient exceeds two weeks. Moreover, as regards the life-

⁴³ During the second week it may be impossible to identify the cause of death, but there is a substantial and increasing probability that death is at least partly due to dehydration.

⁴⁴ The estimation of the actual time span between sedation and death given by doctors in the 2007 report (p. 131) is more than 2 weeks in 2% of all cases. In the 2003 report (p. 84) it was 1-4 weeks in 21% and more than a month in 6% of all cases. If terminal sedation is indeed being restricted to dying patients, that may help to explain the rising number of euthanasia cases since 2003, see footnote xxxiv.

expectancy of the patients we have only the opinions of the responsible doctors to go by, which, even if sincere are not very reliable. That very fact should be a reason –one out of several- to insist (and not only to advise, as the guideline does) that doctors who decide to start terminal sedation should consult an expert in palliative care.⁴⁵

5. *Merely a façade?*

I have argued that the traditional criticisms of the Dutch model have only limited force.^{46,xlvi} Morphine is still being used as a euthanaticum, whether illusionary or not, and probably considered attractive precisely because of this elusiveness. In some cases the life of a severely suffering patient is being ended, in which, in the absence of a request, terminal sedation would have been the preferable option. But the number of these cases is small and decreasing.

In addition a new grey area has developed, consisting of cases in which doctors use terminal sedation without providing artificial hydration, even when the life expectancy of the patient should rule out this option. As far as we know, however, this practice doesn't concern substantial numbers either.^{47,xlvii} At the same time we see an emerging practice in which physicians who consider either euthanasia or PAS, habitually follow the proper legal procedure. The ideal of transparency of medical

⁴⁵ Other reasons include: (1) to prevent doctors to decide on terminal sedation too early, when with sophisticated palliative care the patient could have had some additional time of conscious life without severe suffering, (2) to give sufficient room for patients to be treated in accordance with their own values. Doctors may be tempted to offer them only the option of terminal sedation if no special procedural requirements of due care apply to that option at all.

⁴⁶ It may be added that, contrary to a rather common view, the requirements of due care over the years have only been tightened, in particular in regard to reporting and consultation. And legalizing euthanasia or PAS in (Oregon and) the Netherlands did not result in a disproportionate number of deaths among the elderly, poor, women, minorities, uninsured, minors, chronically ill, less educated or psychiatric patients.

⁴⁷ At present no international comparison on this issue is possible, because we have only some data about the total number of cases of terminal sedation without artificial hydration (ca 3% of deaths in the Netherlands, Belgium, Switzerland and Italy in 2001, somewhat lower in Sweden and Denmark⁴⁷) but no data about life-expectancy for any country but the Netherlands.

decisions in this area has, therefore, largely been achieved, and certainly to a much larger extent than in any other country.^{48,16}

One could still be skeptical about this result, however, arguing that it is only an optical achievement. Dutch doctors, one could suggest, allow themselves to be controlled because the controlling system has no bite. From 1998 until 2008 20283 cases have been reported to the review committees. Only in 38 cases they have concluded that the doctor had not satisfied the legal criteria of careful action. Moreover, in none of these ‘not careful’ cases the public prosecution has decided to start a legal procedure, and so no conviction has taken place. The most severe measure has been a conditional dismissal in which the doctor has been warned that he could still be prosecuted for his misstep if he acted in a similar way again.⁴⁹

In making these decisions the public prosecution acts on an instruction which distinguishes between the procedural and the substantial criteria of due care. If a doctor has failed to satisfy a procedural requirement, for example the requirement that the colleague called for consultation should be ‘independent’, the prosecutor will consider whether, as a result of this failure, there is any doubt whether the doctor has also failed to satisfy any of the substantial criteria, in particular the requirement that there should be a voluntary and well-considered request, and hopeless and unbearable suffering.⁵⁰

The criticism that the control procedure is merely ritual, all bark and no bite, does not only threaten the claim that it promotes transparency, but also the claim that the legal system is based on a principle of mercy. Many Dutch citizens believe that they have a moral, if not a legal right to euthanasia, based merely on their general right to self-

⁴⁸ At this moment probably still including Belgium.

⁴⁹ The Inspectorate of Health Care has brought two disciplinary cases, both resulting in the imposition of sanctions. Already in 2001 the UN Human Rights Committee expressed its concern about the low number (at that time only 4) of “not careful” judgments of the Review Committees, Concluding Observations of the Human Rights Committee: Netherlands, 20/07/2001, CCPR/CO/72/Net.

⁵⁰ Clearly this should mean that, in the absence of a proper consultation report, the report of the doctor of what happened can be corroborated by other independent testimony. If the judgment whether the substantial criteria have been satisfied would only be made on the basis of the doctor’s report, that would effectively undermine the consultation requirement of the law. This seems the proper way to interpret the instruction, but it is not fully clear whether it is correspondingly implemented in practice.

determination. It is only to be expected that at least some doctors share this moral view, even if among doctors they form a minority. So they will be prepared to accept a request for euthanasia if they are satisfied it has been made voluntarily by a competent patient, even if they are not satisfied that his suffering is unbearable. For example, some cancer patients at a rather early stage decide that they prefer to avoid going through the dying process altogether, whether or not it involves extreme suffering. If it is not really assessed whether all the requirements have been satisfied, the system of control fails to achieve its moral aim.

From the beginning opponents of the *indirect paternalism*⁵¹ of the Dutch legal system have maintained that it is only the patient himself who can, and therefore should decide whether he is in a state of unbearable suffering.^{52,xlviii} For that reason they have claimed that this requirement should be taken in the same way as the requirement of a state of emergency in the Dutch abortion law: a woman is supposed to be in such a state if she says she is. Though formally the abortion law at the time of its enactment has not been justified in terms of women's right to self-determination, this interpretation made the law indistinguishable from a law justified in that way, and, indeed, recently the Dutch Supreme Court has re-interpreted the law as implementing a right to self-determination.⁵³ It could be suggested that the Review Committees actually accept that the patient is in a state of unbearable suffering as soon as he says he is. In that case the law is not really paternalistic at all: it permits doctors to accede to any voluntary and well-considered request, even if it also permits them to make additional requirements, including requirements of their own making, for example their own interpretation of the requirement of unbearable suffering.^{54,xlix}

⁵¹ See § 1.

⁵² Wijsbek⁴⁸ convincingly criticizes this claim. See also Wijsbek (Chapter 21).

⁵³ HR 18/3/2005, (*Kelly*-decision) The very fact that this reinterpretation has been hardly noticed is telling. The pioneer of Dutch health law H.J. Leenen, who during his lifetime has always championed the legalization of euthanasia in terms of respect for autonomy, had proposed the requirement of an 'uitzichtloze noodtoestand', a state of emergency without perspective, in his first draft of the euthanasia law, and it is arguable that he took the abortion law as his model.

⁵⁴ Possibly relevant on this point is the finding by Buiting et al.⁴⁹ that 53 % of doctors (57% of GP's, of 27% specialists) report to have had problems in deciding whether they themselves were convinced of the patient's unbearable suffering. Problems to assess whether the request was well-considered have been reported by 23% of doctors

I believe that the criticism misinterprets the nature of the control procedure, and actually of any possible control procedure in this area. Being essentially dependent on the voluntary cooperation of doctors it should not be seen as a method to catch crooks and bring them to justice, though it can have this result accidentally. It is only marginally an instrument of the criminal law. Therefore the essential instruments of the control system are not prosecution and punishment. The most effective instrument is the consultation requirement, in particular in the actual form it takes of the SCEN procedure.⁵⁵ Almost all consultants nowadays are SCEN consultants. SCEN-consultants usually have volunteered because of their interest in and loyalty to the aims of the procedure, they teach each other through discussion and peer review, they are better informed than the average doctor about the interpretation the review committees give to the requirements of due care, and they also tend to have an interest in their standing with these committees. The doctor who doesn't take the unbearable suffering criterion seriously enough himself cannot expect to get a SCEN-consultant who shares his attitude. In addition the committees in about 6 % of the cases ask either the doctor or the consultant or both for additional information. Most of these questions concern the unbearable suffering criterion. In about 10-20 cases each year, they are not satisfied with the answers they get and invite the doctor for an interview. Most doctors experience this as a kind of informal penalty itself. The committees can inform the doctor about minor flaws in his behavior without arriving at a "not careful" judgment during these interviews, in the considerations preceding the judgment, or in a letter accompanying it. All in all the best way to interpret the control mechanism is as a learning system through which the criteria of due care are being interpreted and the doctors receive feedback on the propriety of their interpretation. It seems likely that such a system has a greater impact on the behavior of doctors than a system which restricts itself to meting out punishment in the few cases of transgression which are brought to its attention.^{56,16,33}

(20% of GP's, 32% of specialists). The finding may suggest that GP's take the requirement of unbearable suffering as an independent condition more seriously than medical specialists do.

⁵⁵ For explanation see Kimsma (Chapter 11).

⁵⁶ 86% of Dutch doctors agree with the statement that the system improves the carefulness of medical action.³³

Let me give some examples of the way in which the criteria of due care have been interpreted during this process. For a time the committees held that only a doctor who is responsible for the treatment of a patient can grant his request for euthanasia or PAS, but later on they decided that it is enough for the doctor to have a relationship to the patient enabling him to make proper decisions about the requirements of due care. It has been suggested that at least for all dying patients there always is an alternative way to avoid severe suffering: terminal sedation. Patients have the legal right to refuse this alternative if it is being offered to them, and the committees have taken the view that if they do so because of their view of a good death, doctor and patient can arrive at the conclusion that terminal sedation is not a reasonable alternative.^{57,33} For some patients the worst aspect of their condition is the very fact that they have become totally dependent on the care of others, even for such things as eating or going to the toilet. One could argue that these people until now have lived in an illusion concerning the human condition, never having been forced to realize that humans because of their vulnerability may at any time, not only on their dying beds, need the care of others. But even if this is true, it would be rather cruel to insist that patients should still learn this lesson at this stage of their life. So it is accepted that loss of independence can be a prominent element of suffering. On the other hand, it is not accepted as such a prominent element that a patient doesn't want to be a burden on others.^{58,1} One reason for this may be that if this motivation is accepted the voluntariness of the patient's request could be compromised. The committees have decided that euthanasia cannot take place if at the agreed moment the patient has got into a coma, because at that moment he can no longer be in a state of suffering.⁵⁹ A difficult topic is the extent to which fear of future suffering counts as a form of

⁵⁷ The government had taken that view already during the parliamentary debate about the law.³³

⁵⁸ Willems et al.⁵⁰ found a significant difference between doctors in the Netherlands and in Oregon in their willingness to accept the patient's wish to avoid being a burden on others as a valid reason for granting his request of physician-assisted suicide (resp. 24 , 9%).

⁵⁹ At present a committee of the Royal Dutch Society for Medicine KNMG is working out guidelines concerning the permissibility of euthanasia in the case of such patients. Difficult issues concern patients who are unable to communicate but still show signs of suffering and patients who have got into a coma as a result of reversible medical actions.

suffering. The official view of the committees is that the fear should be well-founded and concern a state of suffering in the very near future. But this is an area in which everything is a matter of degree and it is hard to judge on the basis of documents alone, as Review Committees have to do. Therefore in this case like in others the main gate-keeping function has to be performed by the consultants.

6. *A well-considered request*

One interesting unclarity in the interpretation of the law arises from the fact that the law doesn't use the notion of competence, in the sense in which it is commonly used in medical ethics (and explained in the chapter by Ron Berghmans). From the beginning of the work of the regional Review Committees at the end of 1998 the form which a physician had to use for reporting a case of euthanasia or PAS contained a notorious *Nota Bene*. It stated, among other things, that in cases involving patients whose capacity to express a well-considered request has possibly (*sic*) been disturbed, for example as a result of depression or dementia, should not be reported to a Review Committee but directly to the public prosecution. When the law took force in 2002, the *Nota Bene* was not eliminated from the form. This means that the ministry of Justice which is responsible for the form, interpreted the law in the following way. When art. 293 makes it a separate crime, distinguishable from murder or manslaughter, to kill a person on his explicit and earnest request, it means that the request should be competently made, otherwise we still have a case of murder or manslaughter. Hence, if a request has not been made competently, the Review Committees have no power to decide whether the action meets the criteria of due care, including the requirement that the request should be voluntary and well-considered. This interpretation has been criticized from the start.^{li,60} It seems clear that a request can be made explicitly and sincerely, but not fully competently. Hence incompetence is not a reason for denying the Review Committee the power to decide the case, but for the committee to give the judgment "not careful".

Recently the minister of justice has agreed to eliminate the *Nota Bene* from the form and hence has accepted this alternative interpretation. The new form has been made available for use in May 2009. However, the requirement that the request should be

⁶⁰ In their Annual Report 2003 the Review Committees have rejected the interpretation of the law of the *Nota Bene*.

well-considered is not equivalent to a requirement that it should have been made competently, in the usual sense in which this term is interpreted in bioethics and health law. A request cannot be well-considered if it is not competently made, but the reverse is not true. The difference is that in assessing whether the request is well-considered we cannot fully abstract from the content of the request. We should normally make sure that the patient is aware of his condition, of the prognosis, both of his disease and of the development of his symptoms, of possible alternative ways to treat the disease or alleviate the symptoms, with their probable effects and burdens. All this is also relevant to a judgment of competence. But in addition the request can only be seen as well-considered if it is at least intelligible that, given this relevant information, it is this particular request which is being made. It is not enough that from other evidence we know that the patient has the mental and emotional capacities which are needed to make an intelligible response to the situation as he knows it. The literature on competence insists on abstracting from any judgment about the content of the decision because it wants to hold on to a clear and clean notion of ('hard') paternalism, either direct or indirect. If a person is considered to be competent, he has the right to make his own decisions, whether they are 'good' or 'bad' decisions. It is debated whether in that case it can ever be permissible to interfere with the execution of that decision (direct hard paternalism) or with others assisting in executing it (indirect hard paternalism), but even if it is, it is always a violation of his right to self-determination. If on the other hand the decision is not competently being made, it is permissible, not a violation of the person's right to self-determination, to interfere with it if it is a 'bad' decision. But we can only take that position if the judgment of competence itself does not depend on our assessment of the decision being a good or bad one.⁶¹

I believe that in general decisions of competence, as they are being made in practice in health care, are hardly ever made in this content-independent way. As long as the patient makes a decision that makes sense, no question of competence is raised, and if the decision is problematic, one of the main considerations used in deciding whether

⁶¹ This requirement is already compromised in an indirect way when the criteria for assessing the competence of a decision are more stringent, if the decision concerns more important matters, e.g. matters of life and death. Berghmans, chapter 15, in effect concedes this when he says that a judgment of competence based on this criterion is not a judgment of a capacity but of an authority.

nevertheless it is being competently made, is how problematic it exactly is. My present point, however, is only that this is the way in which doctors, consultants and Review Committees judge, and have to judge, whether a request for euthanasia has been well-considered.

The consequence of this is that the two main substantive criteria of the law, the requirements concerning the request and the condition of the patient, are not fully independent of each other. If the request is made at a moment when the burden of physical symptoms is still modest, the patient has a lot of explaining to do before his request will be accepted as well-considered. The explanation should at least make his request intelligible to others. If, on the other hand, the patient is in a very pitiful condition in which his request is perfectly understandable, the fact that he may be unable to give the consultant an extended exposé about the history of his illness and about the reasons he has had for various decisions he has made along the way, does not necessarily lead the consultant to conclude that the request is not well-considered. The condition of the patient speaks for him. Similarly, if such a patient has an untreatable psychiatric condition, that condition may be seen as increasing the burden of his suffering and therefore the intelligibility of his request, rather than throwing doubt on whether it is well-considered (or voluntary).^{lii,62}

The fact that the law requires the request to be well-considered and not merely competently made, therefore confirms the priority of the requirement of unbearable and hopeless suffering, and hence the foundational importance of the principle of mercy. It is always against the background of the condition of the patient that his request will be assessed.

7. Too restrictive?

That the system as a whole has a clear restrictive effect on the conditions in which patients are considered to be eligible for having their request accepted, is, if not shown at least made likely, by the results. They may even suggest the restrictive effect

⁶² In many contexts a decision is voluntary not because the agent, being who he is, could have made another choice, but precisely because the choice is the only one which is true to the person he is. In this case the patient's death wish may be seen as voluntary because there is no position, which he will ever be actually able to take, from which he would not identify with his wish.

to be too large. Here we meet the second and opposite worry one can have as regards the actual working of the control system.

In order to specify this worry we have to know, first how often requests for euthanasia are being refused, and, secondly, to what extent these refusals track the legal criteria of due care.

As regards the first point, the survey report of 2007 tells us that in 8400 cases explicit and repeated requests for euthanasia or PAS had been made, of which 2425 (almost 30%) had been granted and acted upon. In almost 40% of the 6000 cases in which the doctor did not act upon the request the patient had died before a final decision had been reached or had been executed. In most of the cases in which the doctor refused to go along with the request he thought that the request was either not voluntary (6% of the 6000 cases) or not well-considered (18%), or because the patient's suffering in his eyes was not unbearable (16%) or not hopeless (8%).^{63,33} A problem with these data is that it is not fully clear what an 'explicit and repeated request' should be taken to include. Often patients make a request for the near future, leaving it open to pinpoint the exact date, sometimes changing their minds about this from one day to the next. This helps to explain the substantial number of cases in which the patient has died before a final decision about his request has been made.

Perhaps more telling are the data from Chabot's recent research.^{liii,64} They may be more telling because they concern people who afterwards have confirmed the urgency and stability of their death wish by going on to end their own lives. Chabot found that, at a minimum, each year 1600 Dutch people took their own lives in a planned way and after shared deliberation with friends and relatives by using deadly pharmaca they have collected in some way. Moreover, 2800 people ended their lives by intentionally ceasing to eat and (in particular) to drink. Almost all of these cases have been reported by the coroner as cases of natural death.⁶⁵ This means that the official statistics for the Netherlands (and probably for other countries as well) only concern suicides which

⁶³ See Pasman's chapter (9) for additional figures from interviews with GP's and from earlier surveys.

⁶⁴ See Chabot (Chapter 20).

⁶⁵ For reasons Chabot explains in his chapter (20).

have been executed impulsively and without consultation of others.⁶⁶ (Because these are the only suicides we knew of until now, our idea of the ‘normal’ case of suicide is largely off the mark.)^{67,53}

In about 50% of these 4400 cases the person involved had first requested the doctor to assist him but had received a refusal. About 40% will not have made the request because they anticipated a refusal, or even preventive action by the physician. The reasons given for the refusal include: the requester is not fatally ill or not in the dying stage of that illness; the death wish has not been caused by any illness at all; the suffering of the requester cannot be considered unbearable or hopeless.⁶⁸

The first reason is interesting for it is not, and never has been, a requirement of due care in the Netherlands that the patient should be terminally ill or in the dying stage of his illness, however this is defined.⁶⁹ Some doctors may be mistaken about the actual requirements, others may knowingly add a requirement of their own.^{33,70}

Though the data from these two sources (the survey report and Chabot) are only roughly comparable, they don’t seem to be fully compatible. It is hardly plausible that the large majority of the people who have been refused euthanasia or PAS on their request go on to end their own lives. Part of the explanation may be that patients may sometimes believe that they have made a request when this has not been perceived or remembered as such by the doctor.⁷¹

⁶⁶ Recently the Dutch minister of health care has announced plans aimed at reducing the number of ‘official’ suicides. Obviously he is not aware of the arbitrary character of the figure.

⁶⁷ We can at present only speculate whether the number of such cases is higher or lower in the Netherlands than elsewhere. It might be lower because a larger number of people with a death wish are being assisted by doctors. But it might also be higher precisely because the availability of legal euthanasia strengthens the belief that this is an area in which decisions can be made.

⁶⁸ These reasons are also reported by Pasma (Chapter 9). She adds: there are alternatives for alleviating the suffering.

⁶⁹ It is a requirement in Oregon. In Belgium the doctor has to satisfy additional procedural requirements if he doesn’t expect the patient to die in the near future.

⁷⁰ 25% of doctors believe that this is a legal requirement, 6% don’t know.

⁷¹ See Pasma (Chapter 9) and Chabot (Chapter 20).

What more do we know about the refusals? By far the largest group of people who successfully request euthanasia are cancer patients in the final stage of their illness.⁷² Cancer is of course generally feared for the physical suffering it often involves, so there is in a sense a presumption that a cancer patient will be suffering severely. The same is true for the other significant class of cases: those of neurological diseases like ALS which often involve almost complete paralysis and severe breathlessness. Euthanasia in other cases, according to the reports to the regional committees, is rare.⁷³ In the case of psychiatric illness it is almost non-existent.^{74,16} Euthanasia in a beginning stage of dementia, when the patient may still be aware of his condition and prognosis, has been reported for the first time in 2004. Since then the number has been slowly rising year by year. Taken together these data suggest that the requests which are most likely to be granted concern patients in the final stages of diseases which are known for their devastating physical symptoms. This is confirmed by the survey results.^{53,75}

A further confirmation of this suggestion can be found in the results of Van Tol's research.³⁸ The answer to the question whether a given case is a case of unbearable suffering obviously depends on our conception of suffering. According to one conception the paradigm of suffering is pain: an unpleasurable state of consciousness which has a location in the body and can normally be related to a physical injury at that location. ("Normally", not always, because you can feel pain in your leg after it is has been amputated.) It is of course agreed that there are other forms of suffering besides pain, for example breathlessness, nausea, physical exhaustion, but according to this conception they have a similar structure. A richer conception of suffering, however, that has impressively been articulated and defended by Eric Cassell, treats

⁷² But the percentage is somewhat decreasing: from 89% in 2005 to 81% in 2008. Annual reports of the Review Committees. Part of the explanation for the rising number of euthanasia cases (see footnote xxxiv) may therefore be that doctors are slightly more willing to consider euthanasia in non-standard cases.

⁷³ Here one should remember that the reporting rate for euthanasia and PAS by proper means is in the neighborhood of 100%. So we cannot expect large numbers of other cases to go unreported.

⁷⁴ Two such cases have been reported to the Review Committees in 2008. For some other data see Griffiths, Weyers, and Adams.¹⁶

⁷⁵ See Pasma (Chapter 9).

pain, breathlessness, nausea etc. only as components of suffering. Another essential characteristic of suffering on this view is the meaning attributed to these components by the suffering person, more specifically that they are being seen as threats to his integrity as a person.^{76,lv,lv} Whether they are seen that way may depend on many other aspects of the person's life and personality, and of the future he anticipates; in that respect this conception of suffering can be called a holistic one.

If we place people on a spectrum ranging from an 'atomistic' conception of suffering which focuses on somatic symptoms only to a holistic conception, Van Tol finds that many, but by no means all doctors are to be located at the atomistic end.^{lvi,77} (SCEN-doctors are on the average farther removed from that end of the spectrum and members of Review Committees even more so.)

This, of course, is not really an unexpected result. It is easy to feel compassion with a person (or a dog) who is shriveling from pain, but it requires more sophisticated capacities of empathy and imagination to understand why a person is suffering because he expects that he will not achieve the basic aims of his life, or even feels these very aims to have been misconceived. Even people who are not lacking in such capacities may feel less sure about their judgment in the latter class of cases. And the professional training of doctors increases their disposition to focus on physical symptoms, although this is less true of GP's than of specialists.

Doctors are, to use a somewhat odd expression, most at ease with dying patients with clear physical symptoms, or at least with diseases known for such symptoms. This tendency has been strongly reinforced by the verdict of the Dutch Supreme Court in the Brongersma case (2002).⁷⁸ In its decision in the Chabot case (1995) the Court had famously declared that it is not the cause but the nature of the suffering which matters, but in the Brongersma decision it held that the unbearable suffering should be caused by a 'medically classified disease or disorder', for only in such cases it would be a matter of professional competence to assess the severity of the suffering. This

⁷⁶ Cassell makes this a defining characteristic, which would imply that animals and newborns who are unable to do the necessary work of interpretation, cannot suffer. A more plausible view is that the dimension of meaning is only essential for beings who have the required interpreting capacities.

⁷⁷ See Pasman (Chapter 9).

⁷⁸ See Weyers (Chapter 3) and Rurup (Chapter 16).

consideration itself seems to identify the suffering of the patient with his physical symptoms, and in any case the decision requires the doctor in assessing the severity of the patient's suffering to abstract from elements not directly caused by the illness. For these reasons the Brongersma decision is incompatible with the holistic conception of suffering. It therefore understandably reinforced the tendency of doctors to focus on the medical facts: the illness as the cause of the suffering and the symptoms it causes. Although it is sometimes suggested that the Brongersma decision has no authority because it has been made before the WTL took force, this view is implausible because that law did not intend to change the existing rules.⁷⁹ The Review Committees in any case do not dispute this authority. Nevertheless they have explicitly subscribed to the holistic conception of suffering which therefore should be seen as the authoritative interpretation of that legal concept.⁸⁰ Hence we can conclude that in a substantial although unknown number of cases the request of the patient is being refused, by doctors who have no principled objection to the law and therefore do not refer the patient to another doctor who hasn't, in which that request satisfied all the legal criteria, in particular the requirement of unbearable suffering, as they should properly be understood.

This is clearly problematical, both from a point of view of legal certainty and equality before the law as from the point of the view of the aims of the legal system.

The people involved include severely ill patients who are not yet in the final stage of their illness and psychiatric patients. Probably the largest group consists of very old people who to a high degree suffer from the usual deteriorations of old age, in particular reduced vision, reduced hearing and reduced mobility, who for that reason are losing their social contacts and opportunities for meaningful activity, and therefore are spending their lives with feelings of futility and loneliness. Actually Schoonheim's patient belonged to this group. So did the patient in the following case: A lady of 96-years old has been living a very active life, including long journeys to other continents, until a year ago, in spite of suffering from cardiac decompensation

⁷⁹ And the Supreme Court did actually take into account the parliamentary discussions about that law. Moreover, the requirement that the patient's suffering should be hopeless is usually taken to mean that the underlying illness cannot be cured, but this presupposes that such an illness exists.

⁸⁰ Most clearly in the Annual Report 2007, from which the relevant passage is being quoted by Kimsma, (Chapter 22). See also Wijsbek (Chapter 21).

and pulmonary emphysema. During that last year she has been hit by what the consultant called a cascade of medical accidents: a painful crural ulcer, a TIA, several cases of falling, several infections, and finally a fracture of the upper leg. None of these accidents is fatal, but together they leave her in a condition of almost total immobility, confinement to bed and dependence on others. As a result of the underlying cardiovascular problems, the fracture and her age she can only look forward to decubitus problems, more infections, emaciation, possible recurrences of the crural ulcer or the TIA and other complications. No one can predict how long it will take before she dies. She has tried to stop eating and drinking but has not been able to sustain the effort. What she considers particularly unbearable is her loss of freedom and of the management of her life.

In this particular case both the doctor and the consultant concluded that it was a case of unbearable suffering, and the Review Committee agreed that they could reasonably have come to that conclusion. Obviously the committee thought that the requirement of the Brongersma decision had been satisfied as well. But it is probable that in a case like this many other doctors who have no principled objections against euthanasia, as well as a substantial number of consultants, would have come to the opposite conclusion. And it is not unthinkable that the patient in that case would have ended her own life, for example by another and better prepared attempt to stop eating and drinking.

8. Four possible ways of dealing with the problem

Requests for euthanasia or PAS are not being granted in a substantial number of cases in which the WTL would allow it. How to address this problem? I will discuss four possible responses to it. A fifth option would be to break down the medical monopoly on the access to euthanatica^{81,lvii} But I believe that society has a proper interest in restricting this access as much as it has in restricting the access to fire-arms.^{82,lviii}

⁸¹ Right-to-die societies across the world have been looking for some time for a euthanaticum which could easily be produced by people from publicly available resources, but this quest has not yet succeeded.

⁸² In 1994 a physician left euthanatica in the house of a patient who had postponed the euthanasia. Her depressive partner committed suicide by using these.

(1) The first option would be to try to redress the physician's bias. Far more attention should be given in educating doctors about the concept of suffering and its importance for medicine. Because SCEN-doctors have a broader conception of suffering than doctors generally, it might help to give patients the right to contact them directly in cases in which they disagree with the refusal of their request by the doctor.

Repealing the Brongersma decision would be a vital part of this enterprise. It is easy to criticize that decision. Clearly people can be ill without their illness being medically classifiable, medical knowledge still being far from complete. The boundaries of the concept of illness are both vague and contested. (Hence, if Brongersma's doctor in consulting a psychiatrist had not only asked for an assessment of his competence but also for a diagnosis, he could probably easily have obtained a relevant DSM IV classification.) More importantly, as I suggested already, even in the case of people dying from a nasty cancer, it may be impossible to sort out neatly the aspects of their suffering which are caused by the illness and by other causes, in particular because these effects may reinforce each other. Finally, it can be disputed whether extreme suffering is only a doctor's business to the extent that it has 'medical' causes. We go to the doctor for sleeping pills, irrespective of the cause of our insomnia. The reason is simply that we have a legitimate need for sleeping pills and the doctor has a monopoly in providing them, or the most effective ones. In the same way it is incoherent for a society to entrust doctors with the key to the euthanatics-case, recognize that unbearable suffering is the proper justification for euthanasia, and then forbid doctors to provide this way out to people whose suffering doesn't have a medical cause.^{83,lix,lx}

But this is all ideal theory. The Brongersma decision has been generally welcomed by the Dutch medical community.⁸⁴ Doctors strongly prefer to keep the domain of their

⁸³ One of the common arguments against legalizing euthanasia is that this would be against the traditional norms governing the practice of medicine as defined by its essential aim, the promotion of health. One of the many weaknesses of this argument is that it doesn't provide us with a reason why people could not have access to euthanatics in ways which bypass 'the practice of medicine'.

⁸⁴ And therefore the report of the Dijkhuis-committee, commissioned by the KNMG, which criticized the exclusion from eligibility for euthanasia or PAS of people "suffering from life", has been quickly shelved.

concern limited, to ‘medical’ causes, ‘medical’ problems, ‘medical’ aims. They do not consider themselves particularly equipped to deal with existential problems. And it is true, I have already conceded it, that to the extent that the suffering of the patient is determined by physical symptoms, it is easier to assess its severity.⁸⁵ If a person is almost suffocating, or vomiting feces, you do not need special capacities of empathy and understanding to be sure that his suffering is extreme. If his life expectancy is very limited, you can’t help thinking that any mistake you make has only limited consequences. Another consideration, which is more than a consideration of non-ideal theory, is that if the suffering of the patient can only be understood in the context of his life and his personality as a whole, to assess the severity of that suffering requires intruding into his private sphere to a larger extent than is normally required of doctors.^{86, lxi} In short, the hope that doctors will really extend the domain of their concern can only be limited. At this point we reach the outer boundary of the Dutch model of indirect medical paternalism.

(2) This may prompt the second response: we should leave the decision with people themselves. In cases outside of the medical domain, in particular in “Brongersma”-cases, it should be up to a person to decide whether he thinks that a longer life will add anything of value to his life, and when he doesn’t believe so, he should be given access to the most humane means available to end his life. If we don’t want such means to be publicly accessible, we should still submit him to a test (possibly by a psychiatric or specialized psychological expert) of his competence, and we should take care that the euthanatics cannot get into other hands. (For example by leaving it to specialized suicide consultants to provide the person with them at the very moment he wants to use them.)

This is the view which the Dutch right to die society NVVE took for some years after the Brongersma-decision. At the time the NVVE did not basically dispute the existing legal regime for doctors, with its procedural and substantial requirements of due care. But of course you cannot really expect the proposal for the Brongersma-cases to

⁸⁵ It doesn’t follow, however, that the suffering of a dying patient is completely due to the symptoms caused by the illness from which he is dying.

⁸⁶ Leenen’s⁶¹ complaint when he observed that the Review Committees were not always satisfied by the declaration of the doctor and the consultant.

simply coexist with that regime. It is unthinkable that doctors would submit cancer patients in the last stage of their illness to requirements which would not be imposed on 'healthy' people who are said to be simply 'weary of life'. They would either stop following the requirements and stop reporting on them, or (more probably) refer their patients to the other procedure.

So what the proposal really amounts to is to exchange the existing legal regime and its basic reliance on a motive of compassion for another regime based exclusively on respect for autonomy. I will not enter into a fundamental comparative ethical evaluation of the two systems at this point.^{87,18} It is sufficient to point out that such a radical change of basic orientation is not likely to happen. Margo Trappenburg had argued that the emergence of the Dutch paternalistic model of regulating euthanasia has been largely a matter of 'path-dependency'. When the Supreme Court decided to break the existing political impasse in 1984, it had hardly any option in the existing law but the appeal to necessity, interpreted as a 'conflict of duties', for identifying a possible legal justification for euthanasia. This implied, as contemporary critics plainly saw, a choice for compassion rather than respect for autonomy as the basic justifying principle. This choice in its turn determined subsequent developments, the specification of the criteria of careful action, the creation of the system of assessment by regional committees and eventually the format of the 2002 law. I do not agree with Trappenburg that the choice of the Dutch model has been largely accidental⁸⁸, but I do agree that having developed that having developed in this direction for decades, it is not likely that any (Dutch coalition) government will change the course of the tanker 90 degrees.

(3) Probably realizing this the NVVE has changed its policy. It now advocates supplementing the legal regime with another procedure which is structurally similar to the existing one. In this procedure similar requirements of due care would be made as regards the voluntary and well-considered character of the request and the absence of viable alternatives. Independent consultation would also be required. But the person

⁸⁷ For some considerations see den Hartogh.¹⁸

⁸⁸ On my view this is largely to be explained by the active involvement of the Dutch medical society KNMG in the development of the criteria of due care as the conditions under which euthanasia and PAS would be allowed.

who would receive the request and go through the procedure would not necessarily be a doctor. He would be a member of a specially trained group of people who can be trusted to consider the existential aspects of the reasons for the request. This group could contain pastoral workers, humanistic counselors, psychologists, but perhaps also specially trained doctors. Let me call such a person a counselor. Finally, the requesting person would not be required to be in a state of unbearable suffering but rather in a condition characterized by an irreversible loss of dignity.^{lxii}

One might perhaps be forgiven for being a bit suspicious of that last proposal. Maybe the NVVE is hoping to get rid of the (indirectly) paternalistic aspects of the present regime by arriving at an analogue of the abortion law after all. If the person says that he has lost his dignity, could the counselor dispute this? In the relevant documents of the NVVE a connection is made between dignity and autonomy which suggests the contrary. It would, it is said, be insulting to a person to deny that he is living an undignified life when he says so.

This view, I believe, rests on a mistake, like the similar view concerning suffering. We should distinguish between two concepts of dignity. The dignity of the person, his moral and legal standing in a community, is not a matter of degrees, and certainly every person who can make a request for euthanasia, has it to the full. It is this form of dignity which is the basis of (or perhaps rather partly identical to) his rights of self-determination, but it is not the loss of dignity in this sense which can be the reason for his request. The dignity of a person's condition, on the other hand, can be a matter of degrees, and the loss of it can be a motive for a death wish. But the dignity of a person's condition is not a private matter which he can only decide about himself. It is on the contrary a social state *par excellence*. To lose one's dignity is to be in a state which one should be ashamed about *vis-à-vis* other people. And it is fully possible to be mistaken in believing that one is in such a state. In fact we have already met an example of such a mistake: people who consider it a loss of dignity to be dependent on other people's care. (Note, however, that even if it is mistaken in this way, the perception of loss of dignity can certainly be a form of suffering.)

The basic problem of the new criterion is its relation to the old one: unbearable suffering. From the very introduction of this requirement of due care, in the Supreme Court's Schoonheim-decision of 1984, the Court did recognize loss of dignity as a possible dimension of suffering. In order to be an aspect of suffering, loss of dignity has to be experienced as such, and this has later on been recognized by the Court.^{lxiii}

But, of course, in order to be the motive for a request for PAS, loss of dignity should also be experienced as such. In cases of euthanasia or PAS which are submitted to the Review Committees loss of dignity is often mentioned as one of the most prominent elements of suffering. It mainly takes the following forms: incontinence, stinking wounds, fecal vomiting, loss of mental capacities or change of personality (for example due to brain metastases or to medication), and dependence on care. In almost all these cases it is hard to imagine that the loss of dignity by itself would justify assistance in PAS, if it would not cause severe suffering. The one possible exception is an advanced state of dementia. It is no accident that doctors are extremely reluctant to kill such patients on the authority of an advance directive, one of the reasons being that the demented person may not be in a state of unbearable suffering.^{89, lxiv, lxv} But this is a special and very complicated case which I will set apart for this moment. Abstracting from this case, the criterion of the loss of dignity doesn't seem substantially to add to the criterion of unbearable suffering. Therefore, it should not be treated as a separate criterion governing its own procedure. That would have the inherent danger of reinforcing, within the existing medical domain, narrow conceptions of suffering which exclude such dimensions.^{90, 62}

At the same time the criterion is too narrow to cover the relevant dimensions of a broader, holistic conception of suffering. Think of a very old person who has almost completely lost her abilities of sight, of hearing and of mobility and, as a result, is unable to be involved in any meaningful activity. Such a person would not have lost her dignity nor necessarily perceive herself as having lost it. Rather it is a loss of meaning which causes her to suffer, perhaps unbearably.

So I see no good reason for supplementing the requirement of unbearable suffering by loss of dignity.

Should we leave that requirement as it is, but allow the category of the people covered by the exception to Articles 293 and 294 (or perhaps only 294, concerning PAS) of the criminal code to be extended to counselors? I have no principled objection to the

⁸⁹ Another reason is the fact that it is impossible to communicate with the patient about the decision, and as a result it cannot be a truly cooperative action. See Hertogh (Chapter 14).

⁹⁰ According to NVVE⁶², it is possible that elderly people suffer a loss of personal dignity without being in a state of unbearable and hopeless suffering "in the strict medical sense". There is no such sense.

proposal, though much would depend on the details of the new regime, in particular on the requirements for receiving the status of counselor.⁹¹ One possible step into this direction, which doesn't require any change in the law, is to involve non-medical experts in the assessment of unbearable suffering, if this has clear existential dimensions.

(4) A final option is to leave the spectrum of alternative choices essentially as it is. Dying patients with a life expectancy of no more than 1 (-2) weeks could avoid unbearable suffering which cannot be alleviated in any other way by being given terminal sedation.^{92, lxvi} Both such patients and others can request either euthanasia or PAS and receive it if the doctor (and the consultant⁹³) agree that the substantial criteria of due care have been met. If they don't agree or haven't been asked, such people (not necessarily patients) can act on their own initiative. The question is whether the political community wrongs them if it leaves them no other alternative for having their death wish enacted.

If we take the underlying morality of the Dutch legal system for granted it can only wrong them if they actually satisfied the criteria, in particular the criterion of unbearable suffering, but nevertheless find their request refused, either because the doctor uses additional requirements of his own (like being in a dying stage), or because he uses his own interpretation of 'suffering', probably exclusively focussing on physical symptoms. Such cases, as we have seen, occur, probably regularly, even if we have no idea to which extent. (I am not suggesting that the 4400 cases of carefully

⁹¹ At present the organizations involved in counseling people with a death wish are all strongly motivated by anti-paternalistic considerations. Hence giving their members this new status might lead to de-emphasizing the requirement of unbearable suffering.

⁹² A separate question is whether we shouldn't allow dying patients to be sedated at the very end simply because they prefer to die in that way, even if they don't have 'refractory symptoms'. The revised KNMG-guideline for palliative sedation 2009 moves into that direction by recognizing existential suffering as a possible 'refractory symptom'.

⁹³ It is not a formal requirement of due care that the consultant agrees with the doctor but for obvious reason it almost never happens that the doctor proceeds with the euthanasia if the consultant thinks that the criteria have not been satisfied. Nevertheless, it has happened a few times, and the Review Committees have judged the doctor to have satisfied the requirement of due care in those cases.

planned suicide found by Chabot all belong to this category.) It would clearly be very problematical for the political community to say to these people: if you are really determined, you can try to collect euthanatics by guile or deception, or by the hidden complicity of a doctor who actually knows how his prescription will be used, and often in the process involving other people in illegal forms of assistance. That would also clearly violate the principle of transparency as a basic principle of the system. But it is less clear that the community cannot say to these people: if you are really determined, you can stop eating and drinking. Of course, this is not a particularly easy way out. (Which, wryly, may be a fortunate fact because it puts determination to the test.) But the results of Chabot's research seem to show that it need not be an inhumane way, if some elementary palliative measures are being taken.^{lxvii,94} If these findings can be confirmed, we could be satisfied with the *status quo*. As Chabot stresses, there has to be change in one respect: doctors should become more clearly aware of the role they could have in this process, without either morally or legally being held to "assist" the suicide, and hence being co-responsible for it. The courts have already made it clear that providing proper information is not a form of assistance.¹⁶ The same is true about providing proper palliative care, in particular mouth care.^{95,lxviii} At present many doctors who have refused a request for assistance in suicide, believe that providing palliative care would be inconsistent with that refusal. Those same doctors, however, would rightly consider it their professional duty to provide palliative care to a dying patient who has not consented to further treatment, even if they themselves believe that decision to be mistaken.

ⁱ Gomez, Carlos F. 1991. *Regulating death: Euthanasia and the case of the Netherlands*. New York: Free Press.

ⁱⁱ Hendin, Herbert. 1998. *Seduced by Death: Doctors, Patients, and Assisted Suicide*. New York: Norton.

ⁱⁱⁱ Keown, John. 2002. *Euthanasia, ethics and public policy: An argument against legislation*. Cambridge: Cambridge University Press.

^{iv} Cohen-Almagor, Raphael. 2004. *Euthanasia in the Netherlands*. Dordrecht: Kluwer.

⁹⁴ Relevant research findings by others are reported in chapter 3 of Chabot.⁶⁷

⁹⁵ The most effective action the NVVE could take at solving the problem it describes in its strategy document NVVE 2007 is to organize the availability of such care.

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- ^v Dworkin, Ronald, Judith Jarvis Thomson, Thomas Nagel, T.M. Scanlon, Robert Nozick, and John Rawls. 1997. Assisted suicide: the philosophers' brief. *New York Review of Books*, March 27.
- ^{vi} Dworkin, Ronald. 1993. *Life's dominion: An argument about abortion and euthanasia*. London: Harper Collins.
- ^{vii} Singer, Peter. 1994. *Rethinking life and death: The collapse of our traditional ethics*. Oxford: Oxford University Press 1994.
- ^{viii} Rachels, James. 1986. *The end of life*. Oxford: Oxford University Press.
- ^{ix} Keown, John, ed. 1995. *Euthanasia examined: Ethical, clinical and legal perspectives*. Cambridge: Cambridge University Press.
- ^x Pans, Esther. 2006. *De normatieve Grondslagen van het Nederlandse Euthanasierecht*. Nijmegen: Wolf Legal Publishers.
- ^{xi} Spreeuwenberg, C. 1981. *Huisarts en Stervenshulp*. Van Loghum Slaterus Deventer.
- ^{xii} Dillmann, R.J.M. 1998. Euthanasie: de morele legitimatie van de arts. In *Levensbeëindigend handelen door een arts: tussen norm en praktijk*, ed. J. Legemaate and R.J.M. Dillmann. Bohn Stafleu Van Loghum: Houten/Diegem.
- ^{xiii} Nys, Herman. 2007. Euthanasie: de toekomst van het belgische model. *Tijdschrift voor Gezondheidsrecht*. 31: 199-203.
- ^{xiv} Holsteyn, J. van, and Margo Trappenburg. 1995. *Het laatste oordeel: meningen over nieuwe vormen van euthanasie*. Baarn: Ambo.
- ^{xv} Rietjens, Judith A., Agnes van der Heide, Bregje D. Onuwteaka-Philipsen, Paul J. van der Maas, and Gerrit van der Wal. 2005. A Comparison of attitudes towards end-of-life decisions: Survey among the Dutch general public and physicians. *Social Science and Medicine* 61: 1723-32.
- ^{xvi} Griffiths, John, Heleen Weyers, and Maurice Adams. 2008. *Euthanasia and law in Europe*. Oxford and Portland: Hart Publishers.
- ^{xvii} Feinberg, J. 1986. *Harm to Self*. Oxford: Oxford University Press.
- ^{xviii} Hartogh, Govert den. 2000. Euthanasia: reflections on the Dutch discussion. In *Medical ethics at the dawn of the 21st century*, ed. Raphael Cohen-Almagor. Annals of the New York Academy of Science.
- ^{xix} Feldman, F. 1992. *Confrontations with the Reaper: A Philosophical Study of the Nature and Value of Death*. New York: Oxford University Press.

-
- ^{xx} McMahan, J. 2002. *The Ethics of Killing: Problems at the Margins of Life*. Oxford: Oxford University Press.
- ^{xxi} Velleman, J. David. 1999. A right to self-termination? *Ethics* 109: 606-628.
- ^{xxii} Velleman, J. David. 2006. *Self to Self: Selected Essays*. Cambridge: Cambridge University Press.
- ^{xxiii} Velleman, J. David. 2008. Beyond Price. *Ethics* 118: 191-212.
- ^{xxiv} Hartogh, Govert den. 2009. Gij zult niet doodslaan. *Algemeen Nederlands Tijdschrift voor Wijsbegeerte* 101:163-195.
- ^{xxv} Schauer, Frederick. 1991. *Playing by the rules: A philosophical examination of rule-based decision-making in law and in life*. Oxford: Oxford University Press.
- ^{xxvi} Schauer, Frederick. 1992. The right to die as a case study in third-order decisionmaking. *Journal of Medicine and Philosophy* 17: 573-587.
- ^{xxvii} Birnbacher, Dieter. 1995. *Tun und Unterlassen*. Stuttgart: Philip Reclam.
- ^{xxviii} Deliëns Luc, F. Mortier, J. Bilsen, M. Cosyns, R. Vander Stichele, J. Vanoverloop, and K. Ingels. 2000. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *The Lancet* 356: 1806-1811.
- ^{xxix} Heide, Agnes van der, Luc Deliëns, Karin Faisst, Tore Nilstun, Michael Norup, Eugenio Paci, Gerrit van der Wal, and Paul J. van der Maas. 2003. End-of-life decision-making in six European countries: A descriptive Study. *The Lancet* 345: 361.
- ^{xxx} Seale, C. 2009. End-of-life decisions in the UK involving medical practitioners. *Palliative Medicine* 23: 198-204.
- ^{xxxi} Griffiths, John, Heleen Weyers, and Alex Bood. 1998. *Euthanasia and the law in the Netherlands*. Amsterdam: Amsterdam University Press.
- ^{xxxii} Quinn, Warren. 1993. Actions, intentions and consequences: the Principle of Double Effect. In *Morality and Action*, ed. Warren Quinn, 175-193. Cambridge: Cambridge University Press.
- ^{xxxiii} Onwuteaka-Philipsen, B.D., Gevers, J.K.M., van der Heide, A., Van Delden, J.J.M., et al. 2007. *Evaluatie wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, Den Haag: ZONMw (Fourth national survey report).
- ^{xxxiv} Stone, Patrick, Clare Philips, Odette Spruyt, Catherine Wright. 1997. A comparison of the use of sedatives in a hospital support team and a hospice. *Palliative Medicine* 11:140-144.

-
- ^{xxxv} Morita, Tatsuya, Junichi Tsunoda, Satoshi Inoue, and Satoshi Chihara. 2001. Effects of high doses opioids and sedatives on survival in terminally ill cancer patients. *Journal of Pain and Symptom Management* 21:282-9.
- ^{xxxvi} Sykes, Nigel, and Andrew Thorns. 2003. The use of opioids and sedatives at the end of life. *The Lancet Oncology* 4: 312-318.
- ^{xxxvii} Portenoy, Russel K., Una Sibirceva, Randall Smout, Susan Horn, Stephen Connor, Ronald H. Blum, Carol Sapence, and Perry G. Fine. 2006. Opioid use and survival at the end of life: A survey of a hospice population. *Journal of Pain and Symptom Management* 32: 532-540.
- ^{xxxviii} Tol, D. van. 2005. Grensgeschillen: een rechtssociologisch onderzoek naar het classificeren van euthanasie en ander medisch handelen rond het levenseinde. PhD diss., University of Groningen.
- ^{xxxix} Regionale Toetsingscommissies Euthanasie. 2004. Jaarverslag (Annual Report).
- ^{xl} Regionale Toetsingscommissies Euthanasie. 2005. Jaarverslag (Annual Report).
- ^{xli} Regionale Toetsingscommissies Euthanasie. 2008. Jaarverslag (Annual Report). Accessible on;
http://www.euthanasiecommissie.nl/Images/jaarverslag%20engels%202008_tcm17-19005.pdf
- ^{xlii} Otlowski, Margaret 2001. The effectiveness of legal control of euthanasia; lessons from comparative law. In: Albert Klijn, Margaret Otlowski, Margor Trappenburg editors, *Regulating physician-negotiated death.*'s Gravenhage: Elsevier Bedrijfsinformatie.
- ^{xliii} Smith, Stephen W. 2005. Evidence of the practical slippery slope in the debate on physician-assisted suicide and euthanasia. *Medical Law Review* 13: 17-44.
- ^{xliv} Battin, Margaret P. 2008. Terminal Sedation: Pulling the sheet over our eyes. *Hastings Center Report* 38: 27-30.
- ^{xlv} AMA, The Report of the AMA Council on Ethical and Judicial Affairs on Sedation to Unconsciousness in End-of-Life Care. 2008.
- ^{xlvi} Battin, Margaret P., Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, and Bregje D Onwuteaka-Philipsen 2007. Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on patients in "vulnerable" groups. *Journal of Medical Ethics* 33:591-597.
- ^{xlvii} Miccinesi, G., J.A. Rietjens, L. Deliens, E. Paci, G. Bosshard, T. Nilstun, M. Norup, G. van der Wal; EURELD Consortium. 2006. Continuous deep sedation: physicians' experiences in six European countries. *Journal of Pain and Symptom Management* 31: 122-129.

-
- ^{xlviii} Wijsbek, H. 2001. Knowing me, knowing you, *Taking Lives Seriously, Philosophical Issues in the Dutch Euthanasia Debate*. PhD diss., Free University of Amsterdam.
- ^{xliv} Buiting, Hilde M., Joseph K.M. Gevers, Judith A.C. Rietjens, Bregje D. Onuwteaka-Philipsen, Paul J. van der Maas, Agnes van der Heide, and Johannes J.M. van Delden. 2008. Dutch criteria of due care for physician-assisted dying in medical practice: A physician perspective. *Journal of medical Ethics* 34: e12
- ^l Willems, D.L. , E.R. Daniels, Gerrit van der Wal, Paul J. van der Maas, and E.J. Emanuel. 2000. Attitudes and practices concerning the end of life: a comparison between physicians from the United States and from The Netherlands. *Archives of Internal Medicine* 10: 63-8.
- ^{li} Tholen, A.J. 2003. Levensbeueindiging en psychisch lijden. *Medisch Contact* 2: 64-67.
- ^{lii} **Hartogh, Govert den. 2008. When are living donations voluntary enough? In *Organ Transplantation: Ethical, Legal and Psychosocial Aspects. Towards a common European Policy*, ed. W. Weimar, M.A. Bos, and J.J. Buschbach, _____. Lengerich: Pabst Science Publishers. 221-231.**
- ^{liii} Chabot, Boudewijn. 2007. Auto-euthanasie: verborgen stervenswegen in gesprek met naasten. Amsterdam; Bert Bakker.
- ^{liv} Cassell, Eric J. 2003. *The nature of suffering and the goals of medicine*. New York: Oxford University.
- ^{lv} Cassell, Eric J. 2004. When suffering patients seek death. In *Physician-assisted dying: The case for palliative care and patient choice*, ed. Timothy Quill and Margaret P. Battin, 75-88. Baltimore: Johns Hopkins University.
- ^{lvi} **Van Tol.***
- ^{lvii} Battin, Margaret P. 2001. New Life in the Assisted-Death Debate in the USA: Scheduled Drugs vs Nu Tech. In *Regulating physician-negotiated death*, ed. Albert Klijn, Margater Otlowski, and Margo Trappenburg, 49-63. Gravenhage' Elsevier.
- ^{lviii} Weyers, Heleen. 2004. *Euthanasie: het proces van rechtsverandering*. Amsterdam: Amsterdam University Press.
- ^{lix} Kass. Leon R. 2002. "I will give no deadly drug": Why doctors must not kill. In: *The case against assisted suicide*, ed. Kathleen Foley, Herbert Hendin, 17-40. Baltimore: Johns Hopkins Press.
- ^{lx} Pellegrino, Edmund D. 2001. Physician-assisted suicide and euthanasia: Rebuttals of rebuttals the moral prohibition remains. *Journal of Medicine and Philosophy* 26: 93-100.

-
- ^{lxi} Leenen, H.J.J. 2000. Toetsing van euthanasie. *Medisch Contact* 55:1090- 1092.
- ^{lxii} Nederlandse Vereniging voor vrijwillig Levens einde NVVE. 2007. Nota Perspectieven op Waardig Sterven. Amsterdam: NVVE.
- ^{lxiii} Decision in the case-van Oijen, 9/11/2002, Nederlandse Jurisprudentie 2005, nr. 217
- ^{lxiv} Hertogh, Cees M.P.M., Marika E. de Boer, Rose-Marie Dröes, and Jan A. Eefsting. 2007. Would we rather lose our life than lose our self? Lessons from the Dutch debate on euthanasia for patients with dementia. *The American Journal of Bioethics* 7:48-56.
- ^{lxv} Norwood, Frances. 2005. Euthanasia Talk: Euthanasia Discourse, General Practice and End-of-Life Care in the Netherlands, *The Maintenance of Life. Preventing Social Death through Euthanasia Talk and End-of-life Care – Lessons from the Netherlands* PhD diss., University of California (Berkeley and San Francisco).
- ^{lxvi} Hartogh, Govert den. 2006. Het recht op inslapen. *Medisch Contact* 37: 1463-1465.
- ^{lxvii} **Chabot, Boudewijn. 2008. A hastened death by self denial of food and drink. Amsterdam.**
- ^{lxviii} Gert, Bernard, Charles Culver, and K. Danner Clouser. 1998. An alternative to physician-assisted suicide: A conceptual and moral analysis. In *Physician-assisted suicide: Expanding the debate*, ed. Margeret P. Battin, Rosamond Rhodes, and Anita Silvers, 182-202. New York/London: Routledge.